ADDRESSING COMMUNITY PRIORITIES IN AUTISM RESEARCH

EDITED BY: Amy Pearson, Sheena Kristine Au-Yeung,
Catherine J. Crompton, Felicity Sedgewick,
Andrew David Ridley Surtees, Dhanya Pillai and Craig Goodall

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ADDRESSING COMMUNITY PRIORITIES IN AUTISM RESEARCH

Topic Editors:
Amy Pearson, University of Sunderland, United Kingdom
Sheena Kristine Au-Yeung, The University of Sheffield, United Kingdom
Catherine J. Crompton, University of Edinburgh, United Kingdom
Felicity Sedgewick, University of Bristol, United Kingdom
Andrew David Ridley Surtees, Université Catholique de Louvain, Belgium
Dhanya Pillai, Perdana University, Malaysia
Craig Goodall, St Mary's University College Belfast, United Kingdom

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Peter Klaver,
Interkantonale Hochschule für Heilpädagogik (HfH), Switzerland

*CORRESPONDENCE
Amy Pearson
amy.pearson@sunderland.ac.uk

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Editorial: Addressing community priorities in autism research

Amy Pearson [1]*, Andrew Surtees[2,3], Catherine J. Crompton [4], Craig Goodall[5], Dhanya Pillai[6], Felicity Sedgewick[7] and Sheena K. Au-Yeung [8]

[1]Faculty of Health and Wellbeing Sciences, School of Psychology, University of Sunderland, Sunderland, United Kingdom, [2]School of Psychology, University of Birmingham, Birmingham, United Kingdom, [3]Birmingham Women's and Children's National Health Service (NHS) Foundation Trust, Birmingham, United Kingdom, [4]The Division of Psychiatry, The Salvesen Mindroom Research Centre, Centre for Clinical Brain Sciences, The University of Edinburgh, Edinburgh, United Kingdom, [5]St Mary's University College, Queen's University, Belfast, United Kingdom, [6]Ara Damansara Medical Centre, Selangor, Malaysia, [7]School of Education, University of Bristol, Bristol, United Kingdom, [8]Clinical Psychology Unit, Department of Psychology, The University of Sheffield, Sheffield, United Kingdom

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Editorial on the Research Topic
Addressing community priorities in autism research

Autism is a form of neurodiversity, currently characterized by differences compared to the neurotypical population across multiple domains including sensory processing (Proff et al., 2021), social communication style (Crompton et al., 2021), attentional processing (Murray et al., 2005), and movement and motor processing (Miller et al., 2021). Historically, autism (and thus autistic people) has been studied through a medical lens (Chapman and Carel, 2022), owing primarily to the characterization of autism as a disorder of childhood development. These conceptualizations led to dehumanizing narratives about autistic people (Botha) and have impacted on who we consider to be knowledgeable about what it is like to be autistic (Kourti). In recent years, there has been a shift toward recognition of autism as a form of neurodivergence; a naturally occurring variation in the human population that may lead to a differential profile of strengths and challenges in comparison to the non-autistic population (Den Houting, 2019). This shift has been primarily driven by the autistic self-advocacy and neurodiversity movements (Kapp et al., 2013; Walker, 2021), which have campaigned for better understanding of autistic people.

The push for a better understanding has included a demand for research which better serves autistic people and their priorities (Poulsen et al., 2022). In 2013, a report from Pellicano et al. (2014) revealed that whilst the majority of funding in autism research was allocated toward genetic profiling and biomedical intervention, very little went toward what community stakeholders (including autistic people and their family members) saw as valuable research. There was a strong desire amongst the autistic and broader autism communities for an increase in research, and associated support outcomes, in areas such

as physical and mental healthcare, education, and employment (see also James Lind Alliance, 2016). In what is now almost a decade since that report was released, we have seen a sharp increase in research that addresses these autistic community priorities.

One way that this has been achieved has been through participatory research, whereby community members and stakeholders engage in developing research in consultation and collaboration (Keating; den Houting et al.) with researchers. Involving autistic people in research about them can shape more ethical and impactful research, as outlined by Keating in his opinion article on how participatory autism research can benefit everyone. However, we still have a way to go. den Houting et al. found that research stakeholders feel that academics are still disconnected from the communities they serve, and have a tendency to tokenize the input of community members when developing research. These sentiments are also compounded by the dehumanizing narratives surrounding autistic people which can make engaging in research as both a community member and a researcher a painful experience as outlined by Botha. For Kourti, the solution requires more than a participatory approach. They argue for the importance of autistic-led theory and practice in autism research, drawing upon a critical realist framework (Bhaskar, 1987) to emphasize how embodied knowledge of what it is like to be autistic can produce more credible work. These articles provide us with a way forward for meaningful autism research: non-autistic researchers need to recognize the burden that autistic people face in engaging with autism research, and work to create a more hospitable (and credible) field for all.

One example of an autistic-led theory which has garnered much empirical support is the Double Empathy Problem (Milton, 2012). Milton proposes that it is not autistic "social deficits" that underlie communication breakdowns between autistic and non-autistic people, but significant differences in how autistic and non-autistic people experience and process the world around them, and a lack of reciprocal understanding between the two groups. Thus, social communication is not a difficulty experienced solely by an autistic person, but a "double problem" that is experienced within an interaction between an autistic and non-autistic person (Davis and Crompton, 2021). Non-autistic people experience similar difficulty in understanding autistic people as autistic people do in understanding non-autistic people (Chown, 2014; Edey et al., 2016; Sheppard et al., 2016; Crompton et al., 2020).

Several papers in this special issue are centered on the concept of Double Empathy, and innovative ways to embody its principles to improve communication between autistic and non-autistic people. Whilst most social interventions for autism are targeted at autistic people, Jones et al. piloted a brief autism acceptance training aimed at non-autistic people to enhance their understanding of autistic people. They then compared dyadic interactions between (i) non-autistic people who had completed the training and autistic people, and between (ii) non-autistic people who had not completed the training and autistic people. In the dyads where the non-autistic person had completed the training, both the non-autistic and the autistic person expressed greater interest in spending social time together in the future. This promising finding suggests that increasing non-autistic people's understanding of autism may minimize the social exclusion faced by autistic people. Chapple, Davis, Billington, Williams, et al. and Chapple, Davis, Billington, Myrick, et al. used a novel approach to examine the facilitation of empathy between autistic and non-autistic partner dyads. Participants read *Of Mice and Men* (Steinbeck, 1937), before completing reading diaries, a creative writing task, and discussing the book with their partner. In Chapple, Davis, Billington, Williams, et al. autistic participants showed enhanced socio-empathic interpretations of the novel compared to the non-autistic participants. In Chapple, Davis, Billington, Myrick, et al. non-autistic participants reported an enhanced understanding of what it means to be autistic, while the autistic group reported feeling valued by their non-autistic reading partners and overcame their worries about non-autistic stereotypes of autism. Working together to appreciate each other's differences and experiences facilitated mutual understanding between autistic and non-autistic people.

Two further papers consider how the double empathy problem may play out in education and social support. Brownlow et al. highlight the crucial role that effective communication between teachers and autistic students plays in supporting successful school participation. Rather than depending on assumptions and stereotypes of autism, pupils wanted teachers to ask them what their individual needs were within a neurodiversity-affirmative framework. Crompton et al. describe interviews about the post-diagnostic phase for autistic adults, discussing peer support and community connection. Autistic adults reflected on the benefits of spending time with other autistic people, especially within the post-diagnostic period. The ease and mutual understanding experienced within an autistic-only space may provide more comfortable support for autistic people following diagnosis than support provided by non-autistic people, and help autistic people to build resilience to manage living in a majority non-autistic world.

Access to diagnosis and post-diagnostic support can be crucial in improving wellbeing for autistic people. Many autistic people experience misdiagnosis prior to being identified as autistic, which Iversen and Kildahl attribute to diagnostic overshadowing and a lack of autism specific expertise in mental health services. In their case report, they describe a patient who experienced misdiagnosis, which led to inappropriate psychopharmacological intervention. Once he was identified as autistic, treatment for his mental health difficulties were adapted and his quality of life improved, with him citing his autism diagnosis as a positive experience. The positive impact of an autism diagnosis was partially supported by

findings from Corden et al. who conducted a mixed-methods exploration of the impact of diagnosis on identity. Time since diagnosis impacted on autistic personal identity, with people diagnosed more recently expressing more dissatisfaction with their identity compared to those for whom more time had passed. Qualitative data from this study suggested that the post-diagnostic adjustment period was emotionally fraught, and people found support throughout this period was often lacking.

Developing effective support for autistic people should be underpinned by understanding factors which impact on autistic quality of life across the lifespan. Phung et al. report findings from interviews with young people (aged 8–18) about the experience of burnout, inertia, meltdowns and shutdowns (BIMS). They identify the need for a more compassionate approach from trusted adults in supporting them during their experiences of these complex phenomena. These findings have important implications, given the prevalence of mental health difficulties reported by autistic adults later in life. Roestorf et al. found that over two thirds of autistic adults report physical and mental health difficulties in a longitudinal exploration of the relationship between mental health and quality of life outcomes. Two studies in this special issue focused on how application of knowledge about autistic mental health and support can improve outcomes for autistic university students. Cheriyan et al. found that autistic university students desired the opportunity to develop career-focused skills alongside mental health support. These findings were further supported by Lucas et al. who found that autistic university students reported feeling ill-prepared for the transition out of university into a career and desired support for this transition that focused on both emotional and career-related factors. Together, these four studies emphasize the need for approaches which identify factors which lead to negative outcomes for autistic people across the lifespan, and provide compassionate support informed by the preferences of autistic people.

Three papers in this special issue focus on how the development of robust and effective support for autistic people is fraught with problems. Two papers focus on effective support for autistic communication. Davis et al. examine the evidence in support of concerns that bilingualism may contribute to cognitive and language delays in autistic children. Their findings suggest autistic bilingual people should have equal access to language learning opportunities, supported by practitioners with up-to-date knowledge about neurodiversity. Similarly, Heyworth et al. discuss polarizing attitudes toward a form of Augmentative and Alternative Communication (AAC) term "facilitated communication" (FC). They argue that research into FC would benefit from a more up-to-date approach including autistic participatory involvement, and the absence of ableist assumptions about communicative competence. The final paper focuses on the presence of undisclosed conflicts of interest (COIs) in the Applied Behavior Analysis (ABA) literature (Bottema-Beutel and Crowley). ABA is frequently recommended as an intervention for autistic people (Xu et al., 2019), yet the evidence base for its efficacy is inconsistent (Sandbank et al., 2020) and Bottema-Beutel and Crowley found pervasive undisclosed COI's in the ABA literature, supporting the concerns of autistic people about the standard of ABA and associated interventions.

Conclusions

The articles in this special issue highlight the evolving landscape of autism research, where increasingly work is starting to address the issues that autistic people and other stakeholders hold most valuable. Importantly, more than half of the articles include at least one autistic author, suggesting that calls for the involvement of autistic expertise in autism research are increasingly being answered. We hope that these advancements continue into the next decade and beyond.

Author contributions

AP and CC wrote the initial draft of the manuscript. AS, CG, DP, FS, and SA-Y reviewed and edited the manuscript. All authors have agreed the final version.

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Pervasive Undisclosed Conflicts of Interest in Applied Behavior Analysis Autism Literature

Kristen Bottema-Beutel and Shannon Crowley*

Lynch School of Education and Human Development, Boston College, Chestnut Hill, MA, United States

Many autistic people (including researchers and non-researchers) are becoming increasingly involved in, and increasingly critical of, autism intervention research. They have expressed concerns regarding applied behavior analysis (ABA) interventions on a number of grounds, one of which is the prevalence of conflicts of interests (COIs) among autism intervention researchers. These concerns are now also being addressed by non-autistic researchers. COIs can introduce bias into the research process, and allow researchers to demonstrate positive effects for interventions that are not actually effective. Despite these concerns, there are no studies to date that examine the prevalence of COIs in behavioral journals. Because ABA services are routinely provided to autistic people in the United States as a means to address difficulties experienced by autistic people, this is an important area of investigation. We tallied author COIs in articles published over a 1-year period that tested, commented on, or reviewed ABA autism intervention strategies, extracted from eight journals devoted to publishing behavioral research. We coded included studies for COIs related to researcher employment as an ABA clinical provider or a training consultant to ABA clinical providers. We found that 84% of studies had at least one author with this type of COI, but they were only disclosed as COIs in 2% of studies. Additionally, 87% of studies with statements claiming the authors did not have COIs, were authored by researchers found to have clinical/training consultancy COIs. Pervasive, undisclosed COIs likely lead to researcher bias, and could at least partially account for persistent poor quality research in this area. The high prevalence of COIs among this research corroborates the concerns expressed by many autistic people. The autism community – including autistic people, autism researchers, and other stakeholders – should be aware of the prevalence of undisclosed COIs in this literature and take this into account when using, providing, or recommending ABA services.

Keywords: autism, intervention – behavioral, applied behavior analysis, conflicts of interest, researcher ethics

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Edited by:
Amy Pearson,
University of Sunderland,
United Kingdom

Reviewed by:
Laura Crane,
University College London,
United Kingdom
Kathy Leadbitter,
The University of Manchester,
United Kingdom

****Correspondence:***
Kristen Bottema-Beutel
kristen.bottema-beutel@bc.edu

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INTRODUCTION

In intervention research, conflicts of interests (COIs) occur when researchers can potentially benefit from demonstrating that interventions are effective in achieving particular outcomes (Gorman, 2018). Researcher COIs do not always indicate that a given study is biased, but failure to acknowledge COIs can mean that the researchers have not taken appropriate precautions to protect against the bias that COIs potentially introduce. In order to alert stakeholder communities to the presence of COIs that could introduce bias into the research process, most journals that

publish intervention research instruct authors to disclose actual, potential, or perceived COIs. The Committee on Publication Ethics (COPE) was established in 1997 in an effort to improve research integrity, with COIs being a chief concern (Committee on Publication Ethics, 2019). Major contributions of COPE are disseminating guidance on the establishment of COI policies and offering procedural advice on resolving COI disputes to member journal editors.

Recently, a review of 150 group design intervention studies for young autistic children concluded that COIs are likely pervasive, but under-reported in this literature, despite the ubiquity of COI disclosure requirements (Bottema-Beutel et al., 2020). A limitation of this study is that it excluded single case designs (SCDs), which is the study design used by the majority of research into the effects of applied behavior analysis (ABA) interventions for autistic people (Dawson and Fletcher-Watson, 2020; described in detail below). It is important to explore COIs in this area of research because many autistic adults (including researchers and non-researchers) and non-autistic researchers have expressed serious ethical concerns about the provision of ABA to autistic people (Dawson, 2004; Devita-Raeburn, 2016), including concerns related to undisclosed COIs (Dawson, 2020). Autistic people are increasingly setting the agenda for autism research, and this includes critiques of intervention practices they may have received as children, or continue to receive into adulthood. Further, ABA interventions are routinely recommended by primary care providers in the United States to parents seeking support for their autistic children (Zwaigenbaum et al., 2015; Hyman et al., 2020), with more than 60% of autistic children in the receiving some form of behavioral intervention rooted in ABA philosophy (Xu et al., 2019). As such, it is important to determine if these recommendations are consistent with available literature and not unduly influenced by researcher bias.

Conflicts of interests vary in the extent to which they present clear-cut opportunities for researcher gain, and therefore also likely vary in the magnitude of their influence on researcher conduct. For example, COIs directly involving the researcher's employment may be a larger source of bias than COIs that provide opportunities for prestige (which is arguably present in most intervention studies given publishing incentives that reward positive findings), but are not explicitly linked to financial gain. In the current study, we focus on the former type of COI; specifically on instances where the intervention researcher is also an ABA clinical provider and/or provides paid training consultation to ABA clinical providers. Employment related COIs are widely recognized as COIs that can contribute to researcher bias, and because of this are regularly required in journal submission policies to be disclosed in research reports.

Applied Behavior Analysis

Applied behavior analysis is an approach to studying and modifying behavior that is based on the principles of behaviorism. Behaviorism is a theory of learning that asserts all behavior is learned via contingencies between antecedents (events preceding the production of a behavior), the behavior, and the consequences following the behavior (Watson, 1924/2017). Behavior that is followed by favorable outcomes will continue to occur, and behavior that is not followed by favorable outcomes will disappear from one's repertoire (Roane et al., 2016). According to this theory, these contingencies can be leveraged to teach children and adults new behavior that expands upon or replaces existing behavior patterns. Principles of ABA were first formulated as an intervention program for autistic children in the early 1960s (Ferster and DeMyer, 1962) and later broadened into a more intensive program by Ivar Lovaas in the 1970s and 1980s (Lovaas, 1987). Since then, ABA services for autistic people have become widely available, and are provided in clinics, schools, and hospitals in the United States and internationally.

Many ABA proponents assert that ABA is not a single intervention approach but a variety of approaches that share underlying principles in regards to behavior and learning (Baer et al., 1968). However, the procedures used by ABA practitioners who provide services to autistic people are often marketed using the umbrella acronym "ABA," even if those services vary in terms of intensity, focus, and delivery context. ABA interventions for autistic people are the most widely known and researched form of ABA intervention, and comprise a sub-specialty of certification by the Behavior Analysis Certification Board (2020). In most states in the US, professionals who provide ABA services are required to receive specialized training to become a Board Certified Behavior Analyst (BCBA), or be supervised by a BCBA. While some literature of reviews have concluded that behavioral approaches are efficacious for supporting autistic children (e.g., Zwaigenbaum et al., 2015), meta-analytic studies that have sufficiently examined study quality using well-established quality indicators (e.g., the Cochrane risk of bias tool; Higgins et al., 2011) report that there is insufficient evidence for these claims (e.g., Sandbank et al., 2020).

Sources of Bias in Single Case Design Intervention Research

A behaviorist approach to understanding human behavior and learning invites the operationalization of discrete behaviors, to determine how they change after alteration of antecedents or consequences. Therefore, ABA intervention researchers often make use of SCDs, in which behaviors are observed and repeatedly measured prior to an intervention (i.e., the baseline condition) and again during the implementation of an intervention (i.e., the "treatment" condition). Through various techniques of staggering the onset of intervention procedures across participants, environments, and/or time, researchers can make claims about functional relations between the intervention procedures and changes in children's observed behavior.

Unlike for group design research, there is no widely agreed upon tool for assessing bias in SCD studies. However, Reichow et al. (2018) propose that risks of bias in SCDs are analogous to risks of bias in group-design studies. They describe three risk of bias categories, including: (a) selection bias (systematic differences in baseline characteristics of participants),

(b) performance bias (systematic differences between participants in care or exposure to factors other than the intervention), (c) and detection bias (systematic differences between participants in the measurement and reporting of outcomes). Each of these sources of bias can increase the likelihood that an intervention procedure will be determined to bear a functional relation with the outcome, when it in fact does not. For example, a researcher could assign participants to a control condition if they have some reason to suspect the intervention will not be successful for that student during a particular session (selection bias). Or, researchers may know which participants are assigned to an intervention condition, and treat them more favorably than participants in the control condition in ways unrelated to the intervention being examined (performance bias). Finally, researchers who track data on participant outcomes may be aware of when the child is in a treatment condition, and may score that child more favorably than when the child is in the control condition (detection bias). In addition to these sources of bias, researchers can also interpret evidence more favorably than is warranted, and determine that a set of intervention practices are effective for improving outcomes, when the data in fact do not support this assertion (Bottema-Beutel and Crowley, 2020).

Because risk of bias evaluation tools for SCDs are relatively new, there are only a few studies to date that have used them to evaluate ABA interventions. One recent review is notable, however. Davis et al. (2019) systematically evaluated research on non-pharmacological interventions for autistic adults over a 50 year period. The majority of included studies were SCDs examining ABA intervention techniques. Using Reichow's risk of bias tool, they found that nearly 75% of included studies had a high risk of bias across all four domains described above. Bias in this area of study therefore appears widespread, and limits our ability to rely on evidence used to make claims of effectiveness. It is possible that author COIs contribute to the persistently large percentage of ABA studies that are low quality designs (see also Sandbank et al., 2020, for a similar evaluation of group design autism intervention research).

The Current Study

In this study, we examined author COIs from articles focusing on interventions for autistic people, extracted from eight peer reviewed journals devoted to publishing research on ABA strategies. We selected ABA journals that represented a variety of publishers, and a range of impact factors. We also ensured that the top journals in the field were represented in our sample; the *Journal of Applied Behavior Analysis* is considered a flagship ABA journal (Kranak et al., 2020), and *Behavior Modification* has a similar Impact Factor in the year this study was conducted. Our aims were to determine: (a) the proportion of articles with one or more authors who either provided ABA clinical services or provided private training to ABA practitioners, (b) the proportion of articles with authors who had clinical and/or training COIs that omitted to disclose these roles as COIs in the manuscript, (c) the proportion of articles with authors who had clinical and/or training COIs that erroneously declared in the manuscript that the authors had no COIs, and (d) whether COI omissions were in violation of journal policies.

We selected studies from behavioral journals, as opposed to examining all autism ABA intervention studies, for three reasons. First, the bulk of autism ABA intervention studies are published in journals devoted to behavioral research. Second, publishing policies and practices are cultivated at the journal level, as journal editors and publishers are responsible for setting and enforcing policies. Third, conclusions that can be drawn in regards to publishing practices in specific journals may be more useful for proposing action steps that can be taken by individual editors and publishers.

We chose to focus on clinical and consultative COIs, as opposed to examining all potential COIs, for four reasons. First, these COIs present clear financial stakes, as the researcher's employment is dependent on clients and practitioners perceiving ABA as an efficacious method for supporting autistic people. The financial incentives for other COIs, such as when researchers are board members but not paid staff members for an entity that provides intervention services, may be less clear. Second, ABA researchers who are employed in these clinical and/or consultative positions can use their published research as advertisements for the efficacy of their services, enhancing the financial incentives for positive findings. Third, these COIs are often directly stated in journal submission policies as the types of COIs that must be disclosed, and researchers across disciplines generally agree that these roles constitute COIs. Finally, clinical and consultative COIs are easy to locate in comparison to other COIs (e.g., the receipt of speaker fees, or royalties received from book sales), because clinical providers and training consultants often advertise their services via web pages. The relative ease of locating these COIs allows for a more accurate estimation of their prevalence, in comparison to other COIs that may not be possible to find via web searches and are not routinely disclosed.

METHODS

Journals

We examined eight journals with a main focus on disseminating research on behavioral interventions, including: *Behavior Modification*, the *Journal of Applied Behavior Analysis, Behavior Analysis in Practice, Perspectives on Behavior Science*, *Journal of the Experimental Analysis of Behavior*, *Journal of Behavioral Education*, *The Analysis of Verbal Behavior*, and *The Psychological Record*. We searched each journal website for policies related to COI disclosures, and report this information in **Table 1**.

Article Selection and Coding

We reviewed articles from the eight journals listed above that were published over a 1 year period (September 2019–September 2020), starting with the most recently available issue and backtracking through issues until a full year was covered. First, titles and abstracts were scanned to determine if the study examined an intervention strategy, reviewed a set of intervention strategies, or provided evaluative commentary on intervention strategies. Next, the participant information in the full text was

TABLE 1 | Author Submission Guidelines Relevant to Conflict of Interest Disclosures.

Journal	COPE member	Conflict of Interest Policy from Author Submission Guidelines
Behavior Modification	Yes	No policy on journal website
Journal of Applied Behavior Analysis	No	No policy on journal website
Behavior Analysis in Practice/Journal of Behavioral Education/The Analysis of Verbal Behavior/The Psychological Record	Yes	Authors are requested to disclose interests *that are directly or indirectly related to the work submitted for publication*. Interests within the last 3 years of beginning the work (conducting the research and preparing the work for submission) should be reported. Interests outside the 3-year time frame must be disclosed if they could reasonably be perceived as influencing the submitted work. Disclosure of interests provides a complete and transparent process and helps readers form their own judgments of potential bias. This is not meant to imply that a financial relationship with an organization that sponsored the research or compensation received for consultancy work is inappropriate . . . **Employment:** Recent (while engaged in the research project), present or anticipated employment by any organization that may gain or lose financially through publication of this manuscript. This includes multiple affiliations (if applicable) . . . **Non-financial interests:** In addition, authors are requested to disclose interests that go beyond financial interests that could impart bias on the work submitted for publication such as professional interests, personal relationships or personal beliefs (amongst others). Examples include, but are not limited to: position on editorial board, advisory board or board of directors or other type of management relationships; writing and/or consulting for educational purposes; expert witness; mentoring relations; and so forth
Perspectives on Behavior Science	Yes	All authors are requested to include information regarding sources of funding, financial or non-financial interests, study-specific approval by the appropriate ethics committee for research involving humans and/or animals, informed consent if the research involved human participants, and a statement on welfare of animals if the research involved animals (as appropriate)
Journal of the Experimental Analysis of Behavior	No	No policy on journal website

COPE = Committee on Publication Ethics.

reviewed to determine if at least one autistic participant was included in the study, or, if the article was a review/commentary, to determine if autistic participants were included in at least one of the primary studies that were included in the paper.

If a study was selected for inclusion, author names were recorded, and a Google search was conducted to determine if the author was employed in a clinical practice providing ABA services, provided private ABA services, or served in a training/consultancy capacity to ABA providers (university faculty who taught courses in BCBA programs were not considered to have this COI). If we could not locate evidence that a given member of the research team held a clinical/consultative COI at the time the study was conducted, we coded this as "no COIs." As such, our COI counts are likely underestimates of the true number of researcher COIs. The KB-B and SC overlapped on 20% of articles to determine inter-coder agreement on designating an article as having at least one author with this COI, which was 86%. Finally, each full text article was scanned to determine if there was a COI disclosure statement. If such a statement was located, it was copied verbatim onto the coding spreadsheet, and a determination was made as to whether the statement covered the clinic and/or consultative COI identified in the first coding step. Because there were so few statements disclosing COIs, coding determinations were made by consensus between the KB-B and SC.

RESULTS

From the eight journals we examined, 180 articles met our inclusion criteria. Only five studies used group designs; the remaining 175 studies were either SCDs, reviews that included SCDs as primary literature, or commentaries on interventions/procedures that incorporated SCD research as evidence. Of the 180 included studies, 151 were authored by at least one person with a clinical and/or training consultancy COI (84%). A total of 501 unique author names were searched, and 260 were found to have a clinical and/or training consultancy COI (52%). COI statements were absent in 105 studies (58%), 70 studies included statements declaring no authors held COIs (39%), and only five studies included statements declaring COIs (3%). Of the 70 studies that declared no COIs, 61 of these were found to have at least one author who provided ABA clinical services and/or training consultations to ABA providers (87%). Two of the five studies that declared COIs disclosed the receipt of royalties from book sales, but did not mention relevant training consultancies performed by the author. Therefore, only 2% of studies adequately accounted for clinical/training consultancy COIs. Information regarding COIs and COI disclosures by journal are presented in **Table 2**.

Authors with COIs were located in seven of the eight journals; only one journal (*The Psychological Record*) did not have any authors with clinical/training consultancy COIs, but this journal contributed only one article relevant to our analysis. For the remaining seven journals, 75–100% of articles were authored by researchers with clinical/training consultancy COIs. In five of the six journals with articles providing COI statements, 79–100% of these statements falsely declared no COIs. The sixth journal only contributed one article to this analysis, and it was not authored by researchers with COIs.

Five of the eight journals provided instructions for authors regarding the disclosure of COIs, which, in our interpretation, included requirements to disclose clinical and/or training

TABLE 2 | Conflict of Interest Information by Journal.

Journal (Most Recently Available Impact Factor)	Total articles	Articles with clinical/training COIs	COI statements	COI statements declaring no COIs	COI statements inaccurately declaring no author COIs*
Behavior Analysis in Practice (NA)	39	34 (87%)	36	32	27 (84%)
Behavior Modification (2.105)	15	15 (100%)	15	15	15 (100%)
Journal of Applied Behavior Analysis (2.108)	87	70 (80%)	0	NA	NA
Journal of Behavioral Education (.894)	18	14 (78%)	15	14	11 (79%)
Journal of the Experimental Analysis of Behavior (1.616)	9	8 (89%)	0	NA	NA
Perspectives on Behavior Science (1.219)	4	3 (75%)	1	1	1 (100%)
The Analysis of Verbal Behavior (NA)	7	7 (100%)	7	7	7 (100%)
The Psychological Record (1.010)	1	0 (0%)	1	1	0 (0%)

COI = Conflict of Interest, NA = Not Available or Not Applicable.
**Percentage calculated from total number of COI statements declaring no COIs.*

roles (readers are again referred to **Table 1**). For four of the five journals with false statements regarding COIs, these statements were in violation of journal policy regarding COI disclosures. For two of three journals that did not provide COI policies (the *Journal of Applied Behavior Analysis* and the *Journal of the Experimental Analysis of Behavior*), there were no COI statements included in any of the articles reviewed. For the third journal (*Behavior Modification*), all 15 articles selected for inclusion provided identical COI statements: "The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article." Despite these statements, all 15 articles were coded as having at least one author with a clinical and/or training consultancy COI. It is unclear how COIs were defined for these authors in the submission instructions, or at what point in the submission process they were prompted to provide this statement. Six of the eight journals are COPE members, and five of the six (all but *The Psychological Record*) published articles falsely claiming that authors did not have COIs.

DISCUSSION

Our findings corroborate ethical concerns raised by autistic people, autistic researchers, and non-autistic researchers in regards to ABA autism intervention research. In the articles we examined, nearly all authors who were employed in clinical and training consultancy roles either omitted to declare them as COIs in their published reports (i.e., there was no COI statement provided), or falsely claimed that the authors held no COIs. In many instances, such statements were in clear violation of the journal's submission guidelines. In our process of searching for these COIs, we found particularly egregious cases where researchers posted links or reference to their published research on websites advertising their private clinical/training consultancy services. As such, these individuals are using their research to market their clinical expertise to prospective clients, but still claiming that their research is free of COIs.

The reasons for such a high prevalence of clinical/training consultancy COIs are likely linked to how ABA researchers are trained to conduct research. Many BCBA graduate programs simultaneously provide training in clinical practice and research methods, which means the majority of program graduates hold dual roles as ABA researchers and practicing BCBAs. Further, more established researchers may be considered leading experts in clinical practice, allowing for the possibility of branding themselves as consultants to existing BCBA practitioners. Researchers may gain important insights into intervention strategies via hands-on clinical practice and consultation roles that can positively inform their research; however, the financial incentives associated with such roles also present clear COIs that should be readily disclosed in research reports. Our findings indicate that ABA researchers not only maintain their BCBA credentials, they hold active roles as clinical providers or training consultants. There was variation in the specific roles held by researchers deemed to have COIs in this category. Roles could include employment as clinicians in large regional ABA centers or private ABA clinics, employment as CEOs/directors of ABA clinics and training consultancies, and employment as clinician, director, or training consultant in University-based clinics.

The prevalence of COIs, and the failure to disclose them, is an issue for autism intervention research more generally, and is not specific to ABA journals (Bottema-Beutel et al., 2020). However, while we recognize that the current study is not directly comparable to Bottema-Beutel et al. (2020) examination of COIs in group-design intervention literature, it is worth noting that they found COIs in 70% of reports when considering *all* COI types, as compared to the current study in which COIs were found in 84% of reports when restricting our search to exclusively cover clinical/consultancy COIs. Omitting to disclose clinical/consultancy COIs, or declaring that no COIs exist when they in fact do, could be common practice precisely because this COI is so prevalent and not considered particularly noteworthy. In addition, there are so few examples of COI statements in this literature that disclosure is simply not a norm governing researcher conduct. Because ABA autism intervention research is routinely published in ABA-specific journals, submitted reports

are likely peer-reviewed by researchers with the same COIs as the submitting authors, and handled by editors who also have these COIs. This insular publication process has culminated in the production of a vast body of literature that has not adhered to basic ethical standards in regards to COI disclosures. The result of this failure of oversight, at a minimum, is that the extent to which we can be confident in study findings is greatly reduced.

Conflicts of interests that involve the provision of ABA services to autistic people or private consultation to ABA providers are pervasive in autism ABA intervention literature. Additionally, the failure to clearly disclose these roles as COIs is equally pervasive. COIs have the potential to introduce bias into the research process in ways that are not always known to the researcher, and ethical guidelines stipulate that COIs should be disclosed in published reports so that appropriate scrutiny and skepticism can be applied to research findings. Reviews that have assessed the quality of ABA research provide evidence that the majority of these studies – both for group design and SCD research – are designed in such a way that the risk of bias is high (Davis et al., 2019; Bottema-Beutel and Crowley, 2020; Sandbank et al., 2020). COIs such as those described in this paper may provide insight into why poor study quality has persisted (Dawson and Fletcher-Watson, 2020).

Limitations

This study is limited by the fact that it covers only 1 year of publication, is restricted to only one type of COI, and focuses exclusively on journals devoted to publishing ABA research. Additional research may determine if trends in COI disclosures change over time, if the prevalence of COI reporting across different types of COIs, and if COI reporting differs for ABA studies that are published in ABA journals as compared to journals that publish a variety of intervention types.

Recommendations and Implications

For ABA journals that do not have a prominently displayed COI disclosure policy (or do not have a policy at all), we recommend journal editors clearly indicate the necessity of declaring clinical/training consultancy roles as COIs, and feature these policies prominently in their instructions for authors. The COIs we explore in this paper already appear in most COI disclosure policies (including several of the journals included in this study), but there may be additional "grey area" COIs with risks of bias that are less clear and more difficult to protect against. A consensus-led tool for identifying and properly disclosing actual, potential, and perceived COIs could be developed and disseminated by journal editors, which benefit researchers both within and outside ABA autism intervention research. We also recommend much stronger oversight so that submitting authors actually follow the policies in place, and in cases where there are violations, editors have a responsibility to investigate and publish corrections as necessary.

Applied behavior analysis researchers, in turn, should routinely and clearly state any ABA clinical or training consultancy roles they perform when submitting research reports. Universities that prepare BCBAs and simultaneously provide research training should include information about ethics related to COIs in their curricula, so that ABA researchers are aware of these issues from the beginning of their careers (Dawson and Fletcher-Watson, 2020). We also recommend that ABA researchers develop procedures that reduce the risk of bias that these COIs likely introduce. In group design intervention research, intervention developers (who have a related, but different COI) have outlined protocols in which they remain a member of the research team, but partition themselves from the collection and analysis of data (Eisner et al., 2015). Likewise, interventionists who are on the research team should remain separate and independent from data collection and analysis teams. Data collection and analysis team members should be recruited who do not have a vested interested in the intervention being provided and are able to remain naïve to whether a child is in an intervention or control phase. Finally, analysis plans should be pre-registered prior to the launch of the study (including plans to protect against bias due to COIs. All procedures designed to reduce bias due to COIs can then be included in the method section of the published report, which would include any deviations from pre-registered procedures. These suggestions may serve as a useful starting point, but we believe it would be helpful for researchers to develop more formal guidance (similar to the Consolidated Standards for Reporting Trials checklist; Schulz et al., 2010) that all researchers could reference and follow, and journal editors could enforce as part of their publication standards.

Given that clinical/training consultancy COIs are so prevalent among ABA autism intervention researchers, implementing these reforms may require a significant restructuring of how research in this area is conducted. This restructuring is necessary if autistic people, and other stakeholders including parents of autistic children, researchers, and practitioners (we note that many of these latter three categories are also autistic people) – are to have any trust in the veracity of ABA autism intervention research findings. While mistrust in ABA research and practice goes beyond the prevalence of COIs, considerable improvements in COI disclosures and increased protections against their influence on research findings, is a small but necessary step toward improving stakeholder perceptions.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

AUTHOR CONTRIBUTIONS

KB-B conceptualized the project, co-designed the study, participated in data collection, analyzed the collected data, contributed to interpreting the analysis, and drafted the manuscript. SC co-designed the study, participated in data

collection, contributed to interpreting the analysis, and edited the manuscript. Both authors contributed to the article and approved the submitted version.

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Conflict of Interest: KB-B has previously received fees for consulting with school districts on intervention practices for autistic children and teaches courses on topics including applied behavior analysis. After the completion of this manuscript (but prior to its acceptance), KB-B accepted speaker fees in the amount of $750 to discuss her work on conflicts of interest. She also receives royalties for a co-edited book entitled Clinical Guide to Early Interventions for Children with Autism, published by Springer. At the time of publication, the total amount of royalties received for this work was $261. SC was formerly affiliated with an entity that trained students to become Board Certified Behavior Analysts and provided early Intensive Behavioral Intervention.

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BRIEF RESEARCH REPORT
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"Just Ask Me": The Importance of Respectful Relationships Within Schools

Charlotte Brownlow[1,2]*, *Wenn Lawson*[1,3], *Yosheen Pillay*[2,4], *Joanne Mahony*[2] and *Ding Abawi*[1]

[1] School of Psychology and Counselling, University of Southern Queensland, Toowoomba, QLD, Australia, [2] Centre for Health Research, Institute for Resilient Regions, University of Southern Queensland, Toowoomba, QLD, Australia, [3] Curtin Autism Research Group, Curtin University, Perth, WA, Australia, [4] School of Education, University of Southern Queensland, Toowoomba, QLD, Australia

An inclusive approach to education requires schools and educators to address the support needs and individual predispositions of all students. Our research highlights the crucial importance of effective and respectful communication with autistic students to facilitate their successful participation in schools. This paper explores the experiences of 24 autistic individuals aged 16–67 years, through synchronous semi-structured interviews and written responses. The research team comprised both autistic and allistic (non-autistic) researchers, who worked together to design the overall project, collect interview data, and analyse the data. Relationships were frequently discussed by participants and the importance of positive relationships was positioned as key to successful participation within educational contexts. Particularly damaging were assumptions made by teachers concerning individual ability based on labels given. Participants recalled ongoing challenges with resisting stereotypes and managing stigma, while trying to craft a positive autistic identity and advocate for rightful supports for their education. At the core of these negotiations were positive relationships, and teachers who asked participants what their needs were, and then listened and proactively responded to their answers. Recommendations for more positive schooling engagements with autistic young people are provided.

Keywords: co-production, education, autistic identity, support, school, student experience, inclusion

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Amy Pearson,
University of Sunderland,
United Kingdom

Reviewed by:
Emily McDougal,
University of Surrey, United Kingdom
Damian Milton,
University of Kent, United Kingdom

***Correspondence:**
Charlotte Brownlow
charlotte.brownlow@usq.edu.au

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INTRODUCTION

There is little debate in the literature that autistic people are neurologically different from allistic[1] (non-autistic) people. However, autistic people have been positioned in research and clinical literature as "lacking," with "deficits" in areas of communicative and social interactions, alongside restricted and repetitive behaviours and interests (American Psychiatric Association, 2013). While it is clear that autistic people do have difficulties with some aspects of their lives, these are *differences* not *deficits*. For example, autistic individuals tend to focus on specific areas of interest

[1]The term allistic has been chosen to describe non-autistic people. Derived from Greek, the terms "allistic" and "autistic" are neutral and non-judgemental descriptors.

much more than allistic individuals, who generally connect to broader, less focussed input from their environment (Lawson, 2011: Mottron et al., 2006). When individuals diverge from the typical, according to traditional thinking, deficit language is often used, which can lead to increased ableism (see Botha et al., 2021; Bottema-Beutel et al., 2021). Over the past six decades, autism has been considered a "disadvantage" and a "disorder." For example, it is common to read statistics such as "autism is a lifelong condition with estimated annual support costs to Australia potentially exceeding $7 billion" (Synergies Economic Consulting, 2011). Not seen however is any official costing or commentary on the personal, social, and/or economic impact on individuals, families, communities, and the nation of *not* adequately including or supporting autistic individuals in appropriate ways. For young people, schools are crucial environments in which to flourish both personally and academically. However, autistic young people are frequently met with exclusionary practices, pervasive discrimination, and bullying (Humphrey and Symes, 2010; Maïano et al., 2016).

Over the last decade, Australia has seen an increase in individuals recognised as being autistic, with 1 in 52 adolescents aged 13–15 years old identified, and an overall increase of 42% since 2012 (Autism Asperger's Advocacy Australia, 2015; Australian Bureau of Statistics, 2018). It is well-documented that autistic students[2] experience difficulties; less well-known is what supports are required to improve this situation. Traditionally, the emphasis has been on changing the autistic student to fit the school system (Lilley, 2014). More recent research suggests that it is more helpful to consider autistic students as different and not deficient, and that communication is the responsibility of all involved (Crompton et al., 2020). Within Australian school systems, the push towards inclusive practices exists within formal legislation that differs across, and between, states With higher numbers of autistic individuals being identified, more attention needs to be provided to their supports in various contexts, including education.

An inclusive approach to education requires schools and educators to address individual preferences and support the needs of all students, including those who are autistic (Batten, 2005; Lynch and Irvine, 2009). According to the Australian Bureau of Statistics (2018), 40% of autistic students accessed special tuition, 32% had support from a counsellor or disability support person, and 28% did not receive any support (Australian Bureau of Statistics, 2018). These statistics suggest that currently, autistic students require additional support to engage with and be successful at school, because the existing educational system does not provide adequate support to nurture all young people (Wei et al., 2014). Recent research with educators, parents, specialists, and autistic students explored support to improve educational outcomes for autistic students, found a lack of funding, limited education and training, time, and specialist support as barriers to supporting needs of autistic students (Saggers et al., 2016). Interviews with teachers and parents identified that the least supported needs of autistic students in educational settings were social and emotional, followed by behavioural, communication, and sensory needs.

It is therefore crucial that research explores both the barriers and enablers to positive educational experiences. We argue that this research needs to be underpinned by two main concepts:

1. An understanding that interactions between autistic and allistic people can be challenging due to inherent differences in neurology, with neither one being better or worse, but both being important aspects of human neurodiversity (see Singer, 1999; Milton, 2012); and
2. Not presuming that autistic equals deficient and, therefore, inferior, or that allistic equals acceptable and, therefore, superior.

Informed by the above, the current research sought to understand the school experiences of autistic young people and adults, adopting an abilities framework, i.e., focusing on *differences* not *deficits* and working from a presumption of "competence" rather than "incompetence" for each participant. The research team comprised both autistic and allistic researchers, who worked together to design the overall project, collect interview data, analyse the data, and write up the findings.

METHOD

Research Design Overview

A central feature of the research design was flexibility to enable participants to contribute to the data in ways that were accessible for them. Participants were able to contribute to an individual semi-structured interview, provide a written account, or engage in a text-based individual interview. Nineteen participants chose a semi-structured interview which was conducted either via Zoom or in person with a member of the research team, five participants chose to contribute via a written account and no participants elected to provide a text-based interview. A clear interview protocol was developed, that included prompt suggestions for interviewers (see **Appendix**). We were particularly interested in educational experiences within schools so we were looking for participants to share their experiences of what they found helpful in supporting their education and also elements that proved to be challenging for them. As such, the interview focused around seven primary open ended questions. However, given the semi-structured design, interviewers responded to participant answers flexibly and asked additional follow up questions where considered appropriate in order to capture fuller understandings of participants' experiences.

Recruitment

Following approval from the host university's Human Research Ethics Committee, an advertisement for the research was circulated via social media calling for participants. Interested individuals contacted a member of the team and were forwarded further information. This informed them of the study's requirements, participation options, participation incentives, and dissemination of study findings. Participants were then sent a consent form, with those 16–18 years sent an assent form

[2]The term "students" throughout the paper refers to individuals who are in school environments including primary, middle, and high school.

and a consent form for parents to complete. On receipt of a signed consent form, a mutually agreeable time for interview, either face-to-face or via Zoom, was arranged. Participants electing to make a written submission sent these to a member of the research team within a time frame convenient to them. Following the interview, all participants were sent a $30 electronic gift card as acknowledgement of their contribution. All interview recordings were professionally transcribed verbatim, and participants created a pseudonym for use in reporting of findings.

Participants

Twenty-four participants elected to contribute to the research. Participants were required to identify as autistic, be over 16 years of age, and be willing to share their experience of the Australian education system with the research team. Participants were not required to have a formal clinical diagnosis. This reflects the position of the research team in understanding autism as a core part of identity and also in recognition of the systemic barriers to seeking and acquiring a formal diagnosis, including availability of clinicians and financial constraints. The research team elected to interview a large participant sample so diverse experiences of educational contexts were captured (see **Table 1**).

Participants ranged from 16 to 67 years and had attended school in Australia. Participants had experiences with a range of school environments including mainstream state school, mainstream Catholic school, travelling teacher education, and specialist schools.

Approach to Data Analysis

The research team adopted a reflexive framework for thematic analysis as outlined by Braun and Clarke (2006, 2019), drawing on Willig's (2013) concept of "empathic" interpretations of the data. An open and reflexive approach to inductive analysis was therefore adopted rather than the development of an apriori coding framework. This allowed for the experiences of the individual participants to be considered in their entirety rather than prioritising particular narratives. Following verbatim transcription, each interview or written response was coded individually by the whole research team. Individual coding was discussed by all researchers and then broader themes were extrapolated. The broader themes were then discussed by the whole team, with agreement being reached concerning themes to be prioritised. The prioritised themes were then drafted by the first author, with finalisation of thematic selection discussed and amended by the entire team.

FINDINGS

Three themes from the findings are prioritised for discussion in this paper. These are *Avoiding assumptions of ability: The need for effective communication*; *The dangers of stereotypes, stigma, and judgements; Fostering skills of advocacy.* The key themes are shown in **Table 2**.

Several participants reported quite different experiences across primary and high school contexts, with a common report of increased challenges at high school compounded by increased experiences of stigma and negative perceptions of autistic differences. Relationships were frequently discussed by participants and the importance of positive relationships was positioned as key to successful participation within educational contexts. Particularly damaging were assumptions made by teachers concerning individual ability based on participant labels. Participants recalled ongoing challenges with resisting stereotypes and managing stigma, while trying to craft a positive autistic identity and advocate for rightful supports for their education. At the core of these negotiations were positive relationships and teachers who asked participants about their needs and listened and proactively responded to their answers. The following themes are proposed to capture the key elements underpinning the participants' reported experiences of schooling. At the core of these themes are the relationships that are built between students and their teachers and peers.

Theme 1: Avoiding Assumptions of Ability: The Need for Effective Communication

Several of the participants recalled instances where teachers had made assumptions about their abilities and needs without asking the students. Sometimes participants reported that teachers seemed to believe they were an autism expert based on their previous experience of teaching an autistic student. Aliya sums up the need for open communication when recounting her experiences at school:

> *So the big one was asking me. What I found out was they only did what they heard or had written and they wouldn't ask me how that made me feel or what would help me…So there were times when it's like if you just asked me, I could clarify things…if the teachers and students had asked me questions of what they were unsure of, that would have helped me a lot because it meant that they were interested and they wanted to help…So not checking on me, not asking questions and then having a belief and false facts already implemented. Aliya, 23 years.*

The lack of communication frequently meant that decisions were made at higher levels, with students being informed about decisions rather than being included in discussions. This held the expectation that they would follow whatever had been decided. For example:

> *So basically, what I felt was that they expected me to trust that they had my interest at heart, that they weren't trying to annoy me, but they were trying to be helpful. But they were also telling me that you can't say that or talk to us like that, because it makes—we feel as though you're getting angry at us, criticising us. Basically, they're expecting me to give them the benefit of the doubt, but I don't think they were giving that to me. I think if there's going to be trust…expectations have to be equal on both sides…It felt like I was expected to do all the work, express myself perfectly and also trust everyone and never think bad thoughts, ill of them, never mistrust them…I think students disengage when they feel like school is against them. Jack, 25 years.*

For students like Jack this meant that he felt communication was one-way, directed *at* him rather than *with* him, with expectations

TABLE 1 | Summary of participants.

Participant*	Age	Age of formal identification	Response type	Education state	Type of school
Aliya	23	Primary school	Interview	VIC	State; Private
Annie	44	43	Interview	UK; VIC	State; Home school; Travelling teacher
Bellae	18	15	Written	QLD	Private
Bobby	17	Primary school	Interview	QLD	Catholic; State
Cassie	41	37	Written	NT; NSW	State; Catholic
Damian	Early 30s	Late teens/early 20s	Interview	QLD	State
Dave	27	3	Interview	VIC	Special school
Dianne	41	37	Interview	VIC; QLD	State
Ella	16	Primary school	Interview	QLD	State
Freya	19	3	Interview	VIC	State
Gayle	35	Self-identified in adulthood	Interview	VIC	State
Helen	19	10	Interview	VIC	State
HY	22	3	Written	VIC	Special school; State
Jack	25	11	Interview	VIC	Catholic; State
Jacob	28	3	Written	TAS	State
Jane	46	44	Interview	VIC	Progressive kindergarten; Private
Jimmy	32	7	Interview	VIC	Catholic
Johnny	16	Before primary school	Interview	QLD	State
Kate	19	12	Interview	NSW	State; Catholic
Kwamay	43	39	Interview	VIC	State
Max	31	18/19	Interview	VIC	State
Pete	67	Not provided	Written	VIC	State
Sam	25	21	Interview	TAS	State
Shannon	19	3	Interview	VIC	State

*All names are pseudonyms.

that he would unquestioningly follow what had been agreed without his input or consent.

When teachers did communicate with students, it was also considered crucial to consider the impact of the words used. Part of this was the need to engage in more discrete communications. For example:

> *I think that there were times when I was singled out and things were said to me in front of other kids that probably could have been saved for a quiet moment or not been bothered to be dealt with at all. Kwamay 43 years.*

Similarly, the importance of carefully constructed written communications was also highlighted. For example:

> *I look at my reports and a lot of reports talk about me being interrupting, me speaking out of turn, me talking when not spoken to and being an obstructive person. But they also talk about not trying hard enough, not putting in my best effort and giving up…maybe my mum shouldn't have let me read my reports and just sort of congratulated me that I was doing the best I could. But we did talk them through, and my mum would say, I know you're doing your best, and I know it's hard, and that was great validation and mum really helped with my self-esteem. But the damage is already done to some degree because that person thinks I'm not trying hard. Annie, 44 years.*

Instead of negative communications such as the examples above, participants argued that more positive and respectful communications that can promote positive relationships were needed. Jane provided the following example:

> *I shot up the reading groups and my Grade 2 teacher said to me, look, I'd like to put you up into the top reading group but it's getting a bit full and I need the reading groups to have roughly even numbers. So, let me tell you that you are ready to move into the pink group but you're staying in the red group…I could accept that because she talked to me like a reasonable adult. She treated me like a sensible person, and it was a perfectly reasonable excuse. I knew there couldn't be 12 people in the pink group when there were 22 people in the class. Jane, 46 years.*

Jane's example demonstrates that clear communication that is positive and validating for the individual, while still managing the mechanics of a busy classroom, is possible if teachers believe in its importance, prioritise its use, and have the necessary skills. The second element that was central to positive relationships was the suspension of stereotypes and judgements that lead to stigma.

TABLE 2 | Thematic summary and definition.

Main theme	Thematic summary	Example quote
Avoiding assumptions of ability: The need for effective communication	This theme reflected the ongoing challenge of effective and respectful communication between teachers and their autistic students. Through clear two-way communication misassumptions concerning abilities could be avoided.	"…So there were times when it's like if you just asked me, I could clarify things…"
The dangers of stereotypes, stigma, and judgements	This theme reflected the impact of misassumptions on autistic individuals and the negative impacts that stereotypes can have on individuals.	"…they treated me as someone with a label. They treated me as if I couldn't do anything…"
Fostering skills of advocacy	This theme reflected the importance of fostering advocacy skills and allowing an individual to claim a positive autistic identity.	"…I realised that being different was a really amazing thing to be because I was already different before I was labelled…"

Theme 2: The Dangers of Stereotypes, Stigma, and Judgements

Participants reported several instances of presumptions about their abilities by others in their reflections on school. For some, the assumptions that accompanied their diagnostic label/s overshadowed the reality of the individual's abilities and strengths. For example:

> *For some time I wasn't even able to use proper scissors because they thought I would cut myself and stuff like that. That was mostly substitute teachers or teachers who didn't really understand. But yeah, the label kind of got in the way of some of that… They kind of knew I was different. They kind of knew I had a label. So in such, they treated me as someone with a label. They treated me as if I couldn't do anything. Aliya, 23 years.*

These assumptions often reflected what was perceived to be a rigid system, where understanding of difference and diversity was limited. Such assumptions sometimes involved an incorrect notion of an autistic person's nature, while at other times an inappropriate use of language and stereotyping of a child's abilities. For example:

> *It's like, well, females, you can't be autistic. It was a male thing. If they ever heard of females on the spectrum it was always they're shy, they don't talk to people. They don't like being around other people. They won't speak to you. Most of them are non-verbal. They're not outgoing, they're not boisterous. They won't be able to process things… So it was kind of like the total opposite of what I was… I wasn't really treated like another person. I was treated very carefully. Aliya, 23 years.*
>
> *There was a time in a class where I, for whatever reason, a frustration was building up over feeling like I was being patronised, by students in the class, teachers. I'm sure they wanted to be helpful, but what I received was they thought that I was incompetent I suppose, I need to be walked through everything and couldn't do things by myself. Jack, 25 years*
>
> *I was at Year 12 camp. I was eating outside because it was too loud. This lady comes up to me, hellooo. Are you eating out—why are you talking to me so slow? I think the issue was… people don't seem to understand that autistic children become autistic adults. It's not like you grow out of it. Kate, 19 years.*

With assumptions comes stigma, and most participants reflected on feeling stigmatised at times during their schooling, sometimes leading to bullying.

> *There was a definite kind of stigma, because it was like there was no complexity around the designation, it was just "special kid." Damian, 30 years.*

Negative experiences were not confined to stereotyping and stigma; they were also an issue when advocating for supports within the school system. Several participants chose to act as if they were allistic, but found this an exhausting act to maintain, and one that many said should not be required of individuals also managing the social and academic challenges that all students encounter within schools.

> *At first, there wasn't a lot of accommodation… that was mostly because of me; I didn't really want to talk about having a diagnosis… the counsellors in my primary school, kind of made me feel like it was something to be ashamed of. That I just couldn't tell people. It was like a horrible secret. Essentially, I just muscled through it and acted like I was neurotypical, for 3 or 4 years. Eventually, I just caved and couldn't do it anymore. Kate, 19 years.*

What is clear from these quotes is that the pretence of "normality" is the underpinning, yet unstated, concept on which school culture is based, with those unable to enact this explicitly singled out as different.

Theme 3: Fostering Skills of Advocacy

Many of the participants, who were now adults, reflected on their time in school and the shifts that they have subsequently made towards positively claiming their autistic identity. Dave, however, reflects on the powerless position that students can find themselves in within educational contexts, which needs to be challenged in order to achieve advocacy:

> *I mean pretty much everyone was powerless so, yeah, we couldn't—we really had to do everything as asked… Because actually I would have loved to have a lot more choice but unfortunately they really just wanted us to do this and that, and this and that, as the way they wanted us to do things. Dave, 27 years.*

For some, high school was the time that they began to positively take ownership of their label and positively embed this within their identity. For example:

> *Well I think by the time I was in high school the Asperger's label was really, really something I'd embraced… something I liked talking about, it's something I was very comfortable identifying with. I think I was aware that some people on the spectrum didn't like a label,*

didn't like labels. But for me I think it was something I needed to make it concrete, to make it feel real. Jack, 25 years.

The culture of the school and the position set by school leadership was, however, seen as central in facilitating this positive identity formation. Also, the school's willingness to promote and encourage self-advocacy programs had important impacts on individuals. For example:

So we were encouraged to speak out if there was something that we were unsure of, and then they'd make changes…I was encouraged to be part of leadership boards, attend leadership training and things to foster self-advocacy skills…I used to be really uncomfortable reaching out when an issue arose. But now I feel a lot more comfortable and I know what to do if there's a situation that requires me to advocate. Freya, 19 years.

It wasn't until I got older when I realised that it was a lot of just self-talk. The fact is that it was okay to be different. I started to see myself a little differently. It wasn't until Year 12 when I was introduced to the ICAN program that I realised that being different was a really amazing thing to be because I was already different before I was labelled. Aliya, 23 years.

Most participants, when reflecting on their experiences in school, spoke of being framed by others' assumptions of their abilities based on the label/s given to them. For some, the claiming of their labels as integral parts of their positive self-identity was delayed but, for others, it was actively facilitated by schools through introduction to peer mentoring programs such as those run by the ICAN network (see: https://icannetwork.online/). The role of peers in providing positive models for young people has attracted increased attention in recent years. Participants contributing to our research who had participated in such programs, repeatedly reflected on the positive outcomes they gained from this mentoring. However, while largely positive moves in self-identity were made during the latter years at school, the general experience of the school environment for some remained a challenge.

DISCUSSION

The three core themes presented in this paper reflected the experiences reported by the participants in their communicative interactions with teachers and peers and the damaging effects of assumptions, stigma, and stereotypes about both them as individuals and autistic people more broadly. While participants shared their stories of both positive and negative encounters within school and the effects that these had on them as individuals and their identities, those who had left school also provided reflections of the effects of these post formal schooling. While some participants reported very negative experiences at school, with their competence continually being questioned by peers, teachers, and the broader system, all reported their current situation as being more positive, reflecting the importance of the nurturing of advocacy skills and positive identity development for young people. Many who were told they were not academic enough to complete an academic high school pathway are now at university studying for a range of degrees. Some are researchers, some are teachers, and some have taken a more applied pathway via the Australian further education college system (TAFE). All participants were passionate about the need to support autistic young people still at school, and some had taken on mentorship roles to provide autistic role models for young people.

A core facilitator for enabling positive educational experiences was the establishment of positive relationships and respectful communication between teachers and students (Theme 1). Effective communication was considered a two-way process, with the need for teachers and others to suspend some of their previous assumptions concerning the capabilities of autistic people, and listen and respond to students as individuals according to the needs for support articulated by them. Key barriers to positive educational engagement that were reported by the participants included negative stereotypes and assumptions about the capabilities of individuals, and not creating a safe space for students to identify, communicate, and/or access appropriate supports, as reflected in Theme 2. Theme 3 outlined the need to create an environment within which self-advocacy skills could flourish. Such an environment is unlikely to be successful without a critical reflection on previously held attitudes and beliefs concerning the abilities of autistic people. For such changes in thinking to occur, positive relationships are likely to be key in effectively supporting autistic students within the classroom. Autistic students should not be pre-judged by their label and educators need to proactively ask, listen, and respond to autistic students and the experiences they have to share.

In summary, this research has highlighted some of the key challenges encountered by autistic students within schools. We hope that future research, using a strengths-based approach that acknowledges differences rather than deficits, will investigate further ways of improving the school experience for autistic students. Based on the three key themes identified in our research, we recommend the following points as positive ways forward within schools in creating supportive and inclusive classrooms:

- Prioritise relationships with autistic students;
- Proactively ask, listen, and respond to autistic students and the experiences they have to share**;**
- Create a safe environment that facilitates conversations, understanding of students' needs, and offers meaningful choices to students;
- Presume competence;
- Remember that every autistic person is different—don't make assumptions based on a label.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

This study involving human participants was reviewed and approved by the Human Research Ethics Committee,

University of Southern Queensland. Written informed consent to participate in this study was provided by the participant/participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

CB, WL, and YP wrote the first draft of the manuscript and JM and DA refined and edited. All authors contributed to the design, data collection, and analysis for this paper.

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Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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APPENDIX

The key questions used in the interviews were:

1. Please tell us a little bit about yourself.
2. Please tell us about a really good teacher who has taught you.
3. In terms of your experience of education, were there things that could have been done differently?
4. What supports were put in place for you during school?
5. How did your experiences affect how you felt about yourself?
6. Please tell us about any non-academic challenges that you faced at school.
7. Is there anything else that you would like to add that you think is important that we know?

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Overcoming the Double Empathy Problem Within Pairs of Autistic and Non-autistic Adults Through the Contemplation of Serious Literature

Melissa Chapple[1], Philip Davis[2], Josie Billington[2], Joe Anthony Myrick[3], Cassie Ruddock[4] and Rhiannon Corcoran[1,2]*

[1] Department of Primary Care and Mental Health, School of Psychology, University of Liverpool, Liverpool, United Kingdom, [2] Centre for Research Into Reading, Literature and Society, University of Liverpool, Liverpool, United Kingdom, [3] Independent Researcher, Hamtramck, MI, United States, [4] Independent Researcher, Gloucester, United Kingdom

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Reviewed by:
Gemma Louise Williams,
University of Brighton,
United Kingdom
Sarinah O'Donoghue,
University of Aberdeen,
United Kingdom

***Correspondence:**
Melissa Chapple
melissa.chapple@liverpool.ac.uk;
melissajanechapple@outlook.com

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Recent research based on the needs of the autistic community has explored the frequent social misunderstandings that arise between autistic and non-autistic people, known as the double empathy problem. Double empathy understandings require both groups to respect neurodiversity by focussing on individuality across groups. This study aimed to explore how literature, through its ability to uncover nuanced emotional response differences between readers, could facilitate double empathy understandings within pairs of autistic and non-autistic adults. A longitudinal, qualitative design was used, with 4 gender-matched pairs. Participants read *Of Mice and Men* for 1 week, whilst completing a structured, reflective diary. This was followed by 4 one-hour paired reading sessions, where pairs discussed the book and their reflections in depth. Participants were then invited to a final one-on-one interview to discuss their thoughts and experiences of the paired reading sessions. Thematic and literary analysis of the session and interview data revealed four themes (1) The Book as Social Oil; (2) From a World of Difference to a World of Affinity; (3) Emotional Intelligence: From Thinking About to Feeling with; and (4) From Overwhelming to Overcoming. All participants reported having achieved an individualised view of one another to explore their nuanced differences. The non-autistic group reported a more sensitive understanding of what it means to be autistic, while the autistic group overcame concerns about non-autistic people stereotyping autism, and instead reported feeling valued and accommodated by their non-autistic partners.

Keywords: autism, autistic community, literary fiction, neurodiversity, emotional intelligence, double empathy

INTRODUCTION

Autism is a neurodevelopmental condition that results in distinguishably different socio-cognitive processing styles which pose advantages and disadvantages within current societal norms (Fletcher-Watson and Happé, 2019; Robinson et al., 2019). Since the identification of autism as a condition in the 1940s, the framing of autistic people has been dominated by the medical model of

disability (Waltz, 2013). More recently, self-identification as autistic has become an important route to inclusion within the autistic community, promoting belongingness and improved self-understanding (Lewis, 2016). However, with many individuals continuing to rely on medical diagnosis for identification (Mogensen and Mason, 2015; Leedham et al., 2020), the medical model continues to influence how autism is thought about and explored, resulting in deficit-based conceptualisations and priorities (Waltz, 2013; Kapp, 2020). These deficit-based approaches result in a "lock and key" mentality toward autistic individuals, assuming that they need to be unlocked in some way to bring their information processing style closer to typical human neurocognition (Waltz, 2013). The problem with this approach is that it rests on the assumption that there is a typical form of human neurocognition, a state of "neuronormativity" often referred to as being neurotypical (Milton, 2020; Mueller, 2020).

As a result of these assumptions, dominant theories such as the mindblindness, empathising-systemising, and extreme male brain (Baron-Cohen, 1997, 2002, 2009) theories have viewed and explained autism through a largely deficit-based lens. These theories build upon a key underpinning idea that autistic individuals have profound perspective-taking difficulties, otherwise known as theory of mind deficits (Baron-Cohen, 1997). This long-standing assumption has led to a belief that autistic individuals have fundamentally impaired social abilities (Baron-Cohen, 2009; Lombardo and Baron-Cohen, 2011). Furthermore, there is an embedded assumption of impaired emotional intelligence amongst autistic individuals, with assumed deficits in recognising and empathically responding to the emotions of others (Baron-Cohen, 2009; Bodner et al., 2015; Rigby et al., 2018). From these theoretical assumptions and medicalised framings, intervention research has typically sought to alter the differential socio-cognitive processing styles that result from being autistic (Waltz, 2013; Pearson and Rose, 2021). In this way, it is seen as advantageous to bring the behaviours of autistic people closer to those associated with neurotypicality (Waltz, 2013). However, any consequent behavioural changes are thought, by some, to be short-term and brought about by conformity pressures (Mueller, 2020).

In contrast, social models of disability oppose these deficit-based assumptions. Instead, social models explore disability that results from disadvantages bounded in social construction and cultural norms as well as inherent disability (Kapp et al., 2013; Waltz, 2013). In taking this view of autism, perceived neurocognitive disadvantages become differences that may be advantageous in enabling contexts (Kapp, 2020). One social movement that has been particularly provocative in changing conceptualisations of autism and autistic people is the neurodiversity paradigm (Singer, 1998, as cited in Milton et al., 2020). This paradigm focusses on equal human rights for those with neurologically divergent conditions such as autism, and contests the idea of neuronormativity (Singer, 2016). Instead, the neurodiversity paradigm follows the view that all human brains and resulting perceptions differ to a degree (Milton, 2020). It is therefore proposed that each individual has a unique processing profile that cannot be grouped into a singular socio-cognitive framing (Milton, 2020; Mueller, 2020). As a result, those who would otherwise be framed as neurotypical are instead viewed as those who find dominant social constructs and norms to be enabling (Murray, 2020). Similarly, attention is drawn to the unique differences between autistic people that are often lost when summarising autism as a condition (Kapp, 2020; Milton, 2020). However, the paradigm also acknowledges the presence of a sense of shared culture and identity that has emerged for many within the autistic community (Kapp, 2020). Furthermore, with the neurodiversity movement has come an increase in autistic self-advocacy, encouraging a focus on the lived experiences of autistic people in framing what it means to be autistic (Bottema-Beutel et al., 2021). As a result, autistic people are increasingly involved in developing research enquiries and subsequent understandings of autism (Wright et al., 2014; Fletcher-Watson et al., 2019).

One theory in particular that has led to a positive-reframing of how we think about autism is Milton's (2012) double empathy problem. The double empathy problem contests the view that autistic people have a theory of mind deficit, and instead draws attention to difficulties of reciprocity and mutuality between autistic and non-autistic people (Milton, 2012; Milton et al., 2018). Although these difficulties can occur between any two people, it is believed that the social realities of autistic and non-autistic people are more likely to differ, resulting in common two-way perspective taking difficulties (Milton, 2012). It is further argued that because a lack of social reciprocity is regarded to be relatively uncommon or easily repaired within non-autistic interactions, then autistic people must be to blame for breakdowns of reciprocity within an autistic - non-autistic interaction (Milton, 2012; Chown, 2014). Research on mixed-neurotype interactions have supported the double empathy problem, finding that non-autistic people recognise fewer autistic facial expressions (Brewer et al., 2016); struggle to identify autistic mental states (Edey et al., 2016; Sheppard et al., 2016); overestimate how helpful they are during communication with autistic participants (Heasman and Gillespie, 2019); and perceive a reduced sense of rapport compared to same-neurotype pairings (Crompton et al., 2020c). Furthermore, research has indicated that when autistic people interact with other autistic individuals, they may share some of the same-neurotype advantages observed within non-autistic pairings. Specifically, research has found that autistic people are more socially comfortable with other autistic individuals (Crompton et al., 2020a; Morrison et al., 2020); communicate information more efficiently (Crompton et al., 2020b); have a better understanding of each other's social intentions (Heasman and Gillespie, 2018); and show an increased willingness to overcome initial negative impressions (DeBrabander et al., 2019). However, findings have indicated that autistic individuals may not have the same-neurotype advantages for perspective taking that are seen for non-autistic individuals (Brewer et al., 2016; Edey et al., 2016). While deficit-models would attribute this to an autism-specific theory of mind deficit (Baron-Cohen, 1997), it is possible that autistic people make more open-ended assessments of mental states that avoid premature conclusions. This is a reasonable suggestion since autistic people are more experienced in dealing with the lack

of mutuality experienced within mixed-neurotype interactions that are commonplace for autistic people (Chown, 2014; Milton, 2020). Such a suggestion is consistent with autistic individuals taking more time to establish mutual social understandings while being less likely to draw rapid, heuristic-based social judgements based upon an assumption of pre-existing mutuality.

Research that explores the double empathy problem through a neurodiversity lens is important in challenging stereotypes toward the autistic community. Stereotyping, the holding of indiscriminate negative assumptions about individuals within a group (Kinnear et al., 2016), derives from the dominant model and deficit views of autism which reduce all autistic people and their experiences down to shared categorical impairments (Green et al., 2005; Pearson and Rose, 2021). This negative stereotyping leads to a polarising "us and them" assessment that further disadvantages autistic people (Goffman, 1990; Cage et al., 2018; Pearson and Rose, 2021). Importantly, this process called "othering" is a component of stigma that often results in discrimination and felt stigma (Goffman, 1990; Link and Phelan, 2001). The resulting felt stigma is reported by parents of autistic children (Gray, 2002; Mak and Kwok, 2010; Liao et al., 2019), as well as by autistic individuals themselves (Shtayermman, 2009; Griffith et al., 2012; Pickard et al., 2018). The stigma toward the autistic community is enhanced for those with intersecting identities, such as autistic individuals from racialised minorities (Broder-Fingert et al., 2020; Spense, 2020). These stereotyped and stigmatising views of autistic people further contribute to the socio-communicative breakdowns reported by the double empathy problem (Sasson et al., 2017; Pearson and Rose, 2021).

By contrast, methodologies that promote neurodiversity framings of autistic people are more likely to draw attention to individual differences, overcoming stereotyping and aiding double empathy (McCreadie and Milton, 2020). When assessing which methodologies to use for this purpose Ida's (2020) theoretical assessments around multiplicity and neurodiversity should be considered. Specifically, Ida (2020) argues that methodologies which afford openness to multiple possibilities should be favoured. Where this multiplicity is achieved, individuals look beyond their separate identities to assess how their differences are constructed (Ida, 2020; McCreadie and Milton, 2020). These assessments of individual differences are believed to be facilitated by shared experiences that enable a dismissal of coarse group-based understandings (Ida, 2020). Additionally, explorations of the nuanced difference within wider similarity are important to overcome the double empathy problem (McCreadie and Milton, 2020; Mueller, 2020). Furthermore, it is argued that strictly scientific research methodologies should be avoided to prevent reliance on binary, neuronormative ideologies (Ida, 2020; Mueller, 2020). Instead, creative and open methodologies that provide an immersive shared experience are more likely to afford multiplicitous, double empathy understandings (Mueller, 2020).

One potential methodology that would afford this type of multiplicitous thinking is the discussion of fiction. This is because the shared reading of fiction promotes communal thinking about a text, whilst also enabling explorations of individual differences within (Longden et al., 2015). Additionally, it is argued that fiction is inherently social, drawing on three levels of perspective-taking or "theory of mind"; (1) the mind of characters, (2) through the mind of the author, and (3) through the mind of the reader (Zunshine, 2011). In this way, shared discussions around fiction may add a 4th level of perspective-taking, exploring the first three levels through the interaction with other readers and thus other minds (Longden et al., 2015). While the first three levels provide a shared experience that results in communal thinking, it is the fourth level that is important for the shared exploration of individual differences. Additionally, it is believed that in the act of reading readers infer emotions and perspectives through the evocation of past, personal memories that promote more mindful self-other comparisons (Mar and Oatley, 2008; Mumper and Gerrig, 2019). This means that shared reading may be a particularly advantageous methodology for autistic people because it engages the ability to make more open-ended and in-depth assessments of perspective. Importantly, the social simulations of fiction are believed to inform real world understandings (Mar and Oatley, 2008; Mumper and Gerrig, 2019). Therefore, any understandings that are developed toward autistic individuals through the contemplation of fiction should result in broader understandings of the autistic community. As a result, shared fictional reading becomes a potentially useful tool in overcoming the double empathy problem.

It is argued that serious literary fiction is the most provocative form of fiction for eliciting empathic understandings of different perspectives, where serious literature refers to literature that engages with significant human situations and as a result enables its readers to do the same (Koopman and Hakemulder, 2015; Davis and Magee, 2020). It is the powerfully moving language of serious literature which is important in this regard because it jolts people out of normative, stereotyped thinking patterns (O'Sullivan et al., 2015; Davis, 2020). Furthermore, serious literature requires the consideration of multifaceted, often ambiguous, meanings within complex social constructs that are not conducive to the drawing of hasty conclusions (Mar and Oatley, 2008; O'Sullivan et al., 2015; Davis, 2020). Reading aloud methodologies incorporate this shared contemplation of serious literature (Longden et al., 2015). Within these groups, the liveness that results from reading aloud results in strong absorption and felt unpredictability that promotes complex literary assessments (Longden et al., 2015; Davis and Magee, 2020). While this type of methodology may be advantageous in overcoming the double empathy problem, research has highlighted that some autistic people are uncomfortable with the idea of reading in a group and being read aloud to (Chapple et al., 2021). Instead, the value of shared reading within pairs of autistic and non-autistic individuals may be more tolerable as well as more likely to elicit double empathy understandings.

The current study qualitatively explores changes in understanding and the double empathy problem between autistic and non-autistic participants as a result of shared reading discussions. Specifically, participants read and subsequently discussed John Steinbeck's novella, *Of Mice and Men* (1937). This book offers a provocative shared experience, with multiple examples of stigma toward minority groups, bringing the necessary consideration of difference to the forefront (Ida, 2020).

To account for the concerns of autistic people in participating in groups, the study focussed on pairs of autistic and non-autistic individuals. Furthermore, in place of live readings, participants completed a structured diary entry per chapter which were subsequently used as discussion aids. The study aimed to address the research question: "can discussions of literary texts involving autistic and non-autistic people overcome the double empathy problem and result in empathic understandings of one another's perspectives?"

MATERIALS AND METHODS

Participants

Participants were recruited through social media and local advertisements into a wider project that included this study and an earlier, unpublished study upon which this one was built (see section "Procedure"). Initially, 20 participants, of whom 15 were non-autistic, indicated a willingness to be involved in the wider project. Due to the lower number of autistic volunteers, these participants were prioritised for study inclusion. Non-autistic participants were paired with autistic participants based on gender and, where possible, age and educational background. Five pairs had been intended for inclusion. However, one autistic participant dropped out of the study due to time restrictions, resulting in four pairs. The decision was made not to include a fifth pair due to having achieved data saturation; a result of the longitudinal nature of the research, with each participant contributing 15 to 16 pieces of qualitative data. Inclusion criteria included being 18 or over, having proficient English language skills, and being able to travel to the University of Liverpool. Non-autistic participants had additional inclusion criteria of scoring below 32 (the suggested cut-off score for autism) on the autism quotient (AQ; Baron-Cohen et al., 2001) due to potential trait overlap. Two non-autistic participants who identified as dyslexic were permitted inclusion into the study. This was because the participants identified as neurotypical rather than neurodivergent, and were comfortable with the reading, writing, and comprehension that the study required. Autistic participants had no additional exclusion criteria, as all participants reported a formal diagnosis and none reported learning difficulties that might have resulted in altered comprehension or difficulties in reading and discussing the text.

Overall, 8 participants (see **Tables 1**, **2** for demographics), within 4 participant pairs, took part in this study. The 4 autistic participants comprised 2 male and 2 female participants aged 19–48 (M = 30.25, SD = 12.53). The 4 non-autistic participants also consisted of 2 male and 2 female participants that were aged 23–33 (M = 28.75, SD = 5.06). It happened that all pairs comprised 1 participant from a racialised minority and 1 who was of white British nationality. Data on race and nationality was not formally collected from participants but was raised by participants themselves within the qualitative discussion sessions. Of those who were from a racialised minority, 3 were autistic and 1 non-autistic. All 8 participants were invited to a follow-up interview with 1 non-autistic participant not providing a follow-up interview. The study was approved by the University of Liverpool Research Ethics Committee.

Screening Measures

A demographics questionnaire asked for participants' age, gender, and highest completed qualification. Eligibility questions were also asked at this stage.

The Autism Quotient (AQ) (Baron-Cohen et al., 2001)

The AQ is a 50-item questionnaire that uses statements to elicit a score that reflects autistic traits in clinical and non-clinical samples. The AQ was used to assess the number of self-reported autistic traits in both samples.

The Quick Test (QT) (Ammons and Ammons, 1962)

A single 50-item version of the QT was used to quickly assess the comprehension abilities of participants, a factor that was considered important within a methodology that relies on text comprehension.

Session and Interview Measures

Participant Diaries

As part of the preceding study (see section "Procedure" for further details), participants read *Of Mice and Men* (Steinbeck, 1937) at a rate of 1 chapter per day for 6 days. For this study, diaries were returned to participants as optional conversational prompts.

For each chapter participants were asked to answer the same 5 questions. Questions 1 to 3 were designed to prompt general reflections about narrative events and characters: (1) *what thoughts or feelings did chapter X prompt?* (2) *do you think the characters in chapter X were realistic?* (3) *did you like or dislike the characters in chapter X?* Questions 4 and 5 were added based on previous findings that autistic readers think more about author intent (Chapple et al., 2021): (4) *did you think about the author when reading chapter X?* (5) *what did you think the author was trying to achieve in chapter X?* In the current study, these 5 questions served as optional conversational prompts during the discussion sessions (see section "Procedure" for further details on the sessions).

Pre-session Questionnaire

A pre-session questionnaire was designed to explore participant views on the group which they did not identify with (neurotypical or autistic). Participants were asked (1) to define what it meant to be autistic/neurotypical as appropriate, (2) how they think the

TABLE 1 | Participant AQ and IQ scores between neurotypes [mean(± SD)].

	AQ[a]	Estimated IQ[b] (WAIS equivalent)
Autistic	40.35 (6.24)	98.50 (6.81)
Non-autistic	11.75 (1.26)	102.50 (3.79)

AQ, autism quotient; QT, quick test; WAIS, wechsler abbreviated scale of intelligence.
[a]*AQ scores.*
[b]*IQ assessed by the QT.*

TABLE 2 | Participant demographics.

Pair no.	Participant no.	Age	Gender	AQ[a]	IQ[b] (WAIS equivalent)	Level of education completed	Neurodiversity status
1	1	29	Male	42	96	GCSE	Autism diagnosis
1	7	23	Male	10	100	Masters	Identifies as neurotypical
2	8	26	Female	12	102	Bachelors	Identifies as neurotypical
2	20	19	Female	31	92	A level	Autism diagnosis
3	9	33	Female	12	100	Doctoral training	Neurotypical
3	11	48	Female	44	108	Doctoral training	Autism diagnosis
4	10	33	Male	13	108	Foundation or diploma	Neurotypical
4	18	25	Male	44	98	Masters	Autism diagnosis

AQ, autism quotient; QT, quick test; WAIS, wechsler abbreviated scale of intelligence.
[a]*AQ scores.*
[b]*IQ assessed by the QT.*

two groups differ, and (3) why they chose to take part. To take account of familiarity with autism, the non-autistic group were asked whether they personally know an autistic person.

Post-session Questionnaire

A post-session questionnaire was designed to evaluate participant thoughts after each session. Participants were asked (1) what things (if any) were discussed about the book or diaries, (2) what things (if any) were discussed outside of the book or diaries, (3) whether the discussion helped them to understand the other participant better, (4) whether they gained any self-understanding, (5) whether they enjoyed the session, and (6) whether their understanding of autistic and neurotypical differences and social interactions had changed as a result of being involved in the discussion sessions.

Interview Schedule

For the 7 participants who chose to take part in the follow-up semi-structured interview, this occurred at least 1 week after their final shared reading session. During the interview, participants were asked about (1) whether they had benefitted from being involved in any way, (2) what they thought of the sessions, (3) if and how their understanding changed toward the other group, (4) whether the study helped their self-understanding, (5) if they felt the other member of their pair had sensitively understood them and the group they identified with, (6) how they would now define the other group, and (7) if anything could have been added to the study that they felt could have improved personal outcomes. The schedule was made up of structured, open questions and follow up questions.

Dictaphones recorded the interviews which were subsequently manually transcribed by the first author. All field notes and questionnaires were also converted into Word documents. Documents were uploaded to NVivo 10 (Castleberry, 2014) to facilitate analysis.

Procedure

Potential participants completed a screening process using the Qualtrics online platform. It included the informed consent procedure, a demographic questionnaire, the QT and the AQ. Participants who screened out based on the exclusion criteria, or who did not leave an email address for contact had their data destroyed. Non-autistic participants who screened in were matched to the four autistic participants and invited into the study.

All 8 participants first took part in the connected study, in which they read *Of Mice and Men* (Steinbeck, 1937) while recording their thoughts in a structured diary. For this preceding study, participants read alone and did not meet with the partners that they were paired with for the current study. The diary was completed for 7 days, the first 6 coincided with reading one chapter of the book per day. On day 7, participants completed 3 writing tasks that prompted reflective thinking about the overall novel. For this preceding study, the participant diaries were analysed to assess whether autistic and non-autistic participants engage with serious literature in similar ways. in the current study, the book and diaries were instead used as conversational prompts for the shared reading sessions.

The discussion sessions occurred weekly for 4 weeks and lasted for 1 h. Two of the participant pairs attended the four sessions in-person in a designated, quiet interview room at the University of Liverpool. The other two pairs took part via Skype due to COVID-19 imposed restrictions at the University. Before the first session, participants completed the pre-session questionnaire. During the informed consent procedure, it was explained to participants that the lead researcher would be present for the full duration of the session and could offer assistance of any kind. However, the researcher otherwise remained silent during these sessions, and participants were made aware that the researcher would not be involved in the discussions. For the in-person sessions, the researcher sat at the other end of the room, in peripheral view of the participants. For the Skype sessions, the researcher remained visible via webcam to try to replicate the in-person discussion sessions. The physical presence of a researcher was incorporated into the study design to ensure discussions remained respectful and to enable note taking. In both settings, it was explained to participants that the researcher would take notes on discussion topics. Field notes were recorded to summarise the topics being discussed within pairs. Where participants were having back and forth discussions that were neither summarising *Of Mice and Men* (Steinbeck, 1937), or repeating

their diary responses, the researcher made direct transcriptions of the dialogue between participants. Field notes and direct transcriptions were chosen to record the session content as opposed to audio or video recordings because it was felt to be less intrusive. Participants were given their individual reading diary at the start of each session and instructed that they could discuss anything, whether related to the book or not and so were allowed to structure their own sessions. Participants were reimbursed £10 for involvement in each study component.

The first author is an autistic, female Ph.D. researcher, who is trained to Master's level on semi-structured interviewing. The first author facilitated all of the discussion sessions and conducted all 7 of the follow-up interviews, with no other researchers present. All autistic participants were informed that the facilitating and interviewing researcher would also be an autistic adult. The researcher was acquainted with two of the autistic interviewees but was unfamiliar with the other six participants.

Participants were later sent the results from the study and invited to provide feedback. Participants were specifically asked (1) "*do you have any thoughts about how we've understood your data?*" (2) "*Have you thought about the sessions since the study?*" (3) "*What things about the study have felt important since?*" (4) "*Has your experience of being involved in the project altered how you approach daily communication?*"

Analysis

SPSS and Microsoft Excel were used to organise and calculate descriptive statistics and scores from the screening questionnaires.

Interviews were transcribed using edited transcription, with the omission of irrelevant false starts, filler sections and repetition, unless used to convey importance or significance. Transcription was completed by the first author who has prior experience of interview transcription for post-graduate research. Resultant transcripts were not sent back to participants as there were no areas of unclarity or missing data due to poor sound quality. One participant was sent their pre-session questionnaire and first post-session questionnaire due to unclear data, this process resulted in recovery of the main points within the data. Qualitative data from session questionnaires, researcher field notes and interview transcripts were analysed primarily using thematic analysis (Clarke and Braun, 2014), with a combination of Framework Analysis (Ritchie and Spencer, 1994) and a form of literary close reading analysis (Billington et al., 2019). The first two stages of Framework Analysis (immersion and organisation) were implemented using NVivo 10 (Castleberry, 2014) due to the rigour of these particular stages that reduced data loss, making it ideal for the longitudinal nature of the data. After this stage, rather than implementing the re-coding process that follows in Framework Analysis, the team switched to a manual thematic analysis to group data into themes. This shift, implemented in stages three and four, was chosen because thematic analysis better enabled the articulation of the narrative flow of the data itself and the inter-disciplinarity of the research. Finally, a form of literary close reading analysis (Billington et al., 2019) was implemented in stage five that relies on participant language as "the main point of access to moments of subtle mental change" that give access to the "imprints" of reading (Kaszynska, 2015). These qualitative analyses combined to ensure a deep and rich exploration of the data, necessary to explore the complexity of human interaction mixed with literary explorations across time. As a result, analysis stages were as follows:

(1) The first author transcribed the raw questionnaire and field note data, and the 7 interview transcripts, followed by a first reading of all data with memo creation for data immersion. The second, third and sixth authors reviewed data from one pair for immersion.
(2) The first author sorted all data into an initial, organisational framework within NVivo 10. Initial ideas were discussed with the rest of the team and the organisational framework was reorganised accordingly.
(3) The first, second, third and sixth authors deliberated on the organised categories and identified four themes. Themes were refined through continued discussion and exploration of the data examples within each theme.
(4) The researchers picked out key quote examples from the data for each theme and sent these quotes grouped into the four categories without labels to the fourth and fifth authors for review. Upon agreement of the categories, the authors were then sent theme names and explanations for review.
(5) To further explore each thematic outcome, the second and third authors, experienced in the literary analysis of texts and participant responses, applied a literary close reading analysis to the data examples chosen by the team for each theme. This final analysis was then reviewed by the rest of the research team for approval.

The first author is an autistic researcher. Additionally, the fourth and fifth authors are autistic adults who were invited to join the research team as experts by experience. These authors were consulted on the analysis as detailed above, as well on the theoretical framings and language used within the paper. Where the fourth and fifth authors raised concerns with regards to the analysis or wider paper framings, alternative framings were agreed. As a result, all data was analysed and subsequently understood from autistic and non-autistic perspectives.

RESULTS

Pre-session Questionnaire Summary

Of the non-autistic participants, two reported no personal link to an autistic person, one reported a professional link, working with autistic children but not adults, and another reported that their partner's relative is autistic.

The most common reason overall for engagement with the study was interest. Half of the non-autistic participants additionally reported getting to hear the lived experience of an autistic adult as a motive. In comparison, half of the autistic participants reported the ethos of the study in meeting wider autistic community goals as a motive. Additionally, financial

reimbursement and self-exploration were listed as unique, individual motives.

Qualitative Analysis Results

The final analysis comprised four themes: (1) the book as social oil (2) from a world of difference to a world of affinity (3) emotional intelligence: from thinking about to feeling with, and (4) from overwhelming to overcoming. Participant quotes are split by neurotype group (A: autistic, N: non-autistic), and by timeframe (S0: pre-session; S1–S4: discussion sessions in order; S5: final interview).

The Book as Social Oil

Although participants were free to discuss any topic of their choosing during the sessions, all pairs centred their discussions on the book and their associated diary responses. In this way, the text acted as a meaningful shared experience for participants to begin their dialogues. That both readers knew the book and its characters, was reported by participants as having reduced the usual social awkwardness often felt on first meeting:

> *(P11A) [S5] "actually having a topic that you could talk about and around helped. I think if we'd have just gone in a room and said "right, chat" then there would have been a lot of awkward silences"*

> *(P8N) [S5] "it's less awkward 'cos you've got like prompts [the literature] gives you a conversation starter, save any like awkward silences."*

Although this initial reduction of social awkwardness stemmed from the book serving as common ground, the narrative additionally provided a shared social setting to operate within during discussion sessions: hence discussion was not just "about" but "around" and "within" the book. Through participant discussions, characters were further *brought to life* as complex, social beings in a developing relationship. The involvement of the readers within this shared immersive experience created more in-depth personal and social discussions, with the perceived safety of the simulated social setting affording more risk-taking:

> *(P7N) [S5] "I think it was a good introduction because it allowed you to go into other topics, 'cos kind of just asking somebody off the bat "how would you feel in this situation?"... people would be a bit more defensive. But I think it was a good introduction of "how would you act in the situation of that character?" And then a conversation expanded from that into the more mundane aspects of your life"*

> *(Pair 4) [S1] P18A: "I dislike George condescending [to] Lennie..., however, it does frustrate me that Lennie doesn't know his own strength. I like and dislike them both in different ways."*

> *P10N: "I'd agree with this, Lennie has good intentions but it results in bad consequences"*

Where social difficulties arose, both participants within the dyads showed an ability to sensitively overcome these difficulties by bringing the focus back to the novel to move discussions on. Difficulties included times when discussions became circular in nature, where long periods of unintentional silence occurred, and where participants expressed uncertainty about how to move discussions forward. Primarily and at least initially, non-autistic participants had wider concerns about dominating conversations, while autistic participants desired more social guidance. This resulted in participants instinctively implementing a planned structure, drawing on the structure of book chapters and diary questions to alleviate their mutual concerns and difficulties:

> *(P18A) [S1] "the other participant gave me cues to speak and to guide me on which parts we should talk about next. I felt this was especially helpful as it maximised my potential in being able to contribute to the conversation as effectively as possible"*

> *(P10N) [S5] "we almost set out a plan. We knew we had four sessions, "we've got this many chapters, these many activities, we're going to kind of split it up like that."...so, we kind of knew from the off what the plan was...what I personally didn't want to do was lead every single question, and then he feels like he had to kind of give an answer that was similar to mine. So, we took it in turns"*

As a result of the shared social setting afforded by the book and the creative overcoming that resulted from times of social difficulty, autistic participants reported feeling valued within discussions. Importantly, they reported that even when their views differed from their partner's, they felt their views were considered and valued, rather than socially ill-fitting:

> *(P20A) [S4] "[session discussions] made me realise that my interpretations of themes throughout the book are just as valid as other interpretations, and therefore my perspective is not necessarily wrong."*

> *(P18A) [S5] "what I found more interesting, was he found them to be acceptable, he found my reasons to be valid, just as much as I thought that his reasons were also valid."*

Contemplation of the book and diary reflections resulted in an openness within pairs. This openness enabled the pairs to explore their nuanced *differences* of reasoning within the context of their shared experience, wider similarities and shared conclusions as readers. In this way, the literature brought their attention to their more subtly and freely found understandings of the text. This moved participants away from thinking about their categorical neurotype differences, toward a focus on their individuality within the experience of shared reading:

> *(P7N) [S5] 'we had mutual agreement on a lot of things and what we reflected on was quite similar... an ice breaker to go "you know what, we're not actually that different because we haven't looked at this and gone miles apart. Our reflection on this piece of literature was similar."'*

> *(P20A) [S5] 'I realised "oh, there are some similarities between us because we've written different things but in similar ways."'*

From a World of Difference to a World of Affinity

With the shared experience and perspectives thus afforded by the literature giving participants a unifying structure within which to explore their differences, the sessions provided room for participants to explore the bidirectional nature of their differing world views:

> *(Pair 1) [S2] P7N: "Why were you so focussed on the dog being shot [in the narrative] as an upsetting event?"*

P1A: "I do have a liking for dogs, and I wish he'd just simply given the puppies away."

P7N: "I can understand them being shot, in these circumstances, the dogs would have died painfully."

[Researcher: P1A doesn't reply but appears to be at ease about the narrative events after this]

P7N: "Have you ever had rabbits?"

P1A: "No, I've only ever had a hamster."

P7N: "I've had rabbits, they bred a lot and so I had to drown them. I also used to shoot rabbits, hunting them was a hobby. We'd eat them afterward, they were tasty, but we had to stop hunting because a local illness wiped the rabbits out."

[Researcher: P1A doesn't reply but looks visibly uncomfortable]

Where wider differences and associated social discomfort had arisen, participants had to work harder to find common ground outside of the shared narrative experience. Participants identified these additional common grounds by re-visiting their shared opinions within the novel, and looking to real-world situations where these opinions translated into a contemporary situation. For example, participants 1A and 7N assimilated their dislike of the aggressive behaviour observed from the character *Curley* to that which they mutually disliked seeing displayed by others in their local areas. Their experiences of such aggressive behaviour being directed onto them in real life then served as new common ground to return to when wider differences of opinion presented. These explorations of common ground still served to move participants away from focussing on the anticipated differences based on neurotype. Therefore, participants were further moved toward understanding each other as sharing these specific human experiences. For the non-autistic individuals, a reframing of their understandings of autistic people emerged that moved away from a focus on basic difference, toward a focus on the emergent recognition of essential similarity:

(P7N) [S5] "it's not a case of "us and them" it's more of a "hang on we agree on a lot of things we're just slightly different." As opposed to "they're miles apart" I think that's probably changed."

This focus on essential partner similarities within pairs provided the scaffold to enable the deeper exploration of the nuanced differences that existed between them: "slightly" rather than "miles apart." All dyads reported that the differences that existed between themselves and their partner were actually subtle and contextual:

(P11A) [S5] "I think as people we probably had a fair amount in common. . .I think our backgrounds are quite different, so she's obviously a lot younger, a lot more widely travelled, she seems to have lived a very straight forward life."

Here, "more widely travelled" but "very straight forward" seems itself to be a subtle account of a particular form of ease that P11A lacked.

(P10N) [S5] "what it probably showed me was that there's probably a lot more similarities than differences, and the differences tend to be a little more subtle than I probably would have expected them to be."

Through (1) establishment of common ground, followed by (2) explorations of the finer differences, participants (3) moved away from constricting over-simple assumptions based on neurotype. Instead, participants started to view each other as suitably complex individuals:

(Pair 4) [S4] P10N: "Our focus on society in the sessions has showed that we have more similarities than differences. It felt no different to socialising with my friends, and if I'd not known you were autistic, I'd have just thought we were different people individually". . .

P18A: "I don't feel we are different from each other by much now, despite our neurological differences"

(P11A) [S5] "I was surprised how similar our perspectives were. . .I didn't really see it as a neurotypical and an autistic way of thinking."

What P11A articulates above is a sense of surprise, relief and pleasure in the fellowship that emerged.

Emotional Intelligence: From Thinking About to Feeling With

A key factor in non-autistic participants developing a more sensitive understanding of their autistic partners was the lived experience accounts that remained at the forefront of discussions throughout the study. Rather than starting from a deficit view and seeking to identify difference, these accounts, which were often proffered in the context of humane discussion of the literary events, enabled non-autistic participants to learn from their partner's explanations and experiences of what it means to be autistic:

(P7N) [S5] 'The lived experience is different from the dictionary definition. So, I kind of feel if we went into it with a dictionary definition, we may just start to categorise people from the offset "well he said that, that roughly correlates to this, so oh yeah that's definitely autistic." I suppose going into it from a bit more of a personal opinion kind of thing, to be quite frank more of a position of ignorance, helped to inform me better, 'cos I think if I went in knowing loads of stuff about autism on paper I would have just went "yeah, his reaction to this means he's got this trait."'

(P10N) [S5] "anyone can read a definition of something and kind of spout it out. But I think the best thing if you want to actually understand somebody is to actually go and find out for yourself really, and actually speak to somebody"

The literature is what took these participants beyond literal, dictionary definitions into a more imaginative and emotional pooling of experience. While the lived-experience nature of the sessions encouraged the development of emotional intelligence toward autistic participants, it was the literature which brought autistic and non-autistic participants to feel with one another. The emotionally provocative events within the narrative encouraged participants to share their own emotional experiences of reading the text:

(P20A) [S4] "I cried a lot, the shortness had a bigger impact, due to there being so much to process in so little time then having to move on."

(Pair 3) [S3] P9N: "I felt too sad during this chapter, with the bad events for the characters."

P11A: "It was sad, it felt like a slow-motion car crash, you knew what was coming so everything felt slower"

Through these shared exchanges, participants began to process their own each other's emotional reactions to the text, exploring the depth behind their emergent feelings. Specifically, the discussions brought their earlier emotional reactions forward into the session in reactivated memory, allowing them to feel through the experience again. This resulted in explorations of what contextual factors had elicited their complex reactions. Through this individual processing of text reactions within discussions, participants were then able to comparatively explore their different understandings, feeling through their emotions together. This was often through exchanges of one participant offering complex insight that evoked surprised silence from their partner, as they processed the depth of the emotions brought forward through the narrative:

(Pair 4) [S3] P11A: "I found it peacefully surreal [the death of Curley's wife and looming death of Lennie], during distress there are brief moments where you forget and have moments of peacefulness."

[Researcher: P9N seems surprised by this.]

Stigma in particular was a recurring point of discussion between pairs, reflecting the experiences of narrative characters. The book acted as a key social catalyst in this way, with complex examples of stigma toward multiple minority groups, resulting in in-group stigma amongst marginalised characters. In particular, participants tended to feel empathy *with* the character Lennie, together. Lennie is a character who was discriminated against by other book characters for his unnamed neurocognitive disability. These empathic responses also resulted in shared frustrations toward characters who mistreated Lennie:

(P18A) [S2]: "the dream [of character's getting their own farm] feels more real now and it makes me worry for Lennie because I empathise with how he's bullied and how Lennie wants to avoid trouble but George is giving him opposing advice."

(Pair 3) [S2] P11A: "I couldn't understand Curley and why he'd hit Lennie if he [Lennie] wouldn't hit back". . .[S3] P9N: [talking about why Lennie responded to the death of Curley's wife the same as he did a mouse] "I think Lennie was scared of George, he relies on him and didn't want to disrupt harmony."

This evocation of empathising with Lennie resulted in the dyads engaging in further complex, emotional discussions of the text. For P20A and P8N this resulted in questioning the surface assumption that Lennie needs George to survive, by imaginatively and sensitively going further to consider the mutuality of this dependence:

(Pair 2) [S1] P20A: "I wonder if George would survive without Lennie and if Lennie would be better off without George?"

P8N: "I think Lennie would find someone else. . ."

[S3] P20A: "George doesn't help himself by hiding it" [Lennie's disability]. . .

P8N: "I don't think George wanted him to be seen or treated as different, but maybe that's why he keeps getting in trouble."

P20A: "I think it shows how much Lennie and George need each other."

Here, the use of "I wonder" and "I think" shows signs of individual, imaginative risk-taking from P20A.

Similarly, all pairs expressed a feeling of mutually shared empathy *with* the character Crooks, who experienced both racial and physical-disability related discrimination. In comparison to Lennie, these feelings were more conflicted, holding in mind a frustration with how Crooks stigmatised Lennie for his disability and at the same time feeling through the difficult emotions that resulted in Crooks behaving this way. This tended to lead to further evaluation of what role Crooks served as a literary device. Below is a short passage showing the interaction between Crooks and Lennie, followed by participant responses:

(A passage from Of Mice and Men of Crooks and Lennie meeting; Steinbeck, 1937)

Noiselessly Lennie appeared in the open doorway and stood there looking in, his big shoulders nearly filling the opening. For a moment Crooks did not see him, but on raising his eyes he stiffened and a scowl came on his face. His hand came out from under his shirt.

Lennie smiled helplessly in an attempt to make friends.

Crooks said sharply, "You got no right to come in my room. This here's my room. Nobody got any right in here but me."

Lennie gulped and his smile grew more fawning. "I ain't doing nothing," he said. "Just come to look at my puppy. And I seen your light," he explained.

"Well, I got a right to have a light. You go on get outa my room. I ain't wanted in the bunkhouse, and you ain't wanted in my room."

"Why ain't you wanted?" Lennie asked.

"Cause I'm black. They play cards in there, but I can't play because I'm black. They say I stink. Well, I tell you, you all of you stink to me."

(Pair 2) [S3] P8N: "I found Crooks the most interesting, it's interesting that he gets his own chapter."

P20A: "Why did he?"

P8N: "There's a lot about race, and that sometimes is sympathetic but also Crooks can be horrible. You start disliking Crooks, then feel sorry for him because he's got the worst life."

P20A: "It shows there is depth to these people, which is why the author took time to speak about him"

(Pair 3) [S2] P9N: "I felt sad for Crooks due to the racism he endures. . . he's denied simple pleasures such as living with others or being involved in games. I think the racism was deep rooted, with him seeing Lennie as intruding and being fearful of others and losing his job, despite the fact that Lennie was too naïve to consider this. I think Crooks is safety-focussed.". . .

P11A: "Crooks would have known the risks and likelihood of being blamed, resulting in avoidance and constant terror. He could have had a nice friendship with Lennie, as Lennie would have had no prejudice against Crooks."

By bringing the realities of complex emotions forward into discussions, the literature encouraged participants to process their own lived experiences of similar events, such as stigma and grief. These experiences were shared within pairs, drawing parallels to narrative events. While participants had already began to mutually feel with one another, these discussions of stigma tended to be unfamiliar for non-autistic participants. However, with the prior evocation of empathic responses elicited by similar events within the literature, non-autistic participants were moved from feeling for to feeling with their partners, although unfamiliar experiences were being disclosed. Conversely, where both participants had a shared, personal experience, disclosure from one resulted in empathic disclosure from the other:

(Pair 1) [S4; after discussing the racism toward Crooks in the book] P1A: "When I was in a choir, as a child, I experienced racism"...

P7N [shocked]: "Who would be racist to a child?"

P1A: "Multiple teachers disliked me and I'm unsure now if it was due to being autistic or if they were being racist."

(Pair 3) [S1; after discussing their empathy toward Candy for having his dog put down in the book] P11A: "I had to put my dog down and that results in complex emotions"

P9N: "I had to put my cat down, it is difficult when you know your pet is suffering."

From Overwhelming to Overcoming

Individuals generally had to overcome over-simple or stereotype-based concerns or barriers that presented between themselves and their partner. For autistic participants, their concerns toward non-autistic people in general were centred upon past experiences of being stereotyped and stigmatised. These concerns were factors that contributed to social concerns *before* participants had met with their non-autistic partners:

(P1A) [S5] "they have a stereotype in their mind, whether it's due to you know the odd film or what they've seen briefly in real life and they don't fully grasp and understand. They think a lot of the traits are tied to all autistic people whereas obviously it varies"

In contrast, the non-autistic group had to overcome previously held general concerns of difference in relation to autistic people:

(P10N) [S5] "maybe I overestimated the impacts that it [being autistic] would have on what I would deem to be like a normal life... At the end of the day, whether you're diagnosed with something it's kind of, it doesn't really matter, everyone's different, everyone's going to take different things from it... you're going to have to take everyone on their individual face-to-face I suppose. So, I suppose it's not being quick to kind of type-cast somebody"

Part of this difficulty was that non-autistic people were viewed generally by autistic participants as not having to face and overcome social difficulties in their day-to-day lives because they belong to the majority neurotype. However, the literature dismantled this over-simple generalisation within pairs by introducing social overcoming. As a result, *both* autistic *and* non-autistic participants showed evidence of having to overcome social challenges drawing on the felt affinities between the literary characters and themselves to do so:

(P8N) [S5] "I thought it was interesting when the participant [20] was saying that they felt more of an affiliation with Lennie, 'cos I guess if I was thinking about it, I probably would feel more of an affinity with George overall.

[SI] George's stubborn and resentful attitude makes him harder to like."

(Pair 4) [S3] P18A: "I don't know why George done that to his so-called friend, but I feel he regretted it..."

P10N: "I felt George had no choice..."

P18A: "I might have done the same if I was George"

The complex reflective statement from P8N indicates that the affinity with George was not one of liking and, in the vein of overcoming, its relation to the participant's own rather critical self-judgement was clear. Similarly, for P18A the shifts and modifications and overall mobility are evidence again of a more complex to-and-fro interaction.

During the first couple of sessions, social difficulties sometimes occurred as participants worked to overcome their differences. While these difficulties tended to centre on minor social discomfort and general awkwardness around continuing to-and-fro conversations, for participants 1A and 7N, there were incidents in the second session of conflicting emotional opinions. This conflict felt overwhelming for P1A, as we have seen. These events stemmed from P1A sharing feelings of unease toward the event in the book which he later felt was not responded to empathically by his partner:

(P1A) [S5 – recalling events from S2] "I kept referring to my distaste for a certain character for drowning puppies, he in real life brought up in an almost gleeful manner that he'd drowned rabbits...that was kind of disturbing."

These isolated incidents of social discomfort between participants seemed to mirror the idea that non-autistics were not experienced in adjusting communication to take account of others. By contrast, autistic participants reported having regularly to adjust their communication in day-to-day life so as to overcome social difficulties that present during communication with non-autistic people. As a result of a so-called "deficiency," autistic participants have to develop an advanced capacity to consider and hold in mind complex, alternative ways of being and perspectives:

(P1A) [S0] "a lot of traits they [neurotypicals] have I either don't relate to or can't stand. Examples, small talk, can be two-faced. Whereas I envy not being able to cope better with sensory issues so there are positives too...though a favourite has to be bluntness which neurotypicals can lack."

It was a perceived lack of honesty, disguised through social skills, which P1A struggled with. The result as here is often a more complex mental syntax in response ("whereas. Though").

For non-autistic participants, social overcoming exemplified within the text seemed to result in a wider acceptance of differing perspectives in participants working together patiently in real time outside it:

> *(P10N) [S5] "it kind of made me re-evaluate that people can pick up different things and neither one is wrong. . .it's just made me think about if something seems odd to me. . .then by taking a little bit of time to kind of chat to somebody and just kind of figure out their process, actually it makes it easier for me to understand how they've got to that point. I mean that works for autistic or non-autistic"*

As the discussion of lived experience contributed to the move from feeling overwhelmed by difference to the emergence of a will to overcome difference, supported by acknowledged similarities, so, taking time over the four sessions resulted in built rapport:

> *(P7N) [S5] "I personally feel having that same person you got to build that relationship and you got to understand what our differences are better. I know it wouldn't be a representative sample. . .but it allowed you to build a relationship in which you felt comfortable to talk about certain things. And I think by the time we got to session three, when we were on some of the shall we say more divisive aspects of the book; the racism, the murder, the sexism and discrimination with disability, you wouldn't be able to necessarily discuss that with somebody you'd just met."*

What emerged was genuinely "built" social connection within pairs and a positive desire to work on a social bond rather than concentrating on neurotype identities:

> *(P10N) [S5] "I looked forward to seeing the participant, and kind of seeing what his take was. . .it almost got to the point where I didn't think it was an autism study"*

This quote from P10N is testimony to the depth of connection achieved.

Participant Feedback

Participants 10N, 1A, 11A, and 20A decided to provide feedback on the overall findings from the study one year later. Participant 1A reported reflecting on the study to consider how his partner viewed him as an autistic adult and how this might translate to the way non-autistic people view autistic people in wider society. However, participant 1A did not find any improvements in communication with non-autistic individuals outside of the research. Participant 11A reported continued reflections on the shared reading sessions and a resultant improvement in making her own intentions clearer for mutual understandings:

> *(P11A) "Now, I try to think about how other people might view me and what I put across. I also try to explain my thinking/feeling a little more, although this can be difficult at times."*

Similarly, participant 20A reported that the feeling of being valued in having a different perspective translated into her everyday life, making her feel more open herself toward differing perspectives:

> *(P20A) "I have realised that my own interpretations of things are not necessarily wrong and there are different perspectives that you can respect. I have tried to be more open listening to what others have to say even if I do not agree."*

Participant 10N reported the biggest changes in his everyday life as a result of taking part in the research. Importantly, the participant reported slower, more careful thinking in assessing the perspectives of others. As a result, the participant felt a sense of improved communication when interacting with others who had a different perspective from his own:

> *(P10N) "When I meet someone with an opinion different from my own, I take a moment and think. My instinct is less likely to be that their thoughts are wrong and more that they are different and that I may be able to find the common ground in between."*

DISCUSSION

Summary of Findings

This study aimed to explore (1) changes in understanding between autistic and non-autistic participants and (2) double empathy exchanges around empathising and perspective-taking, through the shared contemplation of serious literature. Relative findings are discussed below in relation to previous research and theory.

Literature as Risk Permitting

Data supported the argument that serious literature forces readers to "bite off more than they can chew," promoting complex, open assessments of what was being read (Davis, 2020; Davis and Magee, 2020). This prevented participants from narrowing their understandings down into simplistic, stereotyped explanations of complex human experience (O'Sullivan et al., 2015; Davis and Magee, 2020). Although the non-autistic participants included in the study did not exhibit stigma toward autistic people in general or within their research pairs, all described having come to the study with some level of stereotyped views of autistic people that were subsequently challenged. This indicates a potential usefulness of literature in challenging these stereotyped views and possible associated stigma that exists toward autistic people (Cage et al., 2018; Pearson and Rose, 2021). While the lived experience of the autistic participants was reported as a key catalyst for these changes, it was the literature itself that prompted imaginative feeling within pairs, in present time. Similarly, although the shared experience of having both read the book was important in uniting pairs, the emotional atmosphere was deepened by the complex literary language within the book: the literary language, through its engagement with raw human emotions, turned the story into an emotionally complex, immersive environment for participants to operate within. In this way, participants went beyond simple discussions around disability and stigma prompted by the book, to operating more thoroughly within the text in a way that enabled them to feel together with the characters. This sharing in raw emotions resulted in an overcoming of the double empathy problem (Milton, 2012),

enabling participants to feel for one another in the same way. Overall, this supports the idea that literature may be particularly provocative of empathic responses and subsequent perspective-taking (Koopman and Hakemulder, 2015; Davis and Magee, 2020).

Furthermore, the literature afforded a sense of safety for social explorations through individual risk taking. This resulted in disclosures of difficult past experiences as well as direct emotional text responses within pairs. This indicates that the current methodology may afford at least some of the benefits observed in shared reading groups (Longden et al., 2015), while also taking into account and ameliorating concerns autistic people may have about live shared readings (Chapple et al., 2021). Additionally, the autistic participants in this study reported concerns around being stereotyped, and consequently stigmatised, that led to some generalised social reluctance. However, the shared warmth and security afforded by the literature resulted in explorations of social difference within pairs. As a result, participants incorporated the duality of their interactions, rather than attributing blame for difficulties that occurred. This contrasts with everyday inter-neurotype communications, where stereotyping and social heuristics result in assumptions of autistic social deficits (Chown, 2014; Milton et al., 2018). This shared appreciation resulted in reports of autistic participants feeling that their differing views were validated by their partners. This further highlights the double empathy problem within everyday inter-neurotype interactions, where autistic people are often encouraged toward an assumed ideal of neuronormativity (Mueller, 2020). Furthermore, this demonstrates the value of shared reading in promoting a multiplicitous thinking style (Ida, 2020) that frames autistic people as having different and valued perspectives.

Literature as an Advantageous Double Empathy Methodology

Importantly, the inherent social nature of fiction that mirrors the complexity of real socio-emotional human experience (Zunshine, 2011; Mumper and Gerrig, 2019) resulted in pairs focussing on their shared, essential experience of human emotion, regardless of their categorical neurotype group. This indicates that literature may be advantageous in tackling the double empathy problem, by challenging problematic social assumptions stemming from "us and them" conceptualisations (Goffman, 1990; Cage et al., 2018; Pearson and Rose, 2021). This move from thinking in terms of categorical neurotype differences, toward thinking as readers and, on a wider scale, human beings shows that shared reading can achieve the dismissal of groupness argued necessary for maximal double empathy understandings (Ida, 2020). In this way, the double empathy problem was resolved amongst participants by transcending these norms and expectations to produce shared and effective communication. This supports Ida's (2020) argument that in order to achieve double empathy and promote neurodiversity, there is a need for open, individualised assessments without binary conceptual framings.

Crucially for this study, the complexity of emotive understanding and response that is required by literature provided live evidence against assumptions that autistic people lack the emotional and social intelligence that is at the core of human experiences. Furthermore, responses to the disadvantaged Lennie fed off these powerful basic human feelings. This prompted participants to start feeling together with Lennie, who was felt as another human presence in the discussions. As a result, participants shared discussions about these core human experiences, adding to the socio-emotional complexity of the thinking. For example, engagement with the literature and characters resulted in conversations about various forms of stigma in wider society. This aligns with discussions that are regularly prompted through shared reading methodologies (Longden et al., 2015), again demonstrating that the current methodology may prompt parallel outcomes in a more comfortable way for autistic participants. Furthermore, it is these explorations of core human situations which are not readily experienced in general, everyday conversations. This rawness in exploring human experience, within a safe setting, encouraged slower assessments of social context, as opposed to the more (neuro)typical reliance on quick attributions. This renewed patience for careful social and individual exploration meant that participants reported intent to sensitively explore differing perspectives in the future, indicating that shared reading may prompt longer-term re-framings away from stereotyped understandings. This supports the important arguments of Ida (2020) and McCreadie and Milton (2020), that open and creative methodologies are needed to effectively overcome the double empathy problem.

Creative Overcoming Contesting Deficit Models

Participants demonstrated contrasting thoughts and feelings toward characters which were experienced in their complexity rather than being "resolved" into simplified conclusions. Given that all autistic participants demonstrated this overcoming, these findings challenge dominant theoretical framings of autism as being inherently associated with a reduced capacity for empathy and perspective-taking (Baron-Cohen, 1997, 2002, 2009). Furthermore, fictional contemplation, it is argued, requires higher-order empathy (Zunshine, 2011) that is furthered by shared communication around reading (Longden et al., 2015). The autistic participants here went beyond the ability to process the complex socio-emotional aspects of the text, but also added deeper levels of their own socio-emotional insight. This demonstration clearly conflicts with arguments that autistic individuals have inherent social and emotional impairments (Baron-Cohen, 2009; Lombardo and Baron-Cohen, 2011; Bodner et al., 2015; Rigby et al., 2018).

Where this overcoming was implemented during times of social difficulty within pairs, there resulted a sensitive understanding and move toward mutual resolution. Specifically, within all pairs, socio-communicative difficulties occurred due to autistic participants desiring structure, and non-autistic participants not wanting to over-dominate. As a result, these social difficulties did not lead to communication breakdowns, and subsequent blame attribution that is often associated

with inter-neurotype communicative difficulties (Milton, 2012; Chown, 2014). Instead, participants took time and care to consider the problem, working together in building a social structure that worked for both. This transference of the slow and careful processing that the literature encouraged supports the view that the salience of literature results in contextual behavioural change (Mumper and Gerrig, 2019). Furthermore, this movement away from quick attributions of blame amidst communicative ambiguity implies a wider move away from deficit framings based on assumed general norms. This, together with feedback provided by participants after the study, further supports the idea that changes resulting from literary contemplations may result in wider changes in an individual's social norms (Mumper and Gerrig, 2019).

Limitations and Future Research

The willingness of the non-autistic participants to take part in research that was seeking to explore interactions with autistic participants indicates a pre-existing willingness to co-operatively engage with autistic people. Therefore, conclusions on how much the literature brought about a change in understandings are limited to this sample. Additionally, the participants in this study were willing to read and discuss literature, and so may have been more readily willing to engage with reflexive thinking than most. For people with pre-existing stigmatising views about autism and autistic people, it remains a question as to whether the shared reading paradigm used here would be ethically and socially appropriate. Future research should seek to explore whether literature that has a neurodiversity focus would bring about double empathy understandings for non-autistic people while reading alone. This is important in order to explore how reading can be used as a double empathy intervention tool for individuals who hold particularly stigmatising views toward autistic people.

Additionally, the methodology implemented in this research lacks the text liveness that is important in other shared reading designs, such as reading aloud groups (Longden et al., 2015; Davis, 2020). Therefore, more research is needed to explore text liveness within shared readings between autistic and non-autistic people in a way that remains comfortable. For example, expansion of the current methodological design could seek to explore the added value of having participants select and read aloud passages which move them. It is also important to identify how larger-scale or longer-term shared reading paradigms might be designed and implemented, given concerns that book club style groups may result in limited demographic inclusion (Davis and Magee, 2020). While this study indicated that the shared experience specific to literature promoted deeper discussions, future research should seek to compare shared reading with discussions of other shared experiences.

The sample used here is also limited because autistic adults were only included if they did not have an additional disability that would affect their reading and writing skills. Similarly, all autistic participants in this study communicated verbally, resulting in limited representation of the autistic community. As a result, more research is needed to assess the utility of shared reading as a means to overcome the double empathy problem where individuals have additional support needs.

CONCLUSION

In conclusion, the findings of this study show the potential utility of serious literature for overcoming the double empathy problem (Milton, 2012). Importantly, the literature resulted in a focus on overarching, essential human similarities, even through felt differences. This moved participants away from binary group assessments that often result in stereotyping and subsequent stigma within general society (Cage et al., 2018; Pearson and Rose, 2021). Therefore, findings imply that shared reading promotes multiplicity (Ida, 2020), moving participants toward a shared identity with sensitive considerations of difference. Importantly, findings contest dominant deficit-based theories of autism (Baron-Cohen, 1997, 2002, 2009), showing that autistic people do empathically respond to the perspectives of others. Similarly, these findings of autistic people engaging emotionally with serious literature contest over-simplistic framings of autistic individuals as inherently lacking in social and emotional understanding (Baron-Cohen, 2009; Lombardo and Baron-Cohen, 2011). In this study, all participants showed the higher-order levels of empathising and perspective-taking necessary for fictional contemplation (Zunshine, 2011). Overall, the findings here support arguments that open, creative research methodologies, fostering a broader shared understanding, are useful for achieving effective double empathy understandings (McCreadie and Milton, 2020; Mueller, 2020). As Steinbeck (1952, p. 444) himself wrote:

> *"You can only understand people if you feel them in yourself."*

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because the ethical approval obtained from the University of Liverpool covered the publication of unrecognisable sections of anonymised data only. Due to the sensitive nature of the data, anonymised data cannot be provided in full due to the potential for participants to be recognised. Requests to access the datasets should be directed to MC.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Health and Life Sciences Research Ethics Committee (Psychology, Health and Society), University of

Liverpool. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

MC, PD, JB, and RC: conceptualization, methodology, and validation. MC: funding acquisition, data curation, project administration, and writing – original draft. MC, PD, JB, JAM, CR, and RC: formal analysis, writing, review, and editing. PD, JB, and RC: supervision. All authors contributed to the article and approved the submitted version.

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Personal Identity After an Autism Diagnosis: Relationships With Self-Esteem, Mental Wellbeing, and Diagnostic Timing

*Kirsten Corden[1], Rebecca Brewer[1] and Eilidh Cage[2]**

[1]Department of Psychology, School of Life Sciences and the Environment, Royal Holloway, University of London, Egham, United Kingdom, [2]Department of Psychology, Faculty of Natural Sciences, University of Stirling, Stirling, United Kingdom

Adults are increasingly seeking autism diagnoses, although less is known about their experiences of diagnosis and personal identity (i.e., autism as part of "me"), and how this relates to self-esteem and wellbeing. One-hundred and fifty-one autistic adults completed an online survey including measures of self-esteem, psychological wellbeing, and autistic personal identity, which considered whether participants took pride in or were dissatisfied with being autistic. Fifty-four participants answered a qualitative question about the impact of receiving an autism diagnosis on their sense of self. Regression analyses found that greater time elapsed since diagnosis related to less dissatisfaction with autistic personal identity. We also found that more dissatisfaction with autistic personal identity predicted lower self-esteem, and more autism pride predicted higher self-esteem. Content analysis of participants' experiences supported the quantitative findings and was suggestive of an emotive post-diagnostic adjustment process. Future research should aim to identify ways to promote the development of a positive autistic personal identity post-diagnosis in adulthood.

Keywords: autism spectrum conditions, autism diagnosis, autistic identity, self-esteem, psychological wellbeing

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Felicity Sedgewick,
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Tanja Gabriele Baudson,
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Michael Richards,
Edge Hill University, United Kingdom

***Correspondence:**
Eilidh Cage
eilidh.cage@stir.ac.uk

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INTRODUCTION

Autism is a life-long neurodevelopmental condition characterised by differences in social communication and interactions, alongside sensory sensitivities, focused interests, and repetitive behaviours (DSM-5; American Psychiatric Association, 2013). Autism is often perceived as a childhood condition, with diagnostic criteria, protocols and service provision tailored to this age group (Howlin, 2008; Gerhardt and Lainer, 2011). However, many people receive an autism diagnosis in adulthood – something which is noted as emotionally impactful, with a notable lack of appropriate post-diagnostic support for adults (Huang et al., 2020). In the disability literature, acquiring a condition later in life necessitates accommodating changes into one's self-concept (Frank, 1993). This process differs according to whether a well-formed identity has already been developed and committed to, known as achieving identity synthesis (Charmaz, 1994, 1995). Although autism is not an acquired condition, the impact of a diagnosis in adulthood, especially if the individual did not previously self-identify as autistic, could pose similar challenges to identity processes. Therefore, the current study firstly aimed to understand how autistic identity and diagnostic timing related to one another.

Social Identity Theory proposes that an individual's self-concept is comprised of social and personal identities (Turner et al., 1987). Here, personal identity includes characteristics that define the individual and differentiate them from others. Personal autistic identity would encompass an individual's own specific interests and values as an autistic person, which they perceive to contribute to their uniqueness and individuality (i.e., characteristics of "I" and "me"). Social identity, contrastingly, represents characteristics shared with a group someone identifies with. Autistic social identity would involve perceived similarities or shared characteristics with other autistic people (i.e., characteristics of "we" and "us") and differentiation from out-groups (e.g., neurotypical people). The present study focused specifically on autistic *personal* identity.

Qualitative research with autistic adults indicates that identity formation may be challenging for those diagnosed later in life. In a study of autistic students' experiences, individuals who received their diagnosis earlier in life expressed more acceptance of being autistic and a more positive sense of self (Cox et al., 2017). Other qualitative work with late-diagnosed older autistic adults (aged over 50) identified how some participants tended to externalise and view autism as separate to themselves, suggesting that they were not incorporating autism into their personal identity (Hickey et al., 2018). One interview study with late-diagnosed autistic females described an emotionally difficult adjustment period, but how diagnosis helped them to make sense of their identity (Leedham et al., 2020). Receiving an earlier diagnosis may link with more positive self-concepts, but it is unclear whether this relates to the age at diagnosis, or the time elapsed since diagnosis for understanding and adaptation. As such, the present study aimed to examine the relationships between personal identity, age of diagnosis, and recency of diagnosis as distinct variables.

Ideally, the process of positive personal identity development should culminate in an understanding, acceptance, and appreciation of the whole self (Gill, 1997). However, it is thought that having a disability or condition (including autism) can relate to challenges in developing a positive self-concept (Gill, 1997), and thus there are complex relationships between identity and psychological health. These complexities may partly link to being or feeling "different," or being treated or stigmatised as such by others (Milton and Sims, 2016; Richards, 2016). Factors contributing to minority stress (e.g., discrimination and internalised stigma) might be internalised into a negative sense of personal identity (Tantam, 1992; Wright et al., 2000; Botha and Frost, 2020). This notion links to Theory of Social Stigma of Goffman (2009) which suggests that certain labels hold the power to "spoil" an individual's identity, leading to ostracization from society and disruption of identity development processes.

As indicated, making sense of one's identity is psychologically demanding, and therefore identity processes may relate to psychological variables such as self-esteem and mental wellbeing. Mental wellbeing refers to a broad concept covering both positive and negative aspects of mental health, such as feelings of depression and being able to cope with these (Maitland et al., 2021). Self-esteem is an evaluative attitude toward the self, indicating self-worth (Luhtanen and Crocker, 1992), and is associated with concepts such as optimism and self-confidence (Rosenberg et al., 1995; Lyubomirsky et al., 2005). Studies have noted both lower mental wellbeing and self-esteem in autistic adults compared to the non-autistic population (Nguyen et al., 2020; Maitland et al., 2021). However, positive relationships have been observed between self-esteem and social identity in non-autistic samples (Greenaway et al., 2015; Jetten et al., 2015). Accordingly, Cooper et al. (2017) found that having a stronger sense of autistic social identity was associated with more positive self-esteem, and noted that greater autistic social identification could link to better mental health *via* increased self-esteem. However, less is known about the role of autistic personal identity (i.e., autism as part of "me") in autistic adults and how it relates to self-esteem and mental wellbeing. Given the high rates of emotional distress and diagnosable mental health conditions which have been reported in autistic individuals (Stewart et al., 2006; Gillott and Standen, 2007; Eaves and Ho, 2008; Lever and Geurts, 2016; Lai et al., 2019), it is important to look at potential contributors, such as identity, to autistic people's mental wellbeing and self-esteem.

Overall, the current study aimed to examine aspects of personal identity for autistic people, with a specific focus on those diagnosed in adulthood. First, the study aimed to investigate relationships between personal autistic identity and diagnostic timing, specifically the age and recency of diagnosis, to understand how receiving a late diagnosis relates to personal identity development processes. Second, this study aimed to investigate the relationship between autistic personal identity and psychological health (self-esteem and wellbeing), as has been documented with autistic social identity (Cooper et al., 2017; Maitland et al., 2021), to examine how personal identity processes may link to self-esteem and wellbeing in late-diagnosed autistic adults.

We hypothesised that: (1) younger age of diagnosis and greater time elapsed since diagnosis would relate to more positive autistic personal identity and (2) more positive autistic personal identity would relate to higher levels of self-esteem and wellbeing. We also used qualitative methods to gather further information on individuals' perceptions of how an autism diagnosis affected their sense of self. This mixed methods approach was deemed appropriate, with a focus on developing a deeper understanding of autistic people's experiences of identity after receiving a diagnosis, while also enabling a larger sample than purely qualitative studies. Although there have been qualitative studies which highlight the potential impact on identity of receiving an autism diagnosis, particularly in adulthood (e.g., Bargiela et al., 2016; Hickey et al., 2018; Stagg and Belcher, 2019; Leedham et al., 2020), this study adds to this literature with our mixed methods approach and is novel in looking quantitatively at relationships with psychological health.

MATERIALS AND METHODS

Participants

One-hundred and fifty-one participants from the United Kingdom took part. We included only participants from

the United Kingdom since diagnostic processes and barriers may differ by country (Huang et al., 2020). One hundred and seventeen participants identified as cisgender female (77.6%), with 30 cisgender male (19.7%) and four non-binary or transgender participants (2.7%). Participants' age ranged from 18 to 65 years old, with a mean of 31.26 (*SD* = 10.23). Further participant characteristics are available in **Table 1**, indicating that most participants were White British, educated to degree level, and in employment.

Participants were required to have a formal autism diagnosis since the study considered the experience of receiving a diagnosis. Eighty-six participants (57.0%) self-reported a diagnosis of "Autism Spectrum Condition," with the remaining 65 participants (43.0%) reporting "Asperger's Syndrome." As this information was self-reported, the Ritvo Autism and Asperger Diagnostic Scale (RAADS-14; Eriksson et al., 2013) was administered to validate the presence of diagnosable autistic characteristics. All participants scored above the RAADS-14 cut-off score of 14. Participants predominantly received their diagnosis through NHS services (96.0%), with few receiving their diagnosis privately (4.0%). Participants received their diagnoses between 2000 and 2020, reporting ages at diagnosis ranging from 6 to 62 years old (mean = 26.42, *SD* = 11.18, 78.8% diagnosed over the age of 18). On average, participants had received their diagnosis 4.95 years previously (*SD* = 4.09, range 0–20). Over half indicated they had additional neurodevelopmental or mental health diagnoses (58.3%).

Participants were recruited online using snowballing methods, with adverts posted on public and private social media (e.g., Facebook and Twitter) and sent directly to relevant autism groups, organisations, and charities between December 2019 and March 2020. Although we were particularly interested in the experiences of those diagnosed late, the survey was open to all. This study was reviewed and approved ethically by the Research Ethics Committee at Royal Holloway, University of London. All participants provided informed consent prior to participation.

TABLE 1 | Demographic characteristics of the study participants.

Variable	Categorical response	%
Ethnicity	White British	72.8
	Mixed or multiple ethnic groups	15.2
	Black British	7.3
	Asian British	4.0
	Other	0.7
Education	GCSEs or equivalent	8.6
	Apprenticeship	6.0
	A-Levels or equivalent	24.5
	Undergraduate degree	36.4
	Postgraduate degree	14.6
	Doctoral degree	8.6
	Prefer not to say	1.3
Employment*	Employed full-time	29.1
	Employed part-time	24.5
	Student	12.6
	Unable to work	9.9
	Unemployed	9.9
	Self-employed	6.6
	Carer	5.3
	Retired	2.0

Denotes that participants could select multiple options.

Materials and Procedure

We used "Qualtrics" as the online survey platform. Participants first completed questions concerning demographics and diagnoses. Due to variation in language preferences within the autistic community (Kenny et al., 2016), participants were given the opportunity to customise the survey to reflect their preferred terminology ("autistic person," "person with autism," or no preference). Accordingly, we presented participants with subsequent questions using either identity-first (64% preferred) or person-first (2%) language, or a combination if no preference (34%). Participants then completed the four measures in the order outlined and an optional qualitative question (see below).

Ritvo Autism and Asperger Diagnostic Scale

The RAADS is a 14-item screening tool for identifying autistic characteristics. Participants responded using a four-point Likert scale ["never true" (0) to "true now and when I was young" (3)], indicating duration of each symptom or experience, with a total possible score between 0 and 42 (Eriksson et al., 2013). Example items include "It is very difficult for me to work and function in groups." Internal reliability of the RAADS-14 in the current study was acceptable (α = 0.60).

Rosenberg Self-Esteem Scale

We used the Rosenberg Self-Esteem Scale (RSE) to measure self-esteem, which includes 10 items scored on a four-point Likert scale ["Strongly Disagree" (1) to "Strongly Agree" (4)], with a total possible score from 10 to 40, with higher scores indicating higher self-esteem (Rosenberg, 1965). Example items include "I feel I have a number of good qualities." Previous studies have demonstrated excellent internal reliability when used with autistic adults (e.g., Cooper et al., 2017; α = 0.91), and internal reliability in the current study was also excellent (α = 0.90).

Warwick-Edinburgh Mental Wellbeing Scale

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) is a 14-item measure of mental wellbeing. Items were rated on a five-point Likert scale ["none of the time" (1) to "all of the time" (5)], with a total possible range of 14–70, with higher scores indicating more positive mental wellbeing (Tennant et al., 2007). Example items include "I've been feeling useful." Past research has shown the WEMWBS has excellent internal reliability with autistic adults (e.g., Cai et al., 2019; α = 0.90). Internal reliability in the current study was very good (α = 0.89).

Questionnaire on Disability Identity and Opportunity

We measured autistic personal identity using two subscales adapted from the Questionnaire on Disability Identity and

Opportunity (QDIO; Darling and Heckert, 2010). This measure was selected as it reflected orientations and self-identification with a disability or condition. In our study, the word "disability" was substituted by the word "autism/autistic" as appropriate. The two subscales of interest were autism pride, reflecting perceived importance of or pride in autism being part of oneself, and exclusion/dissatisfaction, capturing feelings of rejecting or being dissatisfied with being autistic. Each subscale consisted of four items [e.g., "Autism is an important part of who I am" (autism pride); "Autism limits my social life" (exclusion/dissatisfaction)]. Participants scored each item on a five-point Likert scale ["Strongly disagree" (1) to "Strongly agree" (5)], with total possible scores ranging between 4 and 20 for each subscale. For autism pride, a higher score would indicate more pride in being autistic, and for exclusion/dissatisfaction, a higher score indicated more dissatisfaction with being autistic. In the original study, the authors reported good overall reliability levels (exclusion/dissatisfaction $\alpha = 0.73$, disability pride $\alpha = 0.78$). In this study, internal reliability was very good for autism pride ($\alpha = 0.84$) and acceptable for exclusion/dissatisfaction ($\alpha = 0.68$).

Qualitative Question

Participants could optionally provide qualitative information on the impact of receiving an autism diagnosis on their sense of identity. This question was presented prior to completion of the QDIO, to ensure qualitative responses were not influenced by the QDIO items: "*How did receiving an autism diagnosis affect how you think and feel about yourself? If possible, please refer to the following two periods of time: (a) When you initially received your diagnosis (b) The present day (i.e., currently).*" The exact wording of the question was discussed with members of the autistic community to ensure clarity and acceptability.

Design

This study used a cross-sectional mixed methods survey design. We selected mixed methods approaches to maintain a high level of empiricism while also acknowledging the exploratory nature of the study. Including qualitative elements in autism research has been highlighted as particularly important in understanding issues from the perspective of autistic people themselves (e.g., Bölte, 2014).

Data Analysis

We analysed quantitative data using SPSS version 27. There were no missing data for any of the quantitative measures. We first calculated descriptive statistics and variables were tested for compliance with standard parametric assumptions. All z scores calculated for skewness and kurtosis were lower than 2.58 ($p > 0.01$), and therefore we considered the data to be normally distributed. We consider p values between 0.05 and 0.005 as suggestively significant and $p < 0.005$ as significant (Ioannidis, 2018).

For the first hypothesis (personal autistic identity, age of diagnosis, and recency of diagnosis), we conducted two separate multiple regressions with personal autistic identity (QDIO subscales) as the dependent variables, and age of diagnosis and recency of diagnosis as predictor variables (controlling for gender). These analyses aimed to show how diagnostic timing related to personal autistic identity, over and above any gender differences in diagnosis.

For the second hypothesis (autistic personal identity, self-esteem, and wellbeing), we used two hierarchical regression analyses. The first hierarchical regression had self-esteem (RSE scores) as the outcome variable. We entered control variables into the first step, specifically autistic characteristics (RAADS-14), wellbeing (WEMWBS), gender (female vs. male only, due to small n of non-binary/other genders), and recency and age of diagnosis. We analysed self-esteem and wellbeing as two separate outcome variables: although there is shared variance between these variables, these concepts can be viewed as distinct, with discriminant validity between the two (Robins et al., 2001; Lyubomirsky et al., 2005), and we aimed to understand how identity contributed to each one uniquely. We thus controlled for wellbeing/self-esteem in the regression analysis predicting the other to ensure that variance explained by these inter-related concepts was taken into account in the model. In step 2, we entered the personal autistic identity variables (the two QDIO subscales: autism pride and exclusion/dissatisfaction) as predictors.

Similarly, we carried out a second hierarchical regression with wellbeing (WEMWBS) as the dependent variable, with the same variables as above controlled for in step 1 (replacing wellbeing with self-esteem), and personal autistic identity (QDIO subscales) in step 2. Together, these analyses aimed to show how personal identity contributed to wellbeing/self-esteem, over and above gender, diagnostic timing, autistic characteristics, and shared variance between wellbeing and self-esteem. All assumptions were met for the regressions, including homoscedasticity and multi-collinearity.

Qualitative Analysis

We used content analysis to interpret qualitative responses (Hsieh and Shannon, 2005). One author (KC) condensed responses into meaning units. Codes that were related to each other through content or context were grouped into categories, which were discussed and agreed with a second independent reviewer (EC; agreement 88%), with any disagreements discussed before coding was finalised. Responses could be coded into multiple categories.

In qualitative research, it is essential to acknowledge and discuss the positionality of the researcher (Braun and Clarke, 2019). One of the researchers is an autistic person who received her diagnosis in early adulthood, a process she found immensely challenging at the time, in part due to a lack of post-diagnostic resources. Her subsequent experiences within training for Clinical Psychology have included involvement in service development. These factors led to her interest in designing and conducting this research. High level of agreement with a second reviewer demonstrates validity in the identified categories.

RESULTS

Descriptive Statistics

Table 2 shows the means and SDs for the quantitative variables included in the study, and **Table 3** includes correlations between the variables.

Age and Recency of Diagnosis

Results from the two multiple regressions, with the personal autistic identity subscales as outcomes and age at and recency of diagnosis as predictors (controlling for gender), are summarised in **Table 4**. With autism pride as the outcome, the model explained 2.2% of the variance and was not significant [$F(3,143) = 1.07$, $p = 0.36$], with no significant predictors. With exclusion/dissatisfaction as the outcome, the model explained 21.5% of the variance and was significant [$F(3,143) = 12.07$, $p < 0.001$]. Here, as number of years since diagnosis increased, exclusion/dissatisfaction decreased (**Figure 1**).

Self-Esteem

The first step, including wellbeing, autistic characteristics, gender, and recency and age of diagnosis explained 77.1% of the variance in self-esteem (**Table 5**), and the model was significant [$F(5, 141) = 95.21$, $p < 0.001$]. Adding the QDIO subscales into step 2 explained an additional 5.7% of the variance in self-esteem, which was a significant increase [$F(2, 139) = 22.84$, $p < 0.001$]. The final model was significant [$F(7,139) = 95.61$, $p < 0.001$] and explained 82.8% of the variance in self-esteem. Specifically, lower exclusion/dissatisfaction significantly predicted higher self-esteem, and greater autism pride predicted higher self-esteem (**Figure 2**). Wellbeing was also a significant predictor in the final model, such that higher wellbeing predicted higher self-esteem. No other variables were significant.

TABLE 2 | Means and SDs for autistic characteristics, self-esteem, wellbeing, and personal identity subscales.

Variable	Mean (SD)	Range
Autistic characteristics	35.47 (4.67)	23–42
Self-esteem	24.97 (4.31)	13–32
Wellbeing	39.54 (6.75)	20–59
Personal identity		
Autistic pride	13.62 (2.34)	9–20
Exclusion/Dissatisfaction	10.87 (2.70)	4–16

Wellbeing

The first step, including self-esteem, gender, autistic characteristics, and recency and age of diagnosis, explained 75.9% of the variance in wellbeing scores (**Table 6**), and the model was significant [$F(5, 141) = 89.01$, $p < 0.001$]. Adding the QDIO subscales as predictors explained an additional 0.9% of the variance in wellbeing, which was not a significant increase [$F(2, 139) = 2.84$, $p = 0.062$]. The final model significantly explained 76.9% of the variance in wellbeing scores [$F(7,139) = 66.05$, $p < 0.001$], with greater exclusion/dissatisfaction predicting lower wellbeing at a suggestively significant threshold (**Figure 3**). As before, higher self-esteem also predicted higher wellbeing, and no other variables were significant in the final model.

Qualitative Analyses

Fifty-four participants (35.7% of the sample) responded to the optional qualitative question, describing how receiving an autism diagnosis impacted on their thoughts and feelings about themselves. **Table 7** illustrates the identified categories and sub-categories, number of coded responses for each category, and example quotes.

The most reported category focused on an "adjustment process," with responses generally reflecting changes experienced by the respondents following diagnosis. Within this category, we identified three sub-categories. First, participants discussed "Making sense of it all over time" whereby they referred to a process of re-evaluating their lives following their diagnosis. Further, participants talked about an "Emotional reaction to diagnosis," describing various reactive emotional responses including both positive (such as relief and happiness) and negative feelings (such as confusion and being overwhelmed). Additionally, some participants discussed "Permanence of difficulties," conveying a sense of grief or frustration over having to accept that their difficulties would not go away.

TABLE 3 | Pearson's correlations between the variables included in the study.

	Gender	Age of diagnosis	Recency of diagnosis	Autistic characteristics	Self-esteem	Well-being	Autistic Pride
Age of diagnosis	−0.123						
Recency of diagnosis	0.599***	−0.399***					
Autistic characteristics	−0.045	0.004	0.005				
Self-esteem	0.285***	−0.184*	0.410***	−0.055			
Wellbeing	0.251**	−0.195*	0.331***	−0.083	0.864***		
Autistic pride	0.102	−0.036	0.131*	0.002	0.592***	0.525***	
Exclusion/Dissatisfaction	−0.108	0.263***	−0.401***	0.049	−0.778***	−0.738***	−0.466***

*Gender coded as 0 = female, 1 = male (inclusion of other genders in statistical analyses precluded by small sample size). ***p < 0.001; **p < 0.01; *p < 0.05 (2-tailed).*

TABLE 4 | Regression results for the two multiple regressions with each of the Questionnaire on Disability Identity and Opportunity (QDIO) subscales as outcomes variables, and age, recency of diagnosis, and gender as the predictors.

	B	B CI	SE B	β	p	f^2
Outcome: Autism pride						
Recency	0.084	[−0.047–0.21]	0.066	0.14	0.21	0.011
Age of diagnosis	0.004	[−0.034–0.041]	0.019	0.017	0.85	0.0003
Gender	0.113	[−1.08–1.30]	0.60	0.019	0.85	0.0002
Outcome: Exclusion/Dissatisfaction						
Recency	−0.35	[−0.49–0.21]	0.069	−0.51	<0.001	0.16
Age of diagnosis	0.024	[−0.015–0.063]	0.020	0.10	0.22	0.008
Gender	1.39	[0.15–2.64]	0.63	0.21	0.028	0.028

B, unstandardised beta coefficient; B CI, confidence intervals at 95% lower and upper bounds; SE B, standard error; β, standardised beta coefficient; f^2, effect size (0.02 considered small effect, 0.15 medium, 0.35 large).

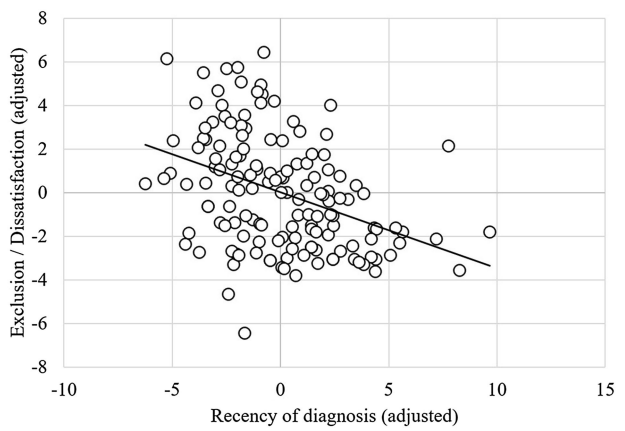

FIGURE 1 | Partial regression plot showing the relationship between recency of diagnosis and exclusion/dissatisfaction (controlling for other variables in the model).

The next most reported category concerned "Self-exploration," referring to the experience or process of self-discovery following diagnosis. There were three sub-categories: most often, participants discussed "Knowing and understanding who I am," highlighting how they had an increased understanding of themselves after diagnosis, in addition to allowing themselves more self-compassion. Some participants discussed "Being myself," describing feeling increasingly able to be more authentic in themselves. However, some participants discussed "Feeling the same about myself," reflecting the sense that the diagnosis had not led to any change in their self-perceptions.

Within the category of "Learning and support needs," participants reflected on a lack of information or knowledge about autism following diagnosis: Within the sub-category "I've learned a lot," participants mentioned their own preconceptions about autism before and after receiving the diagnosis and discussed finding out more about autism by doing research following diagnosis. The sub-category "More support needed post-diagnosis" referred to a perceived lack of post-diagnostic support and services available. A few participants mentioned "Late identification," questioning how it had taken until adulthood for others to recognise them as autistic. Relatedly, some participants specifically mentioned "Autism in women," describing a specific lack of information available about autistic females.

The next category focused on "Responses from others," referring to the reactions (both positive and negative) from other people to the respondent's diagnosis. Here, within the sub-category "Lack of understanding and acceptance from others," participants discussed difficult interactions they had with others on receiving their diagnosis, particularly in managing others' poor autism knowledge and being disbelieved or not accepted by others. Some discussed the sub-category of "Issues with disclosure," reporting concerns about disclosing their diagnosis to others. A few participants described "Positive reactions," giving examples of others responding positively to the diagnosis, often in terms of increased understanding.

In the category "Autism as a positive difference," responses included descriptions of positive aspects of receiving a diagnosis. Here, within the sub-category "Autistic pride and appreciation," participants discussed the strengths associated with being autistic, in addition to experiencing a positive autistic identity. Some participants mentioned "Thinking differently/being different" where they discussed positive aspects of difference and described the diagnosis as replacing a previous sense of something being "wrong" with themselves. A few participants discussed the sub-category of "Self-advocacy," reflecting on an increased ability to advocate for themselves and their needs following diagnosis.

Less often, we coded responses into the category "Challenges of the diagnosis," where participants reflected on negative aspects of receiving a diagnosis. Within the sub-category "Struggling to come to terms and find my place," participants reflected on feelings of low self-confidence and not relating to their pre-existing perceptions of autism. We coded a few responses as "Autism as a negative," where participants described a sense of negative difference or focused on difficulties associated with being autistic.

The final category, "I now feel part of something with others like me," reflected a sense of connection with the autistic community, how receiving an autism diagnosis helped participants to feel less lonely, and provided a sense of hope that there were other people who have similar experiences.

DISCUSSION

The current study sought to understand aspects of identity, self-esteem, and wellbeing in relation to an autism diagnosis in adulthood. We found that with greater number of years since diagnosis (but not age of diagnosis), participants reported less exclusion/dissatisfaction with being autistic. Our results also indicated that greater dissatisfaction with being autistic related to lower self-esteem, and higher pride in being autistic related to greater self-esteem. Greater dissatisfaction also related to poorer wellbeing, although this finding is treated with caution. Qualitative responses reflected a process of cognitive and emotional reaction to receiving a diagnosis and gave a sense

TABLE 5 | Hierarchical regression results with self-esteem as the outcome variable.

Predictor	B	B CI	SE B	*β*	*p*	f^2
Step One						
Wellbeing	0.53	[0.47–0.58]	0.028	0.83	<0.001	1.34
Autistic characteristics	−0.014	[−0.089–0.061]	0.038	−0.015	0.72	0.0002
Gender	−0.03	[−1.11–1.05]	0.55	−0.003	0.96	0.000004
Recency of diagnosis	0.16	[0.034–0.28]	0.062	0.14	0.013	0.011
Age of diagnosis	0.014	[−0.019–0.048]	0.017	0.037	0.40	0.001
Step Two						
Wellbeing	0.35	[0.27–0.42]	0.036	0.54	<0.001	0.13
Autistic characteristics	−0.016	[−0.082–0.050]	0.033	−0.017	0.63	0.00002
Gender	0.77	[0.23–1.76]	0.502	0.071	0.13	0.002
Recency of diagnosis	0.065	[−0.048–0.18]	0.057	0.059	0.26	0.001
Age of diagnosis	0.015	[−0.014–0.045]	0.015	0.040	0.30	0.001
Autism pride	0.27	[0.12–0.43]	0.079	0.15	<0.001	0.015
Exclusion/Dissatisfaction	−0.47	[−0.65–−0.29]	0.092	-0.29	<0.001	0.033

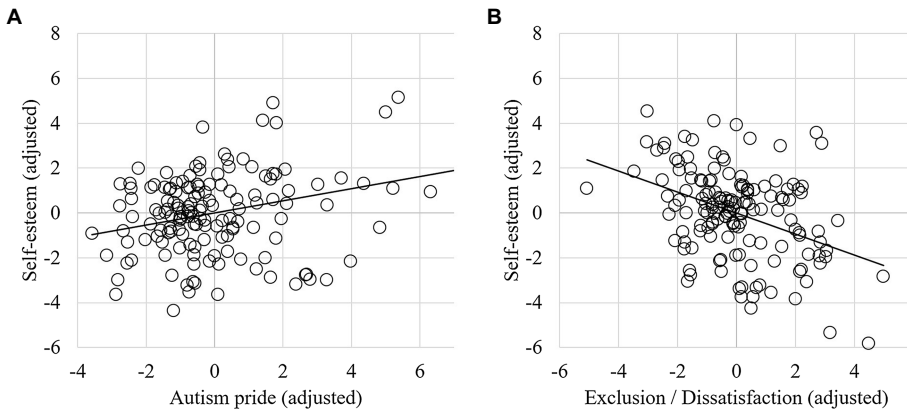

FIGURE 2 | Partial regression plots showing the relationship between self-esteem and **(A)** "autism pride" and **(B)** "exclusion/dissatisfaction" (controlling for other variables in the model).

TABLE 6 | Hierarchical regression results, with wellbeing as the outcome variable.

Predictor	B	B CI	SE B	*β*	*p*	f^2
Step One						
Self-esteem	1.36	[1.22–1.50]	0.072	0.87	<0.001	1.52
Autistic characteristics	−0.024	[−0.15–0.097]	0.061	−0.016	0.70	0.0003
Gender	0.028	[−1.47–2.02]	0.88	0.016	0.76	0.0002
Recency of diagnosis	−0.058	[−0.26–0.14]	0.10	−0.034	0.57	0.0006
Age of diagnosis	−0.034	[−0.088–0.020]	0.027	−0.056	0.21	0.003
Step Two						
Self-esteem	1.14	[0.90–1.38]	0.12	0.73	<0.001	0.18
Autistic characteristics	−0.026	[−0.15–0.093]	0.060	−0.018	0.67	0.0003
Gender	0.95	[−0.86–2.76]	0.92	0.056	0.30	0.002
Recency of diagnosis	−0.114	[−0.32–0.093]	0.10	−0.066	0.28	0.002
Age of diagnosis	−0.027	[−0.081–0.027]	0.027	−0.045	0.32	0.002
Autism Pride	0.068	[−0.23–0.36]	0.15	0.023	0.65	0.0004
Exclusion/Dissatisfaction	−0.41	[−0.77–−0.059]	0.18	−0.17	0.023	0.009

of learning and change over time, supporting our quantitative findings. The qualitative data also elucidated other psychological processes following diagnosis in terms of self-exploration, social connection, and support-seeking.

Contrary to our hypothesis, only recency of diagnosis predicted exclusion/dissatisfaction, with participants feeling more satisfied with being autistic as years passed following diagnosis. These findings could indicate that receiving a diagnosis offers a growing awareness of "being autistic," and as such, a sense of exoneration in explaining the underlying basis of a person's strengths and difficulties over time (Punshon et al., 2009). Indeed, qualitative work with autistic people suggests that the navigation of stigma,

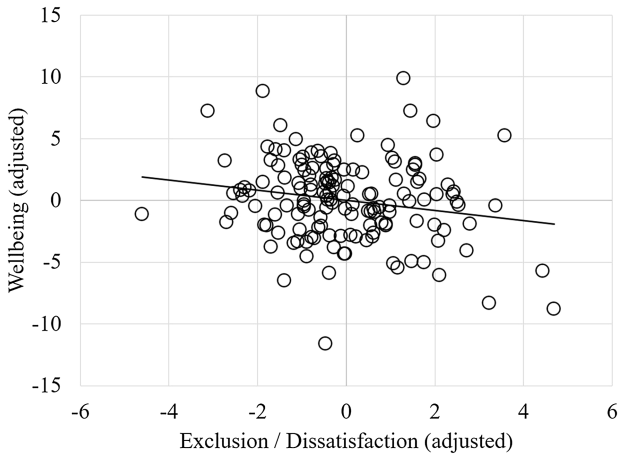

FIGURE 3 | Partial regression plot showing the relationship between wellbeing and exclusion/dissatisfaction (controlling for other variables in the model).

stereotypes, and discrimination can be exceptionally challenging for autistic people when they conceptualise their identity (Botha et al., 2020). Our findings also support qualitative research with older late-diagnosed autistic adults, some of whom appeared to externalise and reject autism as part of their identity (Hickey et al., 2018). Over time, increasing self-identification as autistic following diagnosis may encourage a view of autism as a positive difference instead of a deficit (Kapp et al., 2013). Our findings fit with other surveys where autistic adults reported negative emotions after having their diagnosis confirmed (Jones et al., 2014), and qualitative studies highlighting "painful" adjustments following diagnosis that eventually leads to greater self-compassion (Leedham et al., 2020). As time passes, autistic people may also feel better equipped to self-advocate and challenge pre-existing stereotypes (Botha et al., 2020). Our qualitative data included references to a learning process following diagnosis, whereby previously held stereotypes or misconceptions about autism were challenged in favour of more positive views. This finding would fit with studies that have shown how learning about autism and neurodiversity helps with the development of a more holistic conception of autism (King et al., 2003; Griffin and Pollak, 2009).

Due to the cross-sectional nature of the present study, it is only possible to theorise about identity mechanisms and other factors. A longitudinal design would be necessary to determine how an autistic personal identity develops over time, as well as identifying potential individual differences in trajectories. Our findings suggest that autistic personal identity varies over time following diagnosis, with more negative elements initially endorsed, and this dissatisfaction may decrease over time. The initial agreement with negative elements post-diagnosis is supported by theories of identity development which account for an initial disruptive impact of "acquiring" a condition or disability (Frank, 1993). Within this theory, adapting to a diagnosis leads to a period of critical reflection (Charmaz, 1994, 1995), with self-change necessary to accommodate disability into one's identity.

Becoming more satisfied with autistic identity could also be understood in terms of undergoing a period of adjustment. This finding would fit with the concept of "identity distress," which relates to the existential anxiety and maladjustment associated with amalgamating a coherent set of beliefs about one's identity (Berman et al., 2004). Further, an analysis of wellbeing in autistic adults identified narratives describing a personal journey from hating "their autism" to seeing themselves as a "person with autism," to an "autistic person" (Milton and Sims, 2016). Indeed, participants who responded qualitatively about their experiences in the present study also described an adjustment process including changes in cognitive and emotional responses, alongside increased knowledge and understanding of autism overall, and in relation to themselves.

Regarding our second hypothesis, we found that greater exclusion/dissatisfaction with being autistic predicted both lower self-esteem and poorer wellbeing, controlling for other variables, such as demographics, diagnostic timing, and autistic characteristics. This finding suggests that irrespective of exactly when someone is diagnosed, identity is an important variable in self-esteem and wellbeing. The exclusion/dissatisfaction subscale represented negative beliefs about autism being part of one's personal identity, relating to perceived limitations on social life, work, and quality of life (Darling and Heckert, 2010). In this way, autism pride and exclusion/dissatisfaction act as opposing sides of the same construct within autistic personal identity. Of interest, however, is that exclusion/dissatisfaction only suggestively predicted wellbeing (with a very small effect size), and autism pride did not predict wellbeing at all. Botha and Frost (2020) outline how autistic individuals are a minority group, subject to stigma and disadvantage. Their study found that minority stressors, such as discrimination, internalised stigma, and concealment predicted poorer mental health and wellbeing. Therefore, aspects of exclusion/dissatisfaction could bear more similarity to internalised stigma, which could thus have a more negative relationship with self-esteem. Additionally, there may have been weaker relationships with wellbeing as the measure may not have captured autistic wellbeing accurately (Lam et al., 2021). Wellbeing may also be more subjective and multi-dimensional than self-esteem (Rosenberg et al., 1995).

Nonetheless, higher feelings of pride in personal autistic identity predicted higher levels of self-esteem. This relationship may be explained when considering how pride involves self-acceptance and self-compassion, which are similar to constructs underlying self-esteem, such as optimism and self-satisfaction (Luhtanen and Crocker, 1992). The finding could also reflect connections between personal and social identities, which likely influence one another. Cooper et al. (2017) suggested that autistic social identity (i.e., identifying with other autistic people as a group) involves not only a connection to the autistic community, but also internalisation of this social identity within one's self-concept. They found that an autistic social identity related to greater self-esteem, and our findings develop this finding by showing that one's personal sense of autistic pride (i.e., "being autistic is an important part of who I am") also relates to higher self-esteem. Additionally, qualitative responses indicated a desire for information and connectedness, which may link to engagement with the autistic community.

TABLE 7 | Categories and sub-categories identified in relation to the qualitative question about receiving an autism diagnosis.

Categories	N	Example quotes
Adjustment process		
Making sense of it all over time	56	*"[The diagnosis] led me to re-evaluate my life;" "It changed everything. Things finally made sense."*
Emotional reaction to diagnosis	39	*"I felt relieved;" "I was upset, confused and angry."*
Permanence of difficulties	12	*"Sometimes now I feel a bit sad about my autism because I know I am always going to find things difficult;" "Confirmed I was different and would never be normal."*
Self-exploration		
Knowing and understanding who I am	77	*"[It's] good to know why I felt different;" "I think probably the diagnosis has helped me more than not as I know myself better."*
Being myself	10	*"I give myself space to be me;" "[I'm] letting myself be the real me."*
Feeling the same about myself	7	*"[The] diagnosis only confirmed what I felt about myself;" "I'm still not a very confident person really."*
Learning and support needs		
I've learned a lot	24	*"It took time, but I read around a lot, learned online…"; "Mostly I've learned from other people online about how to help myself."*
More support needed post-diagnosis	13	*"It was frustrating that there was nobody to help me through;" "They did not really tell me very much about my diagnosis, so for years I thought that being autistic meant having meltdowns and being crap at human interaction and that was pretty much it."*
Late identification	10	*"Why had not it [autism] been picked up sooner?;" "It was a double edged sword though as it also caused anger since no one has noticed for so long."*
Autism in women	6	*"People do not understand autism in girls;" "A friend mentioned something about women with autism, which prompted me to do loads of research and reading. I was amazed!"*
Responses from others		
Lack of understanding/acceptance from others	30	*"People said my diagnosis is fake;" "People do not understand autism."*
Issues with disclosure	6	*"I'm still reluctant to tell people I'm autistic;" "2020s still not safe to be openly autistic as a professional person."*
Positive reactions	6	*"I felt seen, heard and understood;" "It helped my family understand too."*
Autism as positive difference		
Autistic pride and appreciation	18	*"[I'm] learning to be proud of my autism;" "Autism is an attribute."*
Thinking differently/being different	13	*"This is how my brain works;" "I've fully embraced my neurology."*
Self-advocacy	6	*"[I'm] more confident asking for accommodations;" "By being able to advocate for my needs, discrimination that happened in the past happens less after the initial denial of services."*
Challenges of the diagnosis		
Struggling to come to terms and find my place	29	*"I was very self-conscious and lost confidence;" "Sometimes it feels lonely. I do not always feel like I have much in common with other autistic people, so I'm not always sure where I fit in or belong"*
Autism as a negative	8	*"It felt very negative at first, like something was broken that could not be fixed;" "I also had quite negative views about autism and felt like people were insulting me when they said that I was very likely to be autistic"*
I now feel part of something with others like me	*15*	*"Other people go through the same;" "[I'm] less alone."*

Indeed, a study of diagnosis disclosure in autistic adolescents found that youth who sought information and support from other autistic people reported better outcomes in self-esteem and diagnosis acceptance than those who learned about autism from other sources (Kiely et al., 2020). Since age and recency of diagnosis were controlled for in all our analyses, and did not significantly contribute to self-esteem or wellbeing, this suggests that autistic identification, rather than diagnosis/recognition itself, might be especially important when it comes to psychological health (although recognition is a step to identification).

Implications

This study particularly highlights the experiences of autistic people who were diagnosed late, and demonstrates relationships between autistic personal identity, self-esteem, wellbeing, and diagnostic timing. Self-esteem and wellbeing can both be understood as closely related to broader psychological health and functioning (Lyubomirsky et al., 2005). Although the correlational nature of the current study design inhibits the ability to determine causation, our results suggest that exploring potential identity-based support for psychological health should be a priority for future research. In the disability literature, it has been recommended that disabled people should be encouraged to engage with their personal disability narrative to aid the development of coping strategies and positive identity development (Dunn and Burcaw, 2013). For autistic people, this could involve a programme supporting newly diagnosed autistic people to think about strengths, challenges, and fostering connections with the wider autistic community. A recent study has highlighted the specific benefits of such group programmes being autistic-led in terms of developing a positive outlook on being autistic (Crane et al., 2020), and research highlights the benefits of autistic-autistic peer communication (Crompton et al., 2020a,b).

Further, Forber-Pratt et al. (2019) suggest that professionals are often the most significant or accessible resource for many following diagnosis, and therefore have a role to play in influencing people's relationship with their autistic identity. However, some participants in the present study noted that lack of post-diagnostic professional support was an issue, which has been reported

previously – with 42% of respondents in one survey not offered any type of post-diagnostic support (Jones et al., 2014). Although it is reassuring that many of the participants in this study connected with other autistic people online for information and support, the current findings suggest there is a need for services and clinicians to provide higher quality post-diagnostic support.

Limitations

There were several limitations with our sample: only four participants identified as either non-binary or transgender, which was too few to include in statistical analyses. This limitation restricted the quantitative analyses to cisgender participants and is particularly relevant given increased gender identity variance in autistic individuals (De Vries et al., 2010; Pasterski et al., 2014). Further, participants were predominantly female (77.6%), suggesting a potential issue in terms of overall representativeness of the female experience. Since there has been a systematic under-identification of autism in females, with females at higher risk of being misdiagnosed or diagnosed late (Mandy et al., 2012; Kreiser and White, 2014; Trubanova et al., 2014), partly due to the male-biased development of assessment measures and diagnostic criteria (Kreiser and White, 2014; Loomes et al., 2017), the study may have been of particular interest to females. Given the challenges faced by autistic females in terms of unmet support needs, social exclusion, and isolation (Baldwin and Costley, 2016), our study indicates that understanding and supporting autistic females to explore their autistic identity may be beneficial. Nonetheless, future research should aim to establish whether the current findings are replicable in a larger sample of males.

The sample was also predominantly white, and university-educated. However, the demographic figures reported in the present study are broadly similar to comparable survey research (e.g., Cooper et al., 2017; Cage and Troxell-Whitman, 2019). Lack of diversity is a frequent criticism of autism literature (Pellicano et al., 2014). However, the sampling of autistic adults and particularly females builds upon a previous lack of representation in autism research (Kirkovski et al., 2013; Pellicano et al., 2014). Further, this study utilised convenience sampling through social media and groups, which may have led to biases in the sample. For example, in a study of autistic adults' participation in research, factors such as altruism, a sense of community, and a keenness to be listened to and understood were found to be particularly motivating (Haas et al., 2016). Additionally, our sample is biased in that it consisted of mostly well-educated individuals recruited *via* the internet, and this sample will not be representative. Our findings represent only a subset of autistic people, and although there was variation in autistic identification, autistic pride was generally high. Future research should attempt to recruit participants from a wider variety of online and offline sources and find ways to capture the views of the autistic community more broadly. Finally, the measure of personal autistic identity was adapted from the disability literature (Darling and Heckert, 2010), and may not have fully captured a personal autistic identity. The development of measures specifically to capture the incorporation of "autism" into personal identity would thus be beneficial. The constructs of wellbeing and self-esteem were also based on measures that have been created by and validated with non-autistic people.

Conclusion

The present study explored the relationships between autistic personal identity, diagnostic timing, and psychological health, with a focus on late-diagnosed autistic people. With more time, since diagnosis there was less dissatisfaction with being autistic and autism pride and exclusion/dissatisfaction significantly predicted self-esteem, and exclusion/dissatisfaction suggestively predicted wellbeing. Qualitative descriptions of diagnosis experiences described a post-diagnostic process that included emotional reactions and self-exploration, which developed into self-acceptance and belonging. Our results add to the literature concerning the experiences of late-diagnosed autistic adults, with implications regarding the need for more frequent and comprehensive provision of information and post-diagnostic support and finding ways to enable all autistic people to explore their autistic personal identity.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available following reasonable request to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Research Ethics Committee, Royal Holloway, University of London. The participants provided their informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

KC conceived the research and managed participant recruitment with the support of EC and RB. All authors contributed to study design. KC and EC analysed the quantitative and qualitative data. KC wrote the first draft of the manuscript as a chapter for her thesis, and EC was a major contributor to subsequent drafts. RB further contributed to manuscript drafts. All authors contributed to the article and approved the submitted version.

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Participatory Autism Research: How Consultation Benefits Everyone

*Connor Tom Keating**

School of Psychology, University of Birmingham, Birmingham, United Kingdom

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Edited by:
Amy Pearson,
University of Sunderland,
United Kingdom

Reviewed by:
Georgia Pavlopoulou,
University College London,
United Kingdom

***Correspondence:**
Connor Tom Keating
cxk655@bham.ac.uk

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INTRODUCTION

In the past decade, there has been increasing concern about the disconnect between researchers and the autism community (autistic people and their family members) (Pellicano and Stears, 2011; Milton and Bracher, 2013; Milton, 2014; Chown et al., 2017; Woods and Waltz, 2019). This disconnect may be due to a number of factors, including a lack of involvement of the autism community in research (Gowen et al., 2019), rare (or non-existent) dissemination of findings to the community, and use of demeaning language about autistic people in scientific works (Gowen et al., 2019). This, alongside a history of controversial claims from scientists (from "refrigerator mothers" to claims vaccines cause autism) has contributed to growing distrust of autism researchers by autistic self-advocates (Dawson, 2004; Bagatell, 2010).

Fortunately, there is a solution—participatory research. Participatory research involves incorporating the views of the autism community about what research gets done, how it is done and how it is implemented (Cornwall and Jewkes, 1995). Specific manifestations of participatory research include "*leadership* by autistic researchers, *partnership* with autistic people or allies in research, *engagement* with the community (e.g., via social media) and *consultation* with relevant individuals or community organizations" (Fletcher-Watson et al., 2019). In addition, an important component to participatory working is making research accessible to *all* members of the autism community—for instance by adapting the research environment (see Pellicano et al., 2017), methodology and dissemination routes to permit the widest engagement and inclusion of under-represented groups in research (e.g., non-speaking autistic individuals and people with co-occurring learning disabilities).

Another key principle of participatory research is the acknowledgment, and undermining, of the power imbalance between researcher and participant (Nelson and Wright, 1995). One way to conceptualize this power imbalance is using the *ladder of participation* (Arnstein, 1969), which outlines that power varies across different types of participation: from no power (e.g., recipient of therapy), through tokenism (e.g., informing after instead of consultation in advance) to devolved power (e.g., partnership and citizen control), where planning and decision-making are shared. Researchers should aim to level the traditional power imbalance by adopting participatory practices and, in their reporting of community involvement, highlight the power dynamics involved (Pickard et al., 2021).

Why Is Participatory Research Important?

There are a multitude of benefits of participatory research. Community input can (a) improve the quality of research methods and place findings within a real-world context, thus facilitating the translation of findings into practice (Grinker et al., 2012; Parsons and Cobb, 2013; Carrington et al., 2016; Fletcher-Watson et al., 2019), (b) ensure that research yields relevant and meaningful benefits for the autism community (Long et al., 2017), and (c) enhance involvement, collaboration and trust between researchers and autistic people and their allies (Gowen et al., 2019). Despite a multitude of benefits, unfortunately, there is evidence to suggest that participatory research is not yet the standard, but rather the exception.

How Common Is Participatory Research?

At present, it is thought that a large proportion of autism research involves no community participation or only tokenistic participation of the autism community (Nicolaidis et al., 2011; Fletcher-Watson et al., 2019). Indeed, the UK report "*A Future Made Together*" (Pellicano et al., 2013), elucidated that opinions on the prevalence of participatory research were contrasting—whilst autism researchers perceived themselves to be engaged with the autism community (e.g., dissemination and consultation), autistic people and their families did not share this view (Pellicano et al., 2014). This report also highlighted that research funding and output in the UK is not in line with the priorities of autistic people, their families and practitioners, with two-thirds responding that they were either *dissatisfied* or *very dissatisfied* with current spending/output.

Unfortunately, in the rare circumstances where there is autism community involvement, at present, this is rarely more than tokenistic (Fletcher-Watson et al., 2019; Michael, 2021). In other words, some researchers will adopt a participatory approach in order to "tick a box" (i.e., to meet a funder, journal of ethics board requirement) rather than to provide the opportunity for the autism community to *actually* influence outcomes. At best, these tokenistic approaches may fail to deliver meaningful results for the community, and at worst, they are insulting and damage the relationship between autistic people and academics, thus leading to non-participation in research (Fletcher-Watson et al., 2019). This is exemplified in the experiences of Cos Michael, who has reported that they have sometimes felt like they were the "token autistic" and have subsequently given up on university-based autism research (Michael, 2021). In order to avoid tokenism, researchers should work with community members who have expertise and experiences relevant to the topic of research; actively listen and learn from this expertise and make changes based on feedback; and recognize the power imbalance in most research scenarios (Fletcher-Watson et al., 2019).

Why Is Effective Participatory Research Not Happening?

There are multiple factors that can complicate attempts to adopt collaborative research practices (Pickard et al., 2021; Redman et al., 2021). One key reason is that the infrastructure of scientific research is not conducive to participatory working in a number of ways (Fletcher-Watson et al., 2019; Pickard et al., 2021). Firstly, there are significant time and funding constraints within academic environments that may prohibit a participatory working style (Fletcher-Watson et al., 2019; Pickard et al., 2021). Secondly, participatory approaches are not incentivized, for instance in terms of career progression, within the current academic structure (Pickard et al., 2021). Finally, some early career researchers feel that there is an absence of support for participatory working from more senior academics (Pickard et al., 2021). Therefore, systemic change is necessary to ensure that participatory practices can be accommodated within current research frameworks.

Another reason that researchers may not adopt a participatory approach is due to challenges relating to objectivity and methodology. Some researchers have raised concerns that objectivity could be compromised through engagement with autistic partners (see Pellicano et al., 2014). However, as Fletcher-Watson et al. (2019) highlight, "serious biases—for example, towards maintenance of the status quo—can occur when research takes place without community influence." Alternatively, some researchers may be concerned that autistic people will say something they disagree with or ask them to do something that is not easy to implement. However, as other researchers have highlighted "the irony of this should be obvious: researchers have been asking autistic people to put up with both of these for decades" (Fletcher-Watson et al., 2019).

In addition, researchers may not engage in participatory practices because they believe effective participatory research requires them to have strong relationships with the community, and forging these relationships takes time (Pickard et al., 2021). However, as one academic explained, investing this time is hugely valuable as it can foster "an extremely powerful interpersonal connection or relationship with people for whom participation had never been very meaningful" (Pickard et al., 2021). Ironically, participatory research can enhance rapport and trust between researchers and the autism community (Gowen et al., 2019), and therefore comprises a strategy, in itself, to improve the relationships that are seen as necessary for effective participatory working. Consequently, researchers should adopt a participatory approach imminently to facilitate the formation of these constructive alliances, thereby improving the efficacy of their collaborations with the autism community in the long-term.

A Brighter Future

Fortunately, more recently there has been increasing recognition that it is time for change, with autistic advocates, academics and activists insisting that participatory research is the way forward (e.g., Pellicano and Stears, 2011; Milton and Bracher, 2013; Fletcher-Watson et al., 2019; Gowen et al., 2019). Indeed, there are some great examples emerging of collaborations that have involved the autism community in priority-setting and research (e.g., Nicolaidis et al., 2011, 2013; Bertilsdotter Rosqvist, 2019; Crane et al., 2019; Fletcher-Watson et al., 2019; Vincent, 2019; Young et al., 2019; Pavlopoulou, 2020; Pellicano et al., 2020).

One gold-standard example of how researchers, autistic people and their allies can effectively collaborate is the "*Shaping Autism Research*" seminar series (Fletcher-Watson et al., 2019). During this seminar series, members of the autism community played prominent roles in every event, including as co-applicants for funding, co-convenors, speakers, panelist and discussion group leaders. Crucially, the organizers also ensured that each seminar was as accessible to autistic individuals as possible by creating a suitable sensory environment and providing a quiet space. The authors reduced power inequalities between delegates by including clear terms of reference for participation, so that all contributors had a shared expectation of what the sessions would involve. In all materials, language was selected that characterized autism in neutral terms (e.g., not a disease or misfortune), thus making respect overt and creating a space where all people were equal. From this seminar series, Pellicano et al. (2017) have produced a starter pack for participatory autism

research, providing principles for how academics and the autism community can work together to shape research. Since then, other research teams have built on these principles, providing detailed guidelines for researchers to consider in order to increase involvement, collaboration and trust between researchers and the autism community (Gowen et al., 2019). As such, the *"Shaping Autism Research"* seminar series has laid the foundation for more effective participatory research, in which relevant communities and stakeholders can work collaboratively to create a better future for autistic people, together.

Another good practice example is the work of Pavlopoulou (2020), which adopted a participatory approach throughout the entirety of the research process to investigate facilitators of sleep for autistic adolescents. At the onset of the study, a consultation group provided input on study objectives, research design, procedures and tools, ideas for public engagement, and other areas relating to the specifics of the project. This work involved participant-driven data collection, in which participants were asked to take 10–15 photographs and keep notes or drawings for one week of various environments, activities and objects that were related to their sleep (e.g., the place they sleep and its surroundings, activities/objects/people that may help them to fall or stay asleep, etc.), and participant-driven data coding. Following this, the consultation group created visual aids that were then used for dissemination at a community exhibition alongside panel discussions and workshops involving various members of the autism community (parents, psychologists, autistic people, etc.). By adopting an experience-sensitive participatory approach grounded within the lifeworld framework (see Hemingway et al., 2015 and Pavlopoulou, 2020), the authors acknowledged the autistic participants as active agents in research, recognized their autonomy of thought, perspectives and ideas, and facilitated the translation of findings into practice (see Pavlopoulou, 2020).

Moreover, the work of Cassidy et al. (2020a,b, 2021a,b) constitutes a good example of effective participatory research. First, in this program of work, autistic people identified a need for better tools to assess suicidality in autism (Cassidy et al., 2020a, 2021a). Following this, the authors conducted two studies to adapt the suicidal behavior questionnaire to improve the clarity and relevance of the items to autistic adults. In the first study (Cassidy et al., 2020b), three focus groups identified potential issues with the original version of the questionnaire (that was designed for non-autistic adults) and suggested adaptations. Following this, autistic and non-autistic adults completed the initial adapted version of the questionnaire to explore the equivalence of the tool between groups and identify problematic items. In the second study (Cassidy et al., 2021b), the authors completed cognitive interviews, that had been co-designed with an autism steering group, with nine autistic adults to assess the initial adapted version of the questionnaire. After making the necessary changes, a large sample of autistic adults provided qualitative feedback on each item of the original and refined versions of the tool. Following this, a large sample of autistic and non-autistic adults provided feedback on, and completed, the finalized version of the questionnaire. Lastly, a focus group discussed the findings from the project and potential next steps at an open public engagement event, thus providing the community with an active role in the dissemination of findings. As such, this work comprises a gold-standard example of participatory research in which there was extensive involvement of the community throughout the research process. Without this involvement, the authors would not have been able to capture the unique experiences of suicidality in autistic adults, thus rendering the tool less effective.

Areas to Focus on

Although there is increasing community involvement in research, autistic individuals with communication differences, such as those who are non-speaking or minimally-speaking (Lebenhagen, 2020) and those with a learning disability (Long and Clarkson, 2017) are less well-represented in this movement (e.g., in Fletcher-Watson et al., 2019; Pavlopoulou, 2020 and Cassidy et al., 2021b, the authors noted that their projects were not fully inclusive of these individuals). Importantly, people with communication differences may require personalized support, unique modes of communication, and well-planned engagement for their voices to be heard (Long and Clarkson, 2017; Long et al., 2017; Lebenhagen, 2020). Without the use of these personalized approaches, communication differences can result in autistic people facing exclusion from processes of consultation and research (Long and Clarkson, 2017) due to communicative normativity (see Lebenhagen, 2020).

The work of Long et al. (2017) exemplifies best practice for conducting research with and for autistic people with communication differences. Specifically, this study aimed to gain the perspective of autistic people with learning disabilities on their experiences of support services (for example regarding support for their health and well-being, support for communication and involvement, the presence of low stress service environments, etc.). Importantly, participants were given the opportunity to communicate in a way that accommodated communicative differences—some moved cut-out photographs or symbols cards around, others wrote or drew onto sheets of paper, and others engaged in purely verbal discussion (see Long et al., 2017; Scott-Barrett et al., 2019 for further guidance on accommodating communicative differences). By accommodating these communication differences, the authors were able to better understand the autistic participants' experiences of their support services, thus allowing their voices to be heard and changes to be implemented accordingly. As such, this work has paved the way for greater participation of autistic individuals with communication differences (for example some individuals with learning disabilities or those who are non-speaking or minimally-speaking) in the research process.

PARTICIPATORY RESEARCH IN THE CONTEXT OF CONSULTATION

One particular strategy that is increasingly being used, more broadly, to promote active involvement of autistic individuals and their allies in the research is *consultation* with the autism community. The idea here is that members of a research team

consult a group of individuals from the autism community to discuss their research. Community input can be highly valuable at all stages of research: from initial conception of a study, through data collection, all the way to dissemination of scientific messages. To illustrate this point, we will run through the typical stages of the research process and give some (but not exhaustive) examples of how consultation can be useful both for the autism community and for researchers themselves.

Generating a Research Question

Input at this early stage of the research process may highlight opportunities to align study objectives with community priorities. To demonstrate the utility of community input at this stage, we will discuss the work of Crane et al. (2019). In this study, the 'community' comprised a group of young autistic people, between the ages of 16 and 25 years, referred to as the myVoice team (from the UK charity Ambitious about Autism). When asked about their priorities for research, the myVoice team unanimously selected mental health in young autistic people, reflecting the views within the wider autism community (Autistica, 2016). Following this, three members of the myVoice team collaborated with a group of academics, as full and equal partners, during all stages (design, implementation, analysis, interpretation and dissemination) of the research process to address their research question. Crucially, gaining their insight from initial conception of the study ensured that the research was relevant and useful outside of academia (Adams et al., 2018), and would have the largest impact on the lives of those who need it most (Pellicano et al., 2014).

Designing the Study

Insight from the community when designing a study can be highly useful: from input on experimental design to construction of questionnaires or other participant-facing documents. To demonstrate how input from the community can be invaluable at this stage, I will draw on my own experiences of working with an autism consultancy committee[1] (Birmingham Psychology Autism Research Team Consultancy Committee; B-PART-CC). We have recently started a project that aims to explore the autism-related language preferences of a diverse set of autistic individuals. We had drafted a questionnaire that asked participants about a broad range of autism-related terminology, for instance asking how they believe is best to refer to someone with an autism diagnosis (e.g., person with autism vs. autistic person etc.). Firstly, the group commented on the clarity and length of each of our questions, thus ensuring the questionnaire was clear and accessible to a range of autistic individuals. In addition, through consultation with the group, we identified some additional terms (e.g., "is neurodivergent"), and an additional category of terms, concerning how we refer to non-autistic people (e.g., "typical" vs. "neurotypical" vs. "non-autistic," etc.). Multiple members of the group made the point that how we refer to people *without* autism is just as important as how we refer to those *with* autism. This is because the terms we use to speak about non-autistic people intrinsically have connotations about autism and autistic people. Accordingly, we have added this category of terms to our questionnaire. Therefore, input at this stage not only improved the clarity of participant-facing documents, but also elucidated a priority for the community (to establish how we should refer to non-autistic people) and broadened the potential impact of our paper.

[1]Please note that you can email Matt Bond at m.bond@bham.ac.uk if you would like to consult the Birmingham Psychology Autism Research Team Consultancy Committee about your research.

Data Collection

At the point of data collection, the autism community could advise on how to create an enabling environment for autistic individuals. For example, they may suggest that you ask each of your participants if they have any specific needs and/or have a preferred way to communicate (e.g., through spoken or written language or symbols and pictures). In my own experience, they may also provide some more general advice like give plenty of warning of any changes to the setting or situation, or to appreciate that not everyone likes eye contact (see Pellicano et al., 2017). They may also identify ways to adjust your study to make it accessible to groups typically under-represented in research (e.g., non-verbal individuals or those with co-occurring learning disabilities), thus making the research and data applicable (and generalizable) to a more diverse range of autistic individuals. Creating an accessible and enabling environment for participants is a necessity—as researchers, we have a duty of care to protect participants and ensure they are as comfortable as possible.

Dissemination of Findings

During this final stage, community input can facilitate the creation of scientific messages that are maximally accessible to members of the autism community. For example, the community could provide feedback on the clarity of messages by commenting on whether the content is written in an accessible manner for the target audience (e.g., jargon-free). They could also comment on whether the medium of the message is accessible to the target-audience and suggest other forms that might facilitate broader engagement (e.g., talks, videos), including engagement of specific groups (e.g., those with co-occurring learning disabilities). The benefits here are broad—the autism community are more able to access scientific messages, thus enhancing trust between scientists and the community, and there is a greater "impact" of researchers' scientific works (which may be seen, for example, in higher Altmetric scores).

DISCUSSION

This article discussed the importance of participatory autism research with a particular focus on the benefits of *consultation* with the autism community. Through worked examples, we have highlighted that consultation is important throughout all stages of the research process. We appreciate that researchers might not have the means to get input from the community at all stages research (for instance if they don't have the funds to pay for this service repeatedly), and therefore we recommend that academics consider at what stages of

the research process input would be most useful. Whilst we have separated our examples into different segments, it is important to note that academics can get input from the community about several parts of the research process in one consultation: for instance, in the final stages of preparing an experiment, one can get recommendations about the design of the study, the wording of participant-facing documents, recruitment, data collection and suggested dissemination routes. Of course, continual involvement of the community is preferable (rather than one instance of engagement), and therefore academics must also consider other manifestations of participatory research such as *leadership* by autistic researchers, continued *partnership* with autistic individuals, and repeated *engagement* with the community (e.g., via social media). However, we believe that, for those who are new to participatory research, consultation with the community comprises a good starting point. Regardless of its specific manifestation, autism researchers should commit to involving the autism community, thus promoting a brighter future for autistic people, together.

AUTHOR CONTRIBUTIONS

CTK conceptualized and wrote the article.

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Autistic People's Access to Bilingualism and Additional Language Learning: Identifying the Barriers and Facilitators for Equal Opportunities

Rachael Davis[1*†], *Sue Fletcher-Watson*[1] *and Bérengère G. Digard*[2†]

[1] *Salvesen Mindroom Research Centre, University of Edinburgh, Edinburgh, United Kingdom,* [2] *Patrick Wild Centre, University of Edinburgh, Edinburgh, United Kingdom*

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Amy Pearson,
University of Sunderland,
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Reviewed by:
Hannah Madaleine Hobson,
University of Greenwich,
United Kingdom
Lorna Hamilton,
York St John University,
United Kingdom

***Correspondence:**
Rachael Davis
rdavis3@ed.ac.uk

[†] *These authors share first authorship*

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Bilingualism is a valuable tool that enriches and facilitates cultural, social and lived experiences for autistic and non-autistic people alike. Research consistently finds no negative effects of bilingualism and highlights the potential for positive effects across cognitive and socio-cultural domains for autistic and non-autistic children. Yet parents of autistic children remain concerned that bilingualism will cause delays in both cognitive and language development and are still frequently advised by practitioners to raise their child monolingually. Evidently, findings from research are not reflected in practice or subsequent advice, and it is essential to identify ways to ensure equal access to additional language learning. We briefly summarise the existing literature on bilingualism and autism, considering perspectives from the bilingual autistic community, and experimental research. We identify the most pertinent barriers to participation for autistic bilingual children in terms of familial, clinical and educational perspectives. We propose novel solutions to promote additional language learning and suggest changes to practice that will contribute to an evidence base for families and practitioners. This commentary makes innovative recommendations at both the individual and societal level to ensure that autistic bilingual people have equal rights and opportunities to language learning and are optimally supported in accessing them.

Keywords: autism, bilingualism, wellbeing, language learning, inclusion

INTRODUCTION

While all children should have access to language learning and the opportunities that come with it, as a fundamental human right, this is currently not the case for all autistic children. The U.N. Convention on the Rights of Persons with Disabilities (UN General Assembly, 2006)—which highlights rights for children—includes "respect for the right of children with disabilities to preserve their identities" and "recognising specific cultural and linguistic identity" (article 3). Although it could, in some instances, be reasonable to violate this right if there was evidence that bilingualism was harmful for development, no research to date has found long-term negative effects of bilingualism.

Additionally, there is evidence to suggest that bilingualism can be beneficial to both autistic and non-autistic children. Indeed, a growing body of research highlights the potential benefits of bilingualism for non-autistic children in terms of sociocultural factors, including family bonds (Opitz and Degner, 2012) and wellbeing (Halle et al., 2014). When bilingual parents raise their children monolingually, there is also the possibility that children can be excluded from bonding with relatives and participating in cultural activities (Jegatheesan, 2011; Park, 2014). Findings are less consistent regarding cognitive benefits, in part because of the confounding factors in the field, such as the heterogeneity of demographic characteristics of bilingual people—i.e., socio-economic status and ethnic minority status—particularly in high-income countries.

While comparatively, there is limited research addressing the effects of bilingualism for autistic people, in terms of cognitive skills, the literature that does exist suggests bilingual exposure does not lead to poorer development. Research assessing executive functions, social cognition and language abilities of autistic people suggest no detrimental effects of bilingualism (e.g., Beauchamp and MacLeod, 2017), and some preliminary indications of positive effects (e.g., Valicenti-McDermott et al., 2013; Gonzalez-Barrero and Nadig, 2019; Montgomery et al., 2021), though more research is needed to quantify these claims. A detailed overview of the cognitive literature is outside the scope of this commentary, but see Drysdale et al. (2015) and Wang et al. (2018) for systematic reviews of this research.

Autistic children in particular could benefit from the close familial and cultural connections that their shared language affords (Yu, 2013; Hampton et al., 2017). As autistic children experience greater levels of adversity in terms of wellbeing and social exclusion (Humphrey and Symes, 2010), preventing another source of positive self-regard—access to the home language—could exacerbate this further. This could be particularly relevant for autistic individuals from ethnic minority populations or lower economic and social backgrounds, who may particularly benefit from immersion in the home language.

Two studies to date have investigated the lived experiences of autistic bilingual people, both highlighting multiple benefits. Howard et al. (2019) reported that bilingual children living in multilingual environments are more positive about bilingualism than their peers in monolingual settings, especially regarding social and communication opportunities linked with bilingualism. Adults also reported that bilingualism had supported their relationships with family and friends and increased their access to hobbies and educational and employment opportunities (Nolte et al., 2021). Importantly, bilingualism had given them feelings of increased self-efficacy, self-confidence and assurance in social interactions and had helped them to better understand themselves and others. Together, these findings highlight that bilingualism is not a burden, and can provide benefits across socio-cultural and cognitive domains for autistic people.

Despite an absence of negative effects of bilingualism (Uljarević et al., 2016), many parents remain concerned about potentially harmful effects of bilingualism on their autistic child's development. Parents are also frequently advised by clinical and educational practitioners to raise their child monolingually, sustaining the now-unsupported view that bilingualism could cause additional confusion or language delay (Kay-Raining Bird et al., 2012; Yu, 2013; Hampton et al., 2017). For example, one source for these concerns is the finding that bilingual children often have reduced vocabulary in each of their languages, even though their overall vocabulary across languages is comparable to that of their monolingual peers. Admittedly, a more restricted vocabulary in the majority language would impact the child's access to clinical support (Bialystok et al., 2010; Hoff and Ribot, 2017). However, research also shows exposure to multiple languages from early childhood is beneficial for language development, with some linguistic skills transferring across languages (e.g., Verhoeven, 2007).

Although research in this area is consistent in its findings cross-culturally and using a variety of different experimental paradigms, it is evident that research is not informing practise or filtering down to parents. In turn, this is leading to autistic children facing barriers to participation. To address this problem, we need to chart the barriers to additional language learning so that they can be overcome.

In this commentary, we identify the main barriers to inclusion in three areas—parental, clinical, and educational—and identify potential solutions to ensure equal access to additional language learning for autistic people.

FAMILIAL CONTEXT

Family Barriers

Specific concerns can arise in predominantly monolingual countries with parents who have a different native language (e.g., immigrant families) but choose to use the majority language at home. Unlike fluent speakers (Hudry et al., 2018), non-fluent speakers of the majority language report difficulty and discomfort communicating with their child and worry about teaching them a "wrong" way to speak the language, which can lead to reduced communication with their child (Kay-Raining Bird et al., 2016). One US-based study with immigrant parents of autistic children who only used English at home showed a decline in parent-child interactions and in the child's participation in family conversations (Kremer-Sadlik, 2005). Given the association between one's native language and emotional processing (Opitz and Degner, 2012), parents may feel more able to connect emotionally with their child in their native language, and choosing to speak a non-native language may undermine the emotional value of parent-child communication. Indeed, parents report feeling less restricted and closer to their autistic child when using their native language (Yu, 2013; Kim and Roberti, 2014). Choosing monolingualism can also have negative consequences on the child's feelings of identity, inclusion, and access to cultural heritage (Park, 2014).

This decision to stop using the home language is often motivated by the fact that the services a child might need would only be provided in the majority language (Kay-Raining Bird et al., 2012, 2016). As such, parents are often made to choose between access to services and the use of their native language with their child.

Additionally, findings suggest a lack of understanding of autism within some communities (Munroe et al., 2016; Hussein et al., 2019) which could also be compounded with social stigma reported by cultural minorities in the UK. In particular, experiences of increased stigma when accessing healthcare (Szczepura, 2005; Kandeh et al., 2020), and stigma around autism within their own and the wider community (Kinnear et al., 2016; Selman et al., 2018; Papoudi et al., 2021), could ultimately lead to increased social exclusion and misunderstanding.

Overall, research suggests parents can be influenced by misinformation on both bilingualism and autism, and this "double hit" could mean that accessing multiple languages at home may be particularly difficult for some autistic bilingual children.

Family Solutions

Solutions to the issues above can be found in providing families with suitable information about autism and bilingualism. First, increasing parents' understanding of autism could be important in reducing stigmatising views. For example, research using short videos to teach non-autistic adults about autism had a significant impact on reducing stigma, increasing knowledge of autism, and increased positive beliefs (Jones et al., 2021). Providing parents with accessible resources combining knowledge of autism with a review of current findings regarding bilingualism could ensure that recommendations from research reach the people who will have a prominent role in the language experiences of their children.

Second, researchers must ensure that information about language exposure does not focus solely on the cognitive effects of bilingualism, but also on familial bonds, identity, community, and social inclusion. Within this, we cannot support an individual's cultural and linguistic identity without an understanding of their identity from their *own* perspective. It is crucial for children to feel involved when decisions are being made about and for them, and resources for families must also reflect the child's perspective. Currently, important questions remain around how autistic bilingual children feel about their language identity, feelings of inclusion with peers and within their cultural communities. Conducting research with children in this way will be an important step in creating a rigorous and complete evidence base for parents.

CLINICAL SUPPORT

Clinical Barriers

Research suggests that practitioners, including speech and language therapists, do not have confidence in the tools available to conduct diagnostic or language assessments with bilingual children (Davis et al., 2020). Although practitioners have a responsibility to maintain equality while conducting assessments, many standardised tools are culturally inappropriate for children from culturally and linguistically diverse populations (Mdlalo et al., 2019). The diagnostic process for bilingual children can bring additional challenges, with observational components of commonly used assessments being misinterpreted as autism-specific differences rather than differences in cultural norms. The absence of eye-contact and pointing behaviours, for example, are generally interpreted as autistic traits, yet in some non-western cultures, for a child to exhibit these behaviours with adults is inappropriate (Zhang et al., 2006). As a result, children from culturally and linguistically diverse populations are commonly diagnosed later (Shattuck et al., 2009) and are more likely to be misdiagnosed (Harris et al., 2014).

Similarly, some intervention strategies are not culturally relevant for all children. Practitioners noted that for some families, parent-child interactions are less direct or do not take place on the floor (Davis et al., 2020), children may be expected to display emotions differently, or the types of toys given to children to play with may not be typical in their culture (Norbury and Sparks, 2013). Recommending training or conducting assessments using these approaches may not be beneficial.

Practitioners themselves have stated they do not feel confident the tools available for use with culturally and linguistically diverse populations are acceptable, and frequently rely on their observations or asking for advice from colleagues or other professionals (Oxley and De Cat, 2019). Furthermore, speech and language therapists report that they have few opportunities to access additional cultural training after they qualify, and they do not have the time or opportunities to keep up to date with relevant research findings (Davis et al., 2020).

Importantly, the issues raised above regarding assessment difficulties for bilingual children mirror findings from research focusing on other neurodevelopmental conditions, such as developmental language disorders (Laasonen et al., 2018). Adapting bilingual-specific tools and practices would therefore benefit not only autistic children, but also children with other developmental conditions.

Clinical Solutions

The solutions identified here relate to a larger tangible transformation that could optimise practice with autistic bilingual children and their families: providing co-produced resources, information, and training to ensure clinicians make confident and informed decisions about how to assess and support children in the diagnostic pathway and beyond. It is evident that more substantial and *ongoing* training opportunities should be available for practitioners.

As practitioners have raised concerns regarding the lack of cultural diversity training currently available, institutions should organise training as part of continual development. In the immediate future, researchers should ensure practitioners are provided with functional, up-to-date information about autism and bilingualism that can be integrated into training, to ensure parents are not choosing a monolingual environment because of practitioner uncertainty.

We must also consider ways of improving access to and understanding of the assessments currently offered. It is likely that where inappropriate recommendations and assessments are being used, practitioners have limited access to resources, such as developmental norms in specific languages or cultures (Oxley and De Cat, 2019). Therefore, providing practitioners with a wider range of assessment tools *and* information around the suitability of assessments and variability between children from

culturally and linguistically diverse backgrounds would be the first step in preventing cultural biases. This can happen in three specific ways.

First, given the cultural variation in the identification and presentation of autism, research should focus on understanding and comparing the applicability and sensitivity of assessments across different cultures. To date, several autism screening tools have been developed for use with people from specific countries, including Iran (Samadi et al., 2014; Samadi and McConkey, 2015), China (Wang et al., 2020) and Brazil (Pacífico et al., 2019). All four studies highlighted a need to account for cultural variation, and that cultural and linguistic backgrounds play a crucial role in interpreting assessments.

Second, and of direct relevance to clinicians, is to create a checklist for common assessments to help practitioners analyse the appropriateness of such measures. For example, Harris et al. (2014) designed a checklist for four of the most common autism screening tools used with culturally and linguistically diverse children. By creating indicators of appropriateness that included compliance with disability requirements, it was evident some tools were more applicable than others. Future studies could develop comparable checklists that practitioners could access online and incorporate into assessments.

Third, the increased use of online diagnostic assessments that occurred during the COVID-19 pandemic could be leveraged to allow trained bilingual diagnostic practitioners to assess these children beyond their own health boards.

EDUCATION

Educational Barriers

In England, at least one in five pupils has English as an additional language, and this number is steadily rising (Leung, 2010; Department for Education, 2018). Despite this, a recent interview study with UK-based educators supporting autistic bilingual children (Howard et al., 2021) showed that although educators hold positive views about bilingualism, opinions vary greatly when it comes to autistic pupils. Many reported not recommending bilingualism for all autistic children, and this was predominantly based on the child's language abilities and autism profile. Educators believed that children with *"high functioning autism"* could choose the language they wanted to speak, but that for most autistic children bilingualism *"is not helpful,"* with potential confusion emerging as a major concern. Additionally, educators reported difficulty in effectively assessing and identifying the needs of autistic bilingual pupils. In special education, data regarding teachers' attitudes to bilingualism for autistic pupils is scarce, but no evidence suggests pupils with limited expressive language would not be able to understand words from different languages.

While some autistic bilinguals report learning their second language at school (Digard et al., 2020), autistic students can encounter barriers to modern language learning in mainstream education. There is a dearth of research addressing best practices for additional language learning for neurodivergent students, but evidence suggests that autistic pupils are often advised not to study modern foreign languages (Essex and MacAskill, 2020), which can penalise them by limiting their education, employment, and leisure opportunities (Nolte et al., 2021). This practice stems from a misunderstanding of autistic people's abilities, and a lack of understanding of autism. Without adequate training, educators find themselves unnecessarily adapting practises in an attempt to support autistic students, which could lead to unintentional exclusion.

Educational Solutions

Monolingual educators, particularly those in monolingual environments, may underestimate the link between bilingualism, identity and inclusion, and a greater linguistic and cultural diversity amongst educators could help them better understand the experiences and needs of their autistic bilingual pupils (Yu and Hsia, 2019). Additionally, including dedicated training would help address some of the misconceptions expressed by educators (Iadarola et al., 2015; Howard et al., 2021) who often have limited experience with autistic bilingual pupils.

It is necessary to provide educators with information to make informed recommendations. The current strategy–focusing on the child's language abilities and autism profile–does not acknowledge the child's receptive language skills. Teachers who have supported autistic bilingual pupils over several years report that while children may experience early language difficulties, they often progress to fluency. Therefore, while a pupil's skills and profile should be considered, decisions should be made in a way that allows the child to develop as bilingual if they wish to do so. As assessing the needs and progress of these pupils can be challenging, developing suitable tools should become a priority area in education, which will also benefit non-autistic bilingual children.

Evidence regarding best practices to support autistic learners of modern languages in the classroom is lacking, and there is an undeniable need for more research in this area. However, there are anecdotal accounts of successful programs introducing foreign languages into classrooms with autistic students (Lumsden and Ruchill Autism Unit, 2009). However, there is a need for more specialised autism training for modern languages teachers, focusing on the best methods to prioritise autistic students' skills, while considering the areas of challenge (Wire, 2005).

CONCLUSION

In this commentary, we identified the most pertinent barriers to participation for autistic bilingual children and young people. Many of these barriers have roots reaching further than the remits of clinical and educational settings, and stem from governmental policies failing autistic people. Public bodies lack awareness regarding the reality and diversity of the autistic population, and consequently, they fail to provide much-needed financial support for educators and clinicians. It is clear that additional resources are necessary to provide training opportunities that ensure optimal support for autistic bilingual people.

Impactful solutions in familial, clinical, and educational settings must be sponsored by local and national institutions through adapted policies. Providing appropriate educational and

clinical support to autistic bilinguals requires practitioners to have access to updated and accessible information and training, and the financial support to develop research and support for educators and clinicians. Additionally, autistic bilinguals would greatly benefit from working with practitioners who can share their linguistic and neurodiverse experiences. Future policies should encourage and support bilingual and autistic bilingual students, particularly those from socially isolated communities who wish to enter educational or clinical careers, allowing them to utilise their own experiences. In summary, dedicated policies will be key to build a systemic change that will ensure autistic people can enjoy the same access to languages as their neurotypical peers.

Implementing such changes will be pivotal in ensuring access to language learning, which should be a fundamental human right for all children, and this will ensure that children who have the opportunity for dual language learning will benefit from equality of opportunity. This may include a richer and more inclusive cultural and social environment which in turn, could mean that children face fewer environmental barriers, allowing for greater individual autonomy and equal access to participation in society.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

RD and BD: conceptualisation, writing–original draught, and writing–review and editing. SF-W: supervision and writing–review and editing. All authors made a substantial contribution to the writing of this paper.

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Greater Social Interest Between Autistic and Non-autistic Conversation Partners Following Autism Acceptance Training for Non-autistic People

Desiree R. Jones, Kerrianne E. Morrison, Kilee M. DeBrabander, Robert A. Ackerman, Amy E. Pinkham and Noah J. Sasson*

Department of Psychology, School of Behavioral and Brain Sciences, The University of Texas at Dallas, Richardson, TX, United States

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***Correspondence:**
Desiree R. Jones
desi.jones@utdallas.edu

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Bi-directional differences in social communication and behavior can contribute to poor interactions between autistic and non-autistic (NA) people, which in turn may reduce social opportunities for autistic adults and contribute to poor outcomes. Historically, interventions to improve social interaction in autism have focused on altering the behaviors of autistic people and have ignored the role of NA people. Recent efforts to improve autism understanding among NA adults via training have resulted in more favorable views toward autistic people, yet it remains unknown whether these benefits extend to real-world interactions between autistic and NA people. The current study explores whether a brief autism acceptance training (AAT) program can improve social interactions between autistic and NA adults. Thirty-nine NA males were randomly assigned to complete AAT or a no-training control condition, then participated in a 5-min unstructured conversation with an unfamiliar autistic male ($n = 39$). Following the conversation, participants rated their perceptions of interaction quality, first impressions of their partner, and their interest in future interactions with their partner. In dyads where the NA individual completed AAT, both the autistic and NA person endorsed greater future interest in hanging out with their partner relative to dyads in which the NA adult did not complete AAT. However, other social interaction outcomes, including ratings of interaction quality and first impressions of autistic partners, largely did not differ between training and no-training conditions, and assessments of the interaction were largely unrelated for autistic and NA partners within dyads. Results also indicated that NA participants, but not autistic participants, demonstrated substantial correspondence between evaluations of their partner and the interaction, suggesting that autistic adults may place less weight on trait judgments when assessing the quality of an interaction. These findings suggest that the brief AAT for NA adults used in this study may increase mutual social interest in real-world interactions between NA and autistic adults, but more systematic changes are likely needed to bridge divides between these individuals. Future work with larger, more diverse samples is recommended to further explore whether interventions targeting NA adults are beneficial for improving autistic experiences within NA social environments.

Keywords: first impressions, inclusion, stigma, intervention, double empathy problem

INTRODUCTION

Difficulties with social interactions are common for autistic adults. They report few close friendships (Howlin et al., 2000; Orsmond et al., 2004) and are more likely to experience social exclusion and low quality of life compared to adults with cognitive or other developmental disabilities (Orsmond et al., 2013; DaWalt et al., 2019). These outcomes are even found for autistic adults without intellectual disability (Farley et al., 2009; Howlin and Moss, 2012; Lord et al., 2020), and appear largely independent of a person's autistic traits (Magiati et al., 2014). In fact, autistic people commonly experience similar, or even worsening, social disability as adults despite a measured reduction in autistic traits from childhood to adulthood (Howlin et al., 2013). Although previous work has primarily attributed interpersonal difficulties in autism to intrinsic deficits in social cognition and behavior (Baron-Cohen et al., 1985; Oberman et al., 2005), more recent empirical advances (Sasson et al., 2017; Morrison et al., 2019a; Crompton et al., 2020b), and informed expertise from autistic people (Yergeau, 2013; Milton and Sims, 2016; Gillespie-Lynch et al., 2017; Kapp, 2019; Raymaker et al., 2020), have increasingly highlighted the role of bi-directional factors, including inhospitable social environments, and the behaviors of non-autistic (NA) people, that also contribute to poor social experiences for autistic people (Milton et al., 2013; Sasson et al., 2017; Morrison et al., 2019a; Crompton et al., 2020b).

This reframing of interpersonal difficulties in autism from individual to relational is exemplified by The Double Empathy Problem (DEP; Milton, 2012). The DEP eschews traditional deficit-model explanations for the social difficulties autistic people often experience in favor of a transactional explanation, driven by a mutual breakdown of communication between people with different modes of social communication and understanding. In contrast with the decades of research documenting autistic difficulties inferring the mental states, emotions, and intentions of NA individuals (Baron-Cohen et al., 1985; Schultz, 2005; Morrison et al., 2019b), a growing empirical literature grounded in the DEP framework has found that NA adults make similar social cognitive errors when trying to understand their autistic peers (Edey et al., 2016; Sheppard et al., 2016). These misperceptions can lead NA adults to view autistic people unfavorably (Alkhaldi et al., 2019), and may contribute to social exclusion and poor mental health among autistic adults (Mitchell et al., 2021).

A bi-directional difference in communication styles for autistic and NA adults is further supported by differences in interaction outcomes for mixed vs. matched neurotype interactions. Within dyadic interactions consisting of either two autistic adults, two NA adults, or an autistic adult paired with a NA adult, both autistic and NA individuals showed a greater interest in future interactions with individuals who shared their neurotype (Morrison et al., 2020). Qualitative reports from autistic adults suggest that this preference may relate to an increased understanding and acceptance of autistic communication styles in interactions between autistic individuals (Crompton et al., 2020a). Indeed, a study of information transfer between autistic and NA adults (Crompton et al., 2020b) found that chains of alternating autistic and NA adults experienced greater communication difficulty than chains consisting entirely of autistic or NA individuals, which did not differ from each other. Collectively, these findings highlight the ways in which a mismatch between autistic and NA communication styles can impact autistic-NA interactions, and suggest that the "fault" of interaction difficulties between autistic and NA partners does not lie with either person alone, but in the intersection between the two.

Traditional deficit-model frameworks of autistic interaction difficulties have almost exclusively centered treatment on the autistic person via social skills and social cognitive training, with the implicit assumption that teaching more normative modes of social understanding and behavior will translate into improved social outcomes. These interventions have generally failed to produce lasting benefits for autistic adults (Bottema-Beutel et al., 2018), and may unintentionally encourage the masking of autistic ways of being (Pearson and Rose, 2021), increase internalized stigma (Botha and Frost, 2020), and contribute to depression (Cage et al., 2018), anxiety (Hull et al., 2021), and even suicidality (Cassidy et al., 2020) in adulthood. Furthermore, because many autistic individuals consider autism to be central to their identity (Botha et al., 2020; Crompton et al., 2020a), interventions designed to alter their core characteristics have been criticized as unnecessary or even abusive (Milton, 2014; Kirkham, 2017; McGill and Robinson, 2020).

Therefore, given that deficit-model treatments for social disability among autistic adults are minimally effective at improving life outcomes, and may in some cases harm mental well-being, alternative approaches for improving interpersonal difficulties between autistic and NA adults are beginning to be considered and tested (Jones et al., 2021). One potential avenue capitalizes on recent findings suggesting that improving autism knowledge and acceptance among NA individuals shows promise for reducing biases toward autistic children and adults (Gillespie-Lynch et al., 2015; Dickter et al., 2020a) and increasing inclusive attitudes (Jones et al., 2021). However, the benefits of autism training may not extend to all forms of bias (Dickter et al., 2020a; Bast et al., 2021; Jones et al., 2021), and it is unknown whether previously reported benefits translate beyond experimental settings to real-world interactions between autistic and NA individuals.

In our previous study (Jones et al., 2021), NA participants viewed a brief autism acceptance training (AAT) video, then rated their first impressions of videos of autistic adults, answered questionnaires assessing their autism stigma, perceptions of autistic abilities, and autism knowledge, and completed an implicit association test (IAT) to measure their implicit biases about autism. We found that compared to adults who completed a general mental-health focused training, as well as those in a no-training condition, participants who completed AAT had more positive perceptions of autistic abilities, greater interest in interacting with autistic individuals, and less autism stigma. However, implicit biases did not differ significantly across training conditions, suggesting that the training may have a

limited impact on more subtle or covert forms of bias. The current study seeks to expand our previous work to a real-world setting to evaluate whether a brief AAT module for NA adults can lead to more positive interactions between autistic and NA adults. Non-autistic adults were assigned to either an AAT condition or a no-training control condition, with participants in the AAT condition initially viewing a 25-min video featuring factual information about autism and firsthand accounts from autistic adults (Jones et al., 2021). Non-autistic participants across both conditions were then paired with an unfamiliar autistic adult and completed a 5-min unstructured dyadic interaction, with participants blinded to their partner's diagnosis. Following the interaction, participants responded to questionnaires assessing their impressions of both the interaction and their interaction partner. Based on our previous findings (Jones et al., 2021), we predicted that NA participants in the AAT condition would rate their autistic partners more favorably and would have greater interest in interacting with them compared to NA participants in the control condition. At the level of the interaction, we predicted that NA participants in the AAT condition would feel closer to their autistic partners and would rate the interaction as higher quality compared to NA participants in the control condition. Because the training was designed to target the NA person, hypotheses centered on their responses to autistic partners, but the employed dyadic analyses also examined whether autistic adults evaluated NA adults who completed the training more favorably than those who did not. If supported, these hypotheses would provide evidence for the use of this training as a brief, accessible tool to improve interactions between autistic and NA adults.

METHODS

Participants

Autistic and NA participants ($N = 80$) were young adult males recruited from The University of Texas at Dallas, the local community, and word of mouth. Participants were approximately matched on race, age, and scheduling availability to form dyads, with each dyad consisting of one autistic adult and one NA adult. Inclusion was restricted to males to limit the influence of gender on interaction dynamics. All autistic participants were administered the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 1989), and those not meeting the cutoff for autism spectrum disorder were excluded from participation, as were those with an approximated IQ score below 80 as estimated by the reading subscale of the Wide Range Achievement Test, Third Edition (WRAT-3; Wilkinson, 1993), a brief assessment that correlates highly with full-scale IQ scores (Powell et al., 2002). Exclusion criteria for NA participants consisted of a self-reported diagnosis of autism or a developmental disability, and/or an estimated IQ under 80 based on the WRAT-3. A total of 40 autistic males and 40 NA males ages 18-27 ($M = 20.46$; SD $= 1.75$) participated in the study. However, one autistic participant failed to meet inclusion criteria and their dyad was therefore excluded from analysis, resulting in a final total of 78 participants across 39 dyads.

Participant demographics are reported in **Table 1**. Overall, autistic and NA participants did not differ significantly on age [$t_{(76)} = -0.19$, $p = 0.849$], race [$\chi^2_{(2)} = 2.67$, $p = 0.434$], ethnicity [$\chi^2_{(2)} = 1.84$, $p = 0.310$], or WRAT-3 IQ [$t_{(76)} = -1.72$, $p = 0.090$]. However, within dyads, WRAT-3 IQ scores were significantly lower in autistic individuals than their NA partners [$F_{(1, 37)} = 4.43$, $p = 0.042$] and were therefore covaried in analyses.

Procedure

Dyads were assigned to either the AAT condition or a control condition. As part of informed consent procedures, all participants were told that they would be participating in a study about social interactions, and that they would be interacting with a stranger who, "may or may not be autistic." Autistic participants were not discouraged from disclosing their diagnosis, but only two participants in the study chose to do so (one in each condition). Before beginning the dyadic portion of the study, NA participants in the AAT condition watched a narrated 25-min AAT module (Jones et al., 2021). This training features firsthand accounts from autistic adults, as well as information on autistic strengths, neurodiversity, sensory sensitivities, and ways to promote inclusion and acceptance of autism among college students. In a previous study of NA adults (Jones et al., 2021), the use of this training was associated with more inclusive attitudes toward autistic adults and fewer misconceptions about autism, when compared to a more general mental-health focused training and a no-training control condition. Autistic participants, as well as NA participants in the control condition, did not receive any training. All other study procedures were consistent across participants.

Participants were seated across from one another to complete a 5-min, unstructured conversation previously used with autistic (Morrison et al., 2020), NA (Berry and Hansen, 1996), and mixed dyads (Usher et al., 2018; Morrison et al., 2020). Participants were instructed to speak freely for the full 5 min with the goal of getting to know one another, and conversations were videotaped. To avoid the potential effect of demand characteristics, the participants were not given information about their partner's diagnostic status. Following the interaction, each participant completed computerized questionnaires in a counterbalanced order that assessed their perceptions of the interaction quality, their partner, and their feelings of closeness, followed by a brief demographics questionnaire. Participants were then administered the WRAT-3 reading subtest (Wilkinson, 1993). Participants were compensated for their time with either $50 or course credit. All study procedures were approved by the university's Institutional Review Board.

Measures

The Social Interaction Evaluation Measure

The Social Interaction Evaluation Measure (Berry and Hansen, 1996) is an 11-item Likert-type scale used to evaluate interaction quality (Berry and Hansen, 1996). Participants rated items reflecting their perceptions of both the interaction (e.g.,

TABLE 1 | Participant demographics by training condition and diagnosis.

	Autism acceptance training (*N* = 19 dyads)		Control (*N* = 20 dyads)	
	Autistic (*N* = 19)	**NA (*N* = 19)**	**Autistic (*N* = 20)**	**NA (*N* = 20)**
Race				
White	84%	90%	95%	89%
Asian	5%	10%	5%	11%
Bi/Multiracial	11%	0%	0%	0%
Ethnicity				
Hispanic/Latino	5%	5%	10%	30%
Age [M (SD)]	20.26 (2.08)	20.26 (1.49)	20.55 (1.47)	20.70 (2.03)
WRAT-3 IQ	109.89 (10.62)	113.47 (7.29)	108.80 (12.33)	112.75 (8.15)

WRAT-3, Wide Range Achievement Test 3.

"how much did you enjoy the interaction," "to what extent was the interaction intimate") and the partner's role in the interaction (e.g., "how much did your partner disclose in the interaction," "how much did your partner influence the conversation") on a scale of 1–8, with higher scores indicating more positive evaluations. Scores on each item were averaged to create a composite score representing interaction quality. This measure has demonstrated validity for observer ratings of interaction quality (Berry and Hansen, 1996) and has been used successfully when assessing interactions in autism (Morrison et al., 2020). Within the present sample, this measure demonstrated acceptable internal consistency (autistic group $\alpha = 0.72$; NA $\alpha = 0.73$).

The Subjective Closeness Index and The Subjective Closeness Index

The Subjective Closeness Index (Berscheid et al., 1989) and the Inclusion of the Other in the Self (Aron et al., 1992) assess a participant's feelings of "closeness" to their partner. For the Subjective Closeness Index (Berscheid et al., 1989), participants rated their perceived closeness with their partner on two Likert-type items. Possible total scores range from 2 to 14, with higher scores indicating greater perceived closeness. For the Inclusion of the Self in the Other (Aron et al., 1992), participants were presented with pairs of increasingly overlapping circles and asked to choose the pair best representing how close they felt with their partner. Scores range from 1 to 7, with 1 indicating no overlap with the other individual and 7 indicating high overlap. Based on previous analyses (Aron et al., 1997; Morrison et al., 2020), a composite score was created by averaging the raw scores of these two scales, resulting in an overall metric of closeness. Previous research has shown strong psychometric properties for this combined scale (Aron et al., 1997; Morrison et al., 2020). In our sample, this measure demonstrated good internal consistency (AUT $\alpha = 0.81$, NA $\alpha = 0.85$).

The International Personality Item Pool-Interpersonal Circumplex

The International Personality Item Pool-Interpersonal Circumplex (IPIP-IPC; Markey and Markey, 2009) is a 32-item questionnaire used to evaluate a participant's assessment of their partner's warmth and dominance, two factors that predict quantity, and quality of social interaction (Wiggins, 1982; McCrae and Costa, 1989; Horowitz et al., 2006). Participants rated their partner on a five-point Likert-type scale for items assessing interpersonal warmth (e.g., "My partner reassures others") and dominance (e.g., "My partner speaks loudly"), with higher scores indicating greater agreement with each item. Items were divided into octants, each containing four items, with octant scores based on the average score of these four items. Octant scores were then used to create indices of interpersonal dominance and warmth ratings attributed to the conversation partner. This measure correlates highly with behavioral indices of warmth and dominance and shows strong psychometric properties in both the general population and autistic adults (Markey and Markey, 2009; Morrison et al., 2020).

The First Impressions Scale

The First Impressions Scale (Sasson et al., 2017) is a 10-item scale designed to assess a rater's initial impressions of a target individual. Six items reflect perceptions of personal traits (awkwardness, attractiveness, dominance, trustworthiness, likeability, and intelligence), while the remaining four items reflect "behavioral intent," or the rater's interest in future interactions with the target individual across different contexts. For each item, participants rated their interaction partner on a four-point Likert-type scale. This scale has previously been used to evaluate perceptions of autistic adults by both autistic and NA raters (Sasson et al., 2017; DeBrabander et al., 2019) and has recently been used for evaluations of in-person interactions between autistic and NA adults (Morrison et al., 2020).

Analysis Plan

Zero-order correlations between participants' interaction ratings were evaluated to assess the relationship between these indicators, as well as the consistency of ratings between partners. To account for unequal variances between autistic and NA participants, two factor mixed-model ANOVAs were run using a Greenhouse-Geisser correction, assessing the effects of diagnosis (autistic vs. NA) and training condition (AAT vs. control) on how participants evaluated their conversation partner and the overall interaction. Specifically, training condition was treated

as a between-subjects variable and autistic and NA interaction ratings (interaction quality, first impressions, closeness, warmth and dominance) were treated as a within-subjects factor, with separate analyses run for each outcome measure. As IQ differed significantly between autistic and NA individuals within dyads, WRAT-3 scores were included as a covariate in each ANOVA. All analyses were completed using SPSS 27 (IBM SPSS Inc., 2015).

RESULTS

Correlations Between Ratings

Zero-order correlations to assess the relationships between interaction ratings in autistic and NA participants are reported in **Table 2**. While interaction quality reported by autistic adults only correlated significantly with their ratings of closeness, higher ratings of interaction quality reported by NA participants correlated with greater closeness and many other factors as well, including higher ratings of their autistic partner being likable, intelligent, and warm, lower ratings of them being awkward, and increased interest in hanging out with and starting conversations with them. Non-autistic participants who rated their autistic partners as more intelligent also endorsed a stronger desire to hang out with, sit near, and have a conversation with them, while autistic participants' ratings of their partner's intelligence were not significantly correlated with any of their other ratings. Perceptions of the partner's intelligence correlated significantly with the partner's measured intelligence for NA participants rating autistic partners ($r = 0.378$, $p = 0.018$), but did not reach significance for autistic participants rating NA partners ($r = 0.244$, $p = 0.135$). In both groups, the desire to sit near, hang out with, and have a conversation with the partner were all moderately correlated with one another. In the NA but not autistic group, the desire to hang out with and have a conversation with the autistic partner were also associated with greater feelings of closeness.

Correlations and covariances between ratings given by autistic participants and their NA partners within dyads are reported in **Table 3**. Overall, outcome ratings were generally unrelated between partners. However, there was a negative correlation between ratings of warmth ($r = -0.358$, $p = 0.025$), with participants whose partners rated them as higher in warmth in turn rating their partners as less warm.

Social Interaction Measures

Means and standard deviations for all social interaction measures are reported in **Table 4** and fixed effects for the impacts of training condition, participant diagnosis, and their interaction on these ratings are reported in **Table 5**. For indicators of interaction quality, there was a significant main effect of training condition on intention to hang out with the partner, with both autistic and NA participants in the AAT condition reporting a stronger intention to hang out with their partner in their free time [$F_{(1,35)} = 6.60$, $p = 0.015$, partial $\eta^2 = 0.159$]. Participants in the training condition rated their partners as less trustworthy compared to those in the control condition [$F_{(1,35)} = 4.99$, $p = 0.032$, partial $\eta^2 = 0.125$]. Ratings on these items did not differ significantly as a function of actor diagnosis

TABLE 2 | Zero-order correlations between social interaction ratings, with correlations for ratings made by autistic participants above the diagonal and those made by non-autistic participants below it.

	Awkward	Attractive	Trustworthy	Dominant	Likable	Intelligent	Live near	Hang out	Sit near	Conversation	Closeness	IPIP-IPC warmth	IPIP-IPC dominance	Interaction quality
Awkward	1	−0.278	−0.148	0.085	−0.083	−0.148	0.277	−0.140	0.149	0.103	0.179	−0.193	−0.251	−0.017
Attractive	**−0.394**	1	**0.319**	0.101	0.174	0.152	**−0.445**	−0.081	−0.046	0.057	−0.104	−0.015	**0.348**	−0.201
Trustworthy	0.037	0.109	1	−0.124	0.128	0.297	−0.090	−0.007	0.007	−0.034	0.073	0.085	0.195	−0.154
Dominant	−0.201	0.002	0.106	1	−0.194	−0.267	0.026	−0.127	−0.158	−0.032	−0.118	**−0.327**	0.154	0.093
Likable	0.077	0.238	0.049	−0.247	1	0.097	0.044	0.164	0.000	−0.066	−0.087	−0.044	0.023	0.125
Intelligent	**−0.409**	0.276	0.275	−0.123	0.134	1	−0.114	0.068	0.038	0.118	0.241	−0.017	0.006	0.046
Live near	0.162	−0.096	−0.055	−0.116	0.184	−0.164	1	0.105	0.239	0.127	0.107	−0.015	−0.216	0.250
Hangout	**−0.494**	0.088	0.149	0.097	0.030	**0.404**	0.043	1	**0.431**	**0.653**	0.264	0.099	−0.070	0.219
Sit near	−0.167	0.123	0.010	0.064	**0.419**	**0.381**	0.245	**0.417**	1	**0.649**	0.169	−0.021	−0.031	0.126
Conversation	**−0.365**	0.015	0.102	0.118	0.254	**0.453**	0.101	**0.535**	**0.458**	1	0.282	−0.099	−0.118	−0.042
Closeness	−0.204	0.000	0.198	0.148	0.172	0.311	−0.084	**0.352**	0.285	**0.435**	1	−0.168	0.083	**0.343**
IPIP-IPC warmth	**−0.500**	**0.432**	0.174	−0.095	0.216	0.100	0.000	0.227	0.082	0.193	0.068	1	0.307	0.072
IPIP-IPC Dominance	−0.206	0.042	−0.293	0.283	0.100	0.046	0.185	0.279	**0.343**	0.315	0.220	0.262	1	0.167
Interaction Quality	**−0.490**	0.120	0.094	−0.068	**0.327**	**0.367**	0.054	**0.403**	0.204	**0.612**	**0.550**	**0.351**	0.263	1

Bold values signify significance at the level of $p < 0.05$. Values reflect an individual's evaluations of the interaction and their conversation partner. IPIP-IPC, International Personality Item Pool-Interpersonal Circumplex.

TABLE 3 | Zero-order correlations and covariances between social interaction ratings for autistic and non-autistic participants within dyads.

	Awkward	Attractive	Trustworthy	Dominant	Likable	Intelligent	Live Near	Hang Out	Sit near	Conversation	Closeness	IPIP-IPC warmth	IPIP-IPC dominance	Interaction quality
Correlation	−0.113	0.005	−0.138	−0.152	0.277	0.087	−0.065	0.039	0.207	−0.056	−0.044	**−0.358**	0.142	0.087
Covariance	−0.049	0.002	−0.020	−0.040	0.070	0.049	−0.039	0.014	0.103	−0.018	−0.050	−0.190	0.134	0.042

Bold values signify significance at the level of $p < 0.05$. Values reflect an individual's evaluations of the interaction and their conversation partner. IPIP-IPC, International Personality Item Pool-Interpersonal Circumplex.

or the interaction between training condition and diagnosis. No significant effects for diagnosis, training condition, or their interaction were found for the IPIP-IPC, closeness, interaction quality, or the remaining first impressions items.

To control for the impact of participant IQ on interaction ratings, WRAT-IQ scores were used as a covariate. Within dyads, the WRAT-3 IQ score of the autistic participant, but not the NA participant, was a significant covariate for perceived awkwardness. When comparing across training conditions, autistic WRAT-3 IQ contributed significantly to both partners' ratings for awkwardness, trust, intelligence, and warmth, as well as the intention to hang out with the partner. All other ratings were not significantly predicted by WRAT-3 IQs of autistic or NA participants. Statistical significance did not change for any reported results when IQ was removed as a covariate.

DISCUSSION

Although previous research has demonstrated that training programs designed to increase autism acceptance and knowledge among NA people can reduce biases and improve inclusive attitudes toward autistic people (Gillespie-Lynch et al., 2015; Dickter et al., 2020a; Jones et al., 2021), no study to date has investigated whether training benefits extend to real-world interactions between autistic and NA people. The current study examines whether an AAT module previously shown to reduce autism stigma among NA adults and increase their interest in interacting with autistic adults presented in videos (Jones et al., 2021) produces improvements to interaction quality and partner evaluation during actual conversations between unfamiliar autistic and NA adults.

Compared to a no-training control condition, both autistic and NA adults reported greater social interest in one another following a "get to know you" conversation when the NA adult had completed AAT. Specifically, both autistic and NA participants in the AAT conditions expressed an increased desire to hang out with their partner in the future, suggesting that AAT not only improved NA adults' social interest in their autistic partners, but also increased their perceived social desirability among autistic participants. Thus, an acceptance training focused solely on NA participants produced a relational effect, leading to social improvements for both partners. Importantly, this improvement occurred despite participants' unawareness of their partner's diagnosis, suggesting that it was not influenced by demand characteristics. This result replicates a previously observed effect of AAT, in which the training increased NA adults' interest in hanging out with autistic people viewed in video clips (Jones et al., 2021), but extends it to real-world interactions with autistic people and, importantly, suggests it may also transfer to increased social interest among autistic adults in their NA partners. Although this result indicates that a brief and relatively easy-to-administer training for NA adults may increase mutual social interest among unfamiliar NA and autistic adults, it remains unclear whether the effect would produce sustained contact and relationship development beyond the experimental session. It is also unknown what, if any, aspects

TABLE 4 | Means and standard deviations of partner ratings.

	Autism acceptance training (*N* = 39)		Control (*N* = 40)	
	Autistic ratings of NA partners [M (SD)]	NA ratings of autistic partners [M (SD)]	Autistic ratings of NA partners [M (SD)]	NA ratings of autistic partners [M (SD)]
IPIP-IPC warmth	0.06 (0.78)	−0.15 (0.78)	0.20 (0.82)	−0.21 (0.57)
IPIP-IPC dominance	−0.11 (0.96)	0.30 (1.15)	0.02 (0.81)	−0.23 (0.97)
Closeness	2.76 (1.09)	2.74 (1.12)	2.60 (1.04)	2.68 (1.09)
Interaction quality	5.53 (0.73)	5.42 (0.69)	5.42 (0.59)	5.14 (0.78)
First impressions				
Awkward	3.11 (0.66)	2.63 (0.68)	3.35 (0.67)	2.45 (0.61)
Attractive	2.58 (0.69)	2.26 (0.73)	2.65 (0.59)	2.15 (0.67)
Dominant	1.74 (0.56)	2.00 (0.47)	1.65 (0.59)	1.75 (0.44)
Likable	3.42 (0.51)	3.26 (0.45)	3.25 (0.44)	3.40 (0.59)
Intelligent	3.21 (0.79)	3.05 (0.71)	2.90 (0.72)	3.10 (0.79)
Trustworthy	3.05 (0.41)	3.05 (0.23)	3.25 (0.44)	3.20 (0.41)
Live near	3.00 (0.88)	3.05 (0.85)	2.75 (0.79)	3.15 (0.59)
Hang out	3.05 (0.62)	2.74 (0.45)	2.65 (0.67)	2.45 (0.61)
Sit near	3.26 (0.65)	3.26 (0.87)	3.05 (0.61)	3.10 (0.72)
Conversation	3.16 (0.60)	2.95 (0.62)	2.95 (0.51)	2.75 (0.55)

Values reflect an individual's evaluations of the interaction and their conversation partner. Higher ratings indicate more positive evaluations. NA, non-autistic; IPIP-IPC, International Personality Item Pool-Interpersonal Circumplex.

TABLE 5 | Fixed effects of training condition, actor diagnosis, and interaction on social interaction measures.

	Main effect of training condition		Main effect of actor diagnosis		Interaction	
	F	*p*	F	*p*	F	*p*
Awkward	0.11	0.74	1.44	0.24	1.71	0.20
Attractive	0.07	0.79	0.81	0.37	0.31	0.58
Dominant	2.41	0.13	0.67	0.42	0.45	0.51
Likable	0.02	0.90	0.47	0.50	2.66	0.11
Intelligent	0.35	0.56	0.03	0.86	1.45	0.24
Trustworthy	**4.99**	**0.03**	1.56	0.22	0.03	0.86
Live near	0.12	0.73	0.85	0.36	0.80	0.38
Hang out	**6.60**	**0.02**	0.51	0.48	0.24	0.62
Sit near	1.02	0.32	2.36	0.13	0.07	0.79
Conversation	1.34	0.23	1.90	0.18	0.01	0.91
IPIP-Warmth	0.18	0.68	0.02	0.88	0.26	0.62
IPIP-Dominance	0.71	0.41	0.28	0.60	2.39	0.13
Closeness	0.18	0.68	2.32	0.14	0.11	0.75
Interaction Quality	1.13	0.28	1.35	0.25	0.23	0.64

Items reflect participants' ratings of their conversation partner within autistic-non-autistic dyads. Bold values represent significance at $p < 0.05$.

of NA behavior and communication differed following AAT and contributed to increases in social interest. Future work is encouraged to attempt to both replicate this effect and measure whether and how training alters NA behavior within interactions with autistic people. Research examining the impact of AAT on social interactions is limited, but additional training with a greater focus on autistic communication and expressivity may improve NA understanding of neurodivergent interaction styles. Because NA adults have been found to misinterpret autistic communication styles (Brewer et al., 2016; Edey et al., 2016), resulting in a breakdown in communication (Crompton et al., 2020b), how a double empathy focused training may affect perceptions of interaction quality for autistic and NA adults is worthy of further examination.

In contrast to this finding, no effects of training were found on the other three behavioral intention items. However,

these items—living near, sitting near, or having a conversation with the person in the future—represent relatively superficial forms of social interaction that can occur with acquaintances or even strangers (Morgan, 2009), whereas the intention to "hang out with" and spend one's free time with another person reflects a closer level of contact associated with the development of friendships (Hays, 1989; Sias and Cahill, 1998), and may be a strong indicator of intimacy, particularly among males (Wood and Inman, 1993; Floyd, 1995; Floyd and Parks, 1995). Autistic individuals often have limited social opportunities (Lord et al., 2020), and can experience difficulties forming friendships (Mazurek, 2014), in part due to how they are perceived by others (Sasson et al., 2017). By increasing interest in future close interactions between autistic and NA adults, AAT may offer potential for improving social opportunities for autistic adults within NA environments.

Independent of training effects, several differences emerged between NA and autistic participants in their evaluations of each other and the interaction. For NA participants, positive ratings of their partner on many first impression and interaction items were associated with higher ratings of interaction quality. In contrast, interaction quality was largely unrelated to how autistic participants evaluated their NA partner. Similarly, NA participants but not autistic participants who perceived their partner to have greater intelligence in turn showed greater social interest in them. This may suggest a greater connection between person and interaction evaluation for NA compared to autistic adults. Such an interpretation is consistent with prior research showing stronger associations between trait evaluation and social interest among NA than autistic people (DeBrabander et al., 2019), and may indicate that trait judgments like awkwardness, likeability, and attractiveness are less relevant to autistic adults than NA adults when judging interaction quality. This interpretation—that autistic individuals place less weight on surface-level traits of their partner when evaluating interactions—is also supported by previous literature suggesting that shared interests rather than individual traits are more of a primary driver of successful friendships for autistic adults (Sosnowy et al., 2019). Future studies investigating other differences in interaction and friendship preferences between NA and autistic adults may highlight additional sources of relational disconnect that, through awareness and understanding, may offer avenues for improving interactions, inclusion, and social outcomes for autistic people.

This interpretation is further supported by the dissociation in ratings made about one another by autistic and NA partners within dyads. Only ratings of warmth significantly correlated between partners, and this correlation was negative, suggesting a disconnect between NA and autistic people in a fundamental aspect of interpersonal assessment. These results are notably different from those found in a previous study of real-world interaction among and between autistic and NA adults using the same outcome measures (Morrison et al., 2020), in which dyadic partner ratings for first impression items, behavioral intentions, interaction quality, and closeness were all significantly related. However, Morrison et al. (2020) included autistic-autistic dyads and NA-NA dyads, in addition to the mixed dyads used in the current study. It may be the case that, consistent with a DEP framework (Milton et al., 2013), inter-partner agreement increases in interactions between people of a shared neurotype and declines within cross-diagnostic interactions.

Contrary to prediction, AAT largely did not affect trait evaluations made of and by autistic adults, nor did it affect participant assessments of interaction quality. While null findings should be interpreted with caution, several factors may account for the lack of training effects for some ratings. First, although a larger sample size may have revealed more effects, it is also likely that a brief, one-time presentation may be insufficient for eliciting the large-scale behavioral changes needed to improve interpersonal perceptions within these interactions. Indeed, previous work suggests that the effects of AAT modules, including the one used in this study, may affect explicit but not implicit biases (Bast et al., 2021; Jones et al., 2021). Implicit biases are automatic, unconscious forms of bias that can contribute to unfavorable judgments about groups of people, and as such, the persistence of these biases previously shown to be prevalent among NA participants toward autism (Dickter et al., 2020b), may have impacted behaviors and attitudes toward autistic interaction partners. Importantly, not all effects of training were beneficial. One unexpected result was that autistic and NA partners in the training condition rated one another as less trustworthy than in the control condition. Perhaps AAT influenced NA behavior in ways that were unappealing to autistic participants and/or raised suspicions among NA adults about their interaction partners. Alternatively, this could be a spurious finding related to using distinct participants in the two training conditions or to the lack of a pre-test/post-test design. The employed analyses did not implement a correction for family-wise error, so future work should examine whether this effect replicates.

While participants' diagnostic status was not disclosed, and only two autistic participants chose to disclose their diagnosis, it remains possible that social desirability biases in NA participants may have influenced the results of the study. Both groups were exposed to the possibility of an autistic conversation partner, but the autism-specific training video may have primed participants in this condition to expect an autistic partner, leading to more favorable ratings in this condition compared to a no-video control condition or a non-autism related control. If present, social desirability biases may represent a potential strength, as the methodology of this study maps onto how similar trainings may be administered in the real world, with participants aware that the training is designed to improve their interactions with autistic people. Regardless, training effects were not consistent across conditions, including a potentially negative finding of reduced trust in training condition participants, suggesting that results were not driven solely by social desirability biases. Additional research examining if and how demand characteristics influence training outcomes are encouraged.

Additionally, NA attitudes toward autism were not assessed prior to participation, so these may have differed between the two training groups, minimizing the potential benefits of AAT. The young adult NA sample included in the study also may have already been more familiar with, and accepting of, autistic

differences than the general population (White et al., 2019). This is particularly relevant for the current NA sample given that it was drawn from a university with one of the largest number of autistic students in the United States (Hoffman, 2016). Further, the diagnostic status of participants was also not disclosed to conversation partners. While this lack of disclosure can be viewed as a methodological strength, producing fewer demand characteristics and more ecologically valid interactions, effects may have been larger if disclosure had occurred, as has been found in previous studies (Sasson and Morrison, 2019). Because the training was compared to a no-training condition, as opposed to an active control, it is difficult to ascertain whether any effects were specific to the training video used here, or rather an effect of training in general. Comparison to a more generic training, such as that used in our previous study (Jones et al., 2021), may illuminate the unique benefit of autism-specific training. Perhaps most importantly, the sample in this study consisted exclusively of White, self-identified males to control for confounding effects of cross-gender and cross-race interactions. Given the impact of gender (Milner et al., 2019; Lai and Szatmari, 2020) and racial biases (Giwa Onaiwu, 2020; Jones et al., 2020) on the experiences of autistic adults, the results of this study may have differed in important ways for a more diverse sample. Finally, participants were young adults with verbal IQs in the average range, so the impact of AAT may not generalize to the broader population of autistic people, including non-speaking people, those with an intellectual disability, or older adults. Therefore, while the current study offers proof of concept for analyzing the effects of NA training on improving interactions for autistic people, future work should consider how NA perceptions of, and behavior toward, autistic people intersect with other salient aspects of identity not examined here.

These limitations notwithstanding, this study provides further insight into the relational aspects that contribute to interaction difficulties between autistic and NA adults and offers some limited support for the benefits of AAT for NA adults. Autism acceptance training in this study was associated with a greater future interest in hanging out for both autistic and NA adults within dyads, but the benefits of training did not extend to other ratings, including evaluations of closeness and interaction quality. Findings also suggest that autistic and NA individuals may evaluate interactions differently, with NA individuals placing greater value on their partner's intelligence and social presentation. Therefore, while these findings offer some promise that the benefits of AAT may extend beyond the laboratory (Jones et al., 2021) into real-world settings and increase social interest between autistic and NA adults, more systematic changes are likely needed to bridge the communicative and interactive divide between autistic and NA adults.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by The University of Texas at Dallas Institutional Review Board. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

KM, DJ, and NS led the design of the study, with contributions from AP and RA. DJ gathered and organized the data, with contributions from KM and KD. DJ conducted data analysis in collaboration with RA. DJ interpreted the data, with help from RA, AP, KD, and NS. DJ and NS wrote the manuscript, with contributions from AP, RA, and KD. All authors contributed to the article and approved the submitted version.

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Academic, Activist, or Advocate? Angry, Entangled, and Emerging: A Critical Reflection on Autism Knowledge Production

*Monique Botha**

Division of Psychology, University of Stirling, Stirling, United Kingdom

There has been a focus on autistic-led and participatory research in autism research, but minimal discussion about whether the field is hospitable to autistic involvement. While the focus on participatory and/or autistic-led research is abundantly welcome, a wider conversation should also happen about how autistic people are treated in the process of knowledge creation. As such, I present a critical reflection on my experiences of academia as an autistic autism researcher. I open by questioning whether I am an academic, an activist, or an advocate before discussing my journey through academia, and my exposure to dehumanizing, objectifying, and violent accounts of autism. I highlight how the construction of objectivity has resulted in a failure to question the validity of these dehumanizing accounts of autism, which are regarded as "scientifically-sound" by virtue of their perceived "objectivity." Furthermore, I discuss how the idea of objectivity is used to side-line autistic expertise in disingenuous ways, especially when this knowledge challenges the status-quo. Despite claiming to be value-free, these dehumanizing accounts of autism embody social and cultural values, with a complete lack of transparency or acknowledgment. I then discuss how these dehumanizing accounts and theories—entangled in values—reverberate into autistic people's lives and come to be ways of constituting us. Following this, I discuss the rationality of the anger autistic people feel when encountering these accounts, and instead of urging people to distance themselves from these emotions, I discuss the value of "leaning-in" as a radical act of dissent in the face of research-based violence. I then make a call to action urging all those who write or speak about autism to engage reflexively with how their values shape their understanding and construction of autistic people. Lastly, I conclude by answering my opening question: I have emerged as an advocate, activist, and academic. For me, belonging to the autistic community, acknowledging our marginalization, and recognizing our suffering within society means that hope for a better and just future has always, and will always underpin my work.

Keywords: autism, critical reflection, ableism, epistemic injustice, research violence, social justice, participatory research, dehumanization

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***Correspondence:**
Monique Botha
mbothapsych@gmail.com

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INTRODUCTION

Let me introduce myself—I am an autism academic. I am first generation university educated, saddled with student debt, and carry the uncomfortable feeling that I do not fully belong most of the time. I did my MSc, followed by my Ph.D. at the University of Surrey, and before this I did my BA in Social Care Practice at Athlone Institute of Technology in Ireland. I worked for 4 years with autistic children and young people, and their families, as a social care practitioner, as well as doing palliative care for young and middle-aged disabled adults. I am unashamedly, and unabashedly autistic. I have been the kind of autistic that was "going nowhere," "disruptive," "awkward," and "failing," and I have been the kind of autistic that is "inspirational," "going places," and "changing the world." I have been the kind of autistic that melted down every day, until I was pinned down on the ground being sedated in the middle of my hometown. Some have described me as being a "dead-end," and the "kind of person with autism who was born to die by suicide anyway," and also as the kind of person with the "easy autism." I am very honest, but mask most of the time and walk a delicate line between "personal" and "professional." Somewhere along the way I decided to be an autism academic, but first I was just autistic, then an advocate, then I was an activist, all before the academy told me to leave those at the door.

In this article, I want to open the door to discussing knowledge production, and what it means to do research into autism. As involvement of autistic people is hopefully increasing in research, blunt and open conversation is needed to address how autistic involvement is received, and whether the field is hospitable for us. As such, I publish this in the hope that it contributes to a conversation on what is needed to ensure equal engagement in research from autistic people in the field of autism research. Furthermore, it has been my experience that autistic scholars at all stages experience a loneliness that silence serves—we are not meant to speak openly about our experiences within academia, especially when negative. It is my hope that on publishing this autoethnographic account, some autistic scholars might feel less alone.

My MSc and Ph.D. research were into the utility of the minority stress model for understanding poor mental health in the autistic community (Botha and Frost, 2020), and whether autistic community connectedness would buffer against the effect of minority stress on mental health (Botha, 2020). I used qualitative and quantitative methods, and did four studies—a qualitative, critical grounded theory investigation into autistic community connectedness; a scale creation and evaluation study for measuring autistic community connectedness; a cross-sectional investigation into whether community moderated the effect of minority stress on mental health in autistic people; and finally, a longitudinal study investigating the effect of minority stress and autistic community connectedness over time. I write this article—somewhere between personal and professional, open, and unambiguous, in the hopes I can spark a wider conversation on autism, objectivity, and positionality—a conversation that needs to happen amongst anyone who researches autism. While there has been wider discussions about participatory and autistic-led research (something I am deeply in favor of myself) (Botha, accepted,i; Pellicano, 2014; Fletcher-Watson et al., 2019), it seems no one has stopped to ask whether autism research is, at its *core* hospitable to autistic involvement, nor fully explored the damage often done to autistic people in their involvement.

POSITIVISM, OBJECTIVITY PSYCHOLOGY, AND AUTISM

Elsewhere I have discussed in more depth how positivism has shaped psychology and in turn, the construction of autism (Botha, accepted) and so here, I will keep this section short. In essence, mainstream psychology has been underpinned by positivism and logical empiricism for most of its relatively short history—this means that in general, psychology aims for establishing reality through the application of the scientific methods (Leahey, 1992). These methods are designed to aim for falsification, deduction, and establishing causality (Popper, 2008). Positivism is predicated on "epistemological transcendence" (Nagel, 1989); the idea that employing the scientific method means that the end product is value-free mean that it is, untied to social and cultural values (Fondacaro and Weinberg, 2002). Objectivity then, is distance from the object. Yet—no one discusses *how* objectivity is *functionally* achieved—instead most quantitative research forgoes discussion of objectivity all together under the assumption that the work simply stands alone. Given this, some have described objectivity as a "useless elevator concept" that is ideal in theory but not does not work in practice (Hacking, 2015).

The history of autism is rooted in the field of medicine (and by extension psychiatry) which tends to treat deviation from the norm as disease, disorder, and dysfunction, and which tends to have a focus on remediation, prevention, and cure (Glynne-Owen, 2010; Evans, 2013). The enshrinement of the idea of the scientific method, positivism, and objectivity within fields like medicine has resulted in both a bio-essentialism and pathologisation of autism, whereby autism at its worst is described as an epidemic (Johansen, 2013). This "disease" or "disorder" is identified through a set of observable behaviors (according to the DSM-5 impairment in social communication, impairment in social interaction, and lastly restrictive and repetitive behaviors), all of which should have been noticeable from a young age. Furthermore, within this medical model, remediation, prevention, and curing should be the primary goals of research—akin to the treatment of other "disorders." Therefore, early interventions, such as applied behavioral analysis, that strive to normalize the perceived deviances of autism are extolled as gold standard interventions.

Autism is not necessarily a natural category—it is a label that was created by technocrats to group together a cohort of people with similar behavioral presentations (Hacking, 2001; Silberman, 2015). As I have highlighted elsewhere (Botha, in review) autism cannot be explained as emerging from biology alone, despite the best efforts of positivism; genes are found in a wide array of combinations, and this is an evolving and

ever-changing combination (De Rubeis et al., 2014), while at a neurobiological level autistic brains are highly heterogenous (Toal et al., 2010; Lenroot and Yeung, 2013; Chapman, 2020). Autism is so heterogenous that some argue that it is no longer meaningful as a single category (Happé et al., 2006; Mottron, 2021). This does not mean that autism is not real—on the contrary I believe, given the knowledge that we have, that 1 day a biological explanation which underpins autistic people will emerge (explaining the sensory differences that unite us, for example (see Proff et al., 2021, for a recent review). What this means instead, is that the actual *meaning* of autism has been something long-debated and shaped by people during its 100-year history, and as such, autism has always been tied to *time, place,* and *culture.* Thus, even if tomorrow, we were to uncover a specific array of genes, or a specific part of the brain that was reliable and valid across the entire all autistic people, we *still* would not understand autism if we did not consider society or culture.

NAVIGATING AUTISM AS A PARADIGM

Undergraduate

As an undergraduate in my penultimate year, my *academic* introduction to autism was in a module entitled "Abnormal Psychology" through the triad of impairments (Wing and Potter, 2002) which categorized "people with autism" as being marked by impairments in our social communication and language, social interaction, and as having restricted interests and cognitive inflexibility. I was taught about autistic people having impaired theory of mind (Baron-Cohen et al., 1985), and told that "people with autism" would struggle to understand the perspective, experiences, and emotions of others—I was well-acquainted with the Sally-Ann task as evidence of my deficiency. I was introduced to the idea that impaired theory of mind meant that autistic people struggled with empathy (Baron-Cohen, 2009b). I was repeatedly told to use person-first language ("person with autism") because identity-first language was out-dated, offensive, and reduced a "person with autism" to their autism alone—"we *must* remember this is a person first." I was taught that autism was a linear scale from "severely autistic" to "mild autism" like Asperger syndrome or "high-functioning autism." "There is no cure" was how I was introduced to Applied Behavioral Analysis as the only scientifically-sound treatment for autism—the goal of which was to teach children to bridge across their intrinsic deficits and into non-autistic communication and sensibility.

I would learn these two-dimensional, seemingly objective accounts of autistic people on one day, and on the next work with these three-dimensional autistic children who were all together more complicated, and more real. Autistic children who were sensory-seeking, inquisitive, and who creatively used social communication to get their needs met only to be chastised for not using *more* words. I would spend countless hours online on various forums with other autistic people building up friendships, asking for advice, giving advice, and quite literally *sharing perspectives* with others like me—and a lot of the stories were of trauma, marginalization, mental health crises, and about the way autistic people were treated in society. But as I tried to express my own experiences as an autistic in class I would be shut down because of my "lack of objectivity," and because "I could not possibly put myself in the shoes of the person with *severe* autism." I spent a lot of time being taught that I lacked theory of mind by people who could not grasp that my experience of and with autism were fundamentally different to the accounts being taught. I discovered Steven Kapp's paper on identity first language and neurodiversity (Kapp et al., 2013) and it brought me a deep-seated joy and certainty because it was so much closer to the reality I was witnessing. I tried to elevate it into discussions only to be told that "I did not understand the literature" and "was not qualified to challenge it." So, when my exams came around, I rote-learned my own dehumanization and rattled off a list of deficits and early-intervention behavioral modifications tools to be used on people like me to pass the exam. I went home and melted down. I graduated with a first-class honor degree, being told that if I were *really* autistic, I probably would have dropped out along the way.

Postgraduate

My MSc research was my first foray into creating academic autism knowledge. I did not intend to do my MSc research on autism—my undergraduate project was on the knowledge and perception that Irish citizens held toward asylum seekers in Ireland, and I thought I would continue down a similar vein. I wanted to do equality and value-based research but did not feel like I had a place amongst autism research. Two things happened which changed my course: firstly, a study was published showing that autistic people have increased early mortality and one of the leading causes of death is suicide (Hirvikoski et al., 2016)—a paper which shook me to my core. Secondly, at the University of Surrey, my paths crossed with an academic who would introduce me to the concept of minority stress (Meyer, 2003). The minority stress model posits that social disadvantage and marginalization results in an increased burden, which in turn can result in mental and physical health disparities (Meyer et al., 2002; Frost et al., 2015). Predominantly, it has been used to investigate the health disparities seen in the queer community. The focus in the minority stress model shifts away from there being something inherent about LGBTQ+ communities and focuses instead on the experiences that sexual and gender minorities have within society. It sounds cliché, but it was a light-bulb moment—it was a lens through which I could reflect on an entire lifetime of experiences and make them coherent for once. Yet, as an idea, minority stress ran counter to the literature which associated the traits of autism itself with suicidality (Mikami et al., 2009), centered suffering as inherent to autism (Baron-Cohen and Bolton, 1993), or focused on the specific thinking styles of autistic people as causative of poor mental health—as if autistic people exist in a societal blackhole, and would still suffer in the absence of our entire social structure.

It is not hard to see the potential utility for the minority stress model when you pause and take stock of how autistic people are treated in society. The minority stress model captures the some of the complexity of existing while autistic. Autistic people are stereotyped—and the vast majority of stereotypes are negative (Wood and Freeth, 2016). Autistic people face employment

discrimination, higher unemployment, and underemployment, as well as experiencing bullying in the workplace (Shattuck et al., 2012; Baldwin et al., 2014). Autistic children are more likely to be excluded from schools (Timpson and Great Britain, 2019). In the United Kingdom (UK), one-third of autistic people have access to neither employment or welfare payments (Redman, 2009), while 12% of Welsh autistic adults report experiencing homelessness (Evans, 2011). Statistics show disproportionate use of force against autistic people and those with learning disability in the UK (Home Office, 2018), while a third to half of all incidents involving the use of excessive force by police involves a disabled person (Perry and Carter-Long, 2016)—experiences which will obviously be further compounded by institutional racism (Holroyd, 2015). Autistic individuals are more likely to experience (poly)victimization, including being four times more likely to experience physical and psychological abuse from adults as children, 27 times more likely to experience teasing, and seven times more likely to experience sexual victimization (Weiss and Fardella, 2018). At the extreme end of the victimization—autistic children are more likely to die to filicide (Lucardie, 2005). Autistic lives are marked by an often-astounding excess stress burden across the life span.

Considering the study by Hirvikoski et al. (2016), I chose to study mental health and minority stress because people like me were (and still are) dying to suicide in their droves. To be clear, wanting a better future for my community is a value, and my work embodied it from the very beginning. I was propelled by values. How can you belong to a community who is actively suffering, and not want to make it better anyway that you can?

At this point, I discovered both the vastness of autism literature, and the endlessness of its dehumanization of autistic people. Dehumanization is defined as the denial of full humanness to others (Haslam, 2006), the denial of a group's community or identity (Kelman, 1973), exclusion of a group from moral boundaries (Opotow, 1990), the denial of a group's ability to experience complex emotions (Leyens et al., 2000), or the denial of specific traits which are said to unite all humans, or separate non-human animals from humans (Haslam, 2006). These traits include civility, refinement, moral sensibility, rationality or logic, maturity, responsiveness, emotional warmth, individuality, depth, or agency (Haslam, 2006). Dehumanization and exclusion from moral boundaries serve to facilitate the permissibility of violence against a group (Opotow, 1990; Haslam and Loughnan, 2014), something which is reflected in how freely, and without restraint the literature debates the eugenic removal of autistic people. In talking about violence, I include physical, psychological, emotional, and verbal violence, including interpersonal victimization (Griffiths et al., 2019), and also systemic violence perpetrated through societal systems such as research (Teo, 2010). Dehumanizing and/or stigmatizing research or narratives are both an act of violence against autistic people, but also facilitate the permissibility of more intimate violence such as interpersonal victimization. As I have pointed to in both empirical (Botha et al., 2020) and theoretical papers (Botha, accepted)—dehumanization of autistic people in research is endemic. Below I highlight some key quotes, and rather than summarize them I include them so that there is no ambiguity or debate about "interpretation" in how research discusses autism and/or autistic people. The quotes below highlight this sort of research-based violence with their dehumanization of autistic people, and are all specific examples of quotes I was exposed to during my MSc and Ph.D.:

> "*Originality is attractive even in the domestic sphere as long as it does not topple over into uncomfortable eccentricity. However, it is only a few people with ASD [autism spectrum disorder] who combine originality with high levels of intelligence and industry who are likely to make a sufficiently sustainable, salient contribution that their absence might be considered unaffordable*" (Tantam, 2009, p. 219).
>
> "*…autism spectrum disorders (ASD) have become preferred labels for problems reaching the criteria for disability for a variety of reasons, including trends in what is considered chic and the increasingly common abandonment of prevention as a goal… We are also concerned that positive views of disability [*including ASD*] inadvertently undermine prevention… preventing them likely becomes a matter of little concern. If being born with a disability is not also seen as being undesirable—in fact, as a birth defect—then we fear there will be little reason to prevent such anomalies. If we care about the quality of life of people with disabilities and their loved ones we will certainly do all we can to… prevent others from having a disability"* (Kauffman and Badar, 2018, p. 53).
>
> *"In general, it seems that neither apes nor children with autism have—at least not to the same extent as typically developing human children—the motivation or capacity to share things psychologically with others. This means that they both have very limited skills for creating things culturally with other persons"* (Tomasello et al., 2005, p. 687).
>
> *"It is our intention to show that people with ASD exhibit less marked domesticated traits at the morphological, physiological, and behavioral levels… specifically, in adults the abnormal shape of the ears is robustly associated with autistic traits, with higher scores correlating with poorer functioning (Manouilenko et al., 2014)... Regarding the changes in the orofacial region, prepubertal boys with ASD show significant differences in facial morphology compared to typically developing (TD) boys (Aldridge et al., 2011)… This distinctive facial phenotype is more pronounced in subjects with severe symptoms, significant cognitive impairment, and language regression (Obafemi-Ajayi et al., 2015). Concerning tooth peculiarities, children with ASD show greater abnormalities in dentition, including missing teeth, diastemas, or reverse overjets (Luppanapornlarp et al., 2010) … Regarding the behavioral traits associated with the domestication syndrome, we wish to highlight that aggressive behaviors are frequent in children with ASD (with about 25% of them having scores in the clinical range), and correlate with lower cognitive outcomes (Hill et al., 2014). Children with ASD display more reactive than proactive aggression attitudes (Farmer et al., 2015)."* (Benítez-Burraco et al., 2016, p. 1).
>
> *"The person with autism's difficulty is more profound, making the possibility of identifying with a community more daunting. While it is true that communities of persons exist, disabled or otherwise, it is not the case that a community of autistic people is one of them. There is not, nor could there be a community of autistic people, since a failure of 'theory of mind' would preclude being a part of any community"* (Barnbaum, 2008, p. 157).
>
> *"One way to describe the social impairment in Asperger syndrome is as an extreme form of egocentrism with the resulting lack of consideration for others… This egocentrism seems to present*

a huge difficulty in forming successful long-term interpersonal relationships. Spouses and family members can experience bitter frustration and distress. They are baffled by the fact that there is no mutual sharing of feelings, even when the Asperger individual in question is highly articulate." (Frith, 2004, p. 676).

"Autistic children are severely disturbed. People seem to be no more than objects to them… You see, you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense—they have hair, a nose and a mouth—but they are not people in the psychological sense." (Lovaas, 1974).

"*Autistic integrity seems more akin to the type of integrity informing environmentalists' familiar demands for consumer and communal responsibility toward non-human animals*" (Russell, 2012, pp. 169–170).

"We have argued above that if the mechanism which underlies the computation of mental states is dysfunctional, then self-knowledge is likely to be impaired just as is the knowledge of other minds. The logical extension of the ToM deficit account of autism is that individuals with autism may know as little about their own minds as about the minds of other people… Autism is a devastating disorder because it disrupts not only understanding of others and their social relationships, but also understanding of self." (Frith and Happe, 1999, p. 7 and 19).

I became not just a triad of impairments, or someone who lacked the ability to infer the minds of others, or empathize, but something that was described in terms of categorical sub-humanness—incapable of culture, friendship, community, and reciprocity; someone who is less domesticated, more aggressive, an economic burden, with integrity equivalent to non-human animals alone. I balanced sitting exams, with sifting through "objective" accounts of my complete insufficiency as a human-being, often getting lost in the most egregious descriptions of what it "means" to be autistic. But it was okay, because some of these very same articles employed person-first language—the language I was repeatedly told made people like me *more* human. I wondered, as I have for years, if that is even something you can forget when you look at autistic people. The literature taught me that certainly it is something some can "forget" while writing about autistic people, and that person-first language is the placation autism researchers offer themselves in the same breath as refusing to acknowledge that there is any human in autistic people at all.

When analyzing the results from my MSc study I found that exposure to minority stress *does* predict significantly worse well-being and higher psychological distress in the autistic community (Botha and Frost, 2020), including exposure to victimization and discrimination, everyday discrimination, expectation of rejection, expectation of rejection, outness (disclosure), concealment (masking of autism), internalized stigma, and it explains a large and significant proportion of the variance—in lay-man's terms—the constant marginalization of autistic people is contributing to high rates of poor mental health. Aside from this, I noticed that despite being normally distributed (and not containing outliers), the mean psychological distress score was above the cut-off for indicating severe psychological distress (Kessler et al., 2003). Between the sadness of these findings and being exposed to all of these disturbing accounts of autism I considered (albeit briefly), giving up on academia all together without pursuing my Ph.D.

At my first conference, in the first year of my Ph.D. I enthusiastically explained my research while standing next to my first real research poster. The poster detailed my MSc paper which found that a large proportion of the variance of poor mental health and well-being could be explained by exposure to minority stress, and parts of my first study of my Ph.D.—a qualitative investigation into autistic community connectedness. A conference delegate asked, "why did you do this research?." I disclosed being autistic, and pointed to the clear need for the research and the delegate's response was "oh… are your supervisors? I just worry that you might be biased in, like… you know… this research?." In that moment I recalled reading all the accounts that I detailed above—all these "objective" accounts of my sub-humanness. I asked the delegate what they meant, and they explained further that they are not necessarily sure that an autistic person would be best placed to talk about autism, but that it should be fine as long as I have non-autistic research supervisors checking over my work, to make sure that I am being "fair," and "equal" in my representation of autistic people. I was discounted again.

During my first year of my Ph.D. I submitted my first paper to be published, on minority stress and mental health in the autistic community—it was desk rejected by the first journal I sent it to, because there are (apparently) not enough autistic people in general for it to be important to a general audience, making it out of the scope of the journal—a journal which regularly publishes arguably niche research about other minority groups. When it goes out for review elsewhere the editor returns the review comments with a long paragraph about why I have objectified autistic people by using identity first language, and that I really should not define autistic people by their autism alone, and that if I said "person with autism" I would be re-iterating autistic people's personness. One reviewer asked me to double check the psychological distress scores because the scores being normally distributed would indicate a very distressed sample. I double-checked the data—it is still accurate, normally distributed, and yes, autistic people are still not okay.

It was toward the middle of my second year on my Ph.D. that I entered a crisis of faith in Psychology because it seemed like Psychology was built as a pyramid of playing-cards—ready to collapse at any moment. The predominant default in my MSc education was a steadfast positivistic Psychology. I was taught about statistics, experimental design, the replication crisis, and the movement toward "objective" measures like fMRI, and neuroscience. I was taught about statistical reliability and validity, but rarely about meta-theory, and what underpins the whole field of Psychology. Indeed, this uncomplicated picture of Psychology was one underpinned by positivism (and its successor logical empiricism) which aims for deduction through controlled experimentation using operationalized variables, and aims for reproducibility, objectivity, and value-freedom (Tolman, 1992). The application of the scientific process is said to create value-free objective knowledge (Fondacaro and Weinberg, 2002) whereby their evaluation transcends social and cultural predilections and represents an aptly named "view from nowhere" (Nagel, 1989).

To juxtapose this extensive education on positivistic Psychology was a limited exposure to qualitative Psychology—predominantly through an interpretivist lens—and some discussion of meta-theory more deeply during one module on the conceptual and historical issues of Psychology alone.

Despite this, as multiple authors have highlighted, and as I realized, there is a lack of transparency in quantitative methods, partly because of the assumption of objectivity awarded almost without question, to statistical work (McGuire, 1983; Gigerenzer, 2004; Tebes, 2005; Bayarri et al., 2016). Yet, data is manipulated without disclosure for many reasons (Gigerenzer, 2004; Cumming, 2014). This manipulation goes beyond carelessness, given that in a study of 697 articles, researchers found that while 63% had inaccurate *p*-values, 20% of which were so grossly misrepresented that it would have changed the decision about significance in favor of authors hypotheses (Veldkamp et al., 2014). This is before acknowledging the fact that interpretation is an action and acknowledging that data do not speak for itself (Teo, 2010), meaning that *even* if you have applied the scientific method you cannot take the scientist out of the science. We discuss data as if it "speaks" for itself, rather than as the product of our measurement, design, and creation, all of which are predicated on the assumptions brought into the investigation (Barad, 2007). As such, all of science is entangled with the people who create it (Barad, 2007). Despite any claims to value-neutrality, and science status Psychology has a bigotry that I highlight elsewhere (Botha, accepted), such as racism (Schaffer, 2007), ableism (Scully and Shakespeare, 2019), and homophobia (Mohr, 2009) all of which involves centring psychology in social and cultural values, without acknowledgment. In particular, for example, Black people have long been racialized by psychologists, with a determined effort to establish group inferiority based on skin colour in empirical psychology (Teo, 2011), while sexuality and gender minorities have been pathologized, misgendered, and devalued (Bayer, 1987; Ansara and Hegarty, 2012). I became disillusioned during my second year specifically because all of these processes (research design, statistical analysis, and quantitative psychology) were sold somewhat as the "objective" saviors of an otherwise previously "subjective," anti-scientific field. Yet, these processes also formed part of the process of autistic marginalization—these theories and studies have themselves have been based upon empirical findings.

There were hundreds of discussions about the replication crisis, and none about the implicit power of claiming that psychology is value-free, nor the violence that it is inflicted on marginalized groups. A violence I saw and experienced first-hand as an autistic doing autism science. Despite my thesis being an empirical thesis, I spent years reading both broadly and deeply on philosophy of science to reconcile my discomfort with Psychology, and my discomfort of being an autistic person creating autism science. Some colleagues told me that they cannot understand why I am so hung up on this. I am told that I am over-thinking this. But I was determined to reconcile this because Psychology has been a field that has shown an abhorrent lack of respect for people like me. I have felt like a traitor to contribute to the field who not only made me into a category, but who also categorically dehumanized me. Drawing on the idea of Ian Hacking once more: autism is not a natural category—it is a category created in the shadow and context of social and cultural values, and one which only came into the public consciousness because of Psychology and related fields (Hacking, 2006). There is no objectivity in this process—only a position from which we look at certain people. I focused so deeply during my Ph.D. on what constitutes objectivity, because on one hand I have been repeatedly told that I cannot be it, while on the other people using value-laden language have been upheld uncritically as being the paragon of objectivity. I surfaced from this crisis abandoning any claim to objectivity in the opening paragraphs of my thesis in favor of radical transparency (Botha, 2020)—acknowledging what I was doing, why I was doing it, and how I was doing it.

During my last year, I submitted another paper (qualitative) first as a pre-print and then for review. It has a section on the dehumanization of autistic people in research—a section that I highlight with specific examples dating over 60 years. Three things happened. Firstly, I received an irate email from an author declaring me slanderous for characterizing their work as dehumanizing, saying that I should remove the reference to the work if I cannot understand it. Secondly, when peer reviews returned, a reviewer asked that I say "not all autism research is dehumanizing" as if any amount would be okay. Thirdly, the *pre-print* is peer-reviewed post-publication of the paper on a reviewing site—in the pre-print I do not disclose being autistic, but in the final publication I do—the public review states the following:

> *"There is a potential bias due to the lead researcher completing the interviews and having autism themselves. This should be stated in the article."*

At this point, I am no longer an undergraduate, I have been awarded my BA, MSc, and Ph.D., I have three peer-reviewed publications with a fourth and fifth on the way—I am still being told that I do not understand the literature, and that I am biased. At a certain point it becomes easy to see that it was never about my education or engagement with the literature, it is about my autism—we do not trust, nor want autistic people to talk about autism. First-hand accounts go ignored, and when they defy the expectations of the experts the writers are dismissed as potentially *not even* autistic (Frith, 2004). Our narratives are described as unreliable *because* of our autism (Frith and Happe, 1999). If we do not have qualifications in the field we are not qualified to speak to our *own* existence, and yet, even when we are we are biased anyway. Epistemic injustice pervades autism research in a way that only ever marginalizes autistic people in knowledge creation while providing an almost all-encompassing blanket of protection for non-autistic researchers—non-autistic people have an assumed objectivity that means they do not have to defend their involvement in the creation of knowledge.

VALUES, TRANSPARENCY, AND RIGOR

I have come to believe that all research is driven by values, and instead it is not the presence of values which biases research, but instead the transparency of said values. Values

sustain my need for accepting autism, and values sustain the researchers who believe that eradicating autism is a necessity or public good. It is about being honest about which values we are embedding in our work and forgoing hiding behind a guise of objectivity. As such, I aim for rigor. Rigor here, is defined as ethical, robust, and thorough research design which addresses research questions in a transparent and repeatable way. This idea of rigorous applies equally between quantitative and qualitative psychology depending on the aim of each individual study. For quantitative research this can mean having methods that reduce the potential for research-design based bias such as random allocation, double-blinded study design, hypothesis registration, and data-sharing. For required qualitative research, this can involve having methods that ensure accessibility of design such multiple ways of partaking beyond speaking, a robust design and coding procedure which does not favor the narrative of specific participants, and of course transparency. Across qualitative, quantitative, empirical, and theoretical work, it means prioritizing transparency and reflexivity. As such, instead I work to lay claim to rigor over objectivity, because I do not believe that any research has the ability to be objective in the sense of value-free.

"I'M NOT TALKING ABOUT YOU" AND "NOT ALL AUTISM RESEARCH…": ANGER

As an autistic person, when I talk to people about the dehumanization of autistic people in research, researchers are quick enough to exclaim "but I am not talking about you!." Indeed, I have often been the exception to the rule. But autistic people always are—one moment researchers will engage with autistic people, and we will be afforded a temporary personhood, that extends only to the life span of the conversation. We are not taken as evidence of the fallibility of the field, we are, all of us, outliers in the metaphorical sense, and the metaphorical sense alone. I say metaphorical because by the time you have so many exceptions to the rule, statistically, it stops being an outlier. There has been a tradition since the birth of autism to be selective about which autistic receives rights and recognition, with Hans Asperger himself relegating some to death (Czech, 2018), and even now, we *still* eagerly discuss which autistics we can afford (Ganz, 2006; Tantam, 2009)—but it is *never me*. It is always the "other kind" of autistics. Researchers always like to say that they are talking about the *hard* autism, and not me, as if they are privy to all the iterations of my autism from babyhood to adulthood. Everyone is quick to fill in my past based on my present and they usually miss the mark—the very same way that when I was younger and struggled, I was told I was going nowhere. They are two sides of the same coin.

With regards to dehumanization of autistic people in research—I am not the first, nor will I be the last autistic who struggles with how dehumanizing, objectifying, or alienating autism research is (Luterman, 2019; Rose, 2020; Michael, 2021). To be involved in autism research when you are autistic, is to constantly experience the aggression of a field which has yet to come to terms with its own ableism. It is not only to face an ableist academia, but one that fails to acknowledge that there is even a problem. Some academics (both autistic and not) have written about the dehumanizing nature of the autism academy (Gernsbacher, 2007; Cowen, 2009; Milton, 2016) but more widely, there is an astounding lack of awareness that we are speaking or writing about, and constituting people—words, descriptions, and constructions of people will have wider consequences. I was in no way surprised when mid-Ph.D. a study was published showing that autistic people are dehumanized by the general population (Cage et al., 2018).

I *feel* angry and frustrated at these objectifying dehumanizing narratives and have since I was an undergraduate. But I am not meant to say this. I have been told many times to leave my emotions at the door. It is not "professional" to engage emotively with science. My sadness is taken as evidence of bias. I am told to be objective, and separate myself from the descriptions, the violence, and dehumanization. Instead, I have leaned-in—in a radical act of defiance I am transparent, vulnerable, and honest. I refuse to experience this anger alone, or in silence anymore because it functions to uphold the status quo. Reflexivity is meant to unsettle the status quo (Pillow, 2003), and I use my own vulnerability and openness to unsettle it further by refusing to remain quiet, compliant, or passive while my community experiences the willing oppression of violent research. I lean into my emotions because they inform my values, keep me tied to the autistic community, generate my sense of epistemic responsibility to the community I come from. I am open because when autistic students (whether undergraduate or postgraduate) approach me to ask how I handle the experience of feeling and living these accounts, they express a loneliness that silence only serves. I now have a policy of honesty and I tell them: I feel angry.

ENTANGLEMENT

The idea of science being entangled with measurement is not radical—it is a Bohrian understanding of science where we acknowledge that the act of measuring a phenomenon can change it (Barad, 2007). Autism has never been free from the people who created it, or who continue to create it. The people who delineated us from any other constitution, or patterns of behaviors by grouping us together based on our behavior and communication, have a routine history of perpetuating the stereotypes that limit us, degrade us, and form the basis of some degree of our oppression. This includes denying us any epistemic authority to give meaning to what it *means* to be autistic (Frith and Happe, 1999; Frith, 2004) so as to remove access to challenging the constant barrage of deficit and disease framings. Another autistic academic said it best: "autism discourse and I are co-constituted" (de Hooge, 2019). As an autistic I feel the reverberations of the scientific discourse into my personal life—it radiates into social media, informs stereotypes, creates discourses, and ideas of autism that comes to grow amongst our families, friends, colleagues, community, and the strangers we encounter.

As a critical realist (expanded on here Botha, in review), I do not conflate these ideas of autism with what autism *actually* is—autism itself is *not* created by discourse. Rather, these ideas

of autism will have materials consequences for autistic people as they become barriers and challenges. Autistic people feel trapped by the stereotypes society has of autism (Treweek et al., 2018), but a lot of these originate in research and trickle down into the press—including the idea that we lack empathy or theory of mind (Gernsbacher, 2017). We *are* a part of the discourse, in that we are created in people's minds by it, and affected by it in our everyday lives—and yet some are quick to point out that *some* autism research is not for autistic people or their families, but rather *about* autistic people, and for academics (as if mutually exclusive) (Baron-Cohen, 2009a). Regardless of whether autistic read these accounts (and both autistic people and autistic autism researchers can and do), there are consequences that the rest of us will come to experience anyway, as it cascades into the media and our lives. Ableism is entangled with our measurements of autism—we create deficit focused measures, which only could measure deficits and use it to confirm ideas of that autism *is* deficit and from it we create deficits narratives that pervade almost all conversations of autism. Autistic people are inherently entangled with these discourses.

As another openly autistic academic put best: "These shitty narratives persist… because their rhetorical power derives from the figure of the autistic as unknowable, as utterly abject and isolated and tragic, as a figure whose actions are construed less like actions and more like neuronally willed middle fingers" (Yergeau, 2018, p. 3). The idea of autistic people as lacking in intentionality, theory of mind, and empathy has left us as objectified at best, dehumanized at worst, and has yet to make for reliable science too. The theory that autistic people have some sort of impaired theory of mind is and has been constantly plagued by innumerable empirical failings (Gernsbacher and Yergeau, 2019) and yet forms the basis for many early interventions aimed at making us "people," or at least people enough to be classed as having been remediated by medicine. But, poor theory has made for poor evidence, with interventions based on theory of mind showing little efficacy anyway (Fletcher-Watson et al., 2014), while other early intervention research too shows little efficacy (Sandbank et al., 2020), and an astounding rate of conflicts of interest (Bottema-Beutel et al., 2020). But, however inaccurate, flawed, or (increasingly) useless these theories are for explaining autism, it seems we cling to them because we cannot get past an idea of autistic people as blank pages, empty shells, bare slates, who cannot think about themselves, nor other people, who are less capable with empathy, socialization, who are wrapped up in restrictive, repetitive behaviors—this is autism academia's great legacy.

EMERGING

An ethical and reflexive approach to creating and discussing autism science is sorely missing—and the lack of it has changed the course of my experience through my undergraduate, into my masters, and throughout my Ph.D., and now beyond. Like many other autistic academics, I did not have the privilege of *just doing* science. I rote-learned my own dehumanization to get my undergraduate, exposed myself to the most damaging literature to get an MSc, and experienced my own systematic dehumanization in the process of getting my Ph.D. For many years, I struggled to make sense of the seeming fragility of Psychology, the marginalizing constructions of objectivity, and the violence perpetrated by a positivistic Psychology (explored in detail here (Botha, accepted). When I say emerging here, I make use of critical realism, and how phenomena emerge from many layers of reality—from the "real," to the social, and cultural. I have emerged from my Ph.D. to understand something I did not previously—Psychology is not precarious, or a house of cards. Psychology is robust, and in some ways unchanging, because it was *designed* to function in this way. Psychology, especially constructed as a science was designed to objectify, which is why it has been so *thorough* at perpetuating racism, transphobia, ableism, homophobia, and bigotry. It was designed to center non-marginalized peoples' perspectives of the marginalized—and it was designed to leave no room for recourse. This is why non-autistic researchers can so readily engage arguments of objectivity to silence the meaning from autistic autobiographies, and autistic researchers (Frith, 2004; Hacking, 2009)—it maintains the status quo.

Yet, I emerge—a product of autism, discourse, activism, and academia, creating pockets of agency, to resist. Much like those who challenge the status quo to produce critical autism literature (Woods and Waldock, 2020). I follow in the footsteps of openly autistic academics, whose visibility was the only reason I saw this as a viable career—such as Damian Milton, or Steven Kapp. More than ever, I hope to hold the door open for other autistic people to follow in our footsteps, and to reclaim knowledge production. For this to be truly sustainable however, we need to speak openly about the hospitability of the field, and as it stands, it is barely hospitable, if at all. We have emerged, but we carry burdens that non-autistic autism researchers do not face. This needs to be acknowledged for any sort of sustainable contribution of autistic people to be realized—I worry that we throw ourselves in, we burnout, and are disposed.

Those with the most power in the field ought to share this burden by challenging the system that creates autistic dehumanization, by challenging the language, the systemic marginalization, by listening to autistic people in research when they say, "this is not okay," and more than ever, by talking about "objectivity." This requires engaging in a constant dynamic learning process as society, culture, and our ideas of autism change, to ensure that we do not become static markers of this time or place. Even the most progressive ideas we have of autism now might be regarded as regressive in a few years from now, and lest we forget to grow and adapt we will perpetuate a similar violence. As such, we have a responsibility to make our own self-change and learning happen alongside our reflection, and a duty to try to ensure our colleagues do the same (including highlighting when someone perpetuates violence within the field). Challenging the system means challenging the permissibility of perpetuating poor, outdated, or harmful science, including as what is defined as such changes over time. As such, it is our responsibility to learn, grow, and to hold colleagues

accountable for the same, such that in no time or place again, it is okay to dehumanize or victimize autistic people.

While some days I have hope that there is change—from an increased focus on participatory research, to what seems to be an increased presence of autistic people both in and leading autism research, as well as what appears to be change from long-standing autism academics who are slowly abandoning person-first language, the puzzle piece, and dehumanizing (and inaccurate) theories of autism—the days that I feel hope from this are few and far between. This is particularly because as I have become more prominent in my role, and increasingly work with students, research assistants, or receive communications from autistic people all over the world, I notice still, how many autistic people drop away from autism research—and most reference just how harmful they have found the field. When I encounter people in this situation, I always do my best to make clear that the system is broken, and no one should have to withstand it. I reiterate that it is the fields loss (and it always is), and that it takes tremendous strength to know one's own best interests and to walk away from a field to which they have often already dedicated years of their life. I am also honest and tell them that I honestly think about leaving academia completely myself too (often), despite what—from the outside—looks like an otherwise great career trajectory. So, more often than not, I do not feel hope for the field despite this progress because I see all the empty space where incredible autistic researchers have left, and I feel impatient for change to come more quickly because I am so desperate for these gaps to happen less often.

REFLEXIVITY

This article is the product of multiple years of ongoing ruminating reflexivity. Elsewhere I discuss the sheer importance of reflexive practice *theoretically* for theoretical and empirical (whether quantitative or qualitative) work (Botha, accepted), especially as a way of instigating change. Instead, here I make a call to action—all researchers, please, engage with your own values, interrogate them, unpick them, doubt yourself, acknowledge your fallibility, acknowledge your mistakes, apologize, and engage with autism reflexively. There is no greater responsibility than constituting people—and we as psychologists do this (Hacking, 2006).

There have been times in which I have been compelled to do things in a certain way because that is how the field or Psychology "works." There have been movements where my insider knowledge of the autistic community has come second to the methodolatry of Psychology—the retainment of an idea of method validity has been prioritized over the effect of such methods on my community. I have been urged to only include diagnosed autistic people to make it "more valid" easier to publish (despite the widely acknowledged racial, economic, class, and gender disparities in diagnosis) (Mandell et al., 2009; Shefcyk, 2015; Newschaffer, 2017). I have been pushed toward deficit-based definitions, concepts, and language—and have a lot of regret for when I did not push back. I have made my own mistakes—including using functioning labels in my very first article (Botha and Frost, 2020) because it was "the 'done' thing." My responsibility after this was to learn, push back harder the next time, and apologize unreservedly for the damage such language has the potential to cause—and as such, I am so completely sorry. My entire thesis did not meet the standards I have now for research despite the elements of agency I tried to embed throughout; to say this is not to devalue my work, but rather, it is to acknowledge learning and growth. If I could do my Ph.D. over, I would make it a participatory project, and embedded autistic voices beyond my own more throughout all of the work. I worked with the tools that I had at the time, but it does not excuse where I went wrong.

In the end, my thesis (Botha, 2020) showed that autistic community connectedness buffered against some of the effects of minority stress and was related to better mental health over time. Yet, I worry constantly that by trying to measure a function of autistic community connectedness, that I objectified it, in a way not dissimilar to the way people objectify autistic people—especially if others come to conflate the *function* of autistic community connectedness with its *value*. I studied autistic community connectedness, because I was worried that to only study minority stress would be to see only the worst of what happened to autistic people, and not appreciate our lives as a whole—which are much bigger than our trauma. But, to me, the numbers only explain a mechanism—the real joy, the real value, and the beauty of the autistic community was captured in my very first study. Autistic people talked about the autistic community with such a warmth, brightness, and with hope. The vibrant stories of belongingness, friendships, and political strength tell you exactly what you need to know about the value of such a community. This is something, that its function cannot, and should not even tell you.

CONCLUSION

In my title, I ask "academic, activist, or advocate?"—and my answer is that I am all three. You cannot belong to a community that suffers from violence, marginalization, and suicide and not be. In my introduction I tell readers all the different types of autistic people I have been in the eyes of the clinicians and professionals who deemed my future limited or limitless because whenever an autistic person tells you anything about what it *means* to be autistic that is not just a list of impairments or limitations, we are told that we must have the "easy" autism. I laid this out so transparently to challenge the idea that just because we (autistic people) have fought to be included in autism research does not mean that you can picture where we have been (including how we experienced our own autism growing up). To conclude: I will not leave my values at the door of the academy—I refuse. I refuse to abandon my community and to engage in the complicit silence. Instead, I offer up transparency, openness, a constantly reflection, and learning. Instead, I make space for growth, action, and strive toward a social change for autistic people. It seems there is nothing more radical than that.

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BRIEF RESEARCH REPORT
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Exploring the Career Motivations, Strengths, and Challenges of Autistic and Non-autistic University Students: Insights From a Participatory Study

*Chinnu Cheriyan[1], Sergey Shevchuk-Hill[1], Ariana Riccio[2], Jonathan Vincent[3], Steven K. Kapp[4], Eilidh Cage[5], Patrick Dwyer[6], Bella Kofner[1], Helen Attwood[3] and Kristen Gillespie-Lynch[1,2]**

[1] College of Staten Island, The City University of New York, Staten Island, NY, United States, [2] The Graduate Center, The City University of New York, New York, NY, United States, [3] School of Education, Language and Psychology, York St John University, York, United Kingdom, [4] Department of Psychology, University of Portsmouth, Portsmouth, United Kingdom, [5] Department of Psychology, University of Stirling, Stirling, United Kingdom, [6] Center for Mind and Brain, University of California, Davis, Sacramento, CA, United States

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Edited by:
Felicity Sedgewick,
University of Bristol, United Kingdom

Reviewed by:
Maria Ashworth,
Centre for Research in Autism and Education, UCL Institute of Education, United Kingdom
Kilee DeBrabander,
The University of Texas at Dallas, United States

***Correspondence:**
Kristen Gillespie-Lynch
kgillyn@gmail.com

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Supports for the growing number of autistic university students often focus on helping them succeed in university. However, even educated autistic people experience discrimination and other challenges which can make it very difficult for them to obtain meaningful jobs. Little remains known about how universities can better support their autistic students and alumni in overcoming barriers to meaningful employment. In this participatory study, a team of autistic and non-autistic researchers asked autistic (n = 92) and non-autistic (n = 774) university students about their career aspirations, strengths they believe will help them succeed in their "dream jobs," and obstacles they expect to encounter. Autistic participants' top goal in attending college was to improve their career prospects. However, relatively few autistic students reported learning career-specific skills at university. Autistic students were more likely to seek an academic job and less likely to seek a career in healthcare than non-autistic students. Autistic students highlighted writing skills and detail orientation as strengths that could help them succeed in their dream jobs more often than non-autistic students. However, they were also more likely to expect discrimination, social, and psychological difficulties to stand in the way of their dream jobs. These findings suggest that universities should prioritize experiential learning opportunities to help autistic (and non-autistic) students develop employment-related skills while providing mental health supports. Universities should demonstrate their commitment to supporting diverse learners by seeking out and hiring autistic professionals and by teaching their own staff and employers how to appreciate and support autistic colleagues.

Keywords: autistic, university, employment, participatory, discrimination, writing, strengths, stigma

INTRODUCTION

Higher education increases the likelihood that autistic people will obtain a job and be paid well for their work (Migliore et al., 2012; Ohl et al., 2017; Rast et al., 2020). Nevertheless, autistic people who successfully graduate from university remain less likely to be employed than university graduates with other disabilities (Association of Graduate Careers Advisory Services, 2019).

A growing body of research examines strategies to help autistic students succeed in university (Kuder and Accardo, 2018). However, little remains known about how university staff can help autistic students and alumni obtain the jobs they deserve. A recent survey revealed that autistic people, their family members, employers, clinicians and researchers in the United States, Sweden, and Australia all agreed that a strong match between autistic peoples' interests and job demands motivates autistic people to succeed in the workplace (Black et al., 2020). In order to help autistic students and alumni obtain jobs that are well matched to their interests, universities need to obtain more information about what autistic students' employment interests are. To begin to address this gap, a participatory team of autistic and non-autistic researchers developed the current study to examine the career aspirations of autistic and non-autistic university students, strengths they believe will help them succeed in their "dream jobs," and obstacles they expect to encounter.

Why Do Autistic People Struggle to Get and Keep Jobs?

In stark contrast to the United Nations Convention on the Rights of Persons with Disabilities, which positions equal access to employment as a human right, autistic people around the world are chronically underemployed, even relative to people with other disabilities (Shattuck et al., 2012; Burgess and Cimera, 2014; Fasciglione, 2015; Farley et al., 2018; Scott et al., 2019). Meaningful employment can provide independence, social connections, and a sense of purpose and self-respect (Blustein, 2008; Hedley et al., 2017; Anderson et al., 2021). Barriers to employment, which are heightened among autistic people who come from lower-income families and/or are minorities (Eilenberg et al., 2019), have remained persistent over time (Burgess and Cimera, 2014). Among autistic people who do eventually obtain employment, many work at entry-level jobs that are not on par with their education and skills, receiving lower rates of pay than their non-autistic colleagues (Howlin et al., 2004; Roux et al., 2013; Baldwin et al., 2014; Coleman and Adams, 2018). In addition to pronounced difficulties *obtaining* employment, autistic people face challenges *maintaining* employment (Taylor et al., 2015; Chan et al., 2018). Although promising employment initiatives continue to emerge (e.g., Remington and Pellicano, 2019), they have primarily remained limited to specific employment sectors (e.g., IT and finance) and do not begin to address the full diversity of autistic people's interests and skills (Lorenz and Heinitz, 2014; Bernick, 2021).

Despite often notable strengths (which may or may not include academic skills, attention to detail, high levels of empathy and moral clarity, creativity, focus, passion, honesty, loyalty, and logic), autistic people often face pronounced challenges obtaining and maintaining employment (Sperry and Mesibov, 2005; Lorenz and Heinitz, 2014; Dreaver et al., 2020; Stenning, 2020; Vincent and Fabri, 2020; Buckley et al., 2021; Fernandes et al., 2021). Social, executive functioning, sensory processing, and mental health differences; discrimination; insufficient autism understanding and needed supports; and poor work conditions contribute to the deeply problematic gap between the employment potential of autistic people and the reality of the employment outcomes they often obtain (Lorenz et al., 2016; Sarrett, 2017; Coleman and Adams, 2018; Farley et al., 2018; Black et al., 2020; Anderson et al., 2021; Bury et al., 2021; Buckley et al., 2021; Jones et al., 2021).

Milton (2012) proposed that non-autistic individuals struggle with taking the perspectives of autistic individuals and vice-versa. Thus, autistic individuals may struggle with adapting to "neurotypical" workplace social norms because the norms were not created with them in mind (Coleman and Adams, 2018). Indeed, when social difficulties arise for autistic employees, employers may often attribute these difficulties to characteristics of the autistic people themselves rather than seeking to improve the workplace (Bury et al., 2021). Autistic employees may also be more likely to attribute social challenges to their own internal characteristics rather than systemic issues. This tendency to attribute challenges to autistic individuals is at odds with increasing recognition that environmental factors play a key role in determining workplace outcomes (Harmuth et al., 2018; Black et al., 2019; Scott et al., 2019; Dreaver et al., 2020). Environmental barriers to succeeding at work, including insufficient support, unexpected changes, and sensory distractions have been associated with mental health issues, including burnout, among autistic educators (Wood and Happé, 2021).

Employment supports for autistic people often take a medical model orientation, focusing on ameliorating "deficits" within autistic individuals, rather than a neurodiversity-aligned approach which recognizes strengths associated with autism, views challenges as arising from dynamic interactions between people and their environments, and aims to systematically address environmental barriers (Singer, 2016; Scott et al., 2019). Yet workplace accessibility and autism understanding, social support, belief in one's strengths, and the aforementioned strong match between autistic peoples' strengths and interests and their job responsibilities have been identified by both autistic people and employers as crucial to employment success (Pfeiffer et al., 2017; Black et al., 2020; Dreaver et al., 2020; Wong et al., 2020; Pesonen et al., 2021).

However, little remains known about how strengths and interests influence the career choices of autistic university students. One of the few studies to examine the employment experiences of autistic university students used interviews with autistic students (n = 10) and alumni (n = 11) and focus groups with varied stakeholders (n = 58), finding that autistic students and alumni often faced extreme challenges obtaining stable jobs (Vincent and Fabri, 2020). Participants described inaccessible hiring practices (e.g., opaque job advertisements, anxiety-provoking interviews wherein autistic students struggled to adapt to "neurotypical" norms, and concerns that disclosing a diagnosis would lead to discrimination). Although university career services were often described as helpful, others described career services as underfunded and under-informed about autism. Pesonen et al. (2020) also documented a desire for more accessible, individualized, and hands-on university career

support among 30 autistic university students in four European countries.

Research Aims and Hypotheses

To help universities better support autistic students in achieving their career goals, we compared autistic and non-autistic students' hopes and concerns about employment. We expected autistic students to more often cite a desire to help others and passion for their interests as reasons for seeking a career than non-autistic students. The first and second author developed these hypotheses based on prior research and their own experiences engaging with autistic mentees and mentors within a participatory mentorship program they were mentors within. Prior research suggests that autistic people may feel intensely for others, particularly those who are vulnerable, and may help others more than non-autistic people do (Smith, 2009; Paulus and Rosal-Grifoll, 2017; Stenning, 2020). Passion for one's interests is also commonly reported as an autism-related strength (e.g., Lorenz and Heinitz, 2014).

We expected autistic students to more often describe detail orientation and writing skills as assets that could help them get their dream jobs than non-autistic students. Many autistic people are able to recognize details that may remain hidden to "neurotypical" individuals (e.g., Dakin and Frith, 2005; Lorenz and Heinitz, 2014). Autistic university students also exhibited enhanced writing skills relative to their non-autistic peers at one university (Gillespie-Lynch et al., 2020). Similar patterns have been observed in more generalizable samples: incoming autistic university students in the Netherlands outperformed their peers on the Dutch Language Proficiency Test (Bakker et al., 2019), as did autistic students in the United States on the verbal SAT (Fernandes et al., 2021).

We expected autistic students to describe discrimination as a hurdle more often than non-autistic students given that autistic people typically identify stigma as the most consequential barrier to employment (Black et al., 2020). We also expected autistic students to describe focus and social skills as potential challenges more often than non-autistic students (Lorenz and Heinitz, 2014; Scott et al., 2019).

METHODS

Community Involvement

The research described in this report was conducted by a participatory group of autistic and non-autistic researchers, including the authors of this paper and a larger group that collaborated more distally. Collaborators included leaders within a participatory mentorship program for autistic and non-autistic university students, Project REACH, and members of the College Autism Network (CAN), an online community of individuals dedicated to advocacy and research related to autistic university students. Contributors to this paper include four autistic co-authors (one academic, one doctoral student, one then-undergraduate and current graduate student, and one undergraduate) and six non-autistic group members (two undergraduates with other diagnoses; one then-doctoral student, who led study development as part of her dissertation research; and three academics).

Autistic and non-autistic co-authors collaboratively developed and revised study measures and hypotheses by co-writing a shared google document. Research questions and hypotheses were collaboratively developed at the top of the google doc, to promote transparency about research goals and member contributions. Transparency is central to the guidelines that AASPIRE, the first participatory autism research group (Jivraj et al., 2014), provided to help researchers practice sound participatory autism research (Nicolaidis et al., 2019).

Survey questions were developed based on collaborators' experiences and knowledge of the literature. Questions were iteratively revised until collaborators were satisfied with their scope and clarity. We began developing measures in April of 2018 and continued revising until recruitment began in February of 2019. Most revisions occurred asynchronously, via edits and/or comments in the study google doc. However, a core group of collaborators, leaders in the aforementioned mentorship program, discussed and polished research questions, hypotheses, and measures during synchronous meetings which occurred in-person or virtually (depending on location and/or preference) via Skype using speech or text chat as preferred. These meetings were held approximately once every 6 weeks. Guided by AASPIRE's guidelines (Nicolaidis et al., 2019), we strove to use flexible communication modalities, to provide sufficient processing time, to develop strategies for power sharing, and to disseminate findings collaboratively. The survey itself was posted on the Open Science Framework before recruitment began. However, the hypotheses described in this report were developed by the first two authors before they gained access to the data.

Survey Development and Recruitment

Data were collected via online surveys hosted on Qualtrics from February to October 2019. Autistic and non-autistic participants were generally recruited via different mechanisms. Autistic participants were primarily recruited via snowball sampling using collaborators' networks (e.g., CAN, social media, and university contacts). Given that convenience samples are always biased toward people who are informed about and decide to participate in a study, we share the exact recruitment invitation here, "Are you a current university student? Are you autistic? Help us learn more about autism and your experiences with higher education!" Interested autistic participants contacted the third author via an institutional email address (to confirm student status) and received a link to participate. They received a $20 Amazon gift card.

Members of the primarily non-autistic comparison sample were invited to participate in a study entitled "community conceptions of diversity" through psychology subject pools at two universities in the United States: one in the Midwest with highly selective admissions criteria and one in the Northeast which is not selective. They received no other information about the study, besides its title, when deciding if they wished to participate. Eight participants recruited via this mechanism identified as autistic. Participants recruited from subject pools completed the questions that are the focus of this report at the beginning of a survey before

TABLE 1 | Demographics.

	Autistic *n* = 92(%)	Non-autistic *n* = 774(%)
Age		
18–24	75.0	92.2
25–34	17.4	2.8
35–44	4.3	0.3
45+	3.3	0.5
Gender		
Male	53.3	35.0
Female	34.8	61.9
Non-binary	11.9	0.6
Race/Ethnicity		
White	77.2	41.5
Black/African	6.5	19.6
Asian	10.9	18.3
Latinx	7.6	25.5
Middle Eastern	–	5.9
Indigenous/Pacific Islander	6.5	2.5
Other	12	0.8
Area of study		
STEM	48.9	53.4
Social Science	21.7	19.8
Medical	3.3	11.4
Humanities	27.2	4.7
Education	5.4	6.2
Business	3.3	8.3
Undecided/Liberal Arts	7.6	4.9

participating in an autism training. They received academic credit for participating.

Participants

All participants completed an IRB-approved consent form prior to beginning the study (see **Table 1** for participant characteristics). Autistic university students (n = 92; 53.3% male) representing eight countries (n = 68 from the United States, n = 15 from the United Kingdom) and about 50 institutions and non-autistic students from two institutions (n = 774; 35.0% male) participated in this study. Although most of the autistic participants (n = 84) were recruited to our CAN survey, eight autistic participants were recruited to the conceptions of diversity survey via the aforementioned subject pools.

Students recruited through the CAN survey provided information about their diagnosis and completed the Ritvo Autism and Asperger Diagnostic Scale (RAADS-14) (Eriksson et al., 2013), a self-report screener for autism in adulthood (α = 0.84). We included this measure to determine what proportion of our autistic sample would be classified as likely to be autistic using a commonly used autism screener. This brief measure provides both a dimensional and a categorical rating of autism likelihood, has relatively strong psychometric properties, and includes a focus on sensory differences, which is often lacking in autistic trait measures (Baghdadli et al., 2017).

Although some members of the autism community view autism screening and trait measures as overly deficit-oriented, only 3 of the participants in the current study critiqued the RAADS-14 when asked if they like to give feedback throughout the survey. Two participants indicated that the response scale was not precise enough. For example, one participant wrote, "For the questions on Autistic behaviors that consisted of a statement to which I had to specify whether it was true, true only now, true when I was younger, or never true, I found these somewhat difficult to answer. They are essentially a binary true/false question with a temporal component, so I cannot answer to what extent I agree with the statement. Some statements were very true when I was younger but are only mildly true currently." One participant specifically critiqued the focus on challenges, "Please phrase questions more autism-positive."

For the 84 students who were recruited through the CAN survey, autism identification was confirmed using self-report of an autism diagnosis by a clinician (n = 81) or self-report of autism identification without a formal diagnosis (n = 3). Participants reported mean RAADS-14 scores of 27.7 (SD = 9.15). Seventy-eight participants reported RAADS-14 scores at or above the suggested cut-off for probable autism of 14; the six who did not meet the cut-off all reported having a formal autism diagnosis.

Students recruited through the subject pool indicated the relationships they had experienced to autism (including being autistic themselves). A total of 782 subject pool students (n = 624 from the school in the Northeast; n = 8 self-identified as autistic) provided demographic information and completed the open-ended questions about employment goals that are the focus of this report.

Autistic participants were more likely to identify as only white (62.0%), male (53.3%), graduate students (20.7%), and humanities majors (27.2%) than non-autistic students (31.9% only white; 35.0% male, 5.7% graduate students, and 4.7% humanities majors; ps < 0.001; see **Table 1**).

Survey Questions

In addition to demographic questions, autistic and non-autistic participants were asked the following open-ended questions (developed through the collaborative process described above):

(1) What is your course of study/major? If you are undecided, please let us know what majors/fields of study you are considering.
(2) What type of job do you hope to get after you graduate?
(3) Why is this job of interest to you?
(4) What skills do you have that could help you succeed in your dream job?
(5) What challenges might you face getting or keeping your dream job?

Only autistic participants recruited through the snowball sampling were asked the following open-ended and closed-ended questions:

(1) What goals do you hope university will help you achieve?
(2) Has your experience in university helped you develop work-related skills? (options: yes or no)
(3) What work-related skills have you developed so far in university?

(4) What is the job you held for the longest time?
(5) Did you receive specialized supports due to autism at your job (options yes/no)?
(6) When do you tell potential or current employers about your autism? (option to select any combination of: on your resume/CV, on your job application, during the interview, soon after being hired, if an issue arises, when I get close to people at work, I only partially disclose, I don't tell people at work anything about autism, other).

Participants were given opportunities to provide feedback on survey questions, "Is there anything you would like to say about the questions so far? Let us know if some questions were unclear or if there were things we should have asked about but didn't. Your feedback will help us improve." Students generally provided positive feedback about the employment-related questions, e.g., "Everything has been clear so far, I have had no problems."

Qualitative Coding and Data Analysis

Responses to open-ended questions were coded using content analysis by pairs of coders who developed codes based on patterns in the data (and hypotheses) and obtained reliability of 80% or higher on all codes. We elected to use content analysis because we wished to compare the frequency at which different strengths, barriers, and motivations emerged from responses. Content analysis, a method of coding raw messages (e.g., text or images) into a classification scheme, first emerged in the 18th century and is increasingly used (Kondracki et al., 2002; Hsieh and Shannon, 2005). It is a broad approach to deriving meaning about a phenomenon that varies along two primary spectrums: manifest (or apparent on the surface) to latent (deeper implied meanings) themes and inductive (data driven) to deductive (theory driven). The coding used in this study focused on manifest meanings. Most codes were developed inductively through an independent review of the data by the first two co-authors. However, codes used to address hypotheses and/or to align coding with existing classification systems were primarily deductive.

The two first authors coded majors into: STEM, humanities, education, business, liberal arts/undecided, and other. They coded dream jobs using O*NET's categories (National Center for O*NET Development, 2021), adding codes for helping professions[1], faculty/academia, and entrepreneurs. For responses about why the job is of interest, they coded motivation as intrinsic (with subcodes helping others, passion, and knowledge) or extrinsic (with subcodes financial security and fame, the latter only occurred once in each sample so is not considered further). For skills that could help students succeed in their dream job, they coded knowledge, motivation, intelligence, detail orientation, executive functioning (with subcodes focus and reliability), patience, social communication (with subcodes social skills, empathy, and writing), and work ethic. For challenges obtaining or maintaining one's dream job, they coded discrimination, motivation, psychological difficulties, competition, executive functioning (with subcodes focus and organization), social communication (with subcodes social skills, empathy, and writing), financial problems, academic issues, and work ethic (see Appendix A for full coding schemes).

A different pair of student co-authors (both autistic) developed coding schemes for the first two open-ended questions asked of only autistic students and obtained reliability. They coded the goals participants hoped college will help them achieve into the following major categories: academic progression, career prospects, personal development, interpersonal, community-oriented reasons, and financial reasons. They coded the skills participants felt they had developed so far at university into these major categories: career skills, academic skills, personal development, and interpersonal (see Appendix A).

We conducted chi-square tests of independence to compare autistic and non-autistic participants' career goals, motivations, and anticipated career-related strengths and challenges. Following Benjamin and Berger's (2019) recommendation, we use an alpha level of 0.005 and consider p values between 0.005 and 0.05 suggestive. To examine if significant group differences were attributable to other differences between the samples besides autism, we conducted follow-up binary logistic regressions with the following characteristics that differed across samples included as predictors: being male, white, a graduate student, and/or majoring in humanities[2].

RESULTS

What Employment Skills Have Autistic Participants Learned at University?

Most autistic participants recruited through the snowball sampling (62%) had already been employed, mostly in entry-level jobs. Autistic participants' top goals in attending university were to improve their career prospects, followed by academic progression, interpersonal and personal development (see Appendix B for code frequencies and illustrative quotes). When asked if they had learned employment-related skills at college, most autistic participants (76%) said they had. When asked what employment-related skills they had learned so far at university, autistic students most often highlighted personal development, followed by academic skills, interpersonal skills and lastly career-specific skills (see Appendix C for code frequencies and illustrative quotes). Career-specific skills were defined as participants specifically indicating employment-related activities and experiences in their responses.

Students expressed diverse perspectives about disclosing their autism at work: 2% indicated that they did or would disclose on their CV, 5% during the interview, 2% soon after being hired, 4% if an issue arises, 5% when they get close to people at work, 4% only partially disclose, 20% indicated that they don't tell anyone at work anything about

[1]The first two authors defined helping professions based on their own understanding of how central helping others is to different jobs. Obviously, this classification is a bit of an overgeneralization, as any career can be focused on helping others depending on the priorities of the person in said career.

[2]We did not include age in these analyses because the question about age was phrased differently in the two samples. However, including a binary age variable (emerging adult or not) in all binary logistic regressions, did not change the pattern of findings.

TABLE 2 | Career goals of autistic and non-autistic students.

Code	Autistic	Non-autistic	*p* value
Helping Profession	**39%**	**60.7%**	**<0.001**
Academic Job	**11%**	**0.3%**	**<0.001**
Entrepreneur	0%	3.2%	0.10
Management	2%	1%	1.00
Business/Finance	*0%*	*4%*	*0.026*
Computer/Math	11%	1%	0.026
Architecture/Engineering	2%	4%	0.57
Science	*17%*	*1%*	*0.015*
Social Service	2%	1%	0.42
Education/Library	*17%*	*3%*	*0.02*
Arts/Media/Sports	*10%*	*4%*	*0.006*
Healthcare	**9%**	**41%**	**<0.001**
Protective	0%	3%	0.15
Don't know	10%	5%	0.10

Motivations underlying career goals of autistic and non-autistic students.

Code	Autistic	Non-autistic	*p* value
Intrinsic Interests	85%	83%	0.77
SC: Help Others	*28%*	*41%*	*0.02*
SC: Passion	38%	33%	0.42
SC: Knowledge	*10%*	*4%*	*0.03*
Extrinsic	9%	11%	0.60
SC: Financial Security	4%	8%	0.30

Italics highlight evidence suggestive of a group difference. Bolded indicates group difference.

autism, and 13% selected other, typically adding that the decision is context-dependent. The rest of the participants (45%) selected multiple options, often indicating that the decision is highly context-dependent. For example, one student wrote, "For my current job, I disclosed much earlier because my autistic identity is integral to my work as a student program coordinator and researcher." However, working in an autism field does not always lead to disclosure. Another student wrote, "Because I worked with autistic individuals I did not feel comfortable disclosing because I didn't want to be treated differently."

What Jobs Do Students Want?

Autistic students were more likely to seek an academic job than non-autistic students ($p < 0.001$; see **Table 2**). They were less likely to seek a helping career and specifically a career in healthcare (ps < 0.001). A binary logistic regression showed that pursuing academia was predicted by being autistic and a graduate student (suggestive; see **Table 3**). Males and humanities majors (suggestive) were less interested in helping careers, although being autistic also contributed suggestively (**Table 3**). Interest in a career in healthcare in particular was predicted by being non-autistic, female and not a graduate student (**Table 3**).[3]

[3]These predictors of seeking a career in healthcare remained significant when the stated desire to help others through one's work (OR = 4.08; $p < 0.001$) was included as a predictor.

Why Are Students Seeking Specific Jobs?

Autistic and non-autistic university students expressed similar reasons for pursuing their dream jobs. Contrary to our hypothesis that autistic students would be more motivated by their interests to pursue their dream jobs, the vast majority of both autistic and non-autistic students were driven by intrinsic interests (**Table 2**). Contrary to our hypothesis that autistic students would more often cite a desire to help others as a reason for seeking a career than non-autistic students, evidence suggested that autistic students were slightly *less* likely to highlight a desire to help others as a career motivation ($p = 0.02$). Although this finding did not meet our criteria for significance, we conducted a follow-up binary logistic regression as it was in the opposite direction of our expectation. This difference was attributable to males being less interested in helping others (OR = 0.33, 95% CI [0.24, 0.45]; $p < 0.001$) rather than autism, race, graduate status, or major (ps > 0.19).

What Skills Do Students Think Will Help Them Succeed in Their Dream Jobs?

Autistic students were more likely to highlight writing skills ($p < 0.001$) and detail orientation ($p = 0.003$) as skills that would help them get their dream job than non-autistic students (**Table 4**; see Appendix D for illustrative quotes). A binary logistic regression with the aforementioned predictors (ps > 0.13) showed that only being autistic was associated with heightened

TABLE 3 | Binary logistic regression predicting seeking an academic career.

Nagelkerke's R^2 (0.39)	OR [95% CI]
Autistic	53.08 [9.91, 284.40]*
Male	0.89 [0.24, 3.23]
White	0.26 [0.06, 1.02]
Graduate student	6.26 [1.65, 23.73]ˆ
Humanities major	0.65 [0.11, 3.68]
Binary logistic regression predicting seeking a helping career.	
Nagelkerke's R^2 (0.18)	**OR [95% CI]**
Autistic	0.54 [0.32, 0.90]ˆ
Male	0.23 [0.17, 0.31]*
White	0.95 [0.69, 1.30]
Graduate student	0.76 [0.43, 1.33]
Humanities major	0.45 [0.25, 0.81]ˆ
Binary logistic regression predicting seeking a career in healthcare.	
Nagelkerke's R^2 (0.15)	**OR [95% CI]**
Autistic	0.15 [0.06, 0.36]*
Male	0.40 [0.29, 0.56]*
White	0.79 [0.58, 1.09]
Graduate student	0.36 [0.17, 0.74]*
Humanities major	0.50 [0.25, 1.03]

*$p < = 0.005$.
ˆ$0.005 < p < 0.05$.

detail orientation (OR = 6.62, 95% CI [2.17, 20.19], $p = 0.001$; Nagelkerke's $R^2 = 0.08$). Similarly, writing skills were predicted by being autistic (OR = 23.55, 95% CI [7.27, 76.33], $p = 0.001$) or a humanities major (suggestive; OR = 3.19, 95% CI [1.10, 9.30], $p = 0.033$; Nagelkerke's $R^2 = 0.31$) but no other predictors (ps > 0.46).

Non-autistic students were more likely to describe patience ($p = 0.003$) as a job strength than autistic students. A binary logistic regression showed that this difference was attributable to males (OR = 0.28, 95% CI [0.15, 0.51], $p < 0.001$; Nagelkerke's $R^2 = 0.08$) being less likely to report patience rather than autism ($p = 0.052$). No group differences were observed in the degree to which motivation, executive functioning, or intelligence were noted as career-skills ($ps > 0.20$).

What Challenges Do Students Expect to Encounter Seeking and Keeping Dream Jobs?

When asked what challenges they expect to face obtaining or maintaining their dream job, autistic students were more likely to highlight discrimination ($p < 0.001$) and social challenges ($p < 0.001$) with evidence suggestive of associations between autism and psychological difficulties ($p = 0.008$) and executive functioning ($p = 0.015$; see **Table 4** and Appendix E for illustrative quotes). Follow-up binary logistic regressions revealed that expecting discrimination (OR = 24.57, 95% CI [8.78, 66.78], $p < 0.001$; Nagelkerke's $R^2 = 0.26$) and social difficulties (OR = 5.90, 95% CI [3.19, 10.91], $p < 0.001$; Nagelkerke's $R^2 = 0.10$) were only predicted by being autistic. Psychological difficulties were predicted by being autistic (OR = 2.98, 95% CI [1.47, 6.06], $p < 0.001$) and not a male (OR = 0.35, 95% CI [0.19, 0.64], $p < 0.001$; Nagelkerke's $R^2 = 0.06$).

Non-autistic students were more likely to report academic challenges as barriers to their dream job than autistic students ($p < 0.001$). Academic difficulties were predicted by being not autistic (OR = 0.12, 95% CI [0.05, 0.32], $p < 0.001$) or a humanities major (suggestive; OR = 0.38, 95% CI [0.17, 0.88], $p = 0.023$; Nagelkerke's $R^2 = 0.08$). Autistic students were slightly more likely to note executive functioning, but not specifically focus, as a challenge ($p = 0.015$; suggestive). No differences in motivation, competition, work ethic, or financial barriers were noted ($ps > 0.25$).[4]

DISCUSSION

Autistic students' primary goal in entering university was to advance in their careers. Although most reported that university helped them develop employment-related skills, most of the career-related skills they described developing were general skills, like self-understanding and academic development, rather than hands-on opportunities to practice applying for and/or succeeding in the workplace. Skills that specifically targeted a career were *least* likely to be highlighted among the work-related skills autistic students felt they developed at university. To align curriculum with autistic students' goals in seeking higher education, universities should provide more targeted support for career-related skill development for autistic students, such as internships and other forms of experiential learning. Such support should be open to students who are and are not autistic, given that many autistic students are not comfortable disclosing that they are autistic and autism is underdiagnosed among people who are not white males (Happé and Frith, 2020).

Difficulties applying one's education to obtain a job one is happy with are far from specific to autistic students. Concerns about the degree to which universities are preparing students more generally to succeed in the workforce have led to calls for more sandwich courses and internships (and greater integration of internships with academic requirements), focused technical education delivered by industry professionals (e.g., data analysis), and more opportunities for students to try out professional tools and roles in the classroom (e.g., UC Berkeley's innovative student led courses, DeCal; Cleary and Van Noy, 2014; Brooks and Youngson, 2016; Frazee and Level, 2018). Although a misalignment between students' educational preparation and the demands of the workforce is a broader concern, autistic people face much more pronounced barriers obtaining meaningful work than other students. Indeed, autistic participants were much more likely to expect discrimination to stand in the way of their dream jobs than other students. Unfortunately, this expectation is not inaccurate; discrimination has emerged as a consistent barrier to autistic employment across varied studies (e.g., Scott et al., 2019; Black et al., 2020). A key factor that is known to help other marginalized groups overcome misconceptions about their

[4]All group differences, except those pertaining to detail orientation, patience, and psychological difficulties, remained apparent when comparisons focused only on non-autistic students from the more selective school.

TABLE 4 | Challenges and strengths autistic and non-autistic students expect in securing their career.

	Challenges			Strengths		
Code	**Autistic**	**Non-autistic**	***p* value**	**Autistic**	**Non-autistic**	***p* value**
Discrimination	**15%**	**1%**	**<0.001**	**–**	**–**	**–**
Academic Issues	**7%**	**34%**	**<0.001**			
Psychological Difficulties	*16%*	*7%*	*0.008*	–	–	–
Competition	13%	17%	0.38			
Financial Problems	7%	7%	1.00			
Motivation	3%	7%	0.26	14%	16%	0.76
Work Ethic	1%	1%	0.72	*4%*	*11%*	*0.046*
Social Communication	**28%**	**7%**	**<0.001**	33%	42%	0.09
SC: Social Skills	**25%**	**6%**	**<0.001**	*16%*	*26%*	*0.06*
SC: Empathy	1%	0.1%	0.21	7%	13%	0.07
SC: Writing	0%	0.1%	1.00	**16%**	**1%**	**<0.001**
Executive Functioning	*9%*	*3%*	*0.015*	12%	9%	0.46
SC: Focus	1%	1%	0.43	3%	2%	0.48
SC: Organization	*7%*	*2%*	*0.02*			
SC: Reliability				7%	7%	0.41
Knowledge	–	–	–	*28%*	*28%*	*0.45*
Intelligence	–	–	–	19%	13%	0.20
Detail Orientation				*8%*	*2%*	*0.003*
Patience				*2%*	*11%*	*0.003*
Don't know	7%	5%	0.63	3%	2%	0.24

Italics highlight evidence suggestive of a group difference.
Bolded indicates group difference.

ability to succeed in a field (e.g., women in STEM) is access to educators and other role models like them in the fields they hope to enter (Cheryan and Plaut, 2010). Therefore, one important way that universities can encourage autistic students to keep striving toward their dream jobs is to hire autistic educators and staff. However, universities rarely prioritize attracting and supporting neurologically diverse staff (Brown and Leigh, 2018; Jones, 2021). Insufficient efforts to recruit and support autistic university staff is particularly problematic given that many autistic people may be drawn to academic careers, as was evident in our study. A central recommendation derived from this work is that universities should act as examples of inclusive hiring practices for the broader community, rather than recapitulating existing inequalities.

Autistic (and other) students need opportunities to connect with diverse industries through their universities. Students more generally often call for more contact with industry professionals, including alumni who can share their own experiences in the workforce (Donald et al., 2018). Attempts to create job opportunities for autistic students must be much broader than their current focus primarily on the tech sector. Participants in our study expressed a wide variety of career interests. Unexpectedly, autistic students were less likely to seek careers in helping fields, particularly healthcare, than non-autistic students. Only 11% sought careers in IT fields, clearly supporting the need for greater diversification of autism employment initiatives.

Contrary to our hypothesis (and inconsistent with the stereotype that autism is defined by "fixated interests"), both autistic *and* non-autistic students were similarly highly guided toward their dream jobs by intrinsic interests. Evidence also unexpectedly suggested that autistic students were slightly *less* likely to be drawn to their dream jobs by a desire to help others than non-autistic students. A follow-up analysis revealed that this difference was attributable to men being less motivated to help others through their work than women. This gender difference has been documented previously (e.g., Morgan et al., 2001).

Extending findings from larger-scale studies focused on the university experiences of autistic students to the employment domain (Bakker et al., 2019; Sturm and Kasari, 2019; Fernandes et al., 2021), autistic students were more likely to highlight writing skills as a career-related strength and less likely to highlight academic difficulties as a challenge than non-autistic students. Aligning with findings from the broader autism employment literature, which has not typically distinguished between university students and others analytically (Scott et al., 2019; Black et al., 2020), autistic students were more likely to report detail orientation as a career-related strength but expected to encounter challenges obtaining and maintaining their dream jobs due to discrimination, social difficulties, and psychological difficulties. Likely due to concerns about discrimination, few autistic participants reported proactively disclosing their autism.

Limitations and Future Directions

Our non-autistic comparison group was not well-matched to our autistic group and autistic participants were predominantly white males. Findings require replication with larger and more generalizable samples. An autistic graduate degree holder responded to our preprint by writing, "this work is absolutely

needed. . . (but) it hit me hard to find there was no representation in the sample for someone like myself." They highlighted the importance of improving representation of autistic people from different cultural backgrounds given that discrimination and access to diagnoses vary across cultures. Given the pronounced limitations in generalizability imposed by our unrepresentative convenience samples, we follow their advice by including a link to a feedback form so readers can share their insights about how to improve future work in this area: https://bit.ly/EmploymentPaperFeedback.

Like most prior work focused on autistic university students (e.g., the large body of work focused on the National Longitudinal Transition Study or the Freshman Survey), we examined students' self-perceptions rather than objective indicators of strengths and challenges. Work is needed that examines whether self-reports align with objective indicators of academic and employment success. Such work should examine if perceived strengths and challenges shape career goals and trajectories longitudinally.

CONCLUSION

These findings indicate that programs aiming to help autistic university students obtain meaningful jobs should provide strengths-focused supports to help all students, and particularly those who face pronounced obstacles gaining meaningful employment, develop employment-related skills at university, while also providing mental health supports. Universities can begin to address the barriers their autistic students expect to face obtaining their dream jobs by proactively seeking out and hiring autistic professionals, by providing hands-on learning experiences co-designed with potential employers to help students develop the skills employers are seeking, and by teaching their own staff and community partners how to appreciate and support autistic colleagues. Employer education programs should focus on making workplaces more inclusive by combatting discrimination and by changing the hiring process and work environment to better suit the needs of autistic individuals. Although the systemic barriers that make it hard for autistic people to find jobs that allow them to express their strengths can feel like a permanent part of our society, they are shaped by cultural and economic forces that are changing (Grinker, 2020) and which we can help to change.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author/s.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by The College of Staten Island Institutional Review Board. The patients/participants provided online informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

CC and SS-H developed the hypotheses and coding schemes and coded the majority of the data (i.e., questions asked of both autistic and non-autistic students). CC wrote numerous initial drafts of this manuscript for her honors thesis. AR led survey development and recruitment in partnership with a larger participatory research group as part of a larger study about autistic university students as part of her doctoral dissertation. CC, JV, SKK, EC, PD, and BK assisted with survey development, recruitment, and/or offered feedback on coding schemes. SKK, JV, BK, PD, AR, and EC edited this manuscript. BK and HA analyzed responses to develop a coding scheme about the goals autistic participants hope college will help them achieve and developed so far at university. As CC's and AR's advisor, KG-L guided survey, coding scheme and thesis development, conducted the final analyses and literature review, wrote the final draft of this manuscript, and addressed reviewer feedback. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2021.719827/full#supplementary-material

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What I Wish You Knew: Insights on Burnout, Inertia, Meltdown, and Shutdown From Autistic Youth

Jasmine Phung[1], Melanie Penner[2]*, Clémentine Pirlot[2] and Christie Welch[1,2]**

[1] Department of Occupational Science and Occupational Therapy, Faculty of Medicine, University of Toronto, Toronto, ON, Canada, [2] Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, ON, Canada

Introduction: Burnout, inertia, meltdown, and shutdown (BIMS) have been identified as important parts of some autistic people's lives. This study builds on our previous work that offered early academic descriptions of these phenomena, based on the perspectives of autistic adults.

Objectives: This study aimed to explore the unique knowledge and insights of eight autistic children and youth to extend and refine our earlier description of burnout, *i*nertia, and meltdown, with additional exploration of shutdown. We also aimed to explore how these youth cope with these phenomena and what others around them do that make things better or worse, with a hope to glean knowledge to design better supports.

Methods: One-to-one interviews were conducted with eight children and youth, who shared their experience with BIMS. To match individual communication strengths of children and youth, we took a flexible approach to interviews, allowing for augmentative communication systems and use of visual images to support verbal interviews, as needed. We conducted a reflexive, inductive thematic analysis, using an iterative process of coding, collating, reviewing, and mapping themes.

Findings: Our analysis has identified that these youth describe BIMS as a multi-faceted experience involving emotional, cognitive and physical components. Moreover, these multifaceted experiences are often misunderstood by neurotypical adults, which contributes to inadequate support in managing BIMS. Of the four experiences, these youth identified meltdowns as most common.

Conclusion: By gaining first-hand perspectives, we have identified novel insights into BIMS and developed a more holistic understanding of these phenomena. These youths' descriptions of supportive strategies for BIMS stress the importance of compassion and collaboration from trusted adults. This new knowledge will provide a foundation for how to better support autistic children and youth. Further research is required to develop an understanding of BIMS, especially with respect to how it is experienced by children and youth. Future research should leverage the insights and experiential knowledge of autistic children and youth to co-design support tool(s) for BIMS.

Keywords: autism, arousal regulation, insider perspectives in research, burnout, meltdown, shutdown, inertia

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Amy Pearson,
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Karen Leneh Buckle,
The University of Manchester,
United Kingdom
Laura Hull,
University College London,
United Kingdom
Amanda Roestorf,
University of Stirling, United Kingdom

****Correspondence:***
Christie Welch
cwelch@hollandbloorview.ca
Melanie Penner
mpenner@hollandbloorview.ca
Jasmine Phung
jasmine.phung@mail.utoronto.ca

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INTRODUCTION

Autistic people who are engaged in public discourse on social media highlight burnout, inertia, meltdown, and shutdown (BIMS) as important parts of their lives (Welch et al., 2020b; Buckle et al., 2021; Higgins et al., 2021). Despite the high frequency and deep importance expressed by autistic people (Welch et al., 2020b; Buckle et al., 2021; Higgins et al., 2021), there is very little exploration of these phenomena in clinical literature. The literature is especially void of empirical explorations of these phenomena from the perspectives of autistic people themselves. For some notable exceptions, please see Raymaker et al. (2020), as well as Higgins et al. (2021) for explorations of burnout, Buckle et al. (2021) for an examination of inertia, and the work of Belek (2018), which explores meltdown and shutdown. Despite the strength of this early work, academic exploration of BIMS has been preliminary and these constructs are not yet clearly defined, delineated, or agreed upon. Our own work exploring BIMS has brought some of these phenomena to the attention of academic literature and offers only an early, somewhat tentative description of these phenomena, but leaves the need for deeper and broader exploration of autistic peoples' experiences and understanding of BIMS phenomena. Additionally, our searches of the literature have not yielded any empirical explorations of these phenomena from the perspectives of children and youth. **Table 1** shows a description of BIMS phenomena according to the current state of the evidence.

The lack of formal study of these phenomena translates to a lack of helpful strategies to support autistic children and youth with experiences of BIMS. Challenges with self-regulation (which we consider to be an important element of BIMS) are identified as a primary barrier to autistic children and youths' success at school (Ghanouni et al., 2019). A support system or intervention approach is needed that can guide autistic children and youth, as well as the important adults in their lives, to effectively manage BIMS in ways that preserve the youth's dignity, meet their individual needs, acknowledge strengths, and are informed by a neurodiversity framework (Milton and Moon, 2012; Leadbitter et al., 2021; Pearson and Rose, 2021). Also needed are new support systems and intervention approaches that support respectful communication and collaboration between autistic youth and their educators (Brownlow et al., 2021).

Our previous work (Welch et al., 2020b) began to address these concerns by generating an early academic description of burnout, inertia, and meltdown based on autistic insider perspective (see **Table 1** for brief descriptions). However, this earlier work did not explore shutdown. Additionally, this work relied on analysis of blog posts and did not allow for further probing of relevant BIMS concepts, such as can be achieved through interviews. Finally, our earlier work did not explore the experiences of autistic children and youth, and so it is not known how or whether children experience BIMS, or whether they may experience the phenomena differently, nor is it known how best to support them.

We embarked on this study to build on our earlier work, to develop new knowledge of whether and how some autistic children and youth experience BIMS, and to draw on their experience, knowledge and insights to explore strategies for managing BIMS, thereby laying a foundation to design insider-informed supports and interventions. In this study, we pursued the following questions:

(Q1) How do these autistic children understand and describe experiences of burnout, inertia, meltdown, and shutdown (BIMS)?
(Q2) What can their experiences and insights teach us about supporting autistic children and youth with experiences of BIMS?

TABLE 1 | Operational definitions of the manifestations of burnout, inertia, meltdown, and shutdown (BIMS) as described by autistic informants of earlier research.

Burnout	Described as a distinct source of severe and chronic exhaustion (Raymaker et al., 2020; Welch et al., 2020b). Autistic bloggers highlighted that the causes of this severe exhaustion are uniquely autistic such as "masking" – the constant need to exhibit appropriate behaviors to complete everyday tasks (Welch et al., 2020b). Informants have explained that this burnout often results in depletion of skills and intolerance to varying stimuli (Raymaker et al., 2020)
Inertia	A prolonged mental state of being "stuck" resulting in the physical inability to engage in activities that the individual wishes to do. Autistic individuals describe the experience of autistic inertia to vary in severity, duration of time and rate of repetition, however, all agree that when it does occur, it has the potential to be debilitating (Welch et al., 2020b)
Meltdown	A phenomenon with varying expressions by which autistic informants feel entirely overwhelmed accompanied by a lack of control and cumulative stress (Welch et al., 2020b). Meltdowns elicit responses of outward anxiety and energy outpour (Schaber, 2014). Some factors that contribute to a meltdown include, but are not limited to: social demands, frustration, embarrassment, challenges with communication, emotional triggers, and overwhelming aversive sensory stimuli (Welch et al., 2020b).
Shutdown	Although similar to meltdowns, shutdowns present as more internal experiences, where the individual withdraws from their surroundings and is accompanied by emotional pain (Belek, 2018). The degree to which one can function during a shutdown ranges from mild (e.g., being able to walk around and talk) to severe (e.g., feeling detached from your limbs and going into a fetal position) (Belek, 2018).

MATERIALS AND METHODS

Context of Larger Study

This study takes place within a larger multi-phase research study. The larger study is called the Relax Recharge Ready (RRR) project and employs co-design methodology to better understand BIMS and to generate BIMS support tools that have been designed by and for autistic people. Both this study and the larger study operate within a constructivist paradigm, in which we acknowledge that every element of this research is influenced by the subjective experiences and assumptions we bring to the work (Annells, 1996). This article reports on

an analysis of a subset of data generated within the larger study, specifically, data generated with our child and youth stakeholder group (ages 8–18). The first author (Phung) is particularly interested in child and adolescent development and took the lead in conducting a thematic analysis of the data that was generated with the children and youth participants of the RRR project.

Ethical Considerations

A number of ethical considerations for research become especially critical for research that involves children (Crane and Broome, 2017). Of major importance, is the consideration of the power differential between researcher (an adult) and participant (a child/youth) (Crane and Broome, 2017). Autistic children and youth in particular, may enter the research process with previous experience of being disempowered when interacting with neurotypical adults (Lonbay et al., 2021). With this in mind, we gathered informed consent from both parents and children/youth prior to each interview. This included an explicit discussion of reasons a child or youth may wish to end the session as well as ways to indicate a preference to do so. We were also concerned that a child or youth may experience stress or distress during an interview, since this would be an unfamiliar experience with an unfamiliar person and focused on a topic that can evoke embarrassment and regret. A plan was created at the beginning of each interview to address and limit potential distress that could arise during the interview. Each interview began with questions such as "are there any signs that I can watch out for to know that you're getting stressed and may need to take a break?," "if you need help who can you call?" and "is there something that you love to talk about that makes you feel relaxed if you're feeling a bit stressed?". This plan provided a guide for the interviewer to observe for signs that the child/youth was distressed and what to do in that scenario. Parents were present while addressing the questions in the safety plan but did not have to stay for the entire interview unless requested by the participant. Of the eight participants, 1 participant requested for a parent to be present for the entire interview. Despite the risks of involving autistic children in youth in research, we believe that it is, on balance, more ethical to include them in the process (with measures in place to minimize potential for harm), than it is to exclude them from research that has the potential to impact their lives.

This study received ethics approval through the Bloorview Research Institute Ethics Review Board and through the Health Sciences Research Ethics Board at the University of Toronto.

Participants

The child and youth participant subset included eight autistic children/youth. The youth were required to have a formal diagnosis of autism, be aware of their diagnosis (to avoid harm by accidentally informing a child/youth of their diagnosis during the research process), be 8–18 years old (median = 14) and able to communicate in English, either verbally or with a non-verbal communication system. Additionally, children and youth were expected to be able to discuss BIMS concepts (verbally or otherwise) as assessed by their parent. Demographic data was collected via a form that parents filled out prior to all interviews. According to the demographic data we collected, participants were from families of middle to high socioeconomic status and of Caucasian or European descent. Of the eight participants, five were reported as male and three as female. All participants also were reported to have an additional diagnosis: either attention deficit hyperactivity disorder (ADHD), anxiety disorder and/or an unspecified learning disability. No participants used alternative methods of communication. Some participants noted that they were currently taking medication and/or receiving therapy/intervention. Participants were recruited both internally and externally to the organization. We contacted individuals from our organization's database of children and youth who are interested in research participation (via phone call to parents). We also sent out an information email via the list provided by a community partner. Additionally, a Tweet describing the study and with PI contact information was sent out from the media relations department of our organization.

Positionality of Researchers

Our research team is made up of an early childhood educator/student occupational therapist (Phung), a developmental pediatrician and autism scientist (Penner), an autistic co-researcher (Pirlot) and an occupational therapist/occupational scientist (Welch). Our varied backgrounds influence everything about this work, from its inception to its implementation and its reporting (Annells, 1996). Immersion in occupational science and occupational therapy has made us particularly sensitive to elements of the youths' accounts that relate to their daily occupations as well as the activity-based nature of strategies that the youth discuss. Despite the insistence that occupational therapy resists the "medical model" (Townsend and Polatajko, 2013), we recognize that we have been influenced by medical framings. Of particular note, the PI (Welch) initially approached BIMS phenomena with an "arousal regulation" lens, which was later revealed to be reductionistic compared to the descriptions given by the youth in this study. Another researcher (Penner) comes from a medical background and has clinical and research experience with autism diagnosis as well as multidisciplinary approaches to complex behaviors. The first author (Phung) conducted the analysis and therefore her perspectives and positionality are of particular importance. Phung approached this study with an appreciation for social emotional well-being in early childhood development, particularly the role of teachers fostering and nurturing this domain. In addition, Phung entered this study with the understanding that children have knowledge and insight of the world around them. However, the first author was cognizant of the previous assumption that autistic children may not be able to demonstrate the same metacognitive skills as neurotypical children. As this study progressed, this assumption has shifted into a greater appreciation of the unique ways autistic children and youth share their insight. Lastly, one researcher (Pirlot) has a background in sociology, as well as experience facilitating a support group for autistic people, whose experiences include BIMS phenomena. She is also an autistic advocate who used her unique position to inform the research, with a particular focus on ensuring autistic interests are represented.

TABLE 2 | Description of using visual images to support interviews.

Step 1	At the introduction to the interview, the child/youth was informed that the interviewer may show pictures about BIMS if it seems like it might be helpful to bring out ideas
Step 2	If during the interview, the interviewer detected challenges in getting verbal descriptions (e.g., participant answered with single-word answers, or gestures, or a response of "I don't know"), the interviewer would share screen and show a Google images search of key words pertaining to the idea explored in the moment (child or teen plus: tantrum, yelling, feeling stuck, tired, and exhausted)
Step 3	Once the images were displayed, the interviewer would then ask: do any of these pictures show how this feels or what this is like? If the child says "no," the interviewer conducts another image search
Step 4	When the child/youth selects an image that is deemed a good representation, the interviewer asks probing questions like – what do you think she is feeling? What do you think she is thinking? What might have happened just before? What might happen next?

As a team, we have approached this research with the shared assumptions that autism comes with unique insights and strengths and can also come with individualized challenges, especially when faced with disabling factors in the environment.

Data Generation

The interviews were completed by the senior author (Welch). Each child/youth completed two interviews ranging from 25 to 45 mins long. We were committed to maximizing each child's/youth's unique communication strengths, and took a flexible approach to the interview process, as suggested by Teachman and Gibson (2013). The interviews occurred on Zoom and youth had the choice of keeping their cameras on or off to increase comfort during interviews. In line with the objectives of the study, interview questions were focused on BIMS phenomena, asking about participants' experiences with each. Visual images were sometimes used to pull out additional details and descriptions, in a technique that had been informally piloted by Welch. The visual images were generated by a "Google Images Search" based on the interview questions and depicted children and adolescents in states of BIMS, according to the perception/interpretation of the interviewer. Of the eight youth, visual images were used with three of them. Participants identified relevant images that appeared through the search and the interviewer probed for better understanding of why images were selected by participants, see **Table 2** for a description. The interviews were audio recorded and professionally transcribed, with the exception of one interview which was transcribed via Zoom (live captions). Transcripts were anonymized and stored on a secure server.

Data Analysis

Two research team members (Phung and Welch) met weekly to discuss the analytic process. A reflexive inductive analysis was used to facilitate a holistic understanding of these insider perspectives. A hallmark of inductive analysis is the process of generating codes based on data interpretations, rather than superimposing a list of codes generated prior to reading the data (Braun and Clarke, 2006, 2020). The analysis followed guidelines highlighted by Braun and Clarke (2006, 2020). Firstly, an open read of the data was completed and paired with analytic memoing to document reactions to the dataset (Braun and Clarke, 2006). The open read process allowed us to remain open minded to novel relationships in the data. Analytic memoing (conducted at all stages of the research) facilitated cognizance of our existing assumptions surrounding how we thought we understood BIMS phenomena (Braun and Clarke, 2020).

TABLE 3 | Renaming BIMS phenomena using the autistic children and youth's language.

Burnout	Inertia	Meltdowns	Shutdowns
Feeling exhausted	Feeling stuck	Feeling out of control	Feeling frozen

Through a second read of the data, initial codes were generated using Microsoft Word and Excel. Codes were then sorted by collating relevant data extracts and potential themes (Braun and Clarke, 2006). Thematic maps were created in order to visually represent the data and develop a better understanding of the relationships (Braun and Clarke, 2006).

Early themes were refined based on two criteria: internal homogeneity and external homogeneity (Braun and Clarke, 2006). Candidate themes were reviewed to ensure that collated extracts depicted coherent patterns (Braun and Clarke, 2006). Once candidate themes were refined, a series of thematic maps were created and further refined. We noticed that our names for BIMS phenomena were not generally used by the youth, with the exception of meltdown and therefore, renamed BIMS using the children and youth's language and only used the BIMS terminology when applicable (see **Table 3** for a translation of BIMS to the children and youths' language). We have purposefully chosen to present the themes in first-person language to maintain the humanistic nature of these narratives. We also noticed that the children and youth used analogies to depict their experiences with BIMS. This was a key point in the analytic process and we decided to integrate the youths' analogies to help structure our analysis. The data set was also revisited to ensure that the thematic map reflected the youth's narratives (Braun and Clarke, 2006). Final themes were then identified and defined (see **Figure 1**).

Steps to Ensure Rigor

Braun and Clarke (2020) provide a 15-point checklist and evaluation tool that was used to guide the quality of this data analysis. Our study places autistic insider perspectives at the forefront. This has been depicted through pivoting our language to match the participants, spontaneously generating codes based on narratives and the iterative process of analytic memoing (Braun and Clarke, 2006; Nowell et al., 2017). This aligns with the nature of reflexive thematic analysis as we have developed meaning and lessons through the collection of stories shared in combination to our unique positionalities (Braun and Clarke, 2020).

Our analysis, which is depicted through a thematic map, provides a visual representation of the relationships we identified

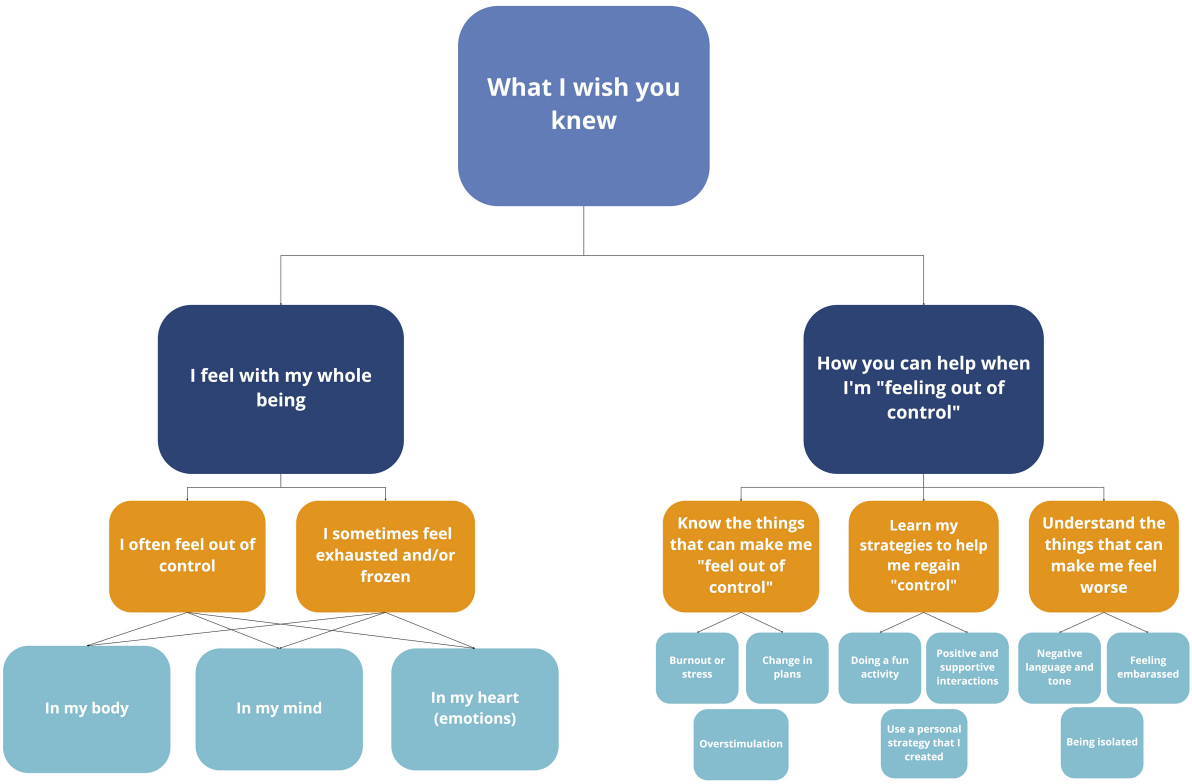

FIGURE 1 | Text provided in quotation marks represent direct quotations from interviews.

between themes, sub-themes, and codes (Braun and Clarke, 2020). We revisited our early stages of coding and reflexive notes that described our early understandings of each theme prior to omitting. We also carefully assessed the relationships between chosen extracts and identified themes to ensure they were linked coherently (Braun and Clarke, 2006; Nowell et al., 2017). Analytic memoing was especially useful to track our justification of codes and themes identified (Nowell et al., 2017). To ensure dependability and confirmability (Nowell et al., 2017), an audit trail was created, retaining audio recordings, verbatim transcripts, documentation of coding process and theme/sub-theme identification, and analytic memoing/reflections.

FINDINGS

Overarching Theme: What I Wish You Knew

During the interviews, the autistic children/youth shared their experiences with BIMS including what BIMS means to them, how they experience BIMS and helpful/unhelpful strategies they have implemented to cope with BIMS. An overarching theme was constructed: *What I Wish You Knew*. For these children and youth, they emphasized the importance of adults actively listening to their narratives to better understand their experiences with BIMS. They acknowledge that neurotypical individuals may experience BIMS to some degree, however, for these autistic children/youth, they acknowledge that they experience it *differently*. Within this overarching theme there are two themes: (1) *I feel with my whole being* and (2) *How you can help when I'm "feeling out of control."* These two themes further consist of sub-themes which are represented by codes (see **Figure 1**).

Theme 1: I Feel With My Whole Being

The participants in this study provided descriptive narratives of their experiences with having meltdowns or "feeling out of control." However, when discussing burnout, inertia, and shutdown, only some participants identified that they experience these. For those who provided descriptions for burnout, inertia, and shutdown, overlapping and synonymous descriptions were used when discussing each phenomena. In order to remain in alignment with the children and youth's narratives, burnout, inertia and shutdown were grouped together using the participants' language: "feeling exhausted" for burnout and "feeling frozen" for shutdown and inertia.

The children and youth utilized analogies to depict their experiences with "feeling out of control" and feeling "exhausted and/or frozen." These analogies elucidate that the aforementioned phenomena are multifaceted experiences that include emotional, physical and cognitive components. These multifaceted components are represented through three codes: *in my body, in my mind*, and *in my heart*. Passages in the interviews that described physical sensations, bodily reactions or behaviors were coded as *in my body* and passages that highlighted

cognitive processing, thoughts or beliefs were coded as *in my mind*. Responses that emphasized an emotional experience such as feeling overwhelmed, helpless, frustration or shame were coded as *in my heart*. Together, these multifaceted components depict how these phenomena are experiences that include the children/youth's whole being.

Subtheme 1: I often "feel out of control" (meltdowns)

One child/youth (CY) presented the follow analogy for "feeling out of control" (meltdowns):

> "You're a passenger on a ride of destruction. . . and it's like hitting a bunch of stuff." – CY 6

In my body: The participants describe the physical experience of "feeling out of control" as consisting of an array of strong bodily reactions reminiscent of a physiological fight or flight response. They describe their bodies experiencing the following:

> "My vision getting blurry" – CY 6

> "Getting tense muscles and I start to get hot." – CY 3

> "My cheeks get warm." – CY 4

> "My hair sticks up." – CY 4

> "Shoulders bunch up." – CY 2

> "Yeah, I started yelling and, like, stuff and then like. . . yeah, I was like I was yelling and yelling and yelling a lot." – CY 2

> "My face gets a little bit red." – CY 3

> "I breathe fast." – CY 2

> "My sight is a little bit more restricted, like, I'd only really be able to see the room that I'm in and nothing else." – CY 6

> "I'll just kinda hold my head from stress." – CY 1

CY 8: It feels like I have a bit more power.

Interviewer (*I*)*:* Oh. Is that something you can feel in your muscles?

CY 8: Yeah. [indistinct] get an adrenaline rush.

In my mind: The thoughts that arise during these physical experiences further illustrate the symbolism of the passenger in the analogy. The participants' cognitive descriptions evoke ideas of "feeling out of control":

> "It's like my subconscious is still out of my control." – CY 1

> ". . . forcing myself to stay calm." – CY 1

> "It's like tunnel vision." – CY 5

> "I don't really remember what happens very well, it's usually a little fuzzy." – CY 5

> "Feeling out of control." – CY 5

> "Like when I'm stressed, I'll kinda stop and just get really stressed out while trying not to have an outburst. Or I'll actually manage to stay calm" – CY 1

> "When I'm in a meltdown it's not easy to get out of and I'm not in full control, like I'm not thinking clearly." – CY 5

> "A by-product of my stress." – CY 1

In my heart: Along with the strong embodied reactions and "tunnel vision," the participants also placed emphasis on the high emotions associated with "feeling out of control." The occurrence of these components reflect intrusiveness to their daily tasks. They stated that despite their efforts to maintain composure, high emotions can build up resulting in stress and frustration, and overall feelings of helplessness and reduced motivation to participate in other activities. The participants stated:

> "What happens when I'm trying to be calm is like, just the stress will just continue building up, that's usually what happens in anything is like, whenever I try to contain any sort of emotion or anything, it'll just keep building up, usually with stress or anger it happens the most where it will just keep on." – CY 1

> "It's kind of like there's just no other thoughts than just anger." – CY 6

> "You feel a different emotion every time a meltdown ends, depending on what it started from." – CY 7

> "It's gotten to the point where I'm so unmotivated that I can't even do things that I want to do." – CY 1

[Looking at pictures generated by Google Images]

I: Hmm, what kind of picture should I look for?

CY 7: Angry.

. . . It has the face, it has the face, just pretend that, like, 10,000 [indistinct] just make that face angrier.

Subtheme 2: I sometimes feel exhausted and/or frozen (burnout, inertia, and shutdown)

In my body: When discussing their experiences with feeling "exhausted" and being in a "frozen" like state, participants described similar physical manifestations of each. One youth presented the following analogy for feeling exhausted (burnout):

> "You can have this really really big dough and it's really hard and tense" – CY 3

This participant's analogy represents the physical effort to knead a tense and hard piece of dough. The continuous effort to knead the dough results in eventual fatigue in our arms. When sharing their experiences with burnout, the youth describe similar physical feelings as depicted in this analogy. They placed emphasis on physical exhaustion when required to complete tasks throughout their daily life such as school work. They stated:

> "Sometimes that happens to me, like, when I come home from school after I've had, like, two tests and a ton of assignments. I just come home and then I just sit at my computer for a few minutes not knowing what to do." – CY 6

When feeling "frozen," some participants provided the following analogies that also depict physical tiredness and a

physical internal conflict that they are trying to overcome. The analogies are provided, respectively:

> "It kind of feels like my blanket weighs 500 pounds and it's weighing me down." – CY 6

> ". . . a slow old computer that's trying to run Google Chrome. . . it just uses up a lot of RAM." – CY 1

The participants use an "old computer" and a "heavy blanket" to represent a combination of feelings: decreased physical energy, lagging, slowness, and being physically stuck. Specifically for shutdowns, one youth identified that their physical tiredness can occur when they are feeling overloaded by environmental stimuli:

> "Just feeling drained, like I don't have the energy to get up." – CY 5

> " Lazy. Tired. Maybe even a little bit of exhaustion. In my whole body. I feel weak, not. . . like my body is heavy." – CY 5

> "Something that is difficult to get out of." – CY 2

> "You're frozen and you can't really get to that thing." – CY 3

> "yeah sensory overload I mean it doesn't happen that often but like with ASD it does definitely happen." – CY 8

In my mind: The participants described the occurrence of cognitive difficulty when overcoming their physical manifestations of "exhaustion" and "frozenness" when balancing a number of responsibilities. These cognitive experiences can occur when having to decide between a number of choices, specifically with completing school work (e.g., either choosing to take a break or to persevere through the task). They highlight this cognitive experience as stressful and hard to overcome, stating that:

> "It's more like artist's block or writer's block when it happens to me" – CY 6

> "I think I should be able to do this on my own, I don't really want to ask for help but I'm still stuck, and I don't know how to do this. It would be great if I asked for help, but I don't really want to ask for help. It's this hard." – CY 3

> "What happens to me is if there is a lot going on like my family arguing and I have to finish my work, it just gets really hard and I need a break but I also feel like I have to do the work." – CY 3

> "It feels like my mind is struggling to do anything." – CY 1

> "Shutdown is just, like, usually 'cause of stress, I'll just completely freeze up, I can't really talk, I'll stutter, I'll like literally freeze up. I'll sit down or something, I'll make weird noises that's basically just the sound of my mind straining to work." – CY 1

Specifically for inertia, one participant identified a fine difference from burnout and shutdown. This participant described inertia as having difficulty with task initiation resulting in challenges with productivity. They stated:

> "Having trouble getting started with something." – CY 8

> "Trouble getting the ball rolling, actually getting to work on something." – CY 8

In my heart: When discussing "exhaustion," participants identified feeling relief when the "exhaustion" passes. One youth recounts:

> "I feel good when it's done, but when it's going I get a little stressed out because it's going too fast for me. When you mentioned that point, for me, I think it's like climbing walls and if I do one, and if I finish one, that's just really really high, I'm happy, but I'm also a little bit scared for the next one that they want me to do." – CY 3

When discussing "feeling frozen," their narratives also highlighted a relationship between their emotional experiences and physical/cognitive components. Participants identified feeling frustrated because they recognized their responsibility to fulfill tasks demands but are unable to. A participant describes their experience of needing to complete a 3-page essay:

> "And so I've been working on, like, just putting it onto a page, right? My Mother is helping me write, like, a [indistinct], but currently I still feel as [indistinct] I'm like okay, but I have all the ideas, why can't I just submit this, like, why do I now have to put it all into a 3-page essay, this is going to be a pain, right?" – CY 8

Another participant also used an analogy to represent two feelings and the cognitive dilemma that they experience when "feeling frozen." Importantly, this quote also demonstrates that these phenomena can evoke a spectrum of experiences (e.g., "feeling frozen" can evoke both an emotional and cognitive experience) rather than each occurring in isolation. This youth recounts this feeling at school:

> "Uh-huh. I. . . it. . . it always, usually it just happens to me when I get angry, or I get really upset, or like. . . it happ. . . like, I have those two emotions at school and it's. . . and, like, a friend did something that I didn't really like, and it's just like I want to say the things at them, but it was. . . it was sort of like tug of war, one side wanted to, like, stomp at them and say mean things at them; and then the other side didn't know what, and then the other sides didn't want to because, like, it's my friends and I should be nice to my friends, and sometimes when that tug of war thing happens, I get stuck. And I don't know what to do, and I want to do some. . . and I want to shout mean things at a friend, but I feel like I can't." – CY 3

Theme 2: How You Can Help When I'm "Feeling Out of Control"

Of the four BIMS phenomena, the participants explicitly identified meltdowns as most prominent in their lives. This may be reflective of their social environments (e.g., topic is

often discussed amongst adults), the intrusiveness to their daily lives, development of vocabulary to allowing richer discussion of meltdowns, or a possible developmental/maturational component. When discussing meltdowns, they highlighted three main ideas: Know the things that can make me "feel out of control," learn my strategies to help me regain "control" and understand the things that can make me feel worse.

Subtheme 1: Know the things that can make me "feel out of control"

Feeling exhausted (*burnout*) *or stressed:* When asked about their experiences with meltdowns, the participants shared instances that led to a meltdown. Their descriptions highlighted that a build-up of burnout and stress, and feeling drained from an accumulation of task demands, may lead to experiencing a meltdown. This indicates that these participants may experience burnout and meltdowns simultaneously. These participants recount:

> " I was all. . . a little bit mad, at first, but I was a little. . . really tired, but then when they got back to school, the education assistant (EA) was constantly bugging me "do the work, do the work, do this, do this work. . ." I don't remember what it was but it was pretty hard work. "Do the work, do the work, do the work." I was like "No, I'm extreme. . . I have no energy left, like, and it wasn't like how I normally say I get tired just to kinda [indistinct] like just to kinda, like. . . like usually when I say I'm tired I'm, like, a little bit tired but this. . . like, just [indistinct] no, I was genuinely for once actually too tired to do any work, like, my brain was just. . . falling asleep. I was, like "please no, I'm extremely tired, like, I'm not even joking." And he was like "no, no no, you're going to do the work" like, "No, I'm tired. And I was getting more agitated." – CY 1

> [Looking at pictures generated by Google Images] "She did too much. . . she did too much work and then she needed to do more." – CY 4

> "Like if a whole bunch of minor things that I'm not in the mood and they are they just keep on stacking up." – CY 8

Unexpected change in plans: Moreover, some participants describe that an unexpected change in their plans like planning to play a specific game during recess but suddenly unable to, can also result in a meltdown:

> "Actually usually it's more because something, like really goes off of your plan, like, it's not that you don't get what you want, like, if you say that you want to play with a ball during recess or something, then someone else takes the ball an hour before recess, that's just plain rude, even if you, specifically told them that you want to play with it." – CY 6

Overstimulation: Lastly, the participants identified that over-stimulation (sensory/social/cognitive) can result in them feeling out of control:

> "That's the best way I can describe it. Yeah, has [indistinct] fun, and of course I got stressed out because lots of stimulation." – CY 1

> "But for me it's just, like, really high pitch, like, when someone's like scraping a fork and knife together or something." – CY 6

Subtheme 2: Learn my strategies to help me regain "control"

The youth provided descriptions that adults advised they try, as strategies to help when *losing control* (see **Table 4** for summary of strategies). However, this participant states that at times these general methods are not as useful as we think:

> "Well, something that every adult that I've ever talked to about this kind of stuff tells me – just walk away. Except it's not very helpful advice because sometimes it isn't possible to walk away, sometimes you're in class and you can't walk away, you're stuck there for the rest of the day." – CY 6

Fun activities: In contrast, the participants identified strategies that they have used and actually found helpful in regaining control of their thoughts, physical reactions and emotions. During discussion of each participant's safety plan, some participants identified that talking about their interests (e.g., dogs, science, and space) helped to calm themselves down. Moreover, many of the participants identified that doing fun activities was also a helpful strategy. A participant noted that doing fun activities like soccer, has allowed them to healthily cope with strong emotions:

> "Playing with Play-Doh" – CY 3

> "Doing a fun outdoor activity" – CY 3

> "Two things that helps me is (1) curling into a ball, and (2) listening to new podcasts or songs that I like in the headphones" – CY 3

> "In third grade I would definitely, that's definitely an aggressive kid. Before, but then I started playing karate actually" – CY 8

> "When I get frustrated, usually I want to kick things and throw things, but I also know that it's not a good idea . . . well, I've been thinking about a way to not hurt anybody, well, it's kicking a soccer ball because it's fun and I usually compete against a wall and you can kick it really really hard, like, you can kick it with all your anger and it could be. . . it could be helpful sometimes." – CY 3

Positive/supportive interactions: From the participants' descriptions, another type of strategy was identified: positive/supportive interactions with family, friends and pets. They highlight that talking through their thoughts and emotions during a meltdown can be helpful in calming them down:

> "Yeah. Well, I think one strategy, the first strategy that I. . . that I think I can do, if it's with my cousins, my sister and my Mom have been telling me if you get upset, talk, and

TABLE 4 | Summary of strategies for meltdowns.

Fun activities	Positive/supportive interactions	Other strategies
Playing with Play-Doh	Sitting with family and friends	Setting a timer on iPad
Doing an outdoor activity	Talking to family and friends about interests	
Listening to podcasts or songs	Hugging/cuddling with pets or stuffed toys	Mindfulness based strategies such as taking deep breaths
Playing sports such as karate and soccer	Stepping away from others or being alone momentarily	Counting to 100 with eyes closed
		Distraction techniques through use of imagination and visualization
		Devise response/support plan based on individual preferences: touch/no touch, talk/no talk, eye contact/no eye contact

I'm unavailable, you can talk to your sister, and then if I'm suddenly available and your sister can talk to me." – CY 3

"Vali is the solution to all of my problems. Well, yeah, she's kinda meant to, she's trained to, she's a service dog." – CY 1

Some of the participants also emphasized the importance of listening to what they have to say during a meltdown:

I: So obviously what people say when someone's in a meltdown is important, so what would be a good thing to say?

CY 1: A good thing to say would be nothing, and to let me talk.

"I liked talking about games" – CY 3

They also noted that at times, physical touch from their loved ones provide a sense of comfort and reassurance:

"Giving me a hug" – CY 3

"Play with my dog" – CY 6

"Often cuddling my mom, and cuddling Wedgie often helps" – CY 5

Instead of receiving physical comfort, other participants discussed having a "body break" or removing themselves from the current social/physical setting, allowing them time and space to calm down:

"Run away . . . run under my bed." – CY 3

"I feel what's helpful for me is just being alone." – CY 1

Strategies I've learned: The third type of strategy that the youth discussed was the internalizing and adapting formal strategies taught by adults. For example, one participant discussed the use of an iPad to help manage their behavior:

"Because I use it so much that, I thought I should probably try setting all my timers on my iPad because I actually pay attention to it, because it's like the. . . one of the few things I actually consistently will pay attention to" – CY 1

Other participants discussed breathing techniques, recounting helpful mindfulness strategies that they previously learned.

"Like taking deep breaths" – CY 2

"Sometimes I just sit there, close my eyes and count to 100, and then. . . and then open them again" – CY 6

Lastly, the participants identified the use of imagination to think about happy things or using distraction techniques like visualization:

"Kind of imagine yourself in your happy place, but, like, imagine that you put on a VR headset and you're, like, wherever you want to be." – CY 6

"Imagine a cat or a dog just, like, standing around you and just, like, brushing up against you sometimes makes you feel calmer because you feel like there's someone there with you kind of protecting you in a way" – CY 6

"Something that I used to do, and I don't. . . it's probably really uncommon, but it could be on your list of strategies was this thing I did where I imagined that there's, like, this guy on a motorcycle or he was running or something, and just all of the little ledges on the wall he could. . . and, like, the lines he could run on. So I made a whole course for him in different rooms." – CY 6

Subtheme 3: Understand the things that can make me feel worse

The participants provided insightful responses regarding behaviors and interactions that have exacerbated feeling out of control, magnifying the stress of their experience. They highlighted the impact of communication, specifically the type of language and tone used when speaking with a child who is already feeling overwhelmed and upset:

"I don't know why, but this one EA gets [indistinct], but she was telling me to do my work, and I was like no, I genuinely am burnt out, tired, I can't. And then. . . I'm. . . like I don't have the full memory, but I know that, like, she genuinely insulted me, like, by telling me like you're acting like a little kid, you're acting like. . . like she said that over and over. Like she was trying to provoke me or something. And I just lost it." – CY 1

"Like, if some. . . if I'm really. . . if I'm really really upset and it's not a person like my Mom, I. . . and if they're just saying,

like, stop, that usually. . . it doesn't really help. And if they're saying it in, like, a mean sort of tone of voice, that makes it even worse, and that you add, and like, add sad to the bucket of negative emotions that I'm feeling in that moment." – CY 3

The participants have identified the value of social support from teachers, principals, family and friends, and further associate feelings of embarrassment and shame when isolated or when a space is being evacuated during a meltdown. They wished that teachers and other supportive adults knew how to support them during a meltdown:

"It felt pretty embarrassing because, like, I was the reason that the class couldn't learn, and. . . that's pretty much all I really felt." – CY 6

"For me it's just I hate being alone. Like. . . I know they're right outside the door, 'cause they're literally barricading me in." – CY 5

". . . I was having a meltdown at school, and. . . and the teacher just got the class to leave the room and that was it, they didn't do anything else. They called the principal and then the principal came and. . . and then the principal calmed me down, the teacher just got the class out of the room and then called the principal" – CY 6

"Yeah. That's why it kind of bugs me when the teacher just calls the principal, because actually now I have a pretty good relationship with the principal because I've been sent up to the office too many times to count." – CY 6

DISCUSSION

This study offers a new understanding of BIMS as experienced by some children and youth. The findings in this study support earlier work (Belek, 2018; Raymaker et al., 2020; Welch et al., 2020a; Buckle et al., 2021) that BIMS is an important part of life for many autistic people. The descriptions offered by these children in many ways align and in some ways differ from descriptions provided by autistic adults who have informed earlier literature.

Raymaker et al. (2020) used interviews as well as internet sources to describe burnout from the perspectives of autistic adults. Like the informants in Raymaker's study, the children and youth described burnout in terms of chronic tiredness, decrease in skills, and reduced tolerance to stimulation. Also similar, the youth in our study linked experiences of burnout to sustained high demands. Interestingly, the informants in the Raymaker study also linked burnout depletive effects of masking, whereas the children and youth in this study did not explicitly discuss masking (though admittedly, there were no interview questions pertaining to masking).

Our findings align with Buckle et al. (2021) examination of inertia which explored the experience of 32 autistic adults. Specifically both studies generated descriptions of inertia that encompassed physical, emotional, and cognitive factors. This is an important consideration in future work aimed at addressing inertia, as it signals a need to avoid over simplifying or reducing inertia to an issue explained only by motoric skills, executive functioning or emotional circumstance. Rather, these studies call for holistic and multifaceted approaches to understanding and supporting inertia.

Belek (2018) explored embodied experiences of autism that touched on both meltdown and shutdown. Belek's description of shutdown emphasizes triggers like sensory overload and internal experiences of fear and paralysis that match descriptions from these children and youth. Belek's description of meltdown also bears similarity to those offered by these children and youth in that they involve "feeling out of control" and can be terrifying. While one of our participants described a meltdown like being "a passenger on a ride of destruction," one of Belek's informants described meltdown as "a jet plane crash" (37). The children and youth in our study placed much more emphasis on meltdown than on shutdown as disruptive factors in their lives, whereas this weighting is not observed in accounts from adults (Belek, 2018; Welch et al., 2020a). It warrants further study to determine whether this represents a maturational effect in which autistic individuals learn to manage or avoid meltdowns, either through alternate strategies or through replacing meltdown with shutdown, as shutdowns often have fewer or milder negative consequences compared to meltdowns. As a participant in Belek's study states, "I normally go in blank shutdown mode to control my meltdown"(36).

When compared to descriptions from our earlier work (Welch et al., 2020a), which was based on adult perspectives, descriptions of BIMS phenomena as provided by these children and youth use different terminology and are less clearly delineated, with some descriptions across phenomena being similar (e.g., the physical manifestations of burnout, inertia, and shutdown). The children also described a sometimes cyclical nature of BIMS phenomena, with partial overlap; for instance, burnout leading to meltdown or having a meltdown right at the beginning of a burnout. As noted earlier, differences in the child and youth descriptions compared to adult descriptions may represent developmental or maturational differences in how BIMS is experienced or expressed. It is also possible that the children and youth in our study have had less exposure to the concepts of burnout, inertia, and shutdown (though all were familiar with meltdown) compared to adults and therefore have less fully developed conceptualizations and vocabulary for these phenomena. The children and youth's familiarity with meltdown terminology may reflect that it is one term often applied to neurotypical children, whereas burnout, inertia and shutdown are terms that come from the autistic community (Welch et al., 2020b).

Implications for Practice

The descriptions from these children and youth illustrate that they experience BIMS in ways that are physical, cognitive and emotional. Their whole-person descriptions stand in contrast to the more reductionist theorizations of dysregulation and behavioral responses that are often seen in current literature and clinical approaches. Current clinical approaches tend

to focus on executive function, physiology or behavioral responses in isolation (Hess et al., 2008). Approaches such as auditory integration training, sensory integration, and cognitive behavioral modification, aim to change autistic children's intrinsic traits in order for them to better fit into their environments (Hess et al., 2008). Instead, the descriptions from the children and youth in our study support Leadbitter et al. (2021) suggestion that a crucial element of advancing autistic research and clinical practice is to understand autistic experiences as a way of being which is complex and dynamic.

The variations across the descriptions from these children and youth highlight the highly individual way in which autistic people experience and respond to things and alert us to the dangers of adopting BIMS as a reductionistic or essentialist way of explaining autistic experience. Rather than advancing a reductionist model, it is our hope that readers use these descriptions of BIMS to expand their thinking in relation to what autistic children and youth experience in daily life and approach the outward manifestations of BIMS, which are sometimes interpreted as laziness, resistant or avoidant behavior, and aggression, with curiosity, compassion and a spirit of collaboration.

Although our study highlighted a number of strategies that are helpful during "out of control" experiences (e.g., meltdown), it is important to remember that these strategies are highly individualized. Some of the youth in our study shared that they prefer physical touch from their loved ones during "out of control" experiences, as it provides security and comfort. However, other youth noted that they prefer to be left alone, which relieves them of demands like making eye contact and maintaining conversation (which makes meltdown and shutdown worse). Iemmi et al. (2017) emphasize that due to the variable presentation of autism, it is necessary that individualized strategies are differentiated by a variety of factors including individual preferences, age, gender and those with multiple diagnoses. Taking time to consider these factors and consult with autistic children and youth about approaches that are helpful to them will facilitate quality, individualized support that best aligns with each individual's needs (National Autistic Taskforce, 2019). Lastly, many of the strategies shared by participants are not exclusive to autistic children and youth. These strategies could also be helpful to non-autistic peers and may fit well into a universal design approach within classrooms.

The thoughtful and actionable insights offered in these descriptions emphasize how autistic youth are the true experts in their own experiences. Some of the strategies highlighted by the youth, such as deep breathing and using cognitive strategies (e.g., visualization), align with conventional clinical approaches (Robert et al., 2013). Some of the strategies they have found helpful, such as supportive interactions and engaging in fun activities, are outside conventional clinical approaches. This is similar to findings from Pavlopoulou (2020) who elicited personalized accounts of effective sleep strategies from 54 autistic adolescents. Like the strategies described by the youth in our study, the successful sleep strategies identified sometimes aligned with conventional wisdom pertaining to sleep (e.g., relaxation before going to sleep), but sometimes diverged (e.g., control over sensory stimuli at bedtime). Both studies highlight the importance of looking beyond neurotypical-informed conventions when collaborating with autistic youth, as this can generate novel approaches for support.

The children and youth in this study express an awareness that most adults in their lives do not understand their experiences of BIMS. To help us understand, the youth frequently employed analogy and metaphor; drawing on something they believed us to know and then making connections to their own experience. This challenges the assumption that all children and youth identified as autistic will struggle with theory of mind or use of metaphor, as is sometimes reflected in the literature (Norbury, 2005), but aligns with findings from Olofson et al. (2014). Our finding that these children and youth do not feel that the adults in their lives understand BIMS, or collaborate with them to generate solutions, aligns with work from Brownlow et al. (2021), who found that autistic youth in classrooms felt that they were not included in informed decisions about their learning. Brownlow et al. (2021) recommend positive communication strategies to foster collaboration and positive relationships between students and teachers, something our data supports.

The children and youth in this study placed very high value on compassionate support and understanding from the adults around them. The youth who described the greatest success in their current management of BIMS described situations in which they had generated and implemented strategies through collaboration with an important adult (usually a parent or education aide). This finding supports a shift in the direction toward something we like to call "collaborative regulation." Collaborative regulation could be seen as similar to a co-regulation approach [e.g., as described by Gulsrud et al. (2010), which used mother-mediated joint attention to support emotional regulation in autistic children], in that it acknowledges the influence of others on an individual's level of arousal; however, collaborative regulation goes beyond co-regulation to acknowledge a shared responsibility for monitoring and supporting a person's state of arousal. Additionally, a collaborative regulation approach, as we would like to put forth, emphasizes mindful and deliberate planning to set an individual up for success and includes consideration for the physical, sensory and social environment.

Collaborative regulation can facilitate opportunities to provide positive support and in turn, reduce feelings of humiliation, regret, and fear (Ting and Weiss, 2017). Adults can work together with autistic youth to scaffold useful strategies (Ting and Weiss, 2017) when they are feeling exhausted, out of control or frozen. Scaffolding includes sensitivity toward children's emotions, providing encouragement and validation, and valuing children's active participation in goal achievement (Hoffman et al., 2006). Buckle et al. (2021) identified that some autistic informants depend on scaffolding from their external environment when overcoming inertia (e.g., completing a task side by side with another individual) as it provides visual prompting, which further facilitates task participation and follow-through. Therefore, through collaborative regulation, autistic youth and teachers can determine together when and how to best apply scaffolding techniques in the classroom.

The youths' emphasis on collaborating with adults for successful management of BIMS is interesting in that it has the potential to address the "double empathy" problem identified by Milton (2012) which suggests that empathetic disconnect between a neurodivergent person and a neurotypical person could improve through mutual and reciprocal efforts from both parties. The recommendations from these youth also align with the social model of disability (Oliver, 2013) in that many of their strategies are designed to remove certain disabling factors that cause or exacerbate BIMS. When discussing helpful strategies for coping with BIMS, the children and youth in this study do not advise hiding, covering up or masking the fact that they are struggling in a certain situation. Rather, they recommend open communication, interaction and collaboration to manage BIMS. Thus, collaborative regulation, individualized coping strategies and the unconventional approaches that were previously identified, are stepping stones for practical approaches that humanize autistic youth's overall experience with the BIMS phenomena.

As highlighted in **Figure 1** under "Things that make these children/youth feel worse," the role of a child/youth's social environment can positively or negatively influence their experience with meltdowns (e.g., how adults respond to meltdowns can result in a youth feeling embarrassed/ashamed). The children and youth in our study have provided a guide for neurotypical individuals on where to begin when providing support during meltdowns including understanding both individualized triggers and personal coping strategies, as well as responses that can exacerbate meltdowns (see **Table 4**). According to Lai and Szatmari (2019), the strategies identified here are aligned with those informed by a neurodiversity approach in that they consider extrinsic factors impacting the autistic individual and endeavor to improve the fit between the child and the environment. Based on the narratives shared by these youth and existing literature surrounding autistic perspective, adopting environmental adaptative approaches requires a shift toward a holistic framework with particular emphasis on social-ecological components.

Implications for Research

This study (and the larger project it resides in) answers the call issued by Leadbitter et al. (2021) to conduct research relevant to autistic children and youth that embraces a neurodiversity framework. It also generates knowledge that can inform options for intervention that support positive coping strategies, personal agency, and wellness, which has been identified by Leadbitter et al. (2021) and the National Autistic Taskforce (2019) as crucial. Iemmi et al. (2017) outlined four core principles that are based on existing drawbacks in research literature as well as steps to move autism research forward. One of these steps is for future research to explore autistic experiences like BIMS, as experienced by autistic children and youth, including whether these phenomena interact with developmental and maturational processes. Through improved understanding, effective supports that are "autistic person-centered" can be generated for autistic children and youth experiencing BIMS (National Autistic Taskforce, 2019). Participatory and emancipatory approaches should be emphasized, particularly co-design approaches for the development of insider-informed supports.

Limitations

A number of limitations should be considered for this study. The children and youth recruited for this study received diagnosis at a young age and are all connected with support services. There was also limited demographic diversity and intersection of multiple minority identities (e.g., socioeconomic status, race, ethnicity, gender, and sexuality) across our sample. Additionally, all the children and youth in this study have parents who believe that their children have valuable insight into their BIMS experience (and should therefore participate in this study), and who also value research. These aforementioned descriptors may explain why meltdowns were prominent in these children and youth's lives as well as contribute to their understanding/experiences of BIMS. We also expect that this homogeneity across our sample has limited the breadth of experience we otherwise may have captured and described for this study. We did not have any child/youth participants who are non-speaking or who use augmentative communication, and so we have not captured potential variations in experience of this phenomena from a non-speaking perspective. This study would have benefited from additional follow up interviews with the youth to elicit more detailed descriptions and to ask more clarifying questions (Charmaz, 2006) regarding jargon, analogies and the content of the participants' stories. While this analysis was inductive and matches Braun and Clarke's (2020) description of a reflexive analysis in that we did not have *a priori* codes, we acknowledge that this analysis is deeply informed by our emerging understanding of BIMS phenomena, stemming from our previous work. The descriptions from these children and youth offer new ways to understand BIMS and the associated observable behaviors, and can be used to expand the thinking of educators, clinicians and parents. However, it is important to recognize that these narratives are unique to these youth and therefore, our descriptions should not be considered representative of the experiences of all members of the greater autistic community.

CONCLUSION

The experience of burnout, inertia, meltdown, and shutdown are important parts of life for some autistic individuals, including children and youth. Children and youth may experience BIMS in ways that are different from autistic adults, and each child or youth has highly unique needs and preferences for support. The children and youth offer descriptions that contrast with clinical and academic approaches, which tend to focus on one component such as executive function, physiological state of arousal or social skills. Rather, they describe whole-person experiences, encompassing physical, cognitive and emotional components. This suggests that approaches to support/intervention should consider all of these elements as well, rather than taking a

reductionistic or siloed approach. The children and youth in this study stress the importance of compassion and collaboration from adults who help them manage BIMS. Further research is required to develop an understanding of BIMS, especially with respect to how it is experienced by children and youth across diverse populations. Future research should leverage the insights and experiential knowledge of autistic children and youth to co-design support tool(s) for BIMS.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because this study is based on a small sample size and releasing generated datasets can potentially identify participants. Requests to access the datasets should be directed to CW, cwelch@hollandbloorview.ca.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Bloorview Research Institute Ethics Review Board Health Sciences Research Ethics Board at the University of Toronto. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

JP conducted the thematic analysis of the data subset and co-wrote the manuscript. MP provided methodological guidance and support throughout all stages of research, provided suggestions and edits for manuscript. CP provided input and guidance from an autistic perspective, throughout all stages of research, provided suggestions and edits for manuscript. CW designed this study as well as the larger study, provided support throughout thematic analysis, and co-wrote manuscript. All authors contributed to the article and approved the submitted version.

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A Critical Realist Approach on Autism: Ontological and Epistemological Implications for Knowledge Production in Autism Research

*Marianthi Kourti**

Department of Social Work and Social Care, University of Birmingham, Birmingham, United Kingdom

The ontological status of autism has been a subject of considerable debate and philosophical approaches of it have been recent and sparse. On the one hand, from its conception, autism has been historically heavily located in the fields of psychiatry, psychology and neuroscience, which often assume access to an "objective," neutral and infallible reality that is external to the research process and is based on the autistic person's biology and behavioural characteristics, which can be scientifically observed and studied. On the other, proponents of the neurodiversity movement argue against medicalised and pathologising approaches to autism and toward approaches that consider social constructions of autism and relations of power. The Critical Realist philosophy can help reconcile the two positions. Critical Realism conceptualises objectivity as a statement about an object, rather than a neutral and infallible reality. Consequently, Critical Realism suggests that access to reality can only occur through fallible theories. It also suggests that effective theorising goes beyond appearances and phenomena and may even contradict them, which can help challenge dominant behaviourist approaches on autism. I then explore how the tenets of Critical Realism can help strengthen autistic-led theories of autism, the arguments they make, as well as how they support the importance of community autism knowledge. Finally, I present how Critical Realism's approach to knowledge itself as well as the process of knowledge creation can strengthen autistic theorising, autistic participation in autism research and autistic emancipation. In the last part of the article, I explore how the concepts of Critical Realism apply to autistic sociability. I start with the debate between structure and agency, how Critical Realism reconciles this debate and the implications for autistic emancipation and autism research. I then present Critical Realism's process of critique and explanation, how they connect to human emancipation and how they can lead to impactful change in autism research by requiring clear links from research to practice, enhancing practices with strong theoretical underpinnings and thus aiding the aims of emancipatory autism research.

Keywords: autism, critical realism (CR), participatory research (PR), autistic theorizing, philosophy of autism

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***Correspondence:**
Marianthi Kourti
m.kourti.1@pgr.bham.ac.uk

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INTRODUCTION

Autism studies have changed significantly over the decades since autism was first conceived by Kanner, 1943 (Feinstein, 2011). In the first decades since its conception, autism was almost exclusively studied under the field of psychiatry. Autism studies later expanded to also be studied by psychology, neuroscience, and education (Bagatell, 2010). In recent years, and mostly thanks to contributions from autistic activists and writers, the ideas around autism have been also seen through the context of humanities and social sciences, aiming to understand the various ways in which social inequalities shape autistic lives (Pellicano et al., 2018). Autism definitions, therefore, range significantly from a deficit-based approach, such as the definition of the DSM-5 (American Psychiatric Association [APA], 2013), which defines autism as "persistent deficits in social communication and social interaction across multiple contexts, and restricted, repetitive patterns of behaviour, interests, or activities, currently or by history" to its perception as a form of neurodiversity (Singer, 1999). The neurodiversity model ranges from approaches to neurodiversity with a basis in biological and genetic differences (e.g., Singer, 1999; Silberman, 2017) to characterising neurodiversity as a form of social identity and movement aiming at social justice and thus forming the neurodiversity paradigm (e.g., Strand, 2017). These approaches are not mutually exclusive, just differing somewhat from each other in focus and framing. What has, until recently (e.g., Chapman, 2020; Botha, 2021b) been missing, however, is a thorough examination of the underlying philosophical implications of each position, and their implications for the knowledge they create. To understand the current contexts around autism and what they may mean, therefore, it is important to introduce a philosophical approach on autism that is able to incorporate all these different disciplines and bring them together whilst still criticising harmful practices and prioritising the needs, perspectives, and emancipation of autistic people.

Perhaps it is wise to start by examining why we might need one. Firstly, attempts to introduce a philosophy of autism have been sparse, relatively recent and mostly overlooked by the majority of traditional autism researchers. Furthermore, as Richman (Bölte and Richman, 2019) notes, philosophy may not tell us what autism *is*, but it can examine the questions we ask and what these might mean for the answers we gather. A philosophy of autism may be less concerned with findings, and more with the frameworks and means of interrogation used, as well as what they might mean for the conclusions reached. Once these are established, the disciplines that study autism can take over to investigate their empirical aspects. The pursuit of a philosophy of autism is, therefore, a question of framework. As Collier (1994) highlights, it is important to consider the metatheoretical aspects of the work of scientists who are explicitly interested in their discipline which they often "*do not need to make explicit and may not even suspect that they use*." This pursuit is not concerned with how thorough someone has been in their attempt to do autism research, and indeed the idea that strict adherence to methodology is what produces good research can in itself be harmful (Botha, 2021a). Instead, it is about the underlying meaning behind those attempts and how they might frame research findings.

Complementary to this, Collier (1994) answers the question "Why philosophy?" by noting that the alternative is not a lack of philosophy, but rather a *bad* philosophy. He suggests that someone who may consider themselves to be, or appear to be, an unphilosophical person, still has a philosophy, but this may be unconscious, lack critical awareness and as a result it may be disjointed and inconsistent. The work of a philosophy of autism, therefore, as with philosophy in general, is to highlight what philosophies are implicit in various practices, how they are used by those practicing that science, even when they are not aware they are using them, and to make them explicit so they can be examined and critiqued. The other role of philosophy (Collier, 1994), is tounravel some practices that do what certain *a priori* theories say cannot be done. This is perhaps especially pertinent in the case of autism and traditional conceptualisations of what it means to be autistic. Critical Realism is the name that has been attributed to the works of Bhaskar (1987, 1989, 1975, 2015), a philosopher whose work is mostly concerned with ontology, the study of *being*, and how various disciplines (Cruickshank, 2003), such as sociology, psychology, biology, and feminist theory, approach it. Its name combines the two ontologies that Bhaskar engages with, *transcendental realism*, which refers to Bhaskar's analysis of the natural sciences, and *critical naturalism*, which refers to the implications of transcendental realism for the human sciences (Archer et al., 2013). Critical Realism aims, to be, therefore, an interdisciplinary meta-theory that explores how science comes to understand the world and how epistemology, the process of knowledge creation, engages with and shapes ontology, our understanding of nature and society (Bhaskar et al., 2017).

Botha (2021b) discusses in further detail how both positivist and interpretivist approaches have been used in psychology generally and autism research more specifically, critically evaluates their shortcomings and explains why Critical Realism is a better alternative. This article will explore how the philosophy of Critical Realism might be applied in autism research, and how it not only supports, but rather requires, autistic participation in autism research. It also considers whether the tensions within autism studies arise from different disciplinary understandings of knowledge and the fact that interdisciplinary research is the exception rather than the rule, even though it is often championed by autistic scholars and activists (e.g., Arnold, 2020).

This article will introduce the philosophy of Critical Realism, give an overview of its main tenets, and will discuss how this philosophy can be applied to autism studies, the framing autism as a concept and knowledge creation in autism studies. Firstly, it will focus on transcendental realism to discuss autistic embodiment, and then on critical naturalism to discuss autistic sociality. I will use examples of autistic-led theory, specifically monotropism and the double empathy problem, its implications and use in various disciplines and their impact in how autism knowledge production. I will also examine how Critical Realism's concepts can support and substantiate participatory and emancipatory autism research.

While this article is an attempt to encourage discussions around the philosophy of autism, I myself am not a philosopher. I am a social studies researcher who has found it increasingly impossible to continue doing autism research without addressing some of its the ontological and epistemological aspects first. As such, the purpose of this article is to encourage autism researchers, professionals and autistic activists who may also not be well versed in philosophy, to consider the philosophical implications of their positions and reflect on how those impact on their theory, research, practice, and activism. It is also an invitation to those more philosophically inclined than I am to further tease out these concepts further in an accessible, inclusive, and participatory way since, as an autistic individual and activist, these will always be at the core of my approach to autism research.

TRANSCENDENTAL REALISM: AUTISTIC EMBODIMENT

Transcendental realism refers to the part of Bhaskar's philosophy that is concerned with the study of the natural world, and therefore can be considered as a philosophy for the natural sciences (Bhaskar, 1975). Transcendental realism accepts the existence of an external reality, an intransitive object, that exists regardless of our knowledge of it. However, it also accepts that our knowledge of this object may only approximately describe the intransitive object, therefore our knowledge is subject to fallibility. In this way, transcendental realism aims to reconcile ontological realism, the existence of an interpretation of reality that is fallible and a definitive definition of reality beyond our knowledge claims (Cruickshank, 2004), epistemological relativism, the idea that our approach to knowledge creation as well as our modes of thinking, perspectives, thoughts processes, dispositions interests and values are deeply rooted in our socio-cultural situations and therefore inseparable from them (Lawson, 2003), and judgemental rationality, the process of showing how some claims are more true than others (Wiltshire, 2018). Judgemental rationality is the critical realist process of evaluating a theory in order to establish why it may be better than another theory. By establishing it as more coherent and representative of its subject, it is less contradictory and disjointed, and is preferable because its internal structure is superior and it is more useful and adequate in practice compared to other theories (Scott, 2010). A theory that is realist considers knowledge to consist of objectivity, fallibility, transphenomenality, and counter-phenomenality (Collier, 1994). In the paragraphs that follow, each of these terms will be explained and the relationship between ontological realism, epistemological relativism and judgemental rationality will be further explored. I will then argue why this approach is useful for a philosophically sound theory of autism and how it can support autistic emancipation.

Objectivity in Transcendental Realism

The term objectivity is a loaded term among critical thinkers and philosophers. In methodologically positivist approaches of science, objectivity, a "neutral" and unbiased observation and recording of a reality that is external, is often treated as a given; one's ability to research, analyse, and theorise on the world regardless of their own personal position, routinely remains unquestioned (Montuschi, 2016). Furthermore, measuring often means adherence to specific methodological processes that are considered to be the best, or even only, way that knowledge can be obtained (Chamberlain, 2000). On the other hand, interpretivist and constructionist approaches present objectivity as impossible since it declares independence from any knowing or valuing subject and reality itself is presented as inherently dependent on our own perception of it (Kirk, 2012). For transcendental realism, however, this definition of objectivity is itself flawed (Collier, 2003). After all, as Collier puts it *"to be the object of knowledge may be to be the subject of self-revelation*" (p. 134). Objects, therefore, need not be bound to a relative subject; they exist regardless of their relation to any subject, regardless of whether their existence is known at all (Collier, 2003). An object does not suddenly come into existence once its existence is known; that is the ontological realism that transcendental realism defends.

The problem with traditionally positivist, traditionally constructionist/constructivist and traditionally interpretivist definitions of objectivity, therefore, is that they have come to equate subjects to mean "people" and objects to mean "things"; and to conflate ontological concepts with epistemological ones, existence itself with our knowledge of it. On the one hand, positivist science conflates ontology with epistemology by claiming that an objective reality is accessible, measurable, and quantifiable and it is so despite the researcher's personal subjectivities. However, as Collier (2003) puts it: "*there is no guarantee that something objective will be measurable, and trying to force the unquantifiable into a quantitative straitjacket is subjectivity in the worst sense*" (p. 132). Interpretivist, and constructionist approaches on science, on the other hand, conflate ontology and epistemology by claiming that we cannot know if reality outside our knowledge exists, thus its existence, or lack thereof, is not epistemologically meaningful. What ends up happening, therefore, is that we conflate an object itself with *our* concept of the object, despite the fact that whatever concepts of that object we have are still *our* concepts (Collier, 1994). Critical realism is not the only philosophy to have pointed that out; Hacking (1999), for example, has also come to similar conclusions when examining how social constructs have been used in American sociology and philosophy and provides similar reasons as to why they might not be as useful. Transcendental realism, therefore, defends epistemological relativism as much as it does ontological realism.

The critical realist use of the concept of objectivity, therefore, differs significantly from both of these definitions. For Critical Realism, objectivity refers to what is true independently of any subject judging it to be true (Sayer, 2000). This does not mean that facts are independent of all judgements (in actuality something may be a fact about a judgement), they are merely independent of the judgement of truth, they need not be judged to be true, in order to be true. Furthermore, human judgements themselves are also objective facts (which does not mean they are neutral and infallible, as this is not the definitions of objectivity Critical Realism uses) because they are judgements *about* something. For transcendental realism, there is a causal theory of perception, a

causal process that links an object to the perception of it (Collier, 2003). Transcendental realism, therefore, claims that objectivity is a human attitude; scientific endeavour, consequently, ought to aim to bring our perception of its scientific object as close to that object as possible, whereas the object itself exists independently of our perception of it and its existence governs our thinking around it (Kolnai, 1977). That is how transcendental realism links epistemological relativism with judgemental rationality.

This type of objectivity can help us untie a lot of ontological and epistemological knots around the theory of autism. First of all, we do not *need* to know about autism for the phenomena we have come to describe as autism themselves to exist. Autism will be autism independent of who is looking into it or describing it. The states and characteristics *themselves* do not exist because of our descriptions of them. Our understanding of them does depend on those descriptions however, and therefore so does our epistemology of autism. But whatever our epistemology may be, it will always be an epistemology *of* autism, in the sense that it will always be about a set of traits and characteristics that we have currently come to label as autism. This does not mean that we will not adjust, redefine, modify, and even expand what can constitute autistic traits or characteristics. Indeed, it is not even dependent on them being called autism at all. It may be decided in the future that the term "autism" is not a helpful term to describe what we currently use it for, just as it was decided that the term "Asperger's Syndrome" was not a useful description in the publication of the DSM-5 (Happé, 2011). It may even be decided that the category of autism is too restrictive or too broad; any and all definitions and descriptions will however, still be definitions and descriptions of an intransitive realm that is, and will always remain, independent of its transitive epistemology.

Furthermore, by using the concept of objectivity as it is described in transcendental realism, one can make the argument that a judgement of the common theories of autism is a fact about those theories, because to say that a theory, an epistemological approach to autism, may be inaccurate, or even harmful, is a characteristic attributed to that theory and it is its characteristic regardless of who its attributor is. To say, for instance, that the weak theory of mind theory of autism dehumanises autistic people as Yergeau (2018) claims, would not merely be about the positionality of the author/subject according to a critical realist approach; rather, it would be about the epistemology of the object, the process of the knowledge creation itself, which occurred prior to, and independently of, any subject judging it. This is important because, particularly in the context of autism and the processing and communication difficulties that often co-occur, it is important to acknowledge that that a theory or practice can be harmful to someone even if that person themselves cannot describe, explain, or even understand why this is the case. This does not, however, mean that it is irrelevant to examine why the theory is critiqued by autistic people *specifically*, and why for decades it was (and still largely is) not deemed as harmful by neurotypical researchers. The concept of judgemental rationality is an important one in defending autistic knowledge creation. It has been argued that in order to understand a skill or theory cognitive comprehension is not enough, but bodily and lived understanding is important as well (Isaksen, 2016). It could be argued, therefore, that these critiques come from autistic people because autistic people have access to deeper domains of autism knowledge, as we shall see below.

Fallibility as a Consequence of Objectivity in Transcendental Realism

To say that a judgement about something is a fact about that something may make a lot of thinkers initially very uncomfortable. This may likely be because, both in lay knowledge and in naïve positivist approaches of science, facts are often considered to be both neutral and infallible. This derives from the belief that facts and values should be kept separately as it is not possible to derive a value from a fact (Gorski, 2013). It is precisely because of these misguided perceptions that interpretivist, social constructionist, and social constructivist approaches of science have aimed to prove that nobody can claim neutrality and infallibility. In the process, of doing so, however, they have created an approach that, if taken to its logical completion, suggests that an object's existence is subjective to our knowledge of it (Kemp, 2005), even though, admittedly, most thinkers who follow these approaches do not take this extreme stance. This is not the objectivity that transcendental realism defends; it does not aim to prove that theories can be neutral or infallible. In fact, the claim that it makes is that *precisely because* knowledge is objective, it is knowledge *about* an object, it is by default *always* fallible (Cruickshank, 2002). It is the very fact that the object it describes is independent of the theory that describes it, that makes the theory's accuracy and effectiveness able to be evaluated. This is why fallibility is another core tenet of the critical realist philosophy that goes hand-in-hand with objectivity. Transcendental realism recognises that because theories make claims about what the world is like *independently* of those theories, all theories are *essentially* fallible and, consequently, open to transformation. One example that Collier (1994, 2003) gives to support this position is the description of an event where one human died because of the deliberate actions of another human. It is accurate to say that the first person died, however, it is also accurate to say that this person was killed and, in so far as the second human intended for the first human to die, it is also accurate to say that the first human was murdered. To say that the first person was murdered, however, is both more objective, because it presents more facts about the incident (the loss of life; the fact that the loss of life was done by another; and the fact that the other person intended for the loss of life to happen) *and* less neutral because it paints what happened in a light that is clearly unfavourable toward the second human, the perpetrator of the act.

Fallibility is a really important concept for the philosophy of autism and for critically evaluating autism theories, whether they be biological, medical, psychological, or social ones. The concept of fallibility, the statement that our claims about reality are fallible and biassed specifically *because* they are objective (about an object), is what can lead to accountability and the evaluation of a theory of autism against the existence of autism itself. If the existence of autism was exclusively dependent on our theories of it and autism did not have its own ontology,

then there would be no reason to assume that medicalised approaches on autism, for example, are more fallible than the concept of neurodiversity and it can simply be a matter of preference which of the two approaches a researcher will follow. Neurodiversity, therefore, loses its polemic bite; it becomes a concept that should be adhered to because autistic people say so, without explaining why neurodiversity should be adhered to *because* autistic people say so; what is it that autistic people can know better about autism that requires for them to be put at the centre of discussion for autism knowledge to be credible. Transcendental realism, therefore, aims to strengthen the neurodiversity movement and its inherently material and discursive dimensions by putting a focus on fallibility and by making the argument that theories made and/or endorsed by autistic communities, are more objective because they represent autism more accurately than neurotypical theories do.

Transphenomenality in Transcendental Realism; A Liberation From Appearances

Transphenomenality refers to the claim that knowledge consists of more than appearances. Knowledge does not consist of simply how things look, but also of underlying structures that last longer than appearances and make those appearances possible (Steinmetz, 1998). The knowledge we have is not just a knowledge of phenomena, but that of underlying factors and conditions that make those phenomena possible. It is that deep knowledge, therefore, that has explanatory power over the phenomena, over the surface-level realism of observation (Roberts, 2001).

Transphenomenality is an important tenet to consider when looking into the epistemology of autism and the agents of knowledge creation that surround it. Given that much of mainstream understanding of autism is a behaviourist one, it is worth examining what kind of understanding of autism it is; is it just a knowledge of phenomena, or does it (or can it) include the knowledge of the underlying causes and conditions as well? Do the mainstream theories of autism entail the deep knowledge that has explanatory power over behavioural observations, or are they surface-level observations that claim to explain more than they actually can?

It can be argued that many of the "traditional" theories of autism do not stand up to philosophic scrutiny because while they may certainly make claims about what the underlying structures and mechanisms of autistic behaviours are [a weak theory of mind (Baron-Cohen et al., 1985); difficulties in central coherence (Happé and Frith, 2006); extreme male brain (Baron-Cohen, 2002)], they only deduce those mechanisms from behavioural (therefore phenomenal) observations. A neurotypical researcher or clinician, therefore, can only rely on their own assessments of autistic behaviours to draw conclusions about what autism *is*, thus making their knowledge of autism a knowledge about *phenomena* of autism, not a knowledge of the underlying factors and mechanisms that cause the phenomena. It is, therefore, by default a shallow, surface-level knowledge of autism.

It should be noted here that this is the case despite methodological rigour on behalf of the researcher. "Shallow" does not mean poorly researched, at least not in so far as methodological rigour is concerned; it simply means that no matter how thorough the research is, it can only ever be research about what autism *looks like* and not what autism *is*, despite any claim to the opposite or attempt to conflate the two. If there is a concession among the scientific community, which at large still seems to be the case, that autism needs only be examined on the basis of lack of social skills, poor theory of mind, lack of central coherence, and an extreme male brain, then no matter how thoroughly a researcher looks into those phenomena, it is only ever those phenomena that are being looked into, not their causes. The phenomena are then explained based on perceptions that are created through observation, and those explanations are mistakenly referred to as causes. This is what a Critical Realist philosophy of autism can help us disentangle, and further address, since, as it was stated earlier, it is not interested in examining how the cognitive results of science are achieved, but rather what concepts are implicit in them, regardless of the philosophical stance of the researcher (or lack thereof) and how these concepts can be made explicit so they can be evaluated and critiqued.

Counter-Phenomenality in Transcendental Realism; When Circumstances Contrast Appearances

Counter-phenomenality refers to the idea that knowledge about the deep structures of a theory may not just simply explain appearances, but also contradict them (Collier, 1994). This idea is not new to Critical Realist philosophy; however, it is a fundamental tenet of it. According to Critical Realist theorising, it is the counter-phenomenality of knowledge that allows us to go beyond appearances, rather than stay bound to them. Counter-phenomenality is important for our liberation from appearances, because, as Marx has stated, appearance being something different from essence (Reichelt, 2005) is an essential presupposition of science, or else science itself would be redundant.

Counter-phenomenality is important to consider when engaging in autism theory, because all the mainstream theories of autism do not consider it. The main rationale behind them is that if autistic people *appear* to lack theory of mind, central coherence, have an extreme male brain etc, then they must *really* lack or have all these qualities as demonstrated in the assessment/questionnaire/parental interview etc. and interpreted by the neurotypical researcher/professional. Because autism knowledge is behaviourist, surface-level and phenomenal, it does not account for what the embodied experience of being autistic might actually *be* like, and only relies on appearances to provide explanatory theories of autism. But a theory that lacks deep realism, a theory that does not attempt to be counter-phenomenal or to consider counter-phenomenality to be possible, can only ever be a theory about appearances, and thus shallow realism.

The argument that I am making here is that the predominant theories of autism do not stand up to philosophic scrutiny, not because they are neurotypical, but because they consist of behaviourist observations that only represent a shallow reality, phenomena, rather than the deeper realities of events and

mechanisms, to which they do not, and cannot, have access to. The reason, however, that they do not and cannot have access to them is *because* they are neurotypical, and therefore do not know what the experience of living an autistic life in an autistic body is like. Those experiences are only ever accessible to autistic people, whether they can communicate them or not. Although it is important to account for the heterogeneity among autistic people and the fact that there may be many non-autistic people who share some of their experiences whether embodied (an impairment with similar presentation for example) or social (the experience of being marginalised), this does not negate the fact that autistic people are forming connections based on the recognition of such similarities in each other. Below I will attempt to explain how the philosophy of Critical Realism supports this assertion and what this might mean for the epistemology of autism.

Transcendental Arguments and Community Autism Knowledge

Transcendental realism introduces transcendental arguments, arguments that attempt to epistemologically transcend the "shallow," surface-level reality of phenomena and instead explain events and mechanisms that cause the phenomena, or experiences, to happen. For Critical Realism, reality consists of three domains: the domain of the empirical, which consists of experiences, the domain of the actual, which consists of experiences and events, and the domain of the real, which consists of mechanisms, events, and experiences (Bhaskar, 1975). According to Bhaskar (1975), the domain of the actual is greater or equal to that of the empirical and the domain of the real is greater or equal to that of the actual. Mechanisms, therefore, have greater explanatory power than events, which in turn have greater explanatory power than experiences.

Transcendental arguments can have significant impact on how we view a critical realist philosophy of autism. As it was stated before, the predominant understanding of autism is a behaviourist, neurotypical interpretation of autistic behaviours and relies, therefore, on the shallowest, most surface-level domain of reality to understand autism; that of experience. The autistic understanding of embodied autism has access to the domain of the empirical and the actual, to both experiences and events. The reason for that is simple, the events themselves manifest within our own bodies. When an autistic person has a meltdown, for example, a non-autistic person can only understand it by witnessing it; the event itself, the meltdown, happens within their autistic body and therefore only the person themselves has access to any information about it (how it feels, how it progresses, what might help etc.). To claim that any non-autistic person has access to the domain of the actual when it comes to embodied autism would be to claim that a person who is not the person themselves can have access inside their body, which obviously is impossible for any human. Of course, autistic people do not understand each other because of some sort of "magical" access to each other's bodies. We can simply interpret each other's experiences, the empirical, with information we draw from both the empirical and the actual; drawing from both information on our own embodiment, which is more likely to have similarities to each other's than a neurotypical person's embodiment has to our own (events) *and* from our interactions with each other (experiences). This is also why tokenistic practices are counterproductive; the phrase "when you've met one autistic person, you've met one autistic person" is a cliché for a reason; no single autistic person could ever provide a credible theory of autism in isolation. It is in a community of autistics, therefore, that autistic knowledge is created, and it is this community knowledge that is a more philosophically credible autism knowledge.

Mechanisms, according to Critical Realism refer to the "causes" of phenomena, what causes phenomena to occur. Each scientific discipline then approaches and explains those mechanisms using a different lens. In genetics, therefore, the causes of autism might be located in the DNA, in neuroscience they would be located in different functions of the brain and the nervous system, in psychology in behaviours, in sociology in societal structures, how they classify various humans and how social practices affect autistic people, in humanities how autism may be presented through various art forms etc. For Critical Realism, reality is stratified and each scientific discipline studies a different stratum of it (Joseph, 1998). Furthermore, many events are not caused by a single mechanism, but by a variety of mechanisms taking place at the same time; we are all, for example bound by the laws of physics and the laws of physics can explain, in some form, most phenomena, but that does not mean that they can explain them fully, as many phenomena, such as functions in the human body, for example, will be also bound to the laws of chemistry and biology (Bygstad et al., 2016). Furthermore, there are no "original" causes; causes have causes (Fairclough et al., 2002). This is important in the case of autism, because significant effort, and funding, has been put into identifying the causal mechanisms that may be linked to (I would argue some) autistic presentations; this has currently not been identified, and many believe that it is unlikely to ever be, but even if it was, it would only be the cause of autism in so far as genetics were concerned, while other scientific disciplines would have other explanations about the causes of autism that would approach the phenomena of autism from the point of view of their field.

Even within genetics, however, identifying a specific genetic sequence is only part of the story; we already know, for example, that Down Syndrome is caused by trisomy 21 on a genetic level (Hultén et al., 2008). But we do not fully know what causes trisomy 21; there are some suspicions, age of the gestational parent being one example, but nothing that fully explains when and how trisomy 21 manifests. Even if these causes were identified, we would have to find the causes of *those* causes and we might have to look further than genetics to do so; many of the reasons that people get pregnant later in life, for example, will be better studied through the social sciences. Further, it will be pertinent to examine the motives and practices behind discovering the genetic mechanisms, which will also be done through disciplines like psychology and sociology. Putting the end of the search for causation at the genetic level, therefore, is somewhat arbitrary and certainly only has partial explanatory power.

The three domains of Bhaskar's deep realism are important to consider in the context of autism studies, because we have to establish a) whether research is studying experiences or events and b) what kind of mechanisms might have better explanatory power over what kinds of events and experiences. In so far as mechanisms refer to the genetics of autism for example, the causes of autism are currently unknown; the question, therefore, that can be posed is what research that is looking into the genetics of autism is actually researching. An argument can be made that if, as Bhaskar (1975) states, the domain of the real is greater or equal to that of the actual which is greater or equal to that of the empirical, the domain of the actual cannot be skipped if mechanisms are to be established; it is impossible, therefore, to "jump" from the experiences to the mechanisms without understanding the events, and therefore it is impossible to discover the genetics of autism without taking autistic perspectives into account.

I am not discussing the genetic mechanisms of autism here to encourage research on the causes of autism; this is justifiably not an autistic priority and there are some understandable anxieties about how this knowledge will be used in an ableist society (Chapman and Veit, 2020). Furthermore, as already established, the mechanisms that may have explanatory power over the phenomena of autism cannot solely be found in any one discipline; understanding social and economic structures will also contribute in our understanding of autism as it is today by investigating, for example, how capitalist structures focussed on productivity and output may approach individuals whose embodied state of being does not conform to their demands and how this may shape research interests of that embodied state of being (Broderick and Roscigno, 2021). What is argued here instead is that the mechanisms of autism would have to be investigated from various disciplines if we are to have a coherent picture, and it would have to include autistic input if it is to be research that explains events as they are embodied as well as experiences as they are observed, which is crucial for impactful theorising. These are all important considerations given the highly disproportionate funding that some types of autism research receive over others and the significant lack of autistic input in autism research overall, which are both based in perceptions that are ontologically inconsistent, epistemologically problematic, and ethically hard to defend.

What transcendental arguments can help establish, therefore, is that autistic people have access to deeper domains of knowledge compared to non-autistic people. This is independent of an individual's ability to communicate, contextualise or even understand that knowledge. The knowledge is there regardless of whether it is consciously understood. For example, I knew I was feeling anxiety years before I knew that what I was feeling was called anxiety and I knew that I had this feeling despite not knowing what it was called; however, learning that I am autistic and getting in touch with other autistic people helped me not only put a name to the feeling (event) of anxiety, but also to understand some of the contributing factors to it, to have a partial understanding of its mechanisms (an understanding that, for me, is only ever going to be somewhat partial). What helps conscious understanding of that knowledge, therefore, is interaction with other autistic people whose bodies manifest similar events (meltdowns, sensory sensitivities, monotropic focus etc.). Consequently, autistic communities are fundamental both for autism knowledge that is more credible to that of any individual autistic person's, and for autism knowledge that is deeper than what neurotypical people, individually or collectively, can produce. Furthermore, community autism knowledge is knowledge that can in great lengths explain any one individual's autistic experience, even if the person themselves may not be in a place to do so at a particular moment in time (Kapp, 2020). For anybody, therefore, who struggles to understand an autistic person, or for an autistic person who struggles to understand and/or express themselves, community autism knowledge can greatly (although not completely!) fill some of those gaps in knowledge.

Community autism knowledge is also important because it can help respond to the "you are not like my child" argument. Neurotypical parents (and professionals) who have (or work with) autistic children (or people) with learning difficulties often claim that autistic knowledge creation, such as the concept of neurodiversity, does not take into consideration the kind of autism that their child "has"[1] (Hillary, 2019, 2020). A transcendental argument in response to that claim would be that autistic community knowledge applies to their child partially, but not completely, as much as it partially, but not completely, applies to any one autistic person. It is also a surface-level understanding of autism that only views autism as a set of observable behaviours, and therefore lacks the transphenomenality and counter-phenomenality that a critical realist approach can provide. Autistic people can, to an extent, understand the events that happen within the body of an autistic person with learning difficulties because they can draw information from both their own autistic bodies (the actual) and interactions with other autistic people (the empirical) and then apply this type of community autism knowledge to the specific autistic presentation of that person. They provide, therefore, an understanding of that person's behaviours that, although inevitably incomplete, will nonetheless be more credible from that of a non-autistic person.

Transcendental Arguments in Autistic Theorising

Autistic theories such as the Double Empathy Problem (Milton, 2012) and the Monotropism theory (Murray et al., 2005) can be two examples of transcendental arguments that, from a Critical Realist standpoint, provide a theory of autism that is deeper than the neurotypical counterparts they are responding to. In the following paragraphs, I will explain why this is the case and what practical implications it might entail.

The Double Empathy Problem (Milton, 2012) is a theory that was developed as a response to the prevalent neurotypical explanation of autism that being autistic entails a lack of theory of mind and a difficulty, or inability, to empathise.

[1] Person first language is deliberately used here, to reflect the type of language often used by the neurotypical parents and professionals that engage in those types of arguments.

Milton (2012) critiques the common tendency of autism research most commonly found in the fields of neuroscience and psychology to present a set of behaviours as the norm and aim to suggest "treatments" that aim to bring behaviour that is deemed to deviate from that norm as close to it as possible. It suggests that these approaches ignore core components of communication, such as relationality and interaction, when in actuality communication is a two-way street, meaning that autistic people may not communicate effectively with neurotypical people, but neurotypical people communicate just as ineffectively with autistic people, thus presenting a double empathy problem.

The theory of monotropism (Murray et al., 2005) discusses the distribution of attention in autistic people. It argues that every person has limited attention at their disposal, however, how different people distribute that attention may differ according to neurotype. Namely, non-autistic people tend to have polytropic modes of attention, meaning that they distribute a little bit of attention many different places. Autistic people, on the other hand, tend to have monotropic modes of attention, meaning that they tend to give most of their attention in few sources at a time, or even in one. They argue that this is a core characteristic of autistic processing, and that it may account for what is commonly perceived by non-autistic researchers as weak central coherence, which they use to mean difficulties in putting information together and in processing information in context. They also argue that this monotropic attention focus may account for some of the sensory integration difficulties autistic people experience, thus making it a core characteristic of the condition.

Both these theories are good examples of transcendental arguments because even though they were not conceptualised as such by the original authors, they fulfil all the tenets of a transcendental argument: they are objective, because they are judgements of the theory of autism that compare autism theory to its object, autistic embodiment, not to a feature of their subject, the perceptions of neurotypical researchers, whose only relation to the object is the empirical experience of its effects; they call for fallibility, because they are attempting to transform existing structures by providing a less fallible framework on which autism can be considered; they are transphenomenal, because they do not rely on shallow, surface-level behaviourist and cognitive criteria to describe autism but rather go beyond those to describe the events that affect those criteria and how these manifest in the autistic body; finally, they are counter-phenomenal, because they argue that despite the fact that autism may be perceived as lack of theory of mind and weak central coherence to a neurotypical observer, it can actually be better understood as a monotropic use of attention and a double empathy problem in interactions between people of different neurotypes.

Some recent studies have, either explicitly or implicitly, further substantiated these theories with empirical research. By looking at them we can understand why autistic theories on the mechanisms of autism have greater explanatory power than their neurotypical predecessors. Heasman and Gillespie (2018), conducted research that investigated how autistic people and their non-autistic family perceived their misunderstandings. They asked their participants to rate various aspects of their relationship in terms of themselves, the other person, and the predicted rating of the other person. By doing so, they identified that autistic people were able to accurately predict what their family members may think about them despite the fact they disagreed with them, whereas family members tended to overestimate how much their autistic relatives will be stuck in their own perspective.

In a recent paper that was published by Crompton et al. (2020) it was noted that rapport between individuals was dependent on neurotype matching rather than being autistic or not. Specifically, two separate studies investigated rapport in couples that were either autistic, non-autistic or mixed while performing specific tasks or having informal conversations. The rapport was self-rated and rated by observers of various neurotypes and in both cases it was reported that neurotype matching provides higher evidence of rapport, both self-reported and observed. The researchers explicitly suggest that the two studies support the Double Empathy Problem theory.

Goldknopf (2013) investigates aspects of the monotropism theory that have to do with resource allocation making, although not explicitly, many links between the current literature available on autism and atypical attention resource allocation. Specifically, atypical resource allocation is linked to differences in shifting and breadth of attention, movement, executive function and various aspects of language and communication, social cognition and interaction, therefore making resource allocation (and thus monotropism) a central characteristic of autistic dispositions. Ashinoff and Abu-Akel (2021) also examine hyperfocus, which has many commonalities with the theory of monotropism, and highlight the benefits on investigating this state further. They also note, however, that are many challenges in doing so, including the different disciplinary approaches to the concept as well as practical difficulties in clinical research that would engage with it. Wood (2021) examines how using monotropic interests in school can help develop a variety of skills in autistic children. Similarly, Leatherland (2018) explores how the monotropism theory is key in understanding the experiences of autistic secondary school pupils. Both of these papers give monotropism a central place in their investigative efforts and report that engaging with the theory gave their data great explanatory potential. It is important, therefore, for more autism researchers to consider putting autistic-led theories in the forefront of their research agenda to further examine their explanatory abilities.

The debate between Milton and Timimi (2016) on whether autism has an essential nature can be seen as another example of the importance of transcendental arguments for impactful theorising. In it, Timimi claims that autism does not have an essential nature, also argued elsewhere (Timimi, 2011; Timimi and McCabe, 2016), frames any autistic identification and culture under a medicalised framework, and states that the idea of neurodiversity is useful only in terms of eradicating the stigma around autism and does not have meaningful explanatory properties. Milton's responses frame autism as a social construct and a spectrum of dispositional diversity and embodied experience (also argued in Milton, 2014, 2017; and elsewhere), by highlighting autistic contributions and the links between the concept of neurodiversity, autistic culture, and

their importance in empowering autistic people to understand themselves away from medicalised discourses.

By considering the characteristics of transcendental arguments, one can clearly identify certain ontological pitfalls in Timimi's approach on autism. He claims that there are no "essential and knowable biological differences," thus equating "essential and biological" with "knowable," falling into constructionist traps that were challenged earlier in the article. Further, he states that "you can't un-diagnose someone with heart failure, but you can un-diagnose someone of autism," which is debatable; one may be "un-diagnosed" with heart failure either by medical error or, more nefariously, intentionally by a doctor fearing a ruined reputation that may follow links to ineffective treatment. The latter would of course constitute malpractice, and if discovered it may be punished, but that is independent of the action itself. Similarly, one may be un-diagnosed as autistic simply because they were misdiagnosed in the first place, by an error in a clinician's judgement, or because a clinician does not think that knowing they are autistic will be of value to them. The latter two could be equally harmful as the first example, since the person would be experiencing the many consequences of being autistic in a neurotypical world, regardless of diagnosis, as many later-identified autistic people will attest. Medicalised approaches do stigmatise autistic people (Grinker, 2015), but the concept of neurodiversity can, and does, help many understand themselves better. Not *all* autistic people will be as invested in understanding autism as some of us are, but this does not devalue the neurodiversity paradigm as an academic approach or a tool for autistic emancipation.

Framing autism as a psychiatric invention to pathologise a set of behaviours neglects that those behaviours pre-existed their pathologisation and therefore can exist outside it. Furthermore, because this framing rejects objectivity, it also attempts to escape fallibility and accountability; interestingly, Timimi does not perceive his approach to autism and his role as a diagnostician as contradictory to one another. Additionally, it is not transphenomenal, because it uses appearances to make ontological and epistemological assumptions about autism by attributing its argued essential inexistence simply to its behaviourist diagnosis. Finally, it is not counter-phenomenal, because by not going past appearances, it also does not consider factors that contradict them.

Milton's responses align very closely with the arguments presented earlier, which meet the criteria of transcendental arguments as I presented above; as far as this discussion is concerned, therefore, the only element that, in my view, weakens his argument is its lack of an explicitly Critical Realist stance. By presenting autism as a social construct, despite acknowledging the existence of embodied diversity, and not untangling the ontological and epistemological implications of this position clearly, he falls into the trap of engaging with red herring questions such as "how do you know that autism exists?" and cannot meaningfully argue why his position is stronger on any other front apart from ethics, which is heavily critiqued by Timimi throughout. Transcendental arguments, therefore, can strengthen his position by asserting that autism indeed has an essential nature even if it cannot be epistemologically accessed, measured, and analysed.

Critical Realism, Interdisciplinarity, and Stratification and Emergence

In the previous section I argued that for theories of autism that are reflective of the deeper realism of autism and thus have greater explanatory power, it is important to include autistic input in our theorising to produce strong, transcendental arguments. In this section, I will discuss how Critical Realism as a philosophy can help set the foundation for effective interdisciplinary autism research. I will present how some of the current approaches on autism conflate autistic input with disciplinary approaches to knowledge. Finally, I will explain why using both interdisciplinarity and substantial autistic participation in autism research are important for an understanding of autism that is as complete as possible.

To understand what interdisciplinarity is, we must first establish how different disciplines are divided, why these divisions exist in the first place, what kind of explanatory power over phenomena the mechanisms that each discipline studies have, and how, by interacting with each other, they can capture a fuller picture (Wiltshire, 2018). Critical Realism uses the terms deep and shallow realism because it views reality as stratified. For Critical Realism, reality consists of a number of strata, some more fundamental than others. These strata are not reducible to one another, and a stratum being more fundamental does not mean that it can explain everything found in subsequent strata (Bhaskar, 1998). For example, physics, which is considered to be the most fundamental stratum from which all subsequent strata develop, is not able to fully explain the behaviours of all plants and animals, even though they are all bound by the laws that physics is concerned with. The most helpful way to perceive the stratification of nature, therefore, is a stratification of mechanisms. At the level of the Actual, however, relations between strata overlap, interact, and affect each other in a multiplicity of ways (Collier, 1994).

To return to the earlier example of an autistic meltdown, for example, one may be able to understand and record its physiological elements both as factors that constitute it and as elements that can partially explain it. However, autistic meltdowns may also have social reasons, psychological reasons, sensory reasons, and be the result of other intersecting experiences, and the overlap of all these factors is likely to be unique in each case. Bhaskar examines the relations between mechanisms that reside in different strata in terms of rootedness and emergence. Higher-level mechanisms are rooted in, and emergent from, more basic ones; rootedness, however, does not mean reducibility, because more basic strata cannot explain higher-level mechanisms. While there may be an argument to be made that current social structures around autism emerged originally from the embodied differences of autistic people that neurotypical people tried to regulate, the social structures themselves cannot be fully explained by these embodied differences, as mechanisms rooted in social structures,

systems, beliefs and values play a huge part in how these embodied characteristics were perceived and managed.

Another element of higher-level strata is that they cannot be understood as closed systems. Closed systems are what makes experimentation possible, and they are more prevalent in lower strata, such as physics and chemistry. This may be less and less possible when it comes to higher and higher strata, which is why studying mechanisms in those strata means that are used for mechanisms that reside in lower strata may be impossible (Wikgren, 2005). On this basis, Bhaskar (1975) concludes that a person's neurophysiology is not a closed system, as it is constantly affected by our interaction with others. This could explain why randomised control trials, a method regularly used in the field of psychiatry and psychology to study autism interventions (Simonoff, 2018) are often criticised. Since autism is identified by behavioural criteria, it is dependent on interactions to be observed. It would be impossible, therefore, for it to be studied as a closed system, because the social nature of that interaction is the very thing that is "intervened" on, and interaction cannot be conceptualised as a closed system as it is always susceptible to external factors that cannot be isolated without the phenomenon itself either changing substantially or seizing to exist overall.

The philosophy of Critical Realism can help us address these epistemological inconsistencies and, consequently, to support interdisciplinary research that can provide deep explanatory theories of autism. To do so, we would need a philosophy that can be applied to all disciplines involved, and, as I hope I have shown here, Critical Realism can be just that. The debates between positivist approaches and interpretivist/social constructivist approaches on autism are often presented as differences between disciplines (e.g., Milton, 2012), making communication between disciplines that much more difficult, and further creating the illusion that the knowledge of one discipline is irrelevant to the knowledge of the other. Knowledge and epistemological ways of acquiring or constructing it often does not crossover from one field to another and scientists hold strong and passionate opinions around the impact and validity of their stance, making this gap even harder to breach (Baringer, 2001). Yet studying an all-encompassing set of phenomena such as autism can surely not be done in the constricts of any one discipline alone. Critical Realism can, therefore, serve as a useful meta-theory that can help communication between the various disciplines, the application of the knowledge of one to the other, and help scientists who wish to examine their own practice philosophically communicate with each other more easily (Bhaskar and Danermark, 2006).

This could be the trap that many of the autistic approaches to autism research have fallen into. In their effort to distance themselves from pathologizing approaches to autism, they have conflated autistic input with certain disciplinary approaches. This is mostly because to this day most autism research does not have either; it is both neurotypically produced *and* rooted in only a small subsection of disciplines (namely psychology, psychiatry, neuroscience, and genetics) which applies mainly positivist approaches to its research, and therefore responses to it can easily conflate lack of autistic input with disciplinary approaches that need not be, and often are not, autistically created. Even though the predominant theories of autism that came out of the fields of psychiatry, psychology and neuroscience are not autistic-led, the theories that social scientists use to criticise the pathologisation of autism, and to portray it from the perspective of their discipline, will not be autistic-led *either*; they were likely written by neurotypical researchers to discuss aspects of life that, according to them, apply to neurotypical and neurodivergent people alike, since that distinction was not considered at all. This does not mean they are not useful; it merely means that they are as neurotypically produced as the theories in other disciplines. There is, however, a reason that many autistic scholars are attracted to them; they can be very helpful in the process of explaining aspects of the autistic experience that are not considered at all from research produced in the medical/natural disciplines, thus providing much-needed nuance, and pointing out that the epistemological conceptions of autism through these disciplines are not the be-all-end-all of what autism is, and in fact because they present it as such autism knowledge can easily be grossly misrepresented, as already explained in the prior sections. It is not, therefore, *just* autistic input they need, but interdisciplinary approaches as well.

Although autistic approaches to autism that lie outside the fields of social sciences and humanities may be rare, that does not mean that they do not exist. One such example is the recent paper by Buckle et al. (2020) on inertia, a concept used by autistic communities to describe the difficulty that autistic people may experience in starting tasks, stopping tasks, and switching from task to task, which has not been explored at all by neurotypically led research. In it, Buckle, an autistic neuroscientist, investigates the participants' experiences of inertia, an interest she developed based on her own experiences of it. In this paper, inertia is presented at least partly as an impairment, rooted in the body, and as something that a purely social constructionist approach on autism may not be able to fully capture or explain. This paper can be viewed as an example that autistic perspectives can be found in any discipline and that to study and understand the embodied experience of autism does not necessarily mean to stigmatise it, regardless of the fact that this is what most neurotypically produced research on autism has historically done. To have a better understanding of autism, therefore, we need both autistic input, which will help us understand the embodied phenomena of autism *and* interdisciplinary approaches, which will help us apply a variety of mechanisms traditionally studied by different disciplines to it in a way that does not stigmatise autistic people but produces a fuller picture of autism instead.

CRITICAL NATURALISM: AUTISTIC SOCIABILITY

Autism, Agency, and Social Structures

So far in this paper, I have used the concepts of transcendental realism to explore how they can be applied to both autism as an embodiment and to the conceptualisation and study of it as an embodied state. In the following part, I will discuss how the second part of Bhaskar's theory, Critical Naturalism, can be used to understand autistic experiences in a sociological context, what

it may mean for how we conceptualise autism and its implications for participatory research.

In his conceptualisation of social beings and social knowledge, Bhaskar (2015) engages with the debate of structure versus agency as it is conceptualised by humanist and structuralist approaches. Humanist approaches examine society purely through the lens of agency and, consequently, as a collection of actions enacted by its agents. Structuralism, on the other hand, sees structure as everything, and considers individuals to be bound by those structures that act in ways that make all agency bound to its relevant structures (Archer, 2003). Bhaskar, following on Marx's footsteps, reconciles those two positions; he suggests that what is needed, instead, is a "this and" theory, one that considers both agency and structure as aspects that shape society. On the one hand, agency can be seen in human actions committed by either individuals or organisations, such as corporations or governments. On the other hand, the meaning of actions, their functions and limits are decided by societal structures; an agent can only act in so far as the limits of the structure will allow. Bhaskar (2015) suggests, therefore, that to understand those structures we must focus on the *relations* between individuals, between individuals and structures, and the relations between these relations. These relations may be ontologically independent, in that they exist before any one person enters them; however, they are also transformed by the actions of the agents that occupy them. In this way, societies make people and people make societies (Archer, 2000).

This conceptualisation of agency and structure can help us conceive the tensions that may arise both between autistic and non-autistic people, and between neurotypical conceptualisations of autism and their autistic-led critiques. First of all, autistic praxis in and of itself may be perceived as a challenge to neurotypically created societal structures. Bhaskar (2015) highlights that social agents' praxis consists both of conscious production and, typically unconscious, reproduction of the structures that make up society. It is this unconscious reproduction of structures that autistic people do not typically partake in, to some degree. This is especially the case when one looks into the microsocial processes (Scheff, 2007) in autistic people's lives, in other words the way that they navigate their day-to-day life. It may be less so the case when we examine macrosocial processes, how autistic people perceive larger social structures (Boatca, 2007), as autistic people are capable of having racist, sexist, homophobic, transphobic and ableist attitudes. Autistic people can, therefore, be just as unreflective about the role these larger social structures play in their lives and society more broadly as anybody else, particularly if they are not impacted by them directly.

Autistic people's, often unconscious, resistance to the reproduction of social structures is, in my mind, both a core tenet of the autistic disposition and difficult to conceptualise. I believe that this autistic resistance to structures, which may be curbed throughout one's lifetime both intentionally and unintentionally, is key to understanding the autistic disposition as it is manifested in the social world. Take capitalist economic structures for example. These typically dictate that most people must spend a third of their day doing some form of monetizable labour in some sort of workplace, to earn enough money to cover their basic necessities. Autistic people, many of whom are unable to sustain meaningful employment under the current neurotypical and capitalist regime, therefore, challenge this structure simply by existing (see also Milton, 2018; Yergeau, 2018), whether they want to or not, and have to live with the consequences of this for their entire lives, much like disabled people in general do (Oliver, 2004).

That is not to say, however, that autistic people do not reproduce some microsocial structures, in varying degrees; both in the case of masking/camouflaging as a survival mechanism adopted by autistic people and in the case of neurotypically-led behavioural interventions on autistic people, the very thing that is targetted is how to make autistic dispositions more compatible with the neurotypical world. As there is no such thing as an autistic society, there is no such thing as a mechanism that regulates autistic (or indeed neurotypical) relations that has been autistically created. Accounting for the second element of the agent-structure relation as well, the ever-present condition of (a neurotypically led/created) society is, therefore, crucial in understanding and conceptualising autism. We can, however, see a demonstration of autistic agency in the creation of autistic-led organisations and events, which show that autistic communities may create social norms that are liberating for autistic people that are participating in them (Sinclair, 2010) and challenge the way dominant neurotypical structures assert how spaces need to operate.

Understanding agent-structure relations is also crucial to conceptualise autistic emancipation. It is because autistic people are independent agents that they are able to enact their own emancipation and it is important to recognise them as such to be able to notice the multiplicity of ways in which autistic dispositions rebel against neurotypical structures. It is also important to recognise that autistic people inevitably change the structures they inhabit in a unique way because they are autistic and despite any neurotypical attempts to kerb their tendency to do that. If their autistic disposition were not what it is, the neurotypical world would not try to manage and control it. Existing as an autistic person, therefore, is almost a forceful demonstration in agency. As Bhaskar points out, social forms may change irrespective of the agent's desire to change them in any particular way, yet it is important to recognise that social agents may also attempt to deliberately change the structures; there is a reason that so many autistic people become activists. It is also important to recognise the extensive pervasiveness of neurotypical societal structures. Autistic people may not even be able to perceive themselves outside of these ever-present and pervasive structures. For many autistic people, they even define how they perceive their own autistic disposition, making it impossible for them to conceptualise themselves away from the neurotypical gaze. Having a careful examination of the relationship between agency and structure, therefore, is key in understanding the various ways in which autistic sociality manifests itself.

Critique, Explanation, Emancipation, and Autistic Participation in Autism Research

In the final part of this paper, I will present how the concepts of Critical Naturalism, namely explanation and emancipation, can help develop autism research that is based on and explanatory of, autism itself and how an ethical naturalist approach on autism research can help develop research that is simultaneously grounded in facts and ethically informed. Price (2019) presents the development of Bhaskar's theory of explanation and emancipation in six levels. The first level is to identify that some belief we hold about an intransitive object is false; for example, the belief that autistic people do not possess theory of mind. The second level consists of applying the process from level one, instrumental rationality, in a particular context, such as a system of domination. For example, autistic people are perceived to lack theory of mind by neurotypical people, and thus the "theory of mind" approach is neurotypically created. At this level, it is also highlighted that there may be more than one problematic belief taking place. In the case of autism, factors like neurotypical assumptions about communication and capitalist structures that focus on monetary perceptions of efficiency and productivity also contribute to what is expected by autistic people in the first place, and therefore how their actions are judged as well. Level three consists of a negative evaluation of the false belief that accounts for the mismatch of the belief with the reality of what it is about. For example, stating that the belief that autistic people lack theory of mind is harmful and dehumanising, and also that in reality the difficulty autistic people have in empathising with non-autistic people is the same as the difficulty that non-autistic people have in empathising with autistic people.

Level four consists of positively evaluating actions that aim to disconnect the false belief from the object, actions that aim to challenge this pre-existing false consciousness. Continuing with the previous example, this would be designing research and practice that takes the double empathy problem into account and adopting an autism ethos that is informed by it. What this stage highlights about the uniqueness of theory for the social world is that the criticism of the belief will rub onto its cause, (Collier, 1994) which in this case would be a certain type of autism research and practice that it seeks to challenge. It is also worth noting that it is in this stage that the process will be faced with significant resistance; as Collier (1994) points out, certain institutions and false beliefs may be in a functional relation, as beliefs of false consciousness may serve to sustain such institutions in the first place. For example, research and funding that has been dedicated into further studying and exploring the lack of theory of mind in autistic people is directly challenged by this process and, should this premise be accepted, such research will have to significantly transform (and, in some cases, even be abandoned altogether). This is a significant challenge that will undoubtedly be met with resistance; however, if scientists are dedicated in pursuing the truth, as they ought to be, then this is a challenge they have to rise up to and adjust their practice accordingly.

Level five consists of a concrete ethical judgement of level four, which is specific to the geohistorical context that the theory was created in. Abstract universalism is, therefore, avoided and even the most powerful explanatory theory becomes a non-deterministic one (Buch-Hansen, 2005). In this way, the critical realist ontology demands a readjusting both in ethics and in epistemology. The stratified nature of reality helps us understand how a theory may be concrete at the level of the real, that of mechanisms, but not at the level of the empirical, that of experiences (Price, 2019). For example, simply because autistic people may be able to better empathise with each other, does not mean that they always do; A good example of that in the case of autism is racial, cultural, or ethnic differences; white autistic people may not always be able to empathise with autistic people of colour, and autistic people from different cultural backgrounds will have cultural barriers in the way of empathising with each other. It is important, therefore, to account for those differences when talking about the double empathy problem; this does not weaken the theory itself since it already recognises that these misunderstandings are, at least partly, cultural in the first place. Rather, it highlights the openness of the system it is applied to, the social world, in which no theory can be universal and deterministic. This is why self-reflexivity is always required as well; as Bhaskar highlights, critique is part of the process it describes because the very description it produces is subject to the same lack of reflexivity it identifies (Archer, 2010). Therefore, critical explanatory theory without self-reflection is just as moot as the theory it criticises.

The final level, level five, is the level in which the action occurs. Practical application of theories, therefore, and theory that informs practice, is how explanatory theories lead to emancipation under critical naturalism. It is by producing explanations that criticise social institutions that we begin the work of their subversion (Collier, 1994) and it is only when the subversion takes place that the process is complete. In this way, Critical Realism sets the roadmap for institutional change and sets a number of guidelines for evaluating the process.

The argument made here is that first of all, autism research ought to try to identify the truth about autism. In the earlier parts of the article, I have argued, I hope convincingly, that this may not happen without both significant autistic involvement in autism research and interdisciplinary approaches. The way autism research operates within current structures, however, may stand in the way of that, as not only do they not facilitate the two processes, but they also do not recognise their importance (Kapp et al., 2013; Milton and Bracher, 2013; Chown et al., 2017; Fletcher-Watson et al., 2019). It will need, therefore, to undergo significant transformation to meet this challenge and effectively produce research that investigates the truth about autism. Additionally, autistic emancipation is intrinsically tied to the recognition of autistic contributions, to autism knowledge that autistic people resonate with, and to the creation of policy and practice that is informed by such knowledge. This is what will transform the structures currently in place, within autism research, education, employment, social policy etc.

It is important to recognise that no research, regardless of its discipline, is completely asocial as all research is bound by the structure of the social world that encompasses it (Sayer, 1997). Commitment to social transformation, therefore, is everyone's

responsibility. Consequently, there needs to be recognition of how the current structures prevent autistic knowledge creation that is impactful. Furthermore, efforts toward autistic emancipation will always fight against larger systems that are fundamentally exclusive, such as capitalism. Given that impactful theory needs to first and foremost be practical, the argument here is not that no progress can be made unless these structures are first overthrown; rather, the argument I am making is that every autism scientist, irrespective of the field they work in, needs to have a basic understanding of how autism operates within neurotypical structures to be able to understand autism in the first place, and thus to be able to form meaningful research questions. Moreover, every autism scientist is responsible for the inclusion of autistic participation in their research if they intend for their research to be as close to the intransitive reality of autism as possible, and thus needs to be aware of the barriers that may prevent autistic people from making meaningful contribution to this process. For every autism research project there should be a concrete argument about how it aids autistic emancipation, and consequently autistic wellbeing, instead of reproducing structures whose knowledge production is inaccurate at least and harmful at most. Finally, every funding decision in autism research needs to justify how the research funded is beneficial, rather than harmful, to autistic people.

CONCLUSION

In this article, I have attempted to summarise the main points of the philosophy of Critical Realism and demonstrate how it can be useful in critically assessing autism research, how it supports autistic participation in autism research and autistic theorising. I have attempted to show why a clear and consistent philosophy of autism, autistic participation in autism research as well as interdisciplinary approaches to knowledge production are crucial in the process of creating impactful autism research. To achieve that, however, the current structures around research and practice will need to be significantly transformed, and some even abandoned altogether. This will be a process that may be met with some resistance however, it is a necessary step forward to address the impasse that autism research finds itself into, and to shape autism research in a way that serves the interests of those that it is about, primarily autistic people and secondly those who live and work with them, parents, caregivers, professionals etc.

A variety of social barriers will have to be overcome for this to be achieved. Several academic disciplines may be inaccessible to autistic people for reasons that are beyond the particular institution's immediate control, such as educational barriers that have prevented them to get the qualifications necessary to become researchers in the first place. There will be other barriers, however, that may be more easily addressed, such as providing an accessible workplace and creating space in the conversation for the autistic voice. Either way a collective, interdisciplinary commitment to autistic emancipation is the way forward and providing philosophically sound research is both a prerequisite and an outcome of it. Finally, although autistic emancipation should be a commitment for everyone producing autism research, even if that goal may sound too vague and political to some, ontologically and epistemologically sound research achieves just that; and Critical Realism is the vehicle to help achieve it. It is in every researcher's best interest, therefore, to ensure that their research is ontologically resonant, epistemologically consistent, and ethically sound. This paper attempted to be the one of the first (see also Botha, 2021b), attempts in this endeavour.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

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CASE REPORT
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Case Report: Mechanisms in Misdiagnosis of Autism as Borderline Personality Disorder

Stine Iversen[1]* *and Arvid Nikolai Kildahl*[1,2]

[1]*Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital, Oslo, Norway,* [2]*NevSom Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Oslo University Hospital, Oslo, Norway*

Autistic individuals without intellectual disabilities are sometimes not diagnosed until adolescence/adulthood. Due to increased risk of co-occurring mental health problems, these individuals may initially be referred to general, mental health services and not always be identified as autistic; some may be misdiagnosed with personality disorder (PD) prior to identification of autism. To explore possible mechanisms in misdiagnosis of autism, we report on the case of a young man with severe, non-suicidal self-injury (NSSI) and attention deficit disorder (ADD) who had been diagnosed with and treated for borderline PD prior to being diagnosed with autism. Following reassessment by mental health clinicians with experience of working with autistic individuals, the patient was diagnosed with autism, ADD, and depression—but not PD. Experiences from this case suggest that presence of co-occurring NSSI, depression, and ADD, as well as lack of comprehensive assessment and lack of autism knowledge in general mental health services, may contribute to risk that autism is misdiagnosed as PD. These findings highlight the need for autism expertise in general mental health services to facilitate appropriate diagnosis for autistic individuals who encounter these services, as well as the importance of undertaking comprehensive assessments.

Keywords: autism, personality disorder, assessment, mental health, self-injurious behavior, misdiagnosis

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***Correspondence:**
Stine Iversen
stiniv@ous-hf.no

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INTRODUCTION

Outcomes applicable to real-world contexts, with the potential of contributing to improvement in the lives of autistic individuals, are viewed as increasingly important in autism research (Roche et al., 2021). Also, there is a growing recognition that collaboration with the autistic community is an important part of the research process. Access to and expertise within services, including how individuals' needs can be met in these services, have been found to be important areas of research for the autism community (Pellicano et al., 2014). A recent review identified the mental health of autistic people, as well as accurate identification and knowledge of autism, as important priorities (Roche et al., 2021).

It is not uncommon for autistic individuals without co-occurring intellectual disabilities to be diagnosed in adolescence/adulthood (Huang et al., 2020). As autism is associated with increased prevalence of psychiatric disorder (Lever and Geurts, 2016; Rosen et al., 2018), many may first be referred to mental health services due to these co-occurring difficulties rather than

because of their autism (Huang et al., 2020; see also Stagg and Belcher, 2019; Henley, 2020; Tromans and Chester, 2020). However, autism characteristics may be confused with symptoms of psychiatric disorder by mental health professionals (Helverschou et al., 2011; Au-Yeung et al., 2019), and autism may thus not always be recognized (Fusar-Poli et al., 2020). Assessment and understanding of the specific individual's autism characteristics are likely to be a prerequisite for differentiation between these characteristics and mental health symptoms, and thus also for adequate diagnosis of co-occurring mental health problems in these individuals (Helverschou et al., 2011; Rosen et al., 2018).

Differentiating autism and psychiatric disorder may be challenging (Helverschou et al., 2011; Rosen et al., 2018) and may be particularly challenging for personality disorders (PDs; Lugnegård et al., 2012; Da Cagna et al., 2019; Gordon et al., 2020). The relationship between autism and PD is poorly understood, and recent studies have led to growing awareness that they share surface symptom similarities contributing to challenges in differential diagnostic assessment (Rydén et al., 2008; Lugnegård et al., 2012; Da Cagna et al., 2019; Gordon et al., 2020). Both conditions affect the ways in which the individual communicates and interacts with other people (American Psychiatric Association, 2013; Da Cagna et al., 2019) and thus may impact several aspects of life, including friendships, intimate relations, and work.

Furthermore, autism and PD both refer to stable characteristics (American Psychiatric Association, 2013; Da Cagna et al., 2019), which makes approaches typically applied to differentiate autism and psychiatric disorder less helpful, i.e., where the clinician looks for changes to level of functioning, behavior, or autism symptomatology (Helverschou et al., 2011). However, autism characteristics are usually to some degree present and observable from early childhood, while symptoms of PD typically manifest during adolescence (Da Cagna et al., 2019; Gordon et al., 2020). A detailed developmental history may therefore be helpful to distinguish these conditions (Da Cagna et al., 2019). In adults, however, this may be challenging because retrospective reports from caregivers alone may not be sufficiently reliable or informative when it comes to early development (Fusar-Poli et al., 2017).

Recent findings indicate that PD may be a relatively common misdiagnosis in autistic adults before their autism is recognized (Kentrou et al., 2021). The current case concerns a young man who had been diagnosed with and treated for borderline PD for several years, before he was reassessed and diagnosed with autism. The current study aims to explore the possible mechanisms in the previous misdiagnosis, to identify potentially contributing mechanisms.

The study was approved by the Data Protection Official at the Oslo University Hospital (#20/14349). The patient has been anonymized.

CASE DESCRIPTION

At referral, "Adrian" was in his early 20s. In childhood, he displayed delayed language development and concentration problems, and was diagnosed with attention deficit disorder (ADD), dyslexia, and specific learning difficulties. Adrian described these difficulties as resulting in low self-esteem: "I could not read or write like the other kids in school. I felt stupid." During adolescence, he developed symptoms of anxiety and depression and started displaying non-suicidal self-injury (NSSI). This resulted in several admittances to acute psychiatric inpatient wards. Adrian also had a history of suicide attempts. At 18, he was diagnosed with borderline PD. During a later admission, Adrian completed the Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R; Ritvo et al., 2011) but scored below the cutoff value for autism. No further autism assessment was undertaken. Assessment of Adrian's intellectual abilities indicated functioning in the low average area.

Adrian had been treated with various kinds of antidepressants, antipsychotics, and anxiolytics. In addition to frequent hospitalizations, he had received outpatient therapy for borderline PD. Adrian lived alone and had daily visits from municipal mental health services which mainly involved delivery of medication. He had a girlfriend and two friends he occasionally spent time with, but described difficulties initiating contact. A lot of Adrian's time was spent engaging in NSSI (typically cutting himself) and seeking out emergency medical and mental health services. Episodes involving NSSI would occur up to 14 times a month, sometimes with more episodes in 1 day if the first episode did not result in a certain number of stitches.

Adrian described his previous contacts with the mental healthcare system as often leading to feelings of rejection. He frequently experienced not being heard or listened to, with mental health professionals emphasizing their own understanding of his difficulties rather than exploring Adrian's own views. This included a primary focus on risk and management of NSSI, while paying less attention to other difficulties.

The current, inpatient assessment in a specialized ward included interviews with Adrian, his family and professional caregivers, use of structured assessment tools, and direct observation by clinicians. The team included a psychologist, a psychiatrist, psychiatric nurses, social education nurses, and experienced nursing assistants. Assessment tools included autism diagnostic tools, conventional assessment tools for mental disorders, and one tool developed for assessment of mental disorders in autistic people.

Adrian described feeling lonely as an important trigger for NSSI. He never communicated to others about it prior to engaging in NSSI, and NSSI most often occurred when he was alone in the evenings or at night. NSSI was not reported to occur as a response to interpersonal conflict. During interviews, it became evident that Adrian had difficulties recognizing and discerning emotions. He had few words for his inner states and expressed that emotions were difficult to manage: "even joy is difficult, emptiness is better." Adrian described fear of being a burden in friendships and relationships with caregivers, and there often was a discrepancy between his inner states and what he communicated to others. In general, Adrian rarely experienced conflicts in his interactions with other people but described reacting to interpersonal difficulties by withdrawing and letting the relationship "fade out."

The autism diagnostic tools included the Autism Diagnostic Observation Schedule-2 (ADOS-2; Lord et al., 2012), a semi-structured interaction observation and interview, and the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994), a semi-structured interview with caregivers. The ADOS-2 was done with Adrian himself, while the ADI-R was completed with his parents. In addition, a detailed developmental history was obtained from Adrian's parents, Adrian himself, and existing medical records and previous assessments. Adrian's scores on the ADOS-2 and the ADI-R indicated presence of a potential autism spectrum disorder, see **Table 1**. While the diagnostic algorithm of the ADI-R focuses on the ages 4–5, Adrian's parents described that several of the relevant behaviors became more evident in Adrian's adolescence, making the "current" score for the ADI-R higher than the one used in the diagnostic algorithm. The clinician completing the ADOS-2 remarked that while Adrian seemed to display several appropriate strategies for social interaction, he tended to use similar strategies throughout the assessment situation, even when they could be perceived by others as less appropriate. Direct observation in the ward indicated that Adrian displayed several good strategies for coping in social interaction but had more extensive difficulties with communication and flexibility. Observations in the ward and during individual therapy also indicated that Adrian's mentalization abilities (i.e., his abilities to make inferences regarding his own and others' mental states; Gordon et al., 2020) did not fluctuate with emotional states or level of emotional activation. Thus, these observations were in line with the results from the ADI-R and the ADOS-2, suggesting that Adrian had difficulties in social interaction and communication, but that his difficulties in communication were more extensive than his difficulties in other aspects of social interaction.

For assessment of PD, the Structured Clinical Interview for DSM-IV Axis II Personality Disorders (First and Gibbon, 2004) was used as an interview with Adrian himself. Adrian reported symptoms in various domains, including schizoid, avoidant, dependent, and borderline PD. However, he did not report sufficient symptoms to meet criteria for any of these disorders. On the Mini International Neuropsychiatric Interview (Sheehan et al., 1998), Adrian reported symptoms of anxiety, depression, and dysthymia. No traumatic experience according to the diagnostic criteria for post-traumatic stress disorder was reported, but Adrian described lifelong difficulties with feeling stupid, out of place, and having difficulties interacting with other people. On the Montgomery and Åsberg Depression Rating Scale (Montgomery and Åsberg, 1979), Adrian scored 24, indicating moderate depression. Further assessment tools included an autism-specific screening tool for mental disorder, the Psychopathology in Autism Checklist (Helverschou et al., 2009), and assessment tools for trauma-related disorders. These yielded no further information relevant to the diagnostic formulation.

TABLE 1 | Scores on the Autism Diagnostic Observation Schedule-2 (ADOS-2) and Autism Diagnostic Interview-Revised (ADI-R), with cutoff values.

Scores and cutoffs on the ADOS-2 and ADI-R subscales			
	Score	**Cutoff autism**	**Cutoff autism spectrum**
Autism Diagnostic Observation Schedule-2			
Communication	5	3	2
Reciprocal social interaction	4	6	4
Communication + Reciprocal social interaction	9	10	7
Creativity	0	N/A	N/A
Restricted and repetitive behaviors	0	N/A	N/A
Autism Diagnostic Interview-Revised			
Reciprocal social interaction	6	10	
Communication	8	8	
Restricted, repetitive and stereotyped behaviors	3	3	
Atypical development apparent at or before 36 months	2	1	

The ADOS-2 uses two different cutoff values, while the diagnostic algorithm of the ADI-R only uses one. Module 4 of the ADOS-2, for adolescents and adults with fluent verbal language, was used.

TIMELINE

Age	Incident/diagnoses
3	Delayed language development.
10	Dyslexia diagnosed. Outpatient treatment for emotional problems.
11	Attention deficit disorder (ADD) diagnosed.
16	Debut of non-suicidal self-injury (NSSI).
17	Debut of what was later understood as recurrent depressive disorder. First suicidal attempt. First admittance to an acute psychiatric ward.
18	Increasing frequency and severity of NSSI. Diagnosed with borderline personality disorder (BPD).
20	Autism suspected. Negative screening.
22	Referred for specialized assessment. Autism diagnosed, with co-occurring ADD and depressive disorder. BPD removed as diagnosis.

DIAGNOSTIC FORMULATION AND TREATMENT PLAN

It was concluded that Adrian met criteria for an autism spectrum disorder, co-occurring ADD, and depressive disorder but not borderline PD. Prior to referral, Adrian had been prescribed olanzapine 10 mg for agitation and restlessness, fluoxetine 40 mg for depressive symptoms, quetiapine 200 mg for sleep, and levomepromazine 50 mg for sleep. Use of a wide range of other psychopharmacological medications had previously been attempted. Because Adrian had possible side

effects (lowered energy and slurred speech) and because he was not assessed to have a psychotic disorder, treatment with antipsychotics (olanzapine and quetiapine) was discontinued. Within a few weeks, a slight change in Adrian's demeanor was observed; he took more social initiatives and seemed more articulate. No negative effects of discontinuation were observed. According to both himself and informants, fluoxetine treatment seemed to have some effect on Adrian's depressive symptoms and was therefore continued, as was levomepromazine to help him sleep.

Individually adapted mental health nursing strategies emphasized providing structure, aiding Adrian in regulating his emotions and performing enjoyable activities. This included maintaining a low degree of criticism and demands, making suggestions of activities while putting little pressure on Adrian. Physical activity, regular meals, and maintaining good sleep habits were emphasized. Adrian agreed to practice making contact with nursing staff whenever he felt anxious or had an impulse to engage in NSSI. In these instances, staff focused on helping Adrian to identify and experience alternative strategies for relieving inner tension, an approach inspired by strategies from dialectical behavior therapy (Iversen et al., 2019; see also Hartmann et al., 2012; Bemmouna et al., 2021).

Adrian had sessions with a therapist 2–3 times a week during the stay, focusing on psychoeducation about autism and depression, as well as identification, recognition, and regulation of emotions. The latter was achieved by Adrian and the therapist making an individually adapted booklet with overview of the different emotions, their functions, how Adrian experienced them, and possible strategies to manage them. The individual therapist and nursing staff collaborated closely throughout the admission, for instance by helping Adrian test potential emotion regulation strategies identified during therapy in other settings. Adrian cut himself only once during the stay. This episode occurred during one of the times he was on leave from the ward.

DISCUSSION

The current patient, a young man with severe NSSI who previously had received a diagnosis of borderline PD, was assessed to meet criteria for autism and depressive disorder. This changed understanding and adaptation of treatment seemed to have positive consequences for the frequency of NSSI, as well as for his relationships with family and caregivers, and led to a change in his strategies for seeking assistance. Lack of previous, comprehensive assessment and the patient displaying severe NSSI, in part possibly due to co-occurring depressive disorder and ADD, seemed to have contributed to misdiagnosis of autism as borderline PD.

In the current assessment, the combination of standardized assessment tools for autism and PD, going through the patient's history, clinical observation, and use of informants together proved sufficient to differentiate autism and borderline PD. Obtaining a thorough developmental history using multiple sources was important, as was use of the ADOS-2 (see Fusar-Poli et al., 2017; Da Cagna et al., 2019). However, the assessment was carried out by a team with specific expertise and experience in mental health problems in autistic individuals, indicating a need for this expertise also in general mental health services. Experiences from this assessment suggest that it may be necessary to collect comprehensive information regarding signs and symptoms of both conditions in order to differentiate them or determine whether they co-occur (Da Cagna et al., 2019; Gordon et al., 2020): The current patient's mentalization abilities did not seem to fluctuate with his emotional state, and he displayed reduced sharing of emotions rather than intense emotional involvement. However, during admission to acute mental health services prior to the current assessment, the patient had frequently been in a state of crisis, likely obscuring these nuances from the professionals treating him. Thus, it was necessary to observe and interact with the patient in an environment where he felt safe and taken care of to distinguish autism and PD.

Moreover, the patient's difficulties with regard to social engagement were pervasive rather than transient; he did not display a pattern of attachment and rejection in interpersonal relationships, and his NSSI rarely occurred as a response to interpersonal conflicts. While his NSSI did seem to serve a function in regulation of emotion, this rarely involved others and he would often hide occurrences of NSSI from significant others (see Gordon et al., 2020). Finally, borderline PD is described to be associated with chronic feelings of emptiness (American Psychiatric Association, 2013). The current patient did not report problems with feelings of emptiness but seemed to pursue such feelings to avoid other, problematic emotions.

No clear, distinctive features have been identified to easily differentiate NSSI in autism and borderline PD, and the mechanisms in development of NSSI seem to share significant overlap between these respective conditions (Wilcox et al., 2012; Moseley et al., 2019). The current case indicates that presence of NSSI may be one factor contributing to risk that autism is misdiagnosed as borderline PD. NSSI in autistic individuals seems to be associated with impulsivity and lowered mood (Licence et al., 2020), suggesting that individuals with co-occurring depression and/or ADD/ADHD may be particularly at risk for this misdiagnosis. While it is unclear whether later autism diagnoses are associated with an increased risk of NSSI (Moseley et al., 2019; Licence et al., 2020; Hosozawa et al., 2021), the mechanisms described by the current patient as contributing to development of NSSI suggest that undiagnosed autism may have played a significant part. Thus, the current case indicates that further exploration of associations between later autism diagnoses and risk of NSSI is warranted, including whether there may be a subset of individuals with difficulties involving impulsivity and depression particularly at risk.

Undiagnosed autistic individuals displaying NSSI may initially be referred to general mental health services, and the current case highlights the need for professionals in these services to

have the knowledge necessary to recognize and diagnose autism (see also Takara et al., 2015; Stagg and Belcher, 2019). The patient received treatment for borderline PD without any observable improvement in his difficulties for several years. In line with previous suggestions (Rydén et al., 2008; Fusar-Poli et al., 2020), screening for autism may thus be warranted in patients with NSSI and assumed PD not benefitting from attempted treatment. However, as in the current case, screening using only a single instrument and not conducting a comprehensive, differential diagnostic assessment may be insufficient (see also Fusar-Poli et al., 2017; Da Cagna et al., 2019).

Finally, the current patient reported experiencing mental health professionals as being primarily focused on risk management, and often feeling that he was not listened to. While risk management is important in instances of severe NSSI, listening to the views of people with NSSI is also important for understanding of triggers for NSSI. Thus, failure to listen to the patient on the part of mental health professionals may constitute another potential mechanism in misdiagnosis of autism as PD.

Limitations and Strengths

The current study concerns a single case and therefore has limited generalizability, but its findings may be transferrable on a case-to-case basis to clinicians undertaking similar assessments (Maxwell and Chmiel, 2014). The exploration of a single case provided further insight into some of the possible mechanisms of misdiagnosis in autistic adults described by previous literature (e.g., Fusar-Poli et al., 2020).

Conclusion

This case highlights the importance of autism knowledge in general psychiatric services. These services may be the first to encounter young, autistic adults who are yet to receive the appropriate diagnosis and have developed co-occurring difficulties, such as depression or NSSI. The ability of clinicians in these services to recognize signs of autism may thus be vital to these patients' course of treatment and later outcomes. This case further underlines the importance of conducting comprehensive assessments when autism is suspected and provides an example that NSSI may constitute a severe and potentially lethal problem for undiagnosed autistic individuals, as well as how the appropriate diagnosis and understanding of these individuals' difficulties may contribute to alleviating this problem. Finally, experiences from this case suggest that possible mechanisms in misdiagnosis of autism as PD may include lack of comprehensive assessment, lack of autism knowledge in general mental health services, and misinterpretation of commonly co-occurring conditions in autism, such as NSSI, ADD, and depression. Contact with mental health professionals primarily in acute phases involving NSSI, when the patient had frequently been in a state of crisis, may also have contributed to this misinterpretation of his difficulties, as may a lack of exploration of the patient's views and his own understanding of his behaviors.

PATIENT PERSPECTIVE

Both Adrian and his parents reported finding the autism diagnosis helpful, as well as being a more appropriate description of how they understood his difficulties. The authors collaborated with Adrian in the writing of this manuscript, discussing the possibility of writing it before he provided written consent. Adrian read and provided important feedback on the manuscript, in particular the sections about how he experienced previous contacts with mental health professionals. Adrian approved the final version of the manuscript prior to submission.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, and further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

The study, involving human participants, was reviewed and approved by the Data Protection Official, Oslo University Hospital. The patient/participant provided their written informed consent to participate in this study. Written informed consent was obtained from the individual for the publication of any potentially identifiable images or data included in this article. Written informed consent was obtained from the participant for the publication of this case report.

AUTHOR CONTRIBUTIONS

SI and AK jointly planned the current study and conducted the analysis. SI prepared the first draft of the manuscript, while SI and AK jointly revised and finalised it. All authors contributed to the article and approved the submitted version.

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Supporting Effective Transitions From University to Post-graduation for Autistic Students

*Rebecca Lucas[1], Eilidh Cage[2] and Alana I. James[3]**

[1] School of Psychology, University of Roehampton, London, United Kingdom, [2] Department of Psychology, Faculty of Natural Sciences, University of Stirling, Stirling, United Kingdom, [3] School of Psychology and Clinical Language Sciences, University of Reading, Reading, United Kingdom

Background: The number of autistic students graduating is increasing; however, little is known regarding their transition out of university. Understanding this transition is particularly pertinent with regard to the employment of autistic graduates. It is vital that we understand autistic people's experiences of the transition and identify what support would be beneficial during this time.

Method: Thirty-four autistic graduates from the United Kingdom took part in a mixed-methods study exploring their transition experience. Both quantitative and qualitative questions were used to obtain in-depth information concerning participants' experiences. Participants completed questions regarding their experiences and emotions in relation to the transition, the support they received for the transition, and their career and post-graduation plans.

Results: Participants reported high levels of fear and low preparedness for the transition. They did not feel well supported in preparing for the transition or for their future career. In the 6 months pre-graduation, 59% of participants had accessed emotion-related transition support and 70% accessed career-related support. Post-graduation, one-third accessed emotion-related or career-related support. Perspectives on this accessed support were mixed, as were transition experiences. Additional support desired included preparation for life changes, career planning, employment accessibility, and autism-specific support. Advice for future students centered on forward planning.

Conclusion: These results highlight the importance of supporting autistic students with the transition out of university. Service provision should be tailored to autistic students' needs and support early planning for the transition.

Keywords: autism, transition, graduates, university, higher education, employment

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Craig Goodall,
St Mary's University College Belfast,
United Kingdom

Reviewed by:
Marc Fabri,
Leeds Beckett University,
United Kingdom
Liudmila Liutsko,
Instituto de Salud Global
de Barcelona (ISGlobal), Spain
Elliott Spaeth,
University of Glasgow,
United Kingdom

***Correspondence:**
Alana I. James
a.i.james@reading.ac.uk

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INTRODUCTION

Increasing numbers of autistic individuals are attending university: in the 2019/20 academic year, 5,785 first-year UK-domiciled undergraduate students declared a diagnosis of autism (Higher Education Statistics Agency [HESA], 2021), a fourfold increase on the 1,065 students who did so in 2009/2010 (Higher Education Statistics Agency [HESA], 2011). Although autistic students[1] may

[1]Following the preferences of our participants, identity-first language is used in this paper.

be at higher risk of not continuing their studies (Cage and Howes, 2020), many do successfully graduate (Anderson et al., 2017; Richardson, 2017). However, securing and maintaining subsequent employment can be a challenge. Six months post-graduation, 12.2% of 2018 autistic graduates were unemployed compared to 5.1% of non-disabled graduates (Association of Graduate Careers Advisory Services [AGCAS] Disability Task Group, 2021). Further, while 60.4% of United Kingdom 2018 graduates without a disability were in full-time work 6 months post-graduation, this was only the case for 36.4% of autistic graduates (Association of Graduate Careers Advisory Services [AGCAS] Disability Task Group, 2021).

Autistic people bring numerous skills and strengths to workplaces (Bury et al., 2020); however, the previously mentioned statistics indicate that autistic students may benefit from additional support for the transition out of university and into employment. Currently, many autistic students make this transition either without any support or only with support from services that are available to the whole student population (van Schalkwyk and Volkmar, 2017). It has been recognized that professional services within the university environment could better support *all* students with this transition (National Educational Association of Disabled Students, 2012). To target support effectively, a greater understanding of the challenges that autistic students specifically face is needed, as this study set out to explore.

University to Post-graduation Transition

The transition from university is a pivotal time in any student's life, marked by great change. This period may be especially challenging for autistic students. Autistic individuals can have preferences for structure, routine, and familiarity (American Psychological Association [APA], 2013), which can link to intolerance of uncertainty and mean change can be challenging (Maisel et al., 2016). The transition out of university involves leaving university and entering employment, further study, or a period of unemployment. Thus, the end of undergraduate studies is characterized by departure from routine and loss of support networks. Adaption to new environments will be necessary if the graduate moves location and/or enters a new place of study or work. Encountering new physical environments and meeting unfamiliar people can be anxiety provoking for many autistic people (Van Hees et al., 2015). Difficulties may be exacerbated if the individual needs to acclimatize to the sensory environment (Robertson and Simmons, 2015).

Mental health difficulties may further impact this transition. Around 70% of autistic individuals have co-occurring mental health conditions, most frequently anxiety and depression (Mazefsky et al., 2008; Simonoff et al., 2008; Skokauskas and Gallagher, 2010; van Steensel et al., 2013). It is unknown whether the transition out of university exacerbates mental health conditions for autistic graduates, or whether it contributes to the development of new mental health difficulties. However, even for non-autistic students, mental health conditions are associated with poorer experiences of transition and higher rates of unemployment and under-employment (Association of Graduate Careers Advisory Services [AGCAS] Disability Task Group, 2021).

Evidently, there are multiple reasons why the transition from university may be challenging, but studies examining the experiences of autistic graduates are necessary to better understand the transition and support needed. To date, there is a concerning paucity of research on this topic (Cashin, 2018). Vincent (2019) interviewed 21 autistic students and graduates about their perception of the transition out of university. Vincent (2019) found that the transition could be a source of anxiety, especially for those who did not have a clear plan for their next steps, and one coping mechanism was avoiding engaging with the transition process. Some participants reported feelings of loss, for example in terms of independence, friendships, and momentum. However, others, often those with a clear plan, viewed the transition as a positive departure, with optimism about their future. For these participants, the transition was considered a shift into adulthood and associated with positive identity development.

Thus, Vincent (2019) provides qualitative insight into both the practical and psychological phenomena associated with the transition from university and highlights the importance of transition planning. Another qualitative study by Vincent and Fabri (2020) noted the role of the ecosystem around autistic students entering employment, such as their family, university support services, and their intended industry and employer. Their study highlighted the importance of a supportive network across this ecosystem, as well as the need for societal level appreciation of autistic people. While these studies help to inform the *focus* of and *need* for support, it is also important to consider in more detail the *format* of potential support systems. Insight may be provided by examining the effectiveness of current support for the transition into and during university.

University Support

Support designed for the transition *into* university is underpinned by evidence that this is a period of increased vulnerability for autistic people (Adreon and Durocher, 2007; Chown and Beavan, 2010; Beresford et al., 2013; Mitchell and Beresford, 2014; Van Hees et al., 2015; Elias and White, 2018). Such support often takes the form of pre-university summer programs, which provide direct experience of university life. Participant feedback on such programs is positive, with attendees reporting a reduction in concerns and an increase in optimism (Lei et al., 2019).

Once at university, support can be substantial and wide ranging, including group (e.g., social clubs and peer support groups), as well as one-to-one support (e.g., mentoring; Anderson et al., 2017). Both peer and specialist mentoring (involving a one-to-one relationship between a professional mentor and student mentee) can effectively support autistic students with their academic and mental health needs during university (Knott and Taylor, 2014; Ames et al., 2015; Hillier et al., 2019; Duerksen et al., 2021), especially when there is a personalized approach underpinned by a strong mentor-mentee partnership

(Roberts and Birmingham, 2017; Siew et al., 2017; Lucas and James, 2018; Thompson et al., 2018; Thompson et al., 2020).

Thus, there is preliminary evidence that *pre*-university transition planning, support groups and mentoring can effectively support autistic students' into and during their time at university. However, these forms of support do not specifically focus on preparing students for the transition *out* of university, and typically do not report on outcomes related to preparing students for independence (Flegenheimer and Scherf, 2021). With the transition *into* university the destination is known, and certain experiences predicted, thus it can be planned for. With the transition *out of* university there are more unknown variables, meaning the need for support may be even greater. Additionally, the degree of support an autistic person may experience during their transition into university and across their studies could mean that an absence of support for the transition out would be keenly felt.

Entering employment can present autistic people with both challenges and opportunities, but the right support can make all the difference (Hedley et al., 2018). To date, few studies have explicitly examined autistic perspectives on factors facilitating the university to work transition and the support universities provide to help prepare students for employment. Pesonen et al. (2020) interviewed 17 current autistic students, two autistic students who had not completed their studies, and 13 autistic graduates, from Finland, France, Netherlands, and United Kingdom. Careers support and internships were considered valuable, but barriers to access were identified such as the need to be self-directive. Support was considered most beneficial when individualized and provided in a caring manner. This study provides useful preliminary insight into autistic individuals' perspectives; however, it can be challenging to generalize the results due to the diverse students' statuses, e.g., students versus graduates and their range of country of study. Another study by Pesonen et al. (2021) with professionals (such as career advisors, academic tutors, employers) qualitatively analyzed suggested support strategies for autistic students seeking employment. The professionals suggested taking a person-centered, strengths-based approach, with a need for autism acceptance. Since the pre-existing studies have been qualitative, further quantitative data would be beneficial to further understand graduate's experiences, and further understand what supports autistic students' desire and need for the transition out of university, and whether any existing provision is well-suited to meet their needs.

Study Rationale and Aims

Given the poorer graduate employment outcomes of disabled students, the latest Association of Graduate Careers Advisory Services [AGCAS] Disability Task Group (2021) report calls for further research on the barriers and facilitators to disabled graduates achieving their career ambitions. Furthermore, transitional and vocational issues have been identified as a priority for autistic adults specifically (Nicholas et al., 2017), although there is a lack of research on this topic (Cashin, 2018). It is important to understand what aspects of the transition autistic graduates find difficult, and why. Further, increased understanding of the types of support accessed or desired is needed, as well as what the impact of such support could be. The current explorative study therefore aimed to investigate the experiences of the transition out of university for autistic students. Both barriers and facilitators were examined, with consideration of both emotional support and career-focused support.

We used an in-depth mixed-methods survey with both qualitative and quantitative questions, to ensure that the study not only gathered numerical data but also heard the perspectives of our participants. Taking a mixed-methods approach can avoid a mismatch between the desired focus of support and support provision, which can frequently occur for disabled students (Anderson et al., 2017). An online survey was selected to best reach a range of participants; the study sample comprised autistic adults who had recently graduated from United Kingdom institutions, to capture the experiences and perceptions of people who had recently experienced the transition (rather than students approaching the transition). Content analysis was used to analyze the open data; this was chosen as the most appropriate analytic technique both as the study was conducted from a broadly realist research lens, believing that useful insights can directly be gained from what autistic graduates have to say about their experiences, and as it is suitable for the quantity of qualitative data generated within open survey items. The knowledge acquired from this research could serve to increase understanding of the transition out of university for autistic students and inform support provision.

MATERIALS AND METHODS

Participants

Thirty-four autistic graduates (26 female, seven male, one preferred not to say) with a mean age of 27.78 (SD = 5.52, range 21–44) participated. The majority (n = 29) had studied full-time, three part-time, and two both full and part-time. Seven had graduated in 2018, eight in 2017, three in 2016, five in 2015, four in 2014, and seven in 2013. In line with national statistics (Higher Education Statistics Agency [HESA], 2021), most graduated with an upper second-class honors (n = 18), 12 with a first, three with lower second-class honors, and one a degree without honors. Participants had graduated from 26 different universities with 18 studying Science, Technology, Engineering, and Mathematics subjects and 16 Arts and Humanities.

Between November 2018 and February 2019, participants were recruited using convenience and voluntary sampling. Those who had graduated within the last 5 years from the authors' universities and had declared an autism diagnosis were invited to participate via an email from their University Disability Service which included the information sheet and study link. In addition, the study was advertised on Twitter, and interested participants were invited to contact the research team for further information. The study was conducted in accordance with the British Psychological Society guidelines for ethical practice, and ethical approval was granted by all authors' institutions. Informed consent was obtained from all participants, and debriefing information was provided at the end.

All participants reported a diagnosis of an Autism Spectrum Condition. Most had been diagnosed between the ages of 18–25 (n = 13), followed by those who had been diagnosed between the ages of 12 and 17 (n = 9) and over the age of 26 (n = 8). Some participants had been diagnosed under the age of 11 (n = 4). Qualitative responses indicated that some participants received their diagnosis after completing university; these participants were retained in the sample to include the experiences of autistic individuals who receive a late diagnosis. All participants scored above 14 on the Ritvo Autism and Asperger Diagnostic Scale-14 (RAADS-14; Eriksson et al., 2013; mean = 31.38; SD = 6.55; range = 19–41). Many participants reported a co-occurring mental health condition: specifically, 18 reported anxiety, 15 reported depression, 10 participants reported another mental health condition, most frequently PTSD (n = 4), and 10 reported other neurodevelopmental conditions, most commonly a specific learning difference of dyslexia, dyspraxia, and/or AD(H)D (n = 5).

Materials and Procedure

Participants completed an online survey, constructed using Qualtrics (Qualtrics, Provo, UT, United States) survey software. The measures included are outlined below in the order presented. The survey took around 25 min and participants received a £5 gift voucher.

Participant Characteristics

Participants were asked about their terminology preferences and this language was used throughout; most preferred "autistic students" (n = 28) and six preferred "students with autism." Demographic items included sex, age, diagnoses, and age of diagnoses, followed by information on undergraduate degree topic, year started, graduation year, and degree classification. Participants then completed a measure of wellbeing–the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS; Tennant et al., 2007), which includes 14 items covering feeling and functioning aspects of mental wellbeing over the last 2 weeks, with items answered a five-point Likert scale. Responses are summed to create a total score, ranging from 14 to 70, with higher scores indicating greater well-being. Next, they completed questions about autistic characteristics, from the RAADS-14 (Eriksson et al., 2013). This measure contains 14 statements covering aspects such as mentalizing, social anxiety, and sensory reactivity answered on a four-point Likert scale.

The Transition Out of University

Participants rated the extent to which they had felt seven different emotions, including sadness, acceptance and calm, selected from Plutchiks' (1991) theory of emotion, in relation to the transition. They also answered how prepared they had felt for the transition. All items were rated using a five-point Likert scale ["strongly disagree" (1) to "strongly agree" (5)]. Strongly agree and agree responses were combined to determine the percentage who reported feeling each emotion overall.

Transition support questions covered support received in preparation for the transition out of university. Participants were asked "While studying for your undergraduate degree, how supported did you feel by the university in terms of preparing for the transition out of university?" and answered using a five-point scale ["not very well supported" (1) to "very well supported" (5)]. They were also asked "During the last 6 months of your undergraduate degree did you access any emotional support related to the transition out of university?" and responded "yes" or "no" to options from a list (e.g., specialist mentor, personal tutor). Each form of support accessed was rated on a five-point scale ["not very helpful" (1) to "very helpful" (5)]. We also asked participants two open questions: "In what ways could the support you received for the transition out of university be improved?" and "What other support would you like your university to have offered for the transition out of university?" Then, participants selected which transition-related support they had accessed since graduating from a list and rated their helpfulness, as above.

Post-graduation Plans

We asked participants about their plans post-graduation, including what they were currently doing and what career-related support they had received. We asked participants who had graduated in 2018 to indicate what their main plan was for the next 6 months, and whether they planned to do anything else in the next 6 months, alongside their main plan. Options included "Paid employment," "Voluntary work or an internship," "Post-graduate study," "Gap year or traveling," "Don't know yet," and "Other, (please specify)." For the first three options, we asked whether a position had yet been secured ("yes," "no," or "awaiting outcome of application(s)"). Participants who graduated 1–5 years ago indicated what they had done in the first 6 months after graduation, as well as what they were currently doing in terms of work or further study.

All participants who had secured paid employment were asked how their job related to their undergraduate degree with response options of "It requires a university degree, and is related to the subject of my degree," "It requires a university degree, and is not related to the subject of my degree," "It does not require a university degree, and is related to the subject of my degree," or "It does not require a university degree, and is not related to the subject of my degree."

Regarding career support, participants rated the question "While studying for your undergraduate degree, how supported did you feel by the university in terms of preparing for your future career?" using the five-point scale detailed above. We also asked whether, during the last 6 months of their undergraduate degree, participants had accessed any career-focused support from a list and rated their helpfulness as above. We then asked two further open questions: "In what ways could the support you received for careers be improved?" and "What other support would you like your university to have offered for careers?" Additionally, participants were asked which forms of career support they had accessed since from a list and rated their helpfulness as before.

The survey concluded with a "final thoughts" section with two open questions: "Is there anything else you would like to say about your experience of the transition out of university?" and "What advice would you give to autistic students who are in their final year at university, to help them plan for when they finish university?"

TABLE 1 | Participants' emotions regarding the transition out of university (rated from 1 to 7).

	Fear	Acceptance	Anticipation	Sadness	Joy	Calm	Prepared	Anger
Mean (*SD*)	3.91 (0.83)	3.56 (1.02)	3.50 (0.90)	3.50 (0.90)	3.00 (0.83)	2.74 (1.02)	2.62 (1.05)	1.88 (1.01)
% Experienced	79.41	58.82	64.71	52.94	38.24	32.35	26.47	8.82

Design and Analysis

A mixed-methods exploratory design was used within a broadly realist research lens; we believed that our participants would self-report useful insights on the topic within both closed and open items in an online survey. Descriptive statistics are reported for the quantitative questionnaire items. Open-ended questions were analyzed using conventional data-driven content analysis (Hsieh and Shannon, 2005) to identify categories of answers.

Content analysis involves categorizing open data, enabling descriptive quantitative information to be reported about the extent to which different aspects are reported by participants. Data-driven content analysis involves developing a coding scheme based upon what is said within the data, rather than interpreting answers through a pre-existing framework derived from existing literature; this approach was chosen to best capture what autistic graduates reported about their support experiences. Developing the coding scheme necessarily involves some degree of researcher interpretation of the data. However, compared to some qualitative analysis techniques, content analysis involves less researcher interpretation as the focus is upon identifying and categorizing what is said by participants.

One author (AJ) initially read all the participants' responses and generated an initial coding scheme with categories and subcategories which most fully captured the different aspects reported by participants. The coding scheme included brief descriptions of all categories and subcategories for each open question, with examples of the type of open responses which would fit within each category/sub-category. This coding scheme was then checked and refined with the other two authors to promote analytic rigor, which involved them reading over the qualitative data and considering whether any aspects of their answers would have been omitted or obscured by the proposed coding scheme. Following the agreement of the coding scheme, all responses were coded into the categories and sub-categories by AJ. This involved reading each open answer and selecting each category and sub-category which represented it; answers could be coded in multiple categories and sub-categories to most fully capture what participants said.

Coding was then further checked by the other two authors which involved them reviewing which categories and sub-categories each open answer had been coded into; a small number of cases where queries were raised over the most appropriate coding were fully considered and resolved in line with the coding framework. Due to high overlap in the categories identified for the two open questions about improvements to current support and desired support (for both careers and the transition more generally), we combined coding across these two questions. Two participants did not provide answers to any of the open questions; all other participants answered two or more open questions. Percentages reported for categories and sub-categories are out of the total sample of 34 participants, including those who did not give an answer for that question. Brief descriptions of each main category and a representative quotation are included within the tables reporting the content analysis findings.

RESULTS

The Transition Out of University: Emotions

Nearly 80% of participants reported having felt fear toward the transition out of university, with 53% having felt sadness (**Table 1**). Less than a third had felt calm about or prepared for the transition. Over half had felt acceptance and anticipation, with few expressions of anger. Additionally, the mean wellbeing (WEMWBS) score for our participants was 41.91 (*SD* = 9.97; range = 20–66). Population surveys (e.g., Braunholtz et al., 2007) indicate that the mean score of the general public is 51, and scores one standard deviation below this (<42.5) indicates low well-being.

The Transition Out of University: Emotional Support

Overall, participants were somewhat negative regarding how well supported they felt for the transition out of university, with a mean score of 2.12 (*SD* = 0.98), equating to "disagree." In the 6 months prior to graduation, 58.82% had accessed emotional support for the transition. Over one-third had sought emotion-related support from a specialist autism mentor, with around a fifth having spoken to either a disability advisor or their personal tutor. Less than 10% had spoken to a wellbeing officer or counselor. Support from all sources was generally rated as helpful (**Table 2**).

Post-graduation, 44.12% of participants had accessed emotion-related transition support. Similar sources of support were utilized post-graduation as pre-graduation and were generally considered to be helpful. In addition, participants had consulted their post-graduate tutor, workplace mentor, and University's Careers Service. However, these were rated as neutral or not helpful (**Table 2**). Overall, 67.65% of participants accessed emotion-related transition support either pre- or post-graduation.

Content analysis of qualitative answers to questions about potential improvements and desired transition support indicated that just under one-third of participants would have valued support preparing for the life changes, both in terms of the emotional aspect and adjusting to non-university life (**Table 3**). Many answers referenced careers and employment support. Nearly a third of participants desired support with employment access, just over a quarter discussed career support, specifically

TABLE 2 | Participants' use and perception of emotion-related transition support and career-related transition support, pre- and post-graduation.

	Emotion-related support				Career-related support			
	Pre-graduation		Post-graduation		Pre-graduation		Post-graduation	
Source of support	***n* (%) utilized**	**Helpfulness Mean (SD)**	***n* (%) utilized**	**Helpfulness Mean (SD)**	***n* (%) utilized**	**Helpfulness Mean (SD)**	***n* (%) utilized**	**Helpfulness Mean (SD)**
Specialist autism mentor	12 (35.3)	3.83 (1.40)	6 (17.6)	4.17 (1.17)	9 (26.5)	3.89 (1.70)	5 (14.7)	3.60 (1.14)
Disability advisor	8 (23.5)	3.13 (1.64)	7 (20.6)	3.14 (1.77)	8 (23.5)	3.63 (1.69)	–	–
Wellbeing or welfare officer/counselor/therapist	6 (17.6)	4.00 (0.89)	2 (5.88)	5.00 (–)	–	–	–	–
Undergraduate personal tutor	7 (20.6)	4.00 (0.82)	5 (14.7)	3.80 (1.64)	17 (50.0)	3.71 (1.36)	3 (8.82)	3.67 (2.31)
Post-graduate personal tutor	–	–	6 (17.6)	2.33 (1.37)	–	–	6 (17.6)	3.67 (1.75)
Workplace/volunteer placement mentor	–	–	3 (8.82)	3.33 (0.58)	1 (2.94)	5.00 (–)	5 (14.7)	2.80 (1.79)
University careers service	–	–	7 (20.6)	2.71 (1.38)	16 (47.1)	2.69 (1.14)	6 (17.6)	3.17 (1.33)
National careers service	–	–	–	–	–	–	3 (8.82)	3.67 (1.53)
Other–recruitment agency	–	–	–	–	–	–	1 (2.94)	4.00 (–)

– represents a lack of data, for example because n = 1 (thus no SD possible), helpfulness was not rated, or the source of support was not specified/available pre/post-graduation.

reporting a need for more career guidance, help finding employment and making contacts. Some wanted support with post-graduate study, such as help with understanding options and applications, and with accessibility. Other answers concerned the nature and timing of support, desiring support that was earlier, for not just when in crisis, and more positive support. Two participants felt that no extra support was needed, and nearly a quarter said they had received little or no transition support, either out of choice or lack of access.

Post-graduation: Future Plans

Seven participants had graduated within the last 6 months. One indicated that they did not have a post-graduation plan, while six reported plans and activities. Two of these six were pursuing paid employment (one while also caring for a family member) and two had secured a place on a post-graduate course (one was also considering part-time employment). Another was on a health-orientated gap year (while also hoping to pursue post-graduate study), and one was self-studying learning a language. Three of these six participants had additionally secured voluntary work or an internship, while the other three intended to do so.

Of the 27 participants who graduated 1–5 years ago, 88.89% had been in post-graduate study and/or paid employment in the first 6 months following graduation (**Table 4**). However, only four of the 11 employed participants had secured a role that required a university degree, with three being related to their degree subject. The remaining seven had a role that did not require a university degree, six of whose job was not related to their degree subject.

For those who had graduated 1–5 years prior, trends were similar; 81.48% were undertaking post-graduate employment and/or studying. However, only four of the 12 employed participants had secured a role that required a university degree, with three being related to their degree subject. The remaining eight had a role that did not require a university degree, six of whose job was not related to their degree subject.

The Transition Out of University: Career Support

Participants were neutral regarding how well supported they felt in terms of preparing for their future career with a mean score of 2.39 (*SD* = 1.20). In the 6 months prior to graduation, 76.47% had accessed career-related support (**Table 2**). Around 50% had spoken with their undergraduate tutor or utilized their undergraduate degree institution's Careers Service. Around 25% had sought career-related support from a disability advisor or specialist mentor. Support was considered helpful, with the exception of the Careers Service which received a neutral mean helpfulness rating of 2.69 (*SD* = 1.14).

Post-graduation, 38.24% of participants had accessed career-related support, only one of whom had not accessed careers support prior to the transition. Thus, 20.59% of participants had not accessed career support either before or after the transition. Furthermore, 17.65% did not access either career or emotional support, pre- or post-graduation.

Of those who did access career-related support post-graduation, around 15% had sought support from their university's Careers Service, post-graduate tutor, specialist mentor, or workplace mentor (**Table 2**). Less than 10% of participants sought support from their undergraduate tutor or the National Careers Service. All forms of support were rated between 2.8 and 4 for helpfulness (i.e., neutral to helpful).

Content analysis of answers to questions about potential improvements or desired career-related support (**Table 5**) identified that over a quarter felt that autism-focused support would be beneficial, specifically in terms of greater understanding of autistic students' needs and more accessible support. Nearly a

TABLE 3 | Content analysis of participants' suggestions for transition support additions or improvements, showing categories (in bold) and sub-categories (bullet pointed).

Categories and sub-categories, with illustrative quotations	%	*N*
Preparation for life changes–transition support could be improved through greater support around preparing for the life changes involved in leaving university "*A bridging course would have been helpful and discussion about what would happen. For me it all seemed to end very suddenly as I didn't really think about it too much and I wasn't prepared*"	**32.35**	**11**
•Emotional support	14.71	5
•Support adjusting to non-university life	17.65	6
Employment access–transition support could be improved through greater support around access to employment "*It would have been nice if there had been some advice for people with disabilities. For example, tips for accessing the workplace, tips for overcoming the additional challenges people face during interviews, and so on*"	**29.41**	**10**
•Accessibility and reasonable adjustments	11.76	4
•Understanding working life	8.82	3
•Applications and interviewing support	8.82	3
•Disability positive employers	2.94	1
Careers support–transition support could be improved through greater careers support "*Help with careers so [I] could find next steps*"	**26.47**	**9**
•Careers guidance	14.71	5
•Support finding employment	8.82	3
•Careers contacts	5.88	2
Post-graduate study support–transition support could be improved through greater support around post-graduate study "*Offer more encouragement or accessibility if possible to places or returning to the university*"	**17.65**	**6**
•Options and applications	8.82	3
•Accessibility and reasonable adjustments	5.88	2
•Preparation for the transition	2.94	1
Nature of Support–the nature of the transition support available could be improved "*I could have known if there were any services around, it could have been made more clear. There was mentoring but it would have been helpful if I could have had specific help on Post-University life*"	**17.65**	**6**
Not just when in crisis	8.82	3
More positive support	5.88	2
Make it easier to access wider support	2.94	1
Timing of Support–the timing of transition support could be improved "*Slowly building up to leaving over the last year- maybe a timeline, things to think about, when to do what etc.*"	**14.71**	**5**
•Earlier support	11.76	4
•Recognition of symptoms	2.94	1
No Changes Needed–"*None. I was quite happy*."	**5.88**	**2**
Little or No Support Received–"*I received no specific support regarding my transition out of university so anything would be an improvement*"	**23.53**	**8**
•No Support Available	11.76	4
•Challenges Accessing Support	5.88	2
•Chose not to Access Support	5.88	2
Unclear Answer	**2.94**	**1**
No Answer	**11.76**	**4**

Sub-category n can total more than the category n as responses could be coded under multiple sub-categories.

quarter indicated a need for more career planning support, and a fifth desired employment access support, including identifying disability positive employers, applications or interviewing support, and accessibility/adjustments. Others suggested careers connections support and two mentioned post-graduate study support. Four felt no extra support or improvements were needed, and around one-fifth had received little or no support either out of choice or lack of access.

Final Thoughts on the Transition

When asked whether there was anything else they would like to say about their transition out of university (**Table 6**), a third of participants commented upon their university experience with most making negative evaluations. A fifth referenced post-graduate study, with most reporting having had a positive transition experience and some having concerns about leaving their post-graduate degree. Around a sixth made evaluative comments about the transition, reporting both positive and negative experiences, and some referenced worries about their future.

When asked what advice they would give to autistic students in their final year (**Table 7**), just over two-fifths of participants gave advice centered on forward planning with nearly a third advising students to plan early, and others suggesting they should do their research but aim to balance studying and career planning. A fifth advised students to prepare for the upcoming

TABLE 4 | Pursuits of participants who graduated 1–5 years ago.

	First 6 months post-graduation *n* (%)	Now *n* (%)
Post-graduate study only	11 (40.7)	8 (29.6)
Post-graduate study + paid employment	2 (7.41)	3 (11.1)
Post-graduate study + volunteering/internship	2 (7.41)	2 (7.41)
Paid employment only	8 (29.6)	9 (33.3)
Paid employment + volunteering/internship	1 (3.70)	0
Unemployed	2 (7.41)	3 (11.1)
Volunteering/internship only/ + gap year	1 (3.70)	2 (7.41)

life changes both in terms of what their emotional and practical needs would be, and around one-sixth gave advice regarding managing expectations for the future. Answers concerning careers and employment included preparation for the workplace, particularly around possible adjustments, several avenues of careers preparation, and building experience while at university. Other advice concerned making use of university support, either before or after graduation.

DISCUSSION

Although numbers of autistic students in higher education have increased, there is little research concerning what happens when these students transition *out* of university. The current study makes an important contribution by examining the experience of autistic graduates. Emotionally, our participants reported high levels of fear and low levels of preparedness for the transition, but half also reported feeling acceptance and anticipation. Generally, participants did not feel particularly supported by their university. In the last 6 months of university, just over half had accessed emotional support for the transition, mainly from their specialist mentor, and 70% had accessed career-related support, with 50% utilizing their university's Careers Service. Although participants rated the support they had received positively, participants expressed that they would have liked more support preparing for life after university, both emotionally and practically, greater careers advice and employment access guidance, and some desired post-graduate study support. Furthermore, participants highlighted the benefits of autism-specific support and for support to be earlier, not just at crisis points, and more positive. Of concern, open comments revealed many negative evaluations of the university experience and transition support, with some participants remaining worried about their future, however more positive experiences of post-graduate study were also reported.

Our participants expressed both negative and positive emotions related to the transition out of university. Qualitative answers also indicated a mix of positive and negative evaluations of the transition and support and ongoing worries. This finding aligns with Vincent's (2019) interview study, where participants also reported that the transition evoked mixed emotions; a sense of anxiety and loss, that could also be accompanied by optimism and positive identity development. Thus, support for the transition out of university could not only address the students' concerns but also encourage focus on the positives. Interestingly, our findings here are broadly comparable to the emotions reported by students with mental health conditions (Cage et al., 2021a). Our autistic participants reported many co-occurring mental health conditions, therefore the emotions experienced may be related to aspects of anxiety and depression (for example). This is in line with Accardo et al.'s (2021) study with autistic students in the United States where mental health needs were identified as a theme affecting university performance.

Around a third of participants indicated that they would have liked more support preparing for the life changes related to the transition out of university, both emotionally and practically. Graduates' desire for support in these areas aligns with evidence on the difficulties of encountering change (Maisel et al., 2016), new physical environments and people (Van Hees et al., 2015) and on sensory challenges experienced by many autistic people (Robertson and Simmons, 2015). Support with the emotional aspects of the transition out of university is especially vital given the high co-occurrence of mental health conditions, and these findings again echo those noted for non-autistic students with mental health conditions (Cage et al., 2021a). Our findings show that it is important for universities to support autistic students with the emotional and practical aspects of transition, not just with careers and employability.

Despite over three-quarters of participants having concerns regarding the transition, only over half had accessed emotional support related to this in the 6 months prior to graduation. The most common sources of support were specialist mentors, disability advisors, and personal tutors, and the support provided was considered helpful. This is consistent with the limited extant research (Pesonen et al., 2020). However, while specialist disability professional service staff may be well equipped to support autistic students, this may not be the case for personal tutors, who tend to be members of academic staff. To ensure that students are receiving optimal guidance, additional training for personal tutors may be beneficial (Dona and Edmister, 2013) and such training is currently being developed and tested (Waisman et al., 2021). Qualitative responses did not indicate any preference for particular formats or sources of support. Preliminary investigations could focus on summer transition programs, support groups, and peer or specialist mentoring as these can effectively support autistic students with the transition into university and their time at university (Knott and Taylor, 2014; Ames et al., 2015; Roberts and Birmingham, 2017; Siew et al., 2017; Lucas and James, 2018; Thompson et al., 2018; Hillier et al., 2019; Lei et al., 2019; Thompson et al., 2020; Duerksen et al., 2021). This approach would enable support to be more autism-specific, which our participants expressed a desire for.

Fewer of our participants accessed transition-related emotional support once they had graduated, although participants who continued studying consulted their post-graduate personal tutor and institutions' Careers Service. Qualitative comments indicated that some participants had positive experiences of the transition from undergraduate to post-graduate study, with some answers making it clear that this was a safe space which avoided the transition out

TABLE 5 | Content analysis of participants' suggestions for career-related support additions or improvements, showing categories (in bold) and sub-categories (bullet pointed).

Categories and sub-categories, with illustrative quotations	%	*N*
Autism Focused Support–careers support tailored to autistic students would be helpful "*Autistic-specific career workshops or workshops in smaller groups*"	**26.47**	**9**
•More understanding of autistic students' needs	17.65	6
•Autism specific careers support	8.82	3
•More accessible careers support	8.82	3
Career Planning Support–more careers planning support would be helpful "*More clarity about my career paths with the course I was doing*"	**23.53**	**8**
•Awareness of possible career paths	11.76	4
•Awareness of wider career options	11.76	4
•Making plans for the future	2.94	1
Employment Access–careers support could be improved through greater support around access to employment "*It would have been good to have gained some advice on career fields that are Autism/disability-friendly*"	**20.59**	**7**
•Disability positive employers/fields	8.82	3
•Interviewing support	8.82	3
•Accessibility and reasonable adjustments	5.88	2
Career Connections–careers support could be improved through greater support in making contacts and finding opportunities "*Careers [support] would be good if I could get a list of contacts for possible employers. Inviting more companies to the campus that operate in different fields*"	**17.65**	**6**
•Finding employment	8.82	3
•Careers contacts	5.88	2
•Campus work opportunities	5.88	2
Nature of Support–the nature of the careers support available could be improved "*Understanding of autism by career services. I found there was an expectation to fail and just being told to take a year to adjust and then try for jobs whereas I just wanted to get on with work and found this bad advice*"	**17.65**	**6**
•More positive support	8.82	3
•More advanced support	8.82	3
Post-graduate Study Support–careers support could be improved through greater support around post-graduate study "*. . .a list of supportive universities and contact with services at those universities about the support they could put in place if I was to come and that to actually be carried through*"	**5.88**	**2**
•General information	5.88	2
•Accessibility and reasonable adjustments	2.94	1
No Extra Support or Improvements Needed–"*I was happy with the support I received*"	**11.76**	**4**
Little or No Support Received–"*I chose not to seek out most support for post-university life so I can't really offer any improvements*"	**20.59**	**7**
•Chose not to access support	11.76	4
•No support available	5.88	2
•Unclear why little support received	2.94	1
No Answer	**17.65**	**6**

Sub-category n can total more than the category n as responses could be coded under multiple sub-categories.

of university. This finding aligns with data showing that the rate of autistic students entering post-graduate study after their first degree is higher than for non-disabled students, and for students with other types of disabilities (Association of Graduate Careers Advisory Services [AGCAS] Disability Task Group, 2021). Unfortunately, graduates may then experience the same difficulties with the transition out of this level of study, with some participants reporting worries about leaving their post-graduate course. Furthermore, employment outcomes for autistic post-graduates are concerning. Autistic post-graduate graduates on taught programs are three times more likely to be unemployed than non-disabled graduates (9.9% compared to 3.3%), while autistic post-graduate research graduates are seven times more likely to be unemployed than non-disabled graduates (16.1% compared to 2.3%; Association of Graduate Careers Advisory Services [AGCAS] Disability Task Group, 2021). Given the financial costs involved in post-graduate study, it is imperative that future research investigates how those who do enter post-graduate degrees can be better supported.

This study also examined career-related support, with our participants rating their careers service neutrally. University Careers Services are specifically designed to offer support, guidance, and opportunities pre- and post-graduation; thus, they should be the optimal form of careers support for students and recent graduates. It is therefore important to consider why it was not rated more favorably. Content analysis indicated that participants felt that it could be more tailored to autistic students' needs, with greater understanding of autism, autism-specific support (such as workshops specifically for autistic students), and for support to be more accessible (such as in smaller groups). Some also recommended more positive support (due to negative experiences) and for support to be more detailed. The extant literature indicates that given the low numbers of disabled students (relative to the student population as a whole), Careers

TABLE 6 | Content analysis of participants' additional open comments about their transition out of university, showing categories (in bold) and sub-categories (bullet pointed).

Categories and sub-categories, with illustrative quotations	%	*N*
University Experience–participants' experiences of university or of support for the transition out of university "*[it] kinda sucks getting dropped at the end*"	**32.35**	**11**
• Positive evaluation of university experience	5.88	2
• Negative evaluation of university experience	8.82	3
• Negative evaluation of university transition support	14.71	5
• Difficulties due to diagnosis after graduation	5.88	2
Post-graduate Study–answers related to the transition into post-graduate study or the eventual transition out of post-graduate study "*I returned, so I feel like I haven't exactly transitioned out of university. I am currently in my final year of Ph.D. and am somewhat uncertain as to what will happen afterward as even now I feel I am going to have difficulty finding employment at the end*"	**20.59**	**7**
•Positive feelings about transition into post-graduate study	14.71	5
•Concerns and difficulties about transition into post-graduate study	5.88	2
•Worries about leaving post-graduate study	11.76	4
Transition Out of University–participants' experiences of the transition out of university "*Still 3 years after graduation I feel like I am not properly equipped for this adult life. I don't feel like anybody expected me to be and feeling like there was little belief in me having any future prospects still makes me feel sad and uncertain. I'm faced with years of life that I do not know how to fill*"	**17.65**	**6**
•Positive evaluation of the transition	8.82	3
•Negative evaluation of the transition	11.76	4
•Valued social support	2.94	1
Worries About the Future–participants' current worries about the future "*Despite feeling ready to graduate, I still find the idea of not going back to the university, being in lectures, or seeing lecturers again distressing as I became so used to that routine*"	**11.76**	**4**
•Going into/finding employment	8.82	3
•Housing post-university	2.94	1
•Loss of university routine	2.94	1
•Friendships post-university	2.94	1
Not Sure/Answer Unclear	**14.71**	**5**
No Answer	**26.47**	**9**

Sub-category n can total more than the category n as responses could be coded under multiple sub-categories.

Service staff may have infrequent experience of supporting such students, which can result in a loss of confidence and expertise over time (Equality Change Unit, 2008). This finding indicates that regular training may be helpful for Careers Service staff. In addition Association of Graduate Careers Advisory Services [AGCAS] Disability Task Group (2021) recommends that university careers services receive appropriate resourcing in order to put effective intervention in place.

It is reassuring that most of our participants had accessed emotional or career-related support. Qualitative comments showed that some participants who received little or no support had chosen not to access it, but others perceived none to have been available or experienced challenges accessing it. This finding aligns with the perspectives of autistic students and graduates from other European universities (Pesonen et al., 2020). It is important that barriers to accessing support and potential facilitators are considered, for universities to best meet the support needs of the autistic student population. One recurring theme from our participants centered around the need for increased support in terms of accessibility and reasonable adjustments, both within the transition and in terms of future careers or post-graduate study. Our study highlights accessibility in employment and further study as a key area with which autistic students require support. Support could potentially aim to increase both students' knowledge of accessibility and their ability to self-advocate for their rights in future work and studies. Self-advocacy has been identified as important for accessing appropriate reasonable adjustments and support during university, both for students with disabilities in general (Fossey et al., 2017) and autistic students specifically (Accardo et al., 2019). Self-advocacy may be especially important for long-term positive outcomes given the reduction in support graduates are likely to experience once they leave university.

Participants also suggested more career planning support is needed, specifically increasing students' awareness of possible career paths related to their degrees or of career options generally. This finding aligns with data that shows a lower proportion of autistic graduates chose their current job role due to alignment with their career plan, compared with non-disabled graduates (Association of Graduate Careers Advisory Services [AGCAS] Disability Task Group, 2021). Additional support with making career connections was also desired, in line with evidence that meeting unfamiliar people can be anxiety-provoking for autistic students (Van Hees et al., 2015). Interestingly, some participants suggested that help gaining work experience on campus would especially benefit autistic students and when asked what advice they would give to final-year autistic students, one participant suggested "*use your preference for socializing with older adults to network*." The time point for transition planning is critical; students recommended that this should begin early and not just take

TABLE 7 | Content analysis of participants' advice for final year autistic students, showing categories (in bold) and sub-categories (bullet pointed).

Categories and sub-categories, with illustrative quotations	%	*N*
Planning–advice which related to planning for the future "*Start thinking about your plan well in advance*"	**41.18**	**14**
•Plan early	29.41	10
•Do your research	11.76	4
•Balance studies and career planning	5.88	2
Prepare for Life Changes–preparing for the life changes involved in the transition out of university, in terms of either your practical or emotional needs "*Try to plan ahead for the changes to your environment and your support network as that will help relieve some anxiety over the unknown*"	**20.59**	**7**
•Practical needs	14.71	5
•Emotional needs	14.71	5
Expectations for the Future–advice about the expectations students should have for the transition "*The world doesn't end but it's not easy*"	**17.65**	**6**
•Expect transition to be difficult	11.76	4
•Don't worry about the future	5.88	2
Prepare for Adjustment to Workplace–consider in advance the need to adjust to the workplace after university "*Find out as much information as possible about further support in the workplace*"	**17.65**	**6**
•Workplace adjustments	14.71	5
•Have an existing job	2.94	1
Careers Preparation–take steps to prepare for developing a career "*Try to network with people within the career you are pursuing*"	**14.71**	**5**
•Make contacts	8.82	3
•Make lots of applications	5.88	2
•Access careers support	5.88	2
Use University Support–make use of support available at university either during your undergraduate degree or when you enter a post-graduate degree "*Reach out and use all services available before graduating and learn whether or not you can use those resources post-graduating so there is no uncertainty*"	**14.71**	**5**
•Pre-graduation	8.82	3
•Post-graduation	8.82	3
Build Experience–build up experience during the degree to help with the transition and careers "*Do lots of other things at university that might improve your prospects, like volunteering*"	**11.76**	**4**
•Volunteer	5.88	2
•General	2.94	1
•Get experience in societies	2.94	1
Not Sure	**5.88**	**2**
No Answer	**8.82**	**3**

Sub-category n can total more than the category n as responses could be coded under multiple sub-categories.

place at crisis points. Helping students to plan their transition out of university earlier could reduce uncertainty. Past research has indicated that programs specifically for autistic people which provide real-world work experience and vocational skills training can be beneficial for the transition to work (Flower et al., 2019).

Limitations

This study makes an important contribution by examining autistic graduates' experiences of the transition out of university. However, the participants in this study were self-selecting, and thus may not be representative. Recruiting a representative sample of autistic graduates can be challenging (cf. Vincent, 2019) but rather than restricting the sample to the authors' universities, participants were recruited from throughout the United Kingdom. This resulted in participants from 26 different universities, increasing variability of experience. However, given the small number from each institution, it was not possible to examine the extent to which findings were influenced by specific university contexts. It is also important to consider the relatively small total sample size; future research could extend this exploratory research.

It is interesting to note that three-quarters of the participants were female. Although this is contrary to the traditional male:female gender distribution of 3:1 in the autistic community (Loomes et al., 2017), some studies suggest that female autistic students' university enrollments could be as high as 47% (Dillenburger et al., 2016). Thus, our sample may be more representative of autistic people in the university community. The data was also retrospective; future research could longitudinally examine both expectations pre-transition and experiences post-transition.

We used a mixed-methods design, within a broadly realist lens, combining closed and open survey items and content analysis to most fully capture what autistic graduates had to say about careers and transition support. We note that there would be much value in further qualitative research from other philosophical positions to provide in-depth explorations of both what autistic graduates have to report and how they communicate about this topic.

Implications

The results of this study indicate that while autistic students are accessing support, and it can be beneficial, there is potential for improvement. Specifically, universities should ensure that autistic students are supported with preparing for the life changes involved in leaving university, particularly in terms of the emotional aspects of this transition, and with the accessibility of employment and further study. Earlier planning for the transition would be beneficial, and universities should consider how to help autistic students access support earlier to facilitate this.

In addition to considering the nature of support, it is also important to consider the delivery of such support. Careers Services could become more effective by providing their staff with additional training in understanding autistic students' needs and guidance on providing more tailored careers support. This conclusion echoes the Association of Graduate Careers Advisory Services [AGCAS] Disability Task Group (2021) report, which also recommends Careers Services provide more tailored careers support for disabled students and receive appropriate resourcing to implement interventions. Our findings also align with reported experiences of non-autistic students with mental health conditions (e.g., Cage et al., 2021a,b), suggesting that improvements are needed to support students with a range of needs more widely. Principles of Universal Design may therefore be useful when it comes to tailoring support: that support is designed with accessibility at its heart, and this serves to benefit *all* students (Gradel and Edson, 2009). Nonetheless, autism-specific understanding was clearly desired by our participants, and staff still need to better understand the unique strengths and challenges faced by autistic students.

Additionally, relationships developed through peer and specialist mentoring could be capitalized upon. Such support can effectively support autistic students with their academic and mental health needs during university (Knott and Taylor, 2014; Ames et al., 2015; Roberts and Birmingham, 2017; Siew et al., 2017; Lucas and James, 2018; Thompson et al., 2018; Hillier et al., 2019) and careers mentoring from tutors and life coaches is rated highly (Pesonen et al., 2020). Thus, peer and specialist mentoring could be extended to also help prepare students for the transition out of university. Furthermore, universities could also work with employers to reduce recruitment barriers. Supportive internships may be one viable route to providing autistic students and graduates with exposure to the work environment and the work experience that many employees require. Such internships have been rated positively by autistic graduates (Remington and Pellicano, 2019; Romualdez et al., 2020; Schall et al., 2020; Remington et al., 2021), but future initiatives should take into consideration the identified areas for improvement.

CONCLUSION

The transition out of university can be a challenging time for autistic students: many autistic graduates consider transition support beneficial and recommend that it should focus on planning for life post-graduation, considering both everyday life and careers guidance. Universities should support students to access pre-existing services and support earlier transition planning. It is recommended that transition support is tailored for autistic students, while using principles of Universal Design, including ensuring that careers staff understand their needs and that support is provided on the accessibility of employment and preparing for life changes. With such support in place, a successful transition from university to post-graduation life is increasingly likely.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, on reasonable request to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Department of Psychology at the University of Roehampton, Royal Holloway, and University of Reading. The participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

RL and AJ conceived the research. RL, EC, and AJ managed participant recruitment and data collection, and analyzed the quantitative data. AJ took primary responsibility for the qualitative data. RL wrote the first draft of the manuscript. EC and AJ made major contributions to subsequent drafts. All authors contributed to the article and approved the submitted version.

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Challenging Empathic Deficit Models of Autism Through Responses to Serious Literature

Melissa Chapple[1], Philip Davis[2], Josie Billington[2], Sophie Williams[1] and Rhiannon Corcoran[1,2]*

[1] Deparment of Primary Care and Mental Health, School of Psychology, University of Liverpool, Liverpool, United Kingdom,
[2] Centre for Research into Reading, Literature and Society, University of Liverpool, Liverpool, United Kingdom

Dominant theoretical models of autism and resultant research enquiries have long centered upon an assumed autism-specific empathy deficit. Associated empirical research has largely relied upon cognitive tests that lack ecological validity and associate empathic skill with heuristic-based judgments from limited snapshots of social information. This artificial separation of thought and feeling fails to replicate the complexity of real-world empathy, and places socially tentative individuals at a relative disadvantage. The present study aimed to qualitatively explore how serious literary fiction, through its ability to simulate real-world empathic response, could therefore enable more ecologically valid insights into the comparative empathic experiences of autistic and non-autistic individuals. Eight autistic and seven non-autistic participants read *Of Mice and Men* for six days while completing a semi-structured reflective diary. On finishing the book, participants were asked to engage in three creative writing tasks that encouraged reflective thinking across the novel. Thematic and literary analysis of the diary reflections and writing tasks revealed three main themes (1) Distance from the Novel; (2) Mobility of Response; (3) Re-Creating Literature. Findings demonstrated the usefulness of serious literature as a research tool for comparing the empathic experiences of autistic and non-autistic individuals. Specifically, autistic individuals often showed enhanced socio-empathic understandings of the literature with no empathy deficits when compared to non-autistic participants.

Keywords: autism, empathy, literary fiction, creative writing, neurodiversity

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United Kingdom

****Correspondence:***
Melissa Chapple
melissa.chapple@liverpool.ac.uk;
melissajanechapple@outlook.com

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INTRODUCTION

There is currently no agreed consensus for defining 'autism' as a concept. However, the term generally refers to a form of human neurocognition that is developmental in nature and which results in divergent socio-cognitive processing styles (Fletcher-Watson and Happé, 2019; Milton, 2020). While there is an increasing move toward understanding autistic people through explorations of their nuanced human experiences (Wright et al., 2014), the medical model of disability continues to largely dominate how society thinks about autism and autistic people (Waltz, 2013; Kapp, 2020; Chapple and Worsley, 2021). Although medical categorisations of autism are consistently evolving, the model typically focusses on socio-communicative difficulties, repetitive behavioral patterns and restricted interests (Murray et al., 2005; American Psychiatric Association, 2013; Kapp, 2020). While medical diagnoses offer a route for self-discovery and

access to formal support (Mogensen and Mason, 2015; Leedham et al., 2020), the treatment of human neurocognitive diversity in much the same way as physiological disease risks overlooking individualised human experiences (Kinderman et al., 2013). As a result of dominant medical framings, autism research has long over-focused on what autistic people lack (Murray, 2020). In this way, autistic people are positioned as being in need of 'fixing' in order to align their behaviors with those typically expected within mainstream cultures (Milton, 2012; Waltz, 2013). As a consequence of these views, the autistic community have been denied agency in shaping their own narratives and influencing how they are viewed within society (Milton, 2012; Yergeau, 2013; Fletcher-Watson and Bird, 2020). Instead, dominant theoretical models and subsequent empirical enquiries often employ and further develop societal understandings of autism that reduce and stereotype the nature of autistic experiences (Chapple and Worsley, 2021).

In particular, dominant theories of autism including the weak central coherence (WCC; Happé, 1999), mindblindness (Baron-Cohen, 1997) and empathising-systemising (E-S; Baron-Cohen, 2002, 2009) theories have broadly sought to identify key autism deficits. Specifically, the WCC theory assumes a global processing deficit amongst autistic individuals, believed to result in increased attention to fine detail alongside resultant difficulties around integrating information within a wider context (Happé, 1999; Hill, 2004). In relation to social processing, autistic cognition is then positioned as problematic against an assumed need within everyday social situations to quickly integrate facets of social information into a coherent whole (Happé, 1999; Baron-Cohen, 2009). By contrast, the mindbliness theory (Baron-Cohen, 1997) proposes that autistic individuals experience profound difficulties in representing and attributing mental states to others, otherwise known as theory of mind (ToM; Premack and Woodruff, 1978; Reniers et al., 2011). While these two theories focus on different aspects of autistic cognition, the E-S theory largely combines the underlying ideas of the two approaches (Baron-Cohen, 2009). Specifically, the original E-S theory positioned autistic individuals as broadly less empathic than their non-autistic peers (Baron-Cohen, 2009). Instead, autistic people are argued to process information in a more systematic way, exploring regularities to extract predictable rules (Baron-Cohen, 2009). This systematic approach to learning is argued to be too rote-based to be applicable to the spontaneity of everyday socio-emotional contexts, resulting in broad empathic difficulties (Baron-Cohen, 2009). As a result, autistic individuals have been argued to implement extreme egocentrism, attributing their own mental states to others regardless of contextual information or similarities to self (Lombardo and Baron-Cohen, 2011; Bodner et al., 2015; Ripley, 2015). It is these assumptions of reduced empathic capacity in particular that risk undermining the core human experiences of autistic people (Yergeau, 2013; Fletcher-Watson and Bird, 2020).

Furthermore, these deficit-based assumptions have left a lasting impact, with a resultant, long-standing focus on researching autism-specific empathy deficits (Peterson et al., 2005; White et al., 2009; Song et al., 2019). While empathy as a term is often used inter-changeably across differing concepts, it can broadly be defined as the ability to recognise, share and respond to the feelings of others (Shamay-Tsoory et al., 2009; Fletcher-Watson and Bird, 2020). However, definitions such as these are argued to be specific to affective empathy (Shamay-Tsoory et al., 2009; Smith, 2009), with ToM or 'cognitive empathy' believed to exist as a separate construct (Shamay-Tsoory et al., 2009; Reniers et al., 2011). Here, affective empathy then refers to the related ability to vicariously experience the emotional states of others (Reniers et al., 2011). With particular influence from the mindblindness theory (Baron-Cohen, 1997), research into assumed empathy deficits amongst autistic individuals has largely focussed on cognitive empathy (Shamay-Tsoory et al., 2009; Smith, 2009). Research into cognitive empathy deficits has concluded that autistic people are impaired in the recognition of complex but not simple emotional states (Icht et al., 2021); are less accurate at inferring emotion from both static and dynamic faces (Rigby et al., 2018); and perform significantly worse than non-autistic individuals on multiple ToM tests (Dziobek et al., 2006). However, these studies often implement standardised ToM tests which rely on fast-paced assumptions to infer in-depth human feelings from limited snapshots of information (Baron-Cohen et al., 2001a; Dziobek et al., 2006). As a result, careful and complex evaluations of mental states would result in unfavorable scoring on such tests. It is these complex considerations that are more reflective of real-world empathy, where affective and cognitive empathic responses cannot be separated so easily into unrelated concepts and instead co-occur in real time (Fletcher-Watson and Bird, 2020).

Additionally, these deficit-based approaches overlook the bi-directional nature of social communication within any given social pair (Milton et al., 2018). Instead, deficit models place an assumption of blame onto autistic individuals when social difficulties arise (Milton, 2012; Chown, 2014). One theory that seeks to address the two-way nature of socio-communicative difficulties is Milton's (2012) double empathy problem. The double empathy problem reframes ToM deficits as an issue of reciprocity and mutuality between individuals within a given socio-communicative exchange (Milton, 2012; Milton et al., 2018). While a lack of mutuality can arise for any two individuals, Milton (2012) suggests that the differing social realities of autistic and non-autistic individuals make breakdowns in communication more likely. Therefore, it is proposed that non-autistic individuals are at least equally likely to misjudge the mental states and feelings of autistic individuals (Milton, 2012; Chown, 2014), an assumption well-supported by empirical research (Brewer et al., 2016; Edey et al., 2016; Sheppard et al., 2016; Heasman and Gillespie, 2019; Crompton et al., 2020b). Furthermore, Milton (2012) opposes the view that autistic individuals fail to incorporate context, highlighting that context is created within a particular exchange. This assumption is supported by findings that when interacting together, autistic individuals experience increased mutuality, resulting in increased social comfort (Crompton et al., 2020a; Morrison et al., 2020); better communicative understandings (Heasman and Gillespie, 2018; Crompton et al., 2020a); and an increased willingness to overcome initial negative impressions (DeBrabander et al., 2019). However, with non-autistic individuals being the majority group,

their increased likelihood for experiencing mutuality during social exchanges results in assumptions of pre-determined norms amongst peers (Milton, 2012). It is these assumptions of pre-set social etiquette and understandings that position different Others, such as autistic individuals, as being defective in some way (Milton, 2012; Chown, 2014).

Furthermore, while the double empathy problem is well-supported by research, the related assumption that autistic individuals may have a better understanding of society than non-autistic individuals (Milton, 2012; Chown, 2014) has largely been overlooked. Specifically, it is suggested that autistic individuals are more likely to take time in developing common ground and understanding different Others as a result of being more experienced in navigating a lack of mutuality (Milton, 2012, 2020; Chown, 2014). In this way, autistic individuals may be more likely to work to sensitively and empathically overcome socio-communicative breakdowns rather than drawing quick conclusions based upon assumed pre-existing mutuality (Milton, 2012; Chown, 2014; DeBrabander et al., 2019; Chapple et al., 2021b). Autistic writer Joanne Limburg (2021) expands upon this assumption by arguing that dehumanised individuals, such as those who are autistic, are forced to think about the ways in which modern society is constructed, giving them deeper understandings of the social world. Therefore, autistic individuals may avoid assumptions of pre-existing social norms to consider the feelings and perspectives of different Others in ways that remain open to the complexity of individual experiences (Lesser and Murray, 2020). This is supported by research findings that autistic individuals are more socially tentative, requiring more time and care at the expense of fast-paced judgements that rely on immediate contextual cues alone (Capps et al., 1992). Therefore, what has previously been framed as difficulties with contextual consideration becomes re-framed as a potential advantage in remaining open to emergent social information (Lesser and Murray, 2020). As a result, autistic people may go beyond what is known immediately to tailor their social and affective responses to each individual social encounter empathically (Lesser and Murray, 2020). These assumptions are further expanded upon by the theory of monotropism (Murray et al., 2005), which seeks to expand upon the WCC through a less pathologised approach (Murray, 2020). Specifically, monotropism suggests that autistic individuals have narrow interest systems that direct and sustain attention toward nuanced topics of interest (Murray et al., 2005). While largely similar to the WCC, monotropism does not assume a broader resultant deficit in the integration of information at the detriment of social experience. Instead, the theory draws attention to the depth of feeling experienced by autistic individuals as a result of highly-focussed interest systems (Murray, 2020). However, the theory still positions these advantages as existing at the expense of understanding social breadth, or the 'modeling of other minds' (Lesser and Murray, 2020; Murray, 2020).

While these open and complex empathic understandings are difficult to research with standardised experimental tests (Fletcher-Watson and Bird, 2020), the exploration of reflection in response to fictional texts offers a unique way to explore empathic understandings within an ecologically valid context (Chapple et al., 2021b). Specifically, fiction is argued to simulate the real social world (Mar and Oatley, 2008; Waytz et al., 2015; Oatley, 2016), where readers can embody character perspectives and feelings to achieve felt empathy (Mumper and Gerrig, 2019). While the use of personal thought and feeling to understand, appreciate and experience a text could be criticised as egocentric (Lombardo and Baron-Cohen, 2011), fiction encourages an overcoming of social pressures and conformity in a way that moves readers away from default or rigid ways of thinking (O'Sullivan et al., 2015; Davis, 2020; Davis and Magee, 2020). Furthermore, fiction is argued to take readers beyond the process of imposing their own thoughts and feelings onto others, instead encouraging a mutual feeling together with the text and the minds within it (Mumper and Gerrig, 2019). Not only does fiction evoke feeling within a text in this way, but also requires co-occurring perspective-taking with the minds that are being represented (Zunshine, 2011). Specifically, readers are required to access the minds of characters through the mind of the author, with those minds ultimately being processed through a reader's own personal perspective (Zunshine, 2011). As a result, the distinction between affective and cognitive empathy becomes artificial while reading, with both thought and feeling working fluidly together in a way that reflects real-world empathy (Koopman, 2016; Fletcher-Watson and Bird, 2020). Therefore, it is argued that fiction acts like a flight simulator, providing the opportunity to engage with multiple minds across social experiences (Mar and Oatley, 2008; Mumper and Gerrig, 2019). This has been supported by research findings which indicate that engagement with fiction may enhance ToM performance and wider empathic capacity (Mar et al., 2009; Bal and Veltkamp, 2013; Kidd and Castano, 2013). Additionally, empathic feeling can be enhanced while reading, due to the ability to feel with different Others without negative social or personal consequence (Koopman and Hakemulder, 2015; Koopman, 2016). Therefore, fiction is thought to be of social benefit to its readers, enhancing a reader's empathic capacity for different Others by providing opportunities for embodied reflection through a pluralism of simulated social experience (Oatley, 2002, 2016; Bal and Veltkamp, 2013).

Furthermore, it is thought that serious literary fiction is particularly advantageous in promoting this empathic embodiment of different Others within a text (Mar and Oatley, 2008; Koopman and Hakemulder, 2015; Davis, 2020; Davis and Magee, 2020). Here, serious literature specifically refers to texts that engage with significant human situations, subsequently enabling its readers to do the same (Koopman and Hakemulder, 2015; Davis and Magee, 2020). While it has been argued that different Others are essentially unknown and unknowable (Levinas, 1969), the mirroring of real human situations within literature is argued to result in imaginative feelings with the characters, situations and feelings within it (Davis, 2020). Therefore, it is argued that serious literature enables readers to form more in-depth understandings of human existence through imaginative feeling with other minds (Koopman, 2016; Davis, 2020). This imaginative capacity to treat literary characters as

real and employ their point of view is believed to be true across narrative settings, regardless of realism (Anderson et al., 2019). Specifically, it is argued that it is the words which hold the potential of powerful and active beings in themselves (Erdman, 1978). In this way, the powerful language within serious literature encourages readers away from processing in easy, heuristically-driven, automatic ways that avoid ambiguity in order to reach quick conclusions (Djikic et al., 2013; O'Sullivan et al., 2015; Davis, 2020). Instead, literature encourages readers to hold onto what feels like emotionally salient moments of a text, also known as close reading, as opposed to information-scanning (Davis, 2013; Wolf, 2018). In this way, the close reading encouraged by serious literature allows for slower reflections to explore the embedded complexities of social realities (Mar and Oatley, 2008; Koopman and Hakemulder, 2015; O'Sullivan et al., 2015; Koopman, 2016). Furthermore, this holding of ambiguity and feeling within literature reflects a suspended judgment in which empathic feelings are enhanced, because the ambiguity of a text means readers cannot rely on schematic inferences (Koopman and Hakemulder, 2015). Instead, readers are moved toward new ways of thinking that are receptive and flexible, enabling sudden re-considerations in real time, in direct response to emergent information (Davis, 2020; Davis and Magee, 2020). These movements evoked by a text are argued to be more powerful when experienced through adversity (Strick and Van Soolingen, 2018; Davis, 2020). It is therefore assumed that texts dealing with adversity may be more moving, prompting new, more careful ways of thinking about different minds (Strick and Van Soolingen, 2018; Davis, 2020).

While some readers may remain on the surface of serious literature, struggling to get within it, those who experience what Limburg (2021) calls undifferentiation show the true advantages of literary reading (Barnes, 2018; Davis, 2020; Davis and Magee, 2020). During this process, it is argued that moving parts of a passage become part of the reader, while simultaneously remaining part of the text and the author who wrote it, all at the same time (Barnes, 2018). In this way, it becomes necessary for readers to re-write serious literature in the act of reading (Barthes, 1969, as cited by Muldoon, 2021). This is to say that readers of serious literature are not simply reading, rather they are mentally 'doing' the literature in the process of reading (Barthes, 1969; as cited by Muldoon, 2021). Therefore, the careful, slower processing of thought and feeling that is commonly observed amongst autistic individuals (Capps et al., 1992; Lesser and Murray, 2020) could make them more 'literary' readers. In particular, those who deal with adversity in their daily lives, such as autistic individuals, may be more powerfully moved by serious literature (Strick and Van Soolingen, 2018; Davis, 2020) and prompted to further reconstruct their views on societal construction (Limburg, 2021). This means that the utilisation of serious literature within autism research offers a way to more accurately compare the empathic experiences of autistic and non-autistic individuals. Furthermore, as serious literature prevents fast-paced assumptions based on schematic inference (Mar and Oatley, 2008; Koopman and Hakemulder, 2015; O'Sullivan et al., 2015; Koopman, 2016) it might then prompt non-autistic readers to think more empathically about minds different from their own. Therefore, reading may serve to overcome the positioning of different minds as defective (Chapple et al., 2021b).

However, as research enquiry into the value of fiction for autistic readers has largely been restricted by deficit-based assumptions, it has been assumed that autistic individuals lack the socio-cognitive capacity to contemplate and enjoy fiction (Baron-Cohen, 1997, 2009). Instead, it has been assumed that autistic individuals would prefer the systematic nature of factual non-fiction (Baron-Cohen, 2009; Barnes, 2012). However, recent findings have contradicted dominant assumptions, showing instead that autistic individuals across age groups do engage with fiction and literary non-fiction (Barnes, 2012; Davidson and Ellis Weismer, 2018; Armstrong et al., 2019; Chapple et al., 2021a). Additionally, findings show that when asked about their experiences of reading, autistic participants report examples of felt empathy for fictional characters and book authors themselves (Chapple et al., 2021a). However, little is known about the way in which autistic individuals would engage with serious literature, and how this might compare to non-autistic individuals. Further research is also needed to examine assumptions of in-depth processing amongst autistic individuals at the expense of modeling other minds (Happé, 1999; Murray et al., 2005). While this in-depth local processing may enhance autistic readers' ability to hold in mind moving passages, monotropism assumptions indicate that their wider considerations of social construction may be limited.

To address this evidence gap, the current study qualitatively explores how autistic adults engage with serious literature in comparison to non-autistic adults. Specifically, participants read *Of Mice and Men* (Steinbeck, 1937) while completing a semi-structured diary that prompted daily reflections on the novel and its characters, with some creative writing tasks upon completion of the novel. The novel was chosen primarily due to its complex exploration of stigma and Othering toward and within groups of disabled characters with inter-sectional marginalized identities (Chapple et al., 2021b). Additionally, the novel was chosen due to the relative ease of initial access to the minds within realistic texts for inexperienced readers. This was advantageous for the current project, where the literary exposure of the participants was unknown, and due to a current lack of research into textual factors that enhance empathic feeling amongst autistic participants and within a double empathy paradigm. Furthermore, the representation of disability within the novel encourages readers to embody feelings of adversity, allowing for the exploration of movement in autistic compared to non-autistic readers (Strick and Van Soolingen, 2018; Davis, 2020). The current study was part of a wider research project, where participants later went on to discuss the novel to explore resultant double empathy understandings between autistic and non-autistic readers (Chapple et al., 2021b). For the present study, the aim was to address two research questions: 'can reflections on a piece of serious literature offer direct evidence that autistic adults engage empathically with complex characters and social content?' and 'is there evidence that autistic adults read in a more 'literary' way than non-autistic readers?' Based on suggestions that autistic individuals are more socially tentative (Capps et al., 1992; Murray et al., 2005; Milton, 2012, 2020; Chown, 2014; Lesser and Murray,

2020), it was predicted that the autistic participants would engage empathically with the novel and read in a more literary way.

METHODS

Participants

Participants were recruited through social media and University advertisements. A total of 27 participants took part in the initial screening process for inclusion in the study. Eight autistic and 8 non-autistic participants were invited to take part in the research. However, 1 non-autistic participant dropped out of the study and was not replaced due to having achieved data saturation within the material collected from the remaining 7 non-autistic participants. Of the remaining 11 participants who were screened, 2 (1 autistic) dropped out of the study early on in the recruitment process. Contact details of the remaining 9 participants were kept on file for another research project. Inclusion criteria included being 18 or over, having proficient English language skills, and scoring an estimated Wechsler Adult Intelligence Scale (WAIS) IQ score of 90 or above as assessed by the Quick Test (QT; Ammons and Ammons, 1962). For autistic adults who did not have an official diagnosis (e.g., referred for assessment or self-identified), there was an exclusion criterion of scoring below 32 (the suggested cut off for autism) on the AQ (Baron-Cohen et al., 2001b). Undiagnosed autistic participants were included to take account of accurate gender representation due to the longstanding underdiagnosis of women (Cooper et al., 2018; Fletcher-Watson and Happé, 2019). Non-autistic participants had an additional exclusion criterion of scoring over 32 on the AQ.

Overall, fifteen participants provided data for this research study (see **Tables 1**, **2** for demographics). Eight were autistic (male $N = 4$; female $N = 4$) aged 19–48 ($M = 30.75$, SD $= 9.22$) and seven were non-autistic (male $N = 3$; female $N = 4$) aged 23–56 ($M = 38.57$, SD $= 13.10$). The study was approved by the University of Liverpool Research Ethics Committee.

Screening Measures

A demographics questionnaire asked for participants' age, gender, and highest completed qualification. Eligibility questions were asked at this stage.

The Autism Quotient (AQ)

The AQ (Baron-Cohen et al., 2001a) is a 50-item questionnaire that uses statements to elicit a score that reflects autistic traits in clinical and non-clinical samples. The AQ was used to assess the number of self-reported autistic traits in both samples.

TABLE 1 | Participant AQ and IQ scores [mean (±SD)].

	AQ[a]	Estimated IQ[b] (WAIS equivalent)
Autistic	40.50 (6.57)	100.00 (5.13)
Non-autistic	11.71 (4.92)	101.14 (6.09)

AQ, Autism quotient; QT, Quick test; WAIS, Wechsler Abbreviated Scale of Intelligence.
[a]AQ scores [b]IQ assessed by the QT.

The Quick Test (QT)

A single 50-item version of the QT (Ammons and Ammons, 1962) was used. The test involves participants looking at 4 pictures and deciding which picture each word goes best with. Given the age of the QT, the raw test score is converted to a WAIS, not WAIS-R, equivalent IQ. Although not ideal and rather dated, this was considered an adequate method for obtaining a rough estimate of reading comprehension ability for this study where its brevity was an asset and where IQ data was not going to be subjected to further analysis.

Diary and Interview Measures

Participant Diaries

A structured diary was designed for participants to record their thoughts while reading Of Mice and Men (Steinbeck, 1937). The diary was completed for 7 days, the first 6 coincided with reading the book at a rate of one chapter per day. For each chapter, participants were asked 5 questions, questions 1 to 3 were designed to prompt general reflections about narrative events and characters: (1) *What thoughts or feelings did chapter X prompt?* (2) *Do you think the characters in chapter X were realistic?* (3) *Did you like or dislike the characters in chapter X?* Questions 4 and 5 were added based on previous findings that autistic readers think more about author intent (Chapple et al., 2021a) (4) *Did you think about the author when reading chapter X?* (5) *What did you think the author was trying to achieve in chapter X?* On day 7, participants completed 3 writing tasks: (1) writing a letter to a character of choice as either (a) themselves, (b) another character, or (c) the author (2) writing a letter to the author as either (a) themselves, or (b) another character and (3) re-writing the ending as they would have preferred it to have ended. These tasks were included to promote reflection on the overall novel and subsequent perspective taking. Tasks 1 and 2 were based on Green's (2020) letter writing methodology for reflective reading, with task 3 included to explore how participants dealt with the novel's emotionally difficult ending.

Procedure

Potential participants completed a screening process via Qualtrics that included the informed consent procedure, a demographic questionnaire, the QT and the AQ. Participants who screened out or did not leave an email address for contact had their data removed. Informed consent was obtained at two points (1) before screening and (2) before commencement of the diary task. At each stage, participants were provided with both a university standard information sheet as well as an easy-read version that avoided complicated explanations and used clear photographs and text segmentation. Both information sheets encouraged participants to contact the first or fifth author for more information at each stage of the process. The informed consent procedure included the disclosure of participant demographics for data processing.

Upon obtaining informed consent, all participants were provided with either a physical or digital copy of Of Mice and

TABLE 2 | Participant demographics.

Participant no.	Age	Gender	AQ[a]	IQ[b] (WAIS equivalent)	Level of education completed	Neurotype
1	29	Male	42	96	GCSE	Autistic: diagnosed
6	46	Male	17	90	A Level	Non-autistic
7	23	Male	10	100	Masters	Non-autistic
8	26	Female	12	102	Bachelors	Non-autistic
9	33	Female	12	100	Doctoral Training	Non-autistic
10	33	Male	13	108	Foundation or Diploma	Non-autistic
11	48	Female	44	108	Doctoral Training	Autistic: diagnosed
14	53	Female	16	100	Masters	Non-autistic
17	56	Female	2	108	Bachelors	Non-autistic
18	25	Male	44	98	Masters	Autistic: diagnosed
20	19	Female	30	92	A Level	Autistic: diagnosed
21	28	Female	48	104	Masters	Autistic: self-diagnosed
23	33	Female	46	104	Bachelors	Autistic: diagnosed
25	39	Male	38	100	Masters	Autistic: diagnosed
27	24	Male	32	98	Bachelors	Autistic: diagnosed

AQ, Autism quotient; QT, Quick test; WAIS, Wechsler Abbreviated Scale of Intelligence. [a]AQ scores [b]IQ assessed by the QT.

Men (Steinbeck, 1937) and a copy of the diary template. The diary template contained a page of clear instructions with warnings about the sensitive content in the novel. Participants were asked to read one chapter per day for 6 days and to complete the writing tasks on the 7th day and, as far as possible, to stick to the 7-day schedule laid out in the instructions. Upon return of the completed diary, participants were reimbursed £10 for their time in the form of either a £10 Amazon voucher or as cash.

Analysis

Thematic analysis was chosen to analyse the data deductively, exploring surface-level psychological themes (Clarke and Braun, 2014). A form of literary close reading analysis (Billington et al., 2019) was implemented alongside thematic analysis to inductively explore the data for evidence of deeper psychological shifts within participants as a result of reading. This analysis relies on participant language as 'the main point of access to moments of subtle mental change' that gives access to the 'imprints' of reading (Kaszynska, 2015). These qualitative analyses combined to ensure a deep and rich exploration of the data. Analysis stages were as follows:

1) The first author read all participant diaries to achieve data immersion.
2) The first and fourth authors separately coded all of the autistic participant diaries using thematic analysis. All authors then met regularly to deliberate on initial themes until agreement was met. The first author then coded the non-autistic participants, organising codes into the same themes agreed for the autistic participant diaries. The fourth author read over the resultant codes and agreed on the interpretation of the non-autistic diaries.
3) The first author highlighted moments of literary interest in 8 diaries (6 autistic) and sent the diaries to the second and third authors who are trained in close literary reading analysis. The second author read all 8 diaries for immersion and highlighted additional important moments of psychological change. The third author read 4 of the diaries (3 autistic), providing additional commentary on areas of interest.
4) The second author decided on key literary themes within the 8 diaries that were analysed. The first and second author then worked together to re-interpret the data until themes from stage 2 and 3 were successfully integrated. These themes were then sent back to the third and fourth authors who agreed with the re-integration.
5) The first author then re-analysed the remaining 7 diaries (2 autistic) and follow-up data using the integrated approach of thematic analysis with close literary reading that had been agreed on in stages 3 and 4.
6) Resulting themes were deliberated by the rest of the team, with theme names and framings adjusted to capture the main elements of significance within the themes.

The first author is an autistic researcher. The fourth author is an autistic adult who took the role of expert by experience. Therefore, all data was analysed from both autistic and non-autistic perspectives.

RESULTS

All participants experienced times of being invested within the literature as well as times of struggling to become or remain invested in the literature. The final analysis (see **Table 3**) comprised three themes: (1) distance from the novel (2) mobility of response and (3) re-creating literature. Participant quotes are split by neurotype group (A: autistic, N: non-autistic). Within

TABLE 3 | Final analysis themes and subthemes.

Distance from the novel	Difficulties with understanding and immersion
	Emotional distancing
	Socio-political and historical representation
Mobility of response	Active responding
	Thinking aloud and thinking along
	Involuntary feeling for
	More than one thing at a time
	Involvement in a character
Re-creating literature	Emotional depth
	Responsive language changes

the participant quotes, words that depict emergent thinking are highlighted in bold.

Distance From the Novel

Difficulties With Understanding and Immersion

All participants experienced moments while reading the novel when they struggled to 'get inside' the text, instead evaluating the novel's characters and events from a distance. This distance was largely created as a result of participants' difficulties, across both groups, in understanding the culture and metaphors embedded in the novel, often as a result of what seemed an unfamiliar language:

> *(P21A) [in response to "s'pose Curley jumps a big guy an' licks him"] 'I'm assuming Curley doesn't actually lick people and it's an expression, but there was an awful lot of them that went over my head.'*
> *(P14N) 'Early in this chapter the expression 'rushing stars' made me question whether this was dialect and why the author has chosen this phrase.'*

Difficulties in becoming immersed centered upon feeling that the novel was unrealistic or through an inability to develop mental imagery.

Emotional Distancing

Where these difficulties arose, participants made surface-level appraisals about the novel within their diary entries. These appraisals included summaries of narrative events or attending to the stereotypes represented by the novel's characters and events:

> *(P25A) 'Lennie- seems like a stereotype of someone with a learning difficulty, like something out of an old film or tv show.'*
> *(P6N) 'some were one-dimensional i.e., the woman, Curley came across like a pantomime villain.'*

Surface-level thinking about the novel meant that participants remained within normative thinking processes, rather than exploring deeper meanings behind human emotions and social constructs. During these times, participants seemed to grow impatient with characters, showing frustration or annoyance toward difficult character behaviors that had culminated in emotionally difficult events within the novel. Rather than seeking to further explore these events and behaviors, participants tended to close down further opportunities to get inside the character's perspective as a defense mechanism:

> *(P1A) 'Annoyance at Curley's wife for not leaving Lennie be. She confided in Lennie that she had big aspirations and hated her husband, so she should have just divorced him and all of this could have been easily avoided.'*
> *(P6N)'It made me angry because Curley's wife was racist, abusive and rude but got away with it because she was in a position of power.'*

For some participants their impatience toward characters continued into their writing, especially where participants were asked to write to a character:

> *(P21A) [letter 2 self to Candy] 'Candy— You're never going to see those rabbits, just because Lennie is dead. George will find a way to do it without you, but use all your money and possibly shoot you in the head.'*
> *(P6N) [letter 2 self to Curley's wife] 'making fun of a person because [of] race and disability is disgusting, it makes you a bully and a vile person, change the way you are and how you treat people or there could be consequences.'*

Here, 'you're never going to see those rabbits' from P21A and 'there could be consequences' from P6N pose threats to the futures of the characters that they are writing to. In this way, the participants' impatience for these characters had resulted in them simply 'writing these characters off' in a way that closed down further empathic consideration.

Socio-Political and Historical Representation

When participants deliberately attempted to overcome their sense of disengagement, their efforts were often expressed through a socio-political and historical lens in place of in-depth feelings of personal involvement *with* the characters. This type of relatedness often resulted from general concerns across both groups with the racism, sexism, and classism within the novel. However, the autistic participants were additionally concerned with disability representation within the novel and surrounding concerns about ableism:

> *(P27A) 'And also, honestly, I wondered if the author just hates people with mental disabilities, or saw such a person like Lennie as some sort of literary device worth fetishizing rather than something that needed to be handled carefully in the literature.'*
> *(P8N) 'the continual negative descriptions of Curley's wife are noticeable. The only women described so far are her and talk about a brothel.'*

When operating from outside the text, participants often summarised these issues as easily recognized problems of the distant past, rather than as issues that are complexly bound into past and present human culture. This distance served as a way for some participants across both groups to emotionally remove themselves from the challenges of the content:

(P27A) 'In a modern context, maybe Lennie could have received the proper help and treatment, but in the 1930s, not so much.'
(P6N) 'The old man was racist but it was a sign of the times and the south unfortunately'

Mobility of Response

Active Responding

One of the signs of immersion as compared to distance lay in participants' ability to move across the distances of the text itself, recreating the work's internal connections:

(P27A) '[Lennie's death] It calls back to Candy's dog and Candy wishing he would've shot the dog himself because the dog was his responsibility; it's a harsher death for the dog to die at the hands of a stranger.'
(P8N) 'A lot of this final chapter mirrors the rest of the book (repeating the dream, the shooting of Candy's dog, Lennie killing a small animal and grabbing a woman to feel the softness of their outfit). All of this was clearly deliberate.'

As well as thinking across time and space, some participants additionally thought across multiple perspectives to gain deeper understandings. This was more common for the autistic participants:

(P27A) 'George felt responsible for Lennie and as much as I hate the author equating a handicapped man to a dog, I can see that same thought process going through George's head.'

Here, P27A has overcome socio-political concerns by moving from the inferred perspective of the author into how the thought feels within the embodied perspective of the character George. Incidences of perspective mobility were especially prominent during the character letter task and, in one instance, the author letter task. Furthermore, perspective mobility was more prominent for autistic participants, who embodied character minds in a way that resulted in felt realism. Although non-autistic participants took character perspectives within their writing, the result was often more simplistic or hard to differentiate from the participants' own perspectives and tones:

(P1A) [writing as Slim to George about him, Curley and Lennie] 'I know that ain't none of your concern or fault as Curley showed you and Lennie no kindness and I don't blame you for getting the hell out of dodge but I was wondering if you'd have me over at your place. I worry that you or Lennie feel you could have stopped it but knowing Curley and how hot headed he was and the way his wife behaved…it was only a matter of time before something bad happened. But I'll do my part at your place, I think I can make a bit of business for us both by selling puppies to strangers and I know Lennie would be happy with a few around.'
(P14N) [letter 2 George to author] 'At times I was mean to him, too, which I feel bad about because he didn't understand.'

In P1A's character letter, he writes from Slim's perspective, aligning his writing with something of Slim's very tone and language, while also considering the perspectives of *both* George and Lennie. While P1A was the only autistic participant who chose to write from the perspective of another character, other autistic participants still addressed multiple character perspectives in their letters.

Thinking Aloud and Thinking Along

Participants who got inside the novel thought beyond the information that was overtly available to them. As a result, they remained open to alternative explanations of the same character:

(P21A) 'So I think the author was trying to make us see that Lennie is hopeless and George is So Good to Him but honestly I think there's something else going on that we haven't been told.'
(P10N) 'I had mixed feelings about Carlson – was he being kind in putting an old dog out of its suffering? Or selfish as he didn't like the dog being in the bunkhouse?'

As a result of this openness to alternative possibilities, sometimes expressed through questions, participants were then able to rethink their position as new information became available. This rethinking meant that participants engaged in live thinking within the ongoing processes of the novel, with the events of the story acting as a present reality to be continuously reassessed in real time:

(P27A) 'Seeing George somewhat portrayed as an unreliable narrator - so to speak - makes me wonder what else he could be lying about, specifically to Lennie, and if I need to rethink what his true intentions for and promises to Lennie could actually be. Something to keep an eye on.'
(P6N) 'At first I thought the author was racist but the way he wrote about Crooks I have totally back tracked.'

The use of 'something to keep an eye on' here by P27A highlights the provisionality of thinking while reading, informed by the prior feelings of George being an 'unreliable narrator.' By contrast, the 'back tracking' from P6N goes beyond a change of mind, instead going back through the narrative to re-assess thoughts and feelings. While instances such as these occurred across both groups, autistic participants seemed more often to remain open to reassessments by thinking beyond the immediately available information.

Involuntary Feeling for

The more that participants had been able to successfully get into the novel, the more there were reports within participants' diaries of involuntary feelings for the novel and its characters. These involuntary feelings of creative discovery contrast to the earlier mentioned socio-political assessments that failed to get participants emotionally into the novel. In particular, the final two chapters of the novel often resulted in reports of overwhelming, involuntary sadness amongst participants:

*(P23A) 'Sadness, resignation, fear of what would **happen** to the characters. I have a **sudden** feeling of terrible sadness about their dream of the farm, which I know – **and I think they know** – is too good to ever be true.'*
(P10N) 'Sadness – when dreaming about their future life – as it was far removed from their current situation'

Here, P23A's 'too good to ever be true' shows an emergent and involuntary saddened knowledge, rather than a cynical closing down of difficult feeling. Similarly, P10N's contrast between the dreams of the future to the present situation results in a wider and deeper understanding of the character's circumstances than they themselves have realised. Rather than this difference in understanding creating a distance between the reader and the characters, a painful knowledge results for the reader.

Where participants experienced these instances of painful knowledge, their emotions were not made any easier despite participant reports of knowing what was to come:

> *(P11A) 'Chapter 5 was a little bit like a car crash in slow motion, from the first couple of lines it's obvious what is going to happen'*
> *(P17N) 'The characters were eerily realistic'*

The obviousness described here by P11A is not a distanced knowingness but rather something that is felt painfully and sympathetically across the distance between P11A as the reader and the characters within the novel. P11A's metaphoric description of 'a car crash in slow motion' shows this depth of empathy, felt across the gap between P11A's knowingness of what is to come and what the characters have yet to realise. These involuntary feelings were experienced by both autistic and non-autistic participants, but generally there was a sense that they appeared to be felt with greater depth by autistic participants.

More Than One Thing at a Time

Where participants had begun to successfully feel within the novel, there was a tendency to feel a greater complexity and register more than one thing at a time:

> *(P27A) 'Beyond that, this was a chapter I really felt like the characters were shades of gray.'*

This meant that participants also held in mind conflicting feelings toward characters, and non-conclusive views that further enhanced their willingness to actively rethink *while* reading in real time:

> *(P1A) 'George was harsh, more than once but I can **also** understand his frustrations with Lennie as **he** is **solely** looking after him and **they** seem to have run into trouble on more than one occasion due to Lennie's actions.'*
> *(P8N) 'George takes the role of a carer, who is exasperated and resentful at the difficulties in looking after Lennie, **but** obviously cares for him. I felt irritation at points, when he was being resentful toward Lennie, **but also** sympathy toward him, as it clear that Lennie's behaviour created patterns of difficulty across their lives.'*

Through P1A's move from 'he' to 'they' he expands upon his first thought of George being harsh by incorporating the realisation that George alone is responsible for what both he and Lennie go through together.

Through this willingness to hold in mind competing and even ambivalent views toward characters, participants were also able to feel for more than one character at a time. These instances remarkably included times where behavior of one character was itself not empathic toward the other characters in the novel, such that the reader even paradoxically tolerated intolerance:

> *(P27A) 'Even though neither Candy or Crooks showed her sympathy and even though she was expressing antagonism rather than vulnerability to match Crooks and Candy's antagonism, I was willing to sympathize with Curley's Wife.'*
> *(P14N) '4 individuals can be so isolated, lonely and dependent even though they've been thrown together; that the differences between them (color, age, gender, 'intelligence') can divide them despite them having so much in common; that they've all developed damaging self-protection mechanisms'*

For P23A, this feeling for more than one thing or person at a time led to her sense of feeling together with other readers:

> *(P23A) 'I was really sad that Lennie hurt the puppy. I knew he would. We all knew he would. He didn't mean to do it, but he did.'*

Here, the call from 'I knew' to 'we all knew' acts as a form of human understanding – a sense of true we-ness in human solidarity - holding together the difficulty of knowing that Lennie would hurt the puppy and feeling the painfulness of this for Lennie's sake too.

By thinking and feeling for more than one thing at a time, participants were then able to see deeper subtexts between characters. These assessments of subtext seemed more common and more in-depth amongst autistic readers:

> *(P23A) 'Lennie was killed at the time when he was gleefully recalling their dreams, their plans – the house, the rabbits, the alfalfa. With the shot to Lennie's head, George is also 'killing' those dreams. He's killing that possible future, and I can't imagine he would want that same dream **without** Lennie there. The dream was **for the two of them, not for just one** – or for him and another.'*
> *(P17N) 'Lennie, **innocent but with** a power he couldn't control. Curley's wife craving attention **but unaware** of the dangers that flirting with Lennie could do'*

Through the breadth of understanding P23A is able to understand that George was also killing his own dreams in the death of Lennie.

Involvement in a Character

While these thoughts and feelings for more than one thing at a time led to a breadth of understanding, participants who got within the novel were also able to feel for the depth of a character by feeling with one character at a time in the midst of an interaction with another. Together with the breadth of feeling, this enabled the participants to further explore the subtext of the novel, particularly where characters had behaved in an unfavorable way:

> (*P27A) 'Even if he never truly expressed his love for Lennie beyond berating him every step of the way, there was a love there and there was a love in his final act of shooting Lennie.'*
> *(P7N) 'I felt sorry for Crooks as it is apparent he is isolated from everyone, **not just** the men on the ranch **but almost all** of Soledad'*

The metaphorical use of 'killing' by P23A above in the 'More Than One Thing at a Time' sub-theme. shows P23A taking on the novel's vocabulary to re-create the novel imaginatively. Comparatively, through deep understanding with George, P27A is able to see the love in the act of killing, an act that participants regularly believed had saved Lennie from an unkinder death at the hands of another character. It feels more paradoxical and more hard-won than a surface description of 'mercy-killing.' This contrasts to the effortful implementation of socio-political empathy, where participants often centered their concerns around Lennie's death being painted as a mercy.

For autistic participants, but not non-autistic participants, this depth of understanding also applied to the character Lennie. Lennie has an unnamed disability, and his perspective comes primarily through the point of view of his non-disabled friend George and that of the other characters. However, autistic participants were able to use subtle cues in the text to infer for themselves Lennie's thoughts and feelings. While one non-autistic participant also briefly discussed Lennie's feelings, this was in contrast to what Lennie was *not* able to think and feel:

> *(P14N) 'Lennie's childlike happiness in hearing his favourite story…especially as a distraction from the fact that George should have been mad at him'*
> *(P20A) 'Lennie only feels shame, which shows that he does care about what he is doing'*
> *(P23A) 'I had great empathy for the ways in which Lennie was mentally beating himself up – saying cruel things to himself through imaginary people.'*

While autistic participants were familiar with considering different Others, it was the depth of feeling for the novel and its characters that prompted non-autistic participants to begin feeling for different Others outside of the text. In this way, the participants were more like a revised version of George. Specifically, it forced them to think about why Lennie was treated as an outcast by the other characters and ultimately unable to be accommodated:

> *(P14N) 'It challenges the reader to consider whether George had actually done the right thing and ultimately to ask why society was unable to accommodate Lennie.'*
> *(P10N) [letter 2 self-author] 'You have skilfully held up a mirror to society, which **many including myself** found uncomfortable when looking at its reflection. It made me reassess the world in which we live and what we as a society should be striving for. I **also loved** how there were so many characters who through no fault of their own were born or found themselves an outsider in an intolerant world (race, disability, poor) and yet many of these **outcasts** were **the warmest, kindest most decent** human beings within the book'*

These feelings, together with the in-depth feelings for Lennie from the autistic participants, contrast with the more generalised socio-political empathy relating to representations of disability. Those well-meaning general attitudes lacked this source-emotion to keep them fresh and authentic. Here, participants were able to feel for the ways in which human culture continues to make people unhappily Othered, whilst starting to unpick what creates this Othering.

Re-creating Literature

Emotional Depth

Where participants were asked to re-write the ending of the book, the autistic participants in particular were able to draw on their thoughts and feelings as experienced from within the novel to re-create the literature in their own writing. Some of this 'readerly imagination', infused with the language and feel of the book, has already been seen above in relation to sub-texts in the 'Mobility of Response' theme. For non-autistic participants, this creation of a literary depth was only evident in creating emotional depth for George:

> *(P1A) 'A smile turns into unease, George tells himself "That son of a bitch and that harlot wife had it coming to them, to hell with them. I made it work Lennie, and I wasn't letting nobody stop me from living out our dream." The sun sets, everybody heads in, life continues as normal.'*
> *(P17N) [From Lennie's death]: 'George felt something run across his leg. He looked down to see a pair of small, dark piercing eyes staring up at him. He stared back at the shapeless little face and stroked its back. "Come with me," he whispered.'*

While P1A chose to undo the killing of Lennie, the result is not a mere escape from pain: the subtleties in his writing, starting with 'a smile turns to unease', shows an understanding of how any ending would have led to emotional difficulty for the novel's characters. While P17N chose to leave the ending with the death of Lennie, the addition of George taking a rabbit with him shows a use of the novel's own materials in the partial compensation for the loss of companionship George felt in the death of Lennie, the rabbit standing in memory of Lennie.

Again, but now in their writing, autistic participants were equally drawn to Lennie's perspective in addition to that of George:

> *(P23A) 'He'd do it. He'd run away into the cave, and live there, no ketchup, just like he'd said.'*
> *(P20A) '"Listen Lennie, we ain't safe" "What you mean we ain't safe? We never safe George"'*

P20A's narrative is still shared between Lennie and George, as were her earlier considerations of character perspectives, adding a now shared knowledge for the precarious nature of their safety. P23A is able to re-use the novel's own language ('no ketchup') to sustain Lennie's new but vulnerable independence.

Autistic participants were also able to use the differing perspectives of George and Lennie to build tension for their assumed readers. This again demonstrated mobility of perspectives for autistic participants—the perspective of two characters as perceived through the perspective of their audience:

> *(P1A) 'George walks up him, staring him in the eyes without blinking "Lennie, what did you do? You tell me now"*

(P20A) "'Yeah Lennie, you right, you right -ere", George says as his voice begins to quieten down, into a soft whisper. "Why you whisperin'? I can't -ere you" Lennie says in normal volume.'

The urgency created by P1A through George toward Lennie creates an elongated moment of tension where George does not yet know what Lennie has done wrong. In this way, the reader, who knows the events of the narrative, is left in suspense through various imaginative alternatives. Similarly, P20A, who previously demonstrated a depth of understanding for Lennie's perspective, here uses Lennie's lack of knowledge for the subtleties of the situation to build tension. In this exchange, readers are able to understand that George's whispering indicates the imminent threat to their safety, building tension around Lennie's lack of ability to understand this particular situation and respond appropriately with the same quiet urgency as George. P1A works through pace and timing; P20A through tone and volume. By such intuitively adapted techniques, autistic participants additionally incorporated the subtleties of human life that are often missed in everyday encounters, building upon the felt realism of the literature:

(P23A) 'He barely noticed breaking skin on his legs as he slipped on his way up over the rocks'
(P11A) 'Despite being tired, the glimpse of their new home gave the men a renewed sense of energy, and had anyone been watching they might have said they moved a little faster and stood a little straighter.'

Responsive Language Changes

Autistic participants further responded empathically by demonstrating responsive language changes, re-embodying the original novel tone through their own language choices:

(P1A) 'He heads over to Lennie, "What's got you all worked up now? You best not hurt that puppy none!"… "I done a bad thing George, but not that. I told her to stop screaming, but she wouldn't listen".'
(P20A) 'George held onto him tight and pulled Lennie in tighter, "Listen -ere, you gotta come with me right now Lennie, I ain't playin no games, none. We gonna be killed if we don't get outta here"
Lennie points to George's hand, "but you got that George, we safe"
"We ain't safe, I ain't even s'posed to have this thing -ere, it ain't mine, so we gotta go".
"Well who's is it?" Lennie asks George, as if George was going to reply.
"Who's is it?"
"It ain't mine!"'

In the movement of readers into writers through reading, a remarkable sustained empathy is created.

DISCUSSION

Summary of Findings

The current study aimed to explore (1) the value of serious literature as a methodology for the exploration and comparison of autistic and non-autistic adult empathy and (2) whether adult autistic readers read in a more advantageous and empathic, 'literary' way than non-autistic adult readers. Resultant findings are discussed below in relation to previous theoretical assumptions and associated findings.

Reading as an Advantageous Methodology for Empathy Research

Findings from the current study demonstrated the previously documented ability of serious literature to mirror the real social world (Mar and Oatley, 2008; Waytz et al., 2015; Oatley, 2016). While everyday socio-emotional encounters often require fast-paced assertions to achieve empathy, findings of improved empathic capacity after reading fiction (Mar et al., 2009; Bal and Veltkamp, 2013; Kidd and Castano, 2013) highlight the ability of literature to simulate everyday social cognition. Furthermore, participants in the present study demonstrated a felt realism for the literature with resulting experiences of embodied perspective and empathic engagement. These findings therefore support prior theoretical suggestions that literature promotes realistic feeling between the mind of the reader and the minds within the text in a way that results in character embodiment (Zunshine, 2011; Barnes, 2018; Mumper and Gerrig, 2019; Limburg, 2021). Additionally, these experiences of empathic embodiment created complex layers of thought together with feeling in a way that replicated the combination of affective and cognitive empathy as it is experienced within the everyday social world (Fletcher-Watson and Bird, 2020). In this way, the present study further demonstrates the advantages of serious literature as an ecologically valid tool within empathy research (Djikic et al., 2013; O'Sullivan et al., 2015; Chapple et al., 2021b). These advantages contrast to standardised ToM tests which instead seek to separate thought from feeling in an attempt to gain experimental control (Fletcher-Watson and Bird, 2020). Not only do such tests lack ecological validity, but they additionally favor simplistic, heuristic-based empathic assertions that prevent deeper empathic explorations (O'Sullivan et al., 2015; Fletcher-Watson and Bird, 2020). Given suggestions and findings that autistic individuals may be more socially tentative in their assertions (Capps et al., 1992; Murray et al., 2005; Milton, 2012, 2020; Chown, 2014; Lesser and Murray, 2020), standardised ToM tests therefore risk underscoring and subsequently underestimating the empathic abilities of autistic individuals. By contrast, the present study was able to demonstrate the complexity of the empathic responses experienced by autistic participants, who at no time demonstrated any specific empathy deficits when compared to non-autistic participants. As a result, the use of literature within empathy research poses an advantage in its ability to explore autistic experiences in a way that rehumanises understandings of autistic empathy by moving the focus away from what autistic people lack (Murray, 2020).

Addressing Theoretical Assumptions of Autistic Deficits

Overall, the multi-faceted empathic responses by autistic participants in the current study contest assumptions of an autism-specific empathy deficit (Baron-Cohen, 1997, 2002, 2009). Instead, autistic participants demonstrated reflexive

thought alongside depth of feeling in a way that was empathic rather than systematic in nature, contrasting to the assumptions of the E-S theory (Baron-Cohen, 2002, 2009). Additionally, where perspective-taking and empathic feeling conflicted with autistic participants' own thoughts and feelings, they were able to draw from the novel's sub-text to overcome their own concerns. Therefore, findings challenge arguments that autistic individuals egocentrically impose their own thoughts onto the perspectives of others without regard to social context (Baron-Cohen, 1997; Lombardo and Baron-Cohen, 2011). These previous assumptions are instead likely to reflect the double empathy problem within research (Milton, 2012, 2020) alongside the overuse of restrictive cognitive ToM measures that prevent in-depth explorations of empathic experience.

Furthermore, autistic participants were able to think reflexively across the novel in a way that challenges the WCC theory's assumption of a resultant global processing deficit amongst autistic individuals (Happé, 1999). Similarly, autistic participants were more likely than non-autistic participants to think across perspectives within the novel. In this way, autistic participants demonstrated an ability to model minds, contesting the monotropism view that depth of feeling comes at the expense of perspective breadth (Lesser and Murray, 2020; Murray, 2020). However, the assumptions of the WCC and monotropism theories that autistic individuals have narrow interest systems which promote a depth of feeling and focus on detail were supported by the current research findings. Specifically, autistic participants demonstrated in-depth, involuntary feelings as well as a focus on subtle socio-emotional cues within the text which enabled them to uncover hard to reach perspectives. Therefore, findings suggest that an autistic neurocognitive advantage around depth of feeling may not result in deficits around breadth of understandings.

Double Empathy Implications

The ability amongst autistic participants to draw upon empathic depth alongside breadth often led to them demonstrating deeper feelings and understandings toward the literature than non-autistic participants. Specifically, autistic participants demonstrated more provisional thinking that enhanced their ability to hold in mind more than one conflicting mind or situation at a time. As a result, autistic participants were often more literary thinkers, able to 'bite off more than they could chew', as required by the literature (Djikic et al., 2013; O'Sullivan et al., 2015; Davis, 2020; Davis and Magee, 2020). For example, where non-autistic participants were only able to use their creative writing to create emotional depth for the main character, George, autistic participants were able to model multiple minds, including harder to reach perspectives such as that of Lennie. Furthermore, autistic participants demonstrated abilities in embodying the language of the novel and drawing upon their literary reflections to re-create the literature in a way that captured the socio-emotional subtleties of character perspective and human feeling. The inclusion of these narrative features by autistic participants expands upon arguments that readers of serious literature 'do' the literature in their reading (Barthes, 1969, as cited by Limburg, 2021; Muldoon, 2021) to suggest that autistic readers may engage more with literary thinking in this way. Overall, these findings support the double empathy problem assumption that autistic individuals may have more advantageous socio-empathic understandings than non-autistic individuals (Milton, 2012; Chown, 2014). Specifically, findings support the notion that, through their experience of navigating a lack of mutuality (Milton, 2012, 2020; Chown, 2014; Limburg, 2021), autistic individuals are more careful and provisional in their thinking and emotional responses (Capps et al., 1992; Lesser and Murray, 2020).

While the serious literature in the current study positioned autistic empathy as a social advantage, it further encouraged such tentative and provisional assertions amongst all participants. Early in the reading process, participants across groups tended to implement fast-paced, conclusive attributions of perspective that resulted in a failure to empathically get inside the literature. However, through literature requiring its readers to take on more than one thought and/or feeling at a time (O'Sullivan et al., 2015; Davis, 2020; Davis and Magee, 2020) participants were then required to go beyond heuristic-based assertions. While autistic participants were largely advantaged in this way of thinking, non-autistic participants began to think and feel for different Others throughout the novel. Furthermore, non-autistic participants began to re-think human culture by unpicking what creates Othering. These findings support previous findings that serious literature moves its readers away from rigid, stereotyped ways of thinking (Djikic et al., 2013; O'Sullivan et al., 2015). Additionally, the process of unpicking societal constructs indicates a potential for literature to give non-autistic individuals insight into the workings of wider society. In this way, literature may therefore be able to move non-autistic participants away from assumptions of pre-set mutuality and social norms (Milton, 2012; Chown, 2014) toward understanding the processes behind the Othering of neurodivergent individuals. Therefore, present findings indicate a potential for literature to promote double empathy understandings between autistic and non-autistic individuals, as shown in Chapple et al. (2021b), through a move away from assumptions of mutuality and pre-set social norms.

Limitations and Future Research

The current sample consisted of participants who had all completed GCSE level education or above, with the majority of participants having completed degree-level education. This may have resulted from an increased willingness amongst individuals with higher education backgrounds to engage with serious literature. Furthermore, autistic participants were only included if they did not have additional disabilities that would affect their reading or writing skills. As a result, conclusions on the value of serious literature as a tool for exploring and comparing empathic experience is limited to the current sample and are not representative of the wider autistic community. Given the under-representation of autistic individuals with higher support needs within autism research, future research should seek to explore the value of reading and reflective writing in

exploring the empathic experiences of autistic individuals from less educated backgrounds and with higher support needs.

Conclusions around autistic neurocognitive advantages in the contemplation of serious literature are also limited to the current sample. Although there was a spread of reader investment across neurotype groups, no data was collected on the wider reading habits of participants in the current sample. As a result, it could be that the autistic participants in the present sample were more experienced readers of serious literature compared to autistic individuals in the wider population of interest. Furthermore, that these participants were willing to engage in the reading of serious literature and subsequent reflections may have reflected an increased ability and willingness for reflexive and tentative thinking amongst these participants. Additionally, while *Of Mice and Men* (Steinbeck, 1937) was chosen due to its representation of adversity and ableism, this increased relevance for autistic participants may have shaped their responses in a different way than the non-autistic participants within the sample. As a result, conclusions around deeper empathic understandings amongst autistic individuals are limited to both the current sample and the piece of serious literature. Therefore, future research should seek to compare the reading experiences and reflections of autistic compared to non-autistic adults in response to various text types with different content relevance. Additionally, further enquiry is needed to explore specific textual factors, such as genre and realism, that enhance double empathy understandings and the ability of autistic readers to get emotionally inside a text.

Conclusion

In conclusion, the findings of the present study demonstrate the utility of serious literature as a research tool for exploring empathic experiences between autistic and non-autistic individuals. Furthermore, the implementation of serious literature in the current study was able to demonstrate the complex empathic experiences of the autistic readers within the study. Importantly, these findings contest previous assumptions of an empathy deficit amongst autistic individuals (Baron-Cohen, 1997, 2002, 2009) as well as assumptions of an autistic deficit in the modeling of other minds (Baron-Cohen, 1997; Happé, 1999; Murray, 2020). Instead, findings supported previous suggestions that autistic individuals are more socially tentative (Capps et al., 1992), feeling with others with advanced depth (Murray et al., 2005; Lesser and Murray, 2020; Murray, 2020) and with provisional assertions. As a result, the present findings support the notion that, possibly through their experience in navigating a lack of mutuality, autistic individuals have enhanced socio-emotional understandings that can prevent socio-communicative breakdowns (Milton, 2012, 2020; Chown, 2014). However, findings from the current study indicate that serious literature may encourage similar provisional assessments and socio-empathic understandings amongst non-autistic readers. Therefore, these findings demonstrate the full potential of serious literature to promote double empathy understandings amongst autistic and non-autistic individuals, to break down barriers and to advance a more nuanced scientific study of autistic psychology.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because the raw data is ethically sensitive, in that participants could possibly be identified from their data. Requests to access the datasets should be directed to Melissa Chapple, melissa.chapple@liverpool.ac.uk.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Liverpool Ethics Committee. The patients/participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individuals for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

MC, PD, JB, and RC: conceptualization, methodology, and validation. MC: funding acquisition, data curation, project administration, and writing—original draft. MC, PD, JB, SW, and RC: formal analysis and writing—review and editing. PD, JB, and RC: supervision. All authors contributed to the article and approved the submitted version.

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"A Group of Fellow Travellers Who Understand": Interviews With Autistic People About Post-diagnostic Peer Support in Adulthood

Catherine J. Crompton[1,2], Sonny Hallett[3], Christine McAuliffe[4], Andrew C. Stanfield[1] and Sue Fletcher-Watson[2]*

[1] Patrick Wild Centre, Division of Psychiatry, Centre for Clinical Brain Sciences, University of Edinburgh, Edinburgh, United Kingdom, [2] Salvesen Mindroom Research Centre, University of Edinburgh, Edinburgh, United Kingdom, [3] The Autistic Mutual Aid Society Edinburgh, Edinburgh, United Kingdom, [4] Department of Psychology, University of Stirling, Stirling, United Kingdom

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***Correspondence:**
Catherine J. Crompton
catherine.crompton@ed.ac.uk

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Receiving a diagnosis of autism in adulthood can be a life changing event, impacting identity, relationships, and mental health. A lack of post-diagnostic support has been highlighted by autistic adults, their allies, clinicians, and service providers. It can be a source of distress for autistic adults, reinforcing feelings of social isolation and rejection. Peer support could be a cost-effective, flexible, and sustainable model to provide community-based support for autistic adults. However, there is little research on the value of peer support, despite calls from the autistic community. This qualitative study explored autistic experiences and needs post-diagnosis, identifying specific ways that peer support may benefit them, and exploring the limitations of peer support. Twelve autistic adults who had all received an autism diagnosis in adulthood completed a semi-structured interview focussing on the diagnostic experience, post-diagnostic support needed and provided, engagement with the autistic community, and post-diagnostic peer support. Thematic analysis of interview transcripts resulted in four themes: (1) Mismatch in support needed and provided; (2) Community connection; (3) Flexible and personalised support; and (4) Sustainability. Participants indicated that peer support may be a useful mechanism to support autistic adults' post-diagnosis and offers unique opportunities not available through other support channels. Though informal peer support exists, it could be more sustainable and effective if well-supported and funded.

Keywords: autism, diagnosis, mental health, peer support, post-diagnostic support

INTRODUCTION

Due to broader diagnostic criteria and increased public awareness (Rutter, 2005; Hansen et al., 2015) many autism diagnoses now occur in adulthood (Fombonne, 2005; Happé et al., 2016). People seeking a diagnosis of autism for the first time in adulthood may diverge from prevailing stereotypes of autism. For example, they are less likely to be male (Gould and Ashton-Smith, 2011; Bargiela et al., 2016) and less likely to have a learning disability than those who receive an earlier diagnosis (Matson and Shoemaker, 2009; Geurts and Jansen, 2012).

Though autism diagnoses are more widely available, there are many barriers to efficient diagnostic assessment pathways, and appropriate post-diagnostic support (Huang et al., 2020). The adult diagnostic process involves standardised measures, alongside clinical interviews requiring knowledge of developmental milestones, and reflecting on challenges and difficulties throughout life (Rutherford et al., 2016a). Difficulties with the diagnostic process, including long waiting lists, multiple referrals, and complex routes to diagnosis (Jones et al., 2014) are well documented (Crane et al., 2018). Moreover, atypical communication styles and social anxiety make reporting symptoms difficult (Murphy et al., 2016). Concurrently, clinicians face an increasing number of referrals and constraints on resources (Rutherford et al., 2016b).

The lack of post-diagnostic support has been highlighted by autistic adults, the families of autistic people, clinicians, and service providers (Griffith et al., 2012; Lewis, 2017; Crane et al., 2018; Raymond-Barker et al., 2018; Huang et al., 2020). Most adults receiving an autism diagnosis are dissatisfied with the availability and quality of post-diagnostic support available, and many autistic adults report that they are offered no support whatsoever (Jones et al., 2014). There can be an assumption that because someone has managed to reach adulthood without support, that no support is needed (Griffith et al., 2012). Some receive only written information, which is considered inadequate (Beresford et al., 2019), and many find that the autism service they are referred to does not meet their needs, as support is aimed at children or those with intellectual disability and/or language delay (Griffith et al., 2012; Crane et al., 2018). Due to a lack of resources, clinicians are often unable to provide post-diagnostic support, leaving autistic adults disappointed with the diagnostic process and outcome (Jones et al., 2014; Crane et al., 2018; Huang et al., 2020). Post-diagnostic support not being offered or available is a source of distress for autistic adults, reinforcing feelings of social isolation and rejection (Beresford et al., 2019). The types of post-diagnostic support most frequently requested by autistic adults are support groups, social skills training, and counselling (Jones et al., 2014), with an individualised approach to support highlighted as enhancing independence (Griffith et al., 2012; Huang et al., 2020).

The Impact of Diagnosis

Receiving an autism diagnosis as an adult can be a life changing event (Arnold et al., 2020). Though most autistic adults report feeling relieved, many also feel anxious, confused, upset, or angry (Jones et al., 2014). While diagnosis can increase self-acceptance and self-understanding, it does not necessarily improve acceptance or understanding from others (Punshon et al., 2009; Crane et al., 2018; Arnold et al., 2020). Previous research has found that long-term partners report initially reacting to diagnosis with anger and hopelessness, before accepting and supporting their partner (Lewis, 2017). Autistic adults report some negative reactions from their parents (Crane et al., 2018), and even when family members accept their diagnosis, effective support from non-autistic family members is hindered by a lack of understanding about autism (Punshon et al., 2009; Crane et al., 2018).

Diagnosis can have a profound impact on identity (Punshon et al., 2009), and some autistic adults have described how identifying as autistic opened up access to a community of autistic people where they felt they fitted in Punshon et al. (2009). Being part of a community can help in developing a sense of acceptance and pride (Davies, 1996), and thus engagement with other autistic people may be beneficial (Skirrow and Farrington, 2008; Punshon et al., 2009). Recent research has found specifically that self-acceptance and pride in being neurodivergent (Milton and Sims, 2016; Gillespie-Lynch et al., 2017) is linked to lower depression scores (Cage et al., 2018), and higher self-esteem (Corden et al., 2021) and feeling part of an autistic community reduces suicide risk (Cassidy et al., 2018). There has been a call for research that identifies ways of promoting the development of a positive autistic identity following a diagnosis in adulthood (Corden et al., 2021; Maitland et al., 2021).

While autistic/non-autistic interactions can be positive (e.g., Smith et al., 2021), autistic adults have often described interacting with other autistic people as more comfortable, validating, and fulfilling than interacting with non-autistic people (Bargiela et al., 2016; Hickey et al., 2018; Tan, 2018; Crompton et al., 2020a). There may be an ease of interaction with other autistic people that is not experienced during interactions with non-autistic people, as difference is normalised, and normative expectations of communication style do not apply (Bargiela et al., 2016; Hickey et al., 2018; Tan, 2018; Crompton et al., 2020a). With other autistic people, there is less need to conceal overtly autistic behaviours such as stimming and rocking (Crompton et al., 2020a). Engaging with this new social world can encourage self-compassion, build resilience, and develop a greater sense of autonomy and agency (Crompton et al., 2020a; Leedham et al., 2020). Recent empirical research suggests that interacting with other autistic people might be easier and more comfortable than interacting with non-autistic people, and that autistic people may have particular communication styles that are enhanced in autism-specific social interactions (Heasman and Gillespie, 2019; Crompton et al., 2020b,c; Rifai et al., 2021). Additionally, autistic adults have high levels of scientifically-based knowledge of autism and lower stigma toward autism than non-autistic people (Gillespie-Lynch et al., 2017). As formal post-diagnostic care for autistic adults is lacking, social relationships can offer valuable support, with support from autistic peers considered as particularly important. Thus, it is pertinent to examine community-based peer-support interventions that enhance autistic wellbeing during the post-diagnostic period.

Peer Support as a Community-Based Post-diagnostic Intervention

The peer support model assumes that shared experience of a phenomenon enhances the development of an empathetic supportive relationship (Repper and Carter, 2011). In non-autistic groups, peer support yields substantial mental health benefits for recipient and provider (Repper and Carter, 2011), and is easily implemented within existing services whilst providing positive benefit at lower cost (Pfeiffer et al., 2011). Peer support structures can take several forms, such as mentoring, befriending,

and support groups (Bradley, 2016). Mentoring, in particular, has been shown to have several benefits, including the provision of a cost-effective personalised supplement to formal support mechanisms, the promotion of rapport due to proximity in age, and increasing the wellbeing of both the mentor and the mentee, with the latter continuing to experience benefits a year later (Jacobi, 1991; MacLeod, 2010; Appel, 2011; Hillier et al., 2019). Despite its popularity, the concept of mentorship is ill-defined and many definitions exist in relation to particular subject areas (Crisp and Cruz, 2009). The most widely accepted definition relates to the formation of a goal-oriented supportive relationship in which one partner is more experienced and offers guidance to the other partner (Jacobi, 1991). Autistic peer support is an opportunity to provide support for autistic people in an accessible way, which embodies their priorities, and unlike many other supports does not involve the centring of a neurotypical lens (MacLeod, 2010; Stevenson et al., 2016; Thompson et al., 2020).

Autism and Peer Support – The Evidence to Date

A small number of studies have examined autism-specific peer support in adults. Most of these studies have involved support delivered through online support groups (MacLeod, 2010; Stevenson et al., 2016). MacLeod (2010) details the creation of an online support network for autistic university students, the AS portal. Discussions were started by moderators and by participants, with the latter evoking a more sustained response and engagement. Although the number of students who participated was relatively small (n = 7), the success of the participant-led discussions was interpreted by the authors as illustrating the willingness of the students to engage with one another and with this form of support. Participants highlighted that they appreciated the opportunity to offer advice and support to others. MacLeod (2010) considered the willingness and engagement of autistic people in these networks to be a "vast untapped resource" and highlighted the potential of online peer support networks as a mechanism to raise "collective consciousness and personal self-confidence" (p. 23). Rosqvist (2018) used focus groups (n = 7) to explore the topic of autistic peer support with a group of autistic adults who worked with and provided support to young autistic adults in an autistic-only workplace. They sought to outline an alternative model of autistic development, underpinned by common experiences, mutual understanding, and a focus on ways of being that are different, rather than deficient. In Martin's et al. (2017) development and evaluation of a training programme for mentors of autistic adults (n = 9 pairs), the importance of supervision and ongoing training was emphasised, as well as reliability and consistency on the part of the mentor. Although the majority of the mentors in this study were not autistic, those in same-neurotype pairings reported benefitting from the enhanced empathetic closeness brought about by similarity of experiences between the mentor and mentee. Finally, Crane's et al. (2020) study involved sixteen participants engaging in 10-week autistic-led programme that aimed to support autistic adults to learn more about autism within a peer group context. This was designed as a post-identification course for people who recently identified as autistic or who had recently received a diagnosis of autism. This study demonstrated the importance of valuing autistic individuals as "experts by experience" and the egalitarian potential of peer support in terms of deconstructing the hierarchy between predominantly non-autistic professionals and autistic individuals.

The Current Study

While further research examining the efficacy of a post-diagnostic peer support intervention for autistic adults is needed, a crucial first step is to ensure any peer intervention is co-designed with or led by autistic people and reflects their views, preferences, and priorities. The purpose of this study was to elicit the views of people who had received a diagnosis of autism in adulthood, exploring their diagnostic experiences, the post-diagnostic support that they needed and were provided. We focussed on what the function and focus of peer support may be, whether they felt it could act in place of other support, should exist alongside it, or not at all, and the benefits and challenges that they suggest it may face. In this study, we used a qualitative methodology to examine these views and explore how these may be incorporated into a future support system.

MATERIALS AND METHODS

Methodological Approach

This study used a qualitative design, with semi-structured interviews analysed thematically. Ethical approval was obtained from the University of Edinburgh Moray House School of Education and Sport Research Ethics Committee.

Participants

Participants were 12 autistic adults (see **Table 1** for demographic information). Participants were recruited through our project website, local autism organisations, and social media. The project advert was titled "post-diagnostic support and peer engagement," and participants were told they would be asked questions about their diagnosis, the support (or lack of) received after diagnosis, and social relationships and support from autistic and non-autistic people. Participants were eligible if they received a formal diagnosis of autism (including Asperger's syndrome and other "on the spectrum" diagnoses) after the age of 18, spoke English to a native level, and had received their diagnosis within the last 10 years. We asked that participants had received their diagnosis within the last 10 years to ensure that the diagnostic experience was recent enough that participants could reflect on their experiences and needs at that time. A limit of 10 years allowed a range of experiences to be represented, while also ensuring that experiences were representative of recent and current practices in autism diagnostic pathways.

Participants (7F/1NB/4M) had a mean age of 44.92 years [standard deviation (SD) = 11.94], and a mean, autism quotient (AQ) score of 41.25 (SD = 3.74). The mean age of diagnosis was 40.75 years (SD = 12.01), and mean time since diagnosis was 4.25 years (SD = 2.8). All participants identified as white British,

TABLE 1 | Participant demographic information.

ID	Gender	Age	Age at diagnosis	Years since diagnosis	AQ score
1	Female	54	47	7	49
2	Non-binary	48	44	4	37
3	Female	31	21	10	39
4	Male	63	61	2	47
5	Male	50	48	2	39
6	Female	30	29	2	39
7	Female	43	41	2	43
8	Female	46	43	3	40
9	Male	36	30	6	42
10	Female	33	30	3	37
11	Female	39	37	2	43
12	Male	66	58	8	40

AQ, autism quotient.

Scottish, or European. A number code was generated for each participant and identifying details redacted from reported quotes.

Procedure

All participants provided written informed consent before the study commenced. Before the interview commenced, participants were told (1) that they could take a break at any time during the session for any reason, (2) they did not have to talk about anything they did not want to talk about, and (3) if they wanted to answer a question in more detail, they could go back to a question or answer it in more detail. The first author conducted interviews either in-person (n = 2), over the phone (n = 1) or via video call (n = 9) depending on the preference of the participant.

Measures

Semi-Structured Interview

Qualitative data were collected using a bespoke semi-structured interview designed for this study in consultation with autistic collaborators. Using a semi-structured approach, the interviewer can probe a participant's response and gain clarity where there is ambiguity (Barriball and While, 1994). The wording of questions was designed to be neutral and not leading, and was reviewed by two autistic people prior to the study commencing to ensure that the language was accessible and comprehensive. The interview questions explored the diagnostic experience, post-diagnostic support needed and provided, engagement with the autistic community, and post-diagnostic peer support (see **Supplementary Table 1**).

The Autism Quotient

The AQ is a 50-item multiple choice questionnaire which yields an approximate measure of autistic traits (Baron-Cohen et al., 2001), and was included to provide additional detail about participants' autistic traits. This was completed individually by participants, using an online form, following the interview. A score over 32 indicates a high level of autistic traits.

Qualitative Data Analysis

Interviews were transcribed by a professional service and checked for accuracy by the first author. The six-phase framework of thematic analysis was then applied (Braun and Clarke, 2006). This method of analysis allows an inductive process: it does not necessarily rely on existing frameworks for interpreting data, and thus it is suitable for an emerging area of research such as this (Willig, 2013). The six-step process involves familiarisation with the data through reading and re-reading interview transcripts, generating codes that highlight pertinent features of the data, searching for themes, ensuring themes relate back to the initial codes, defining and naming themes, and relating the findings back to the research literature (Braun and Clarke, 2006). The analysis was led by the first and second authors. The first author completed initial coding of the data, and these were then discussed with the second author. A broadly inductive approach to analysis was taken; data were coded by category, and the similarities and contrasts between participant responses were examined using a constant comparative method (Glaser and Strauss, 1967; Miles and Huberman, 1994). In collaboration, the first and second author then searched for sub-themes and themes, reviewed these themes, and defined and named the themes. Establishing themes was a data driven process rather than attempting to work within a pre-conceived coding framework (Saldaña, 2021), though our knowledge and experience of the literature may have shaped the analysis phase (Braun and Clarke, 2021). The first author is a non-autistic researcher, and the second author is an autistic adult with a background in advocacy: thus the views of mainstream psychological theory and the lived experience perspective of autistic adults are incorporated in this analysis.

RESULTS

Participants reflected on their experience of diagnosis, their support needs around that time, and their experiences interacting with autistic and non-autistic peers. Four main themes were identified and 12 subthemes were identified from the interview data (**Figure 1**). Participants quotations are reported along with their gender and age in brackets.

Theme 1: Mismatch in Support Needed and Support Provided

The first theme focussed on the mismatch that participants experienced between the support they needed and the support they received following their diagnosis. Participants felt that the support they received (if any was received at all) did not meet their needs. They stated that support should focus on enhancing understanding on how this diagnosis applied to their lives, their relationships, and future plans, and that support should come from sources that understood their experiences.

Subtheme 1: Facts-Based Knowledge vs Applied Understanding

The information provided post-diagnosis was mostly in written form and described what autism is, which participants found

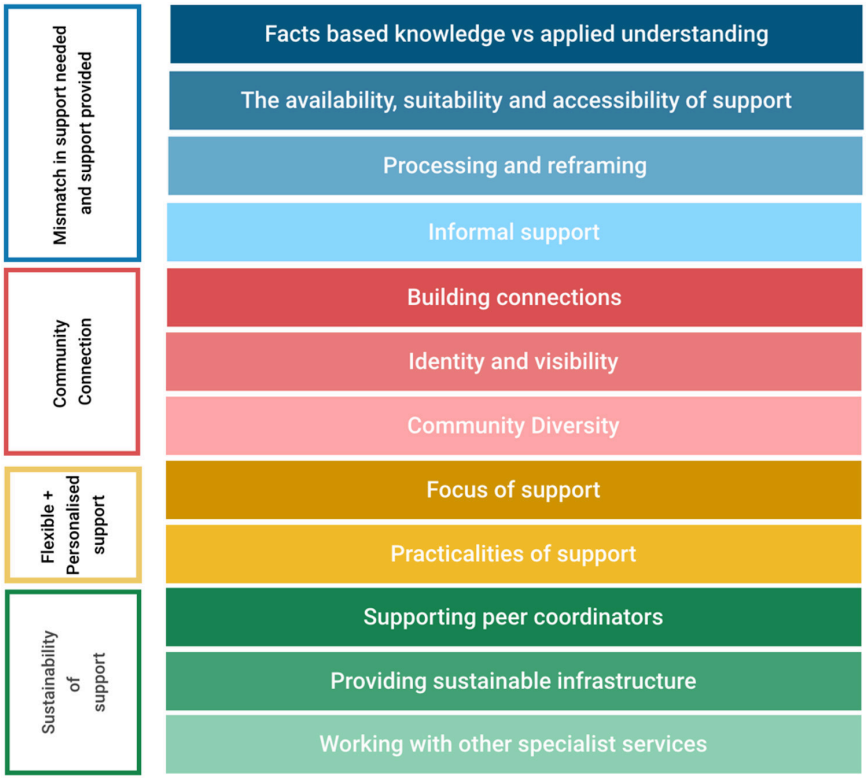

FIGURE 1 | Structure of themes and subthemes.

insufficient and not helpful. The content of written resources focussed on facts about autism, whereas participants wanted to know what being autistic meant/looked like for them, and what it meant for their relationships and identity.

> *"I got a print out leaflet about Asperger's. They weren't particularly useful suggestions. I already knew about autism cause I had studied it, and I had worked with autistic kids, so that wasn't much use to me"* – Participant 3 (F, 31).

The personalised information that participants received in their diagnostic report was often framed in a very negative and pathologising way, and was difficult to process. "*Reading the report, it is written in quite a negative way. Because it is the deficit model. So it was quite hard reading the things about myself that I am bad at. Cause I have tried my best to hide them, for the last 40 years. [. . .] I am an intelligent person, I am a very capable person but [. . .] this new diagnosis and this new information [. . .] I was still not quite sure what to do with it.*" – Participant 11 (F, 39). Some participants described the negative impact this had on their self-esteem – *"the diagnosis had a knock-on effect on my confidence at that time [. . .] I think I needed probably a bit of help to process some of that stuff."* – Participant 6 (F, 30).

Participants had a good understanding of autism and its core diagnostic features in a general sense, but had difficulty understanding what this meant for them on an individual level. As autism is very heterogeneous, many struggled to identify with the information provided to them. What most participants wanted was the opportunity to discuss what the diagnosis meant to them.

> *"There wasn't any help. You've just been diagnosed with something which is a neurodevelopmental condition and a disability and you have had it all your life, it was quite. . . well it was frustrating but it also it was quite. . . in a way quite scary to be sort of . . . left unsure how to manage this in. . . from the rest of my life going forward"* – Participant 5 (M, 50).

Subtheme 2: The Availability, Suitability, and Accessibility of Post-diagnostic Support

Many participants reported requesting post-diagnostic support and being refused, or told none was available.

> *"I mean there is nothing available really [. . .] I did go to my GP a few months after my diagnosis and explained. . .but they couldn't help me. My GP was quite understanding. . . really understanding, really, and put me in touch with somebody fairly senior from the local adult autism team. . . but they weren't very helpful."* – Participant 8 (F, 46).

Some participants had been signposted to post-diagnostic support, however this had been designed for autistic people with high support needs or a learning disability, and was therefore not suitable for their needs [*"if there is any support available it is very much geared towards people with much higher support needs in terms of day to day living."* – Participant 8 (F, 46)]. Some participants reported being perceived as too "high functioning"

to require support (*"I said 'what support is there?' and they said 'there isn't any, because you are high functioning'"* – Participant 4 (M, 63). Services did not offer support to build understanding of the diagnosis, how it fits within a person's identity, and build strategies to help them move forward.

> *"Getting a diagnosis was also a frustrating thing because [. . .] there wasn't really anything in the report that I was given at my diagnosis or after my diagnosis that really said anything like 'well this is how it seems to us how your autism has affected you'."* Participant 5 (M, 50).

Participants also reported barriers to accessing autism services. Some were oversubscribed with long waiting lists, so support was significantly delayed and not available when most needed ("*I had to wait a year for the post diagnostic group to start again. When I went along to that, only two of us turned up so they cancelled it so then I had to wait another four months until they set up another one, I was in crisis at that point and I really needed the support right then and there. Not. . . wait a few months. . . and then wait a year. . . it wasn't great*" – Participant 3 (F, 31). Some faced geographical barriers due to living a long distance from services, especially those who did not live in cities ["*I found post diagnosis support tends to be concentrated in cities in Scotland, which is not very useful if you don't live in those cities. Post diagnosis support should be throughout all towns and cities. I think that is why kind of models like peer support would be better. . .it would be easier to support people that way*" – Participant 7 (F, 43)]. Some found that communication difficulties related to being autistic made it difficult to reach out to services. Referrals had also been made to services with insecure funding, and the lack of consistent or sustainable long-term funding increased anxiety when engaging with a service, which in some cases led to reduced engagement.

> *"The adult autism team are responsible for post diagnostic support but because of funding, I think it is just a four week programme now. And then that is it. You have had your support, that is all we have got."* – Participant 3 (F, 31).

Some participants also found that receiving an autism diagnosis resulted in them losing support from health providers or third sector organisations, as it was assumed that their support was not suitable for an autistic person.

> *"I asked our (local NHS) counselling service, I wanted to talk to somebody about stuff, but because I asked them 'I want some help talking through stuff in relation to my autism diagnosis' they said 'oh no, we can't help you, we are not specialist enough for that.'"* – Participant 11 (F, 39).

> *"I did phone mental health services and ask them for help. and they said autism isn't a mental health issue. Even though that was where I got diagnosed and that I sounded quite articulate and I would be all right."* – Participant 4 (M, 63).

In general, participants said that the most beneficial support to them would have included building a sense of identity and community, as well as self-care skills and tools to manage stress and sensory and social overload ["Figuring out what your autism is; what your sensory issues are; where you should avoid communication, things like that." – Participant 7 (F, 43)].

Explaining what autism is to family, friends, and employers, and identifying and requesting beneficial adjustments could be difficult. Some participants highlighted that friends and family had difficulty in accepting and understanding their diagnosis, and it was particularly difficult when others doubted or disbelieved their diagnosis, or perceived them as so "high functioning" to not require adjustments.

> *"I needed help explaining it to my family. Cause even though my mum was there (at the diagnosis) and got it explained to her, she hadn't quite. . . she knew what autism was but she didn't really know what it was in relation to me."* – Participant 3 (F, 31).

> *"I think people who weren't autistic didn't understand why it was important"* – Participant 6 (F, 30).

Subtheme 3: Processing and Reframing

All participants described their difficulties processing the diagnosis, and reframing history in light of their diagnosis. Though some highlighted that diagnosis does not change who you are as a person and that you are still the same person afterward, it is still an adjustment and a lot of information to process, and it can take a long time to get used to.

> *"I guess it was. . . well it still is, a bit of a rollercoaster because you have to. . . it kind of forces you to look back on your life through a different lens. Lots of stuff made sense. There was a lot of positives, where I could look back and think. . . well actually I didn't fail at this thing that I didn't manage to do. There was a reason that I now understand so I can forgive myself for not going to a top university and becoming a high-flying lawyer or whatever. Because that just wasn't the right thing. And now I understand why I struggled with certain things. So that made sense."* – Participant 8 (F, 46).

> *"I think maybe some kind of support to just sort of deal with the transition into sort of knowing. I usually describe it like if you had your skirt caught in your knickers or something and you realised in that moment and you are like 'oh my god, it has been like this the whole time' and you think back to all these social situations that you thought you were so dead on with and then you look back and you were like 'no'."* – Participant 6 (F, 30).

Participants experienced many emotions in the aftermath of diagnosis, including fear, happiness, validation, relief, upset, and anger, but lacked an understanding person to discuss this with. *"Initially you had this bounce of . . . you have this sort of elation of knowing what things are, and being able to reframe things, but actually the problems were still there. But then actually once that has subsided then it is still the 'oh god, what do I do now?' sort of a feeling."* – Participant 9 (M, 36).

Prior to their diagnosis, participants had often experienced difficulties in their social life, complex sensory processing differences, and difficulties with executive function. Many participants felt an important part of the post-diagnostic process was to develop self-compassion and understanding of what being autistic means, and reframing their identity and expectations around them being an autistic person, rather than a "failed neurotypical." Spending time with other autistic people in a peer support setting may have been particularly beneficial in understanding oneself and validating their experiences.

"I would have been very happy to just to be in a room with people who had that new diagnosis in common... because I have found that in trying to understand how the course of my life has run, in the light of this new diagnosis I have very often figured things out on the basis of something that somebody else has said about the course of their life. And it has not always been... 'oh that has happened to me too'. It has sometimes been 'oh well that didn't happen to me' or 'I don't have that particular expression of the condition so... how does it work in me instead?'. But it has been that prompt of having somebody else's life story, if you like, that has been really important for me understanding myself I suppose, ultimately." – Participant 5 (M, 50).

"Just having someone kind of validate your symptoms and what you have been through, and when you have been in that mindset of 'no it is just me, I am just not coping well with this'. Suddenly going from seeing myself as like a slightly defective neurotypical person, to actually a pretty well coping autistic person." Participant 11 (F, 39).

Subtheme 4: Informal Support

In the absence of the formal support desired by autistic adults post-diagnosis, many participants reported turning to social media groups to connect with other autistic people [*"Most of the support I get is through social media...there is no real official diagnosis support"* – Participant 7 (F, 43)/*"Through twitter and facebook, I have found a community in which I get support. But when it comes to actual formal support in healthcare, it is a dead end for me"* – Participant 9 (M, 36)]. They noted how useful it could be to learn about autism from other autistic people [*"Through social media platforms, there are a lot of autistic advocates having their voice heard, which is absolutely fantastic, connecting with each other, and it has been invaluable to me"* – Participant 10 (F, 33)]. However, not all participants enjoyed social media engagement (*"Twitter, I found, fed a lot of my anxieties. And while you could meet people on it, it didn't feel like an actual connection with people"* – Participant 6 (F, 30). *"Some people are very angry on there [social media] or really struggling and sometimes it can be quite depressing to read those things"* – Participant 2 (NB, 48), and thought they would have benefitted from in-person peer support [*"I got a lot of (autistic peer) support online, but I think I would have benefitted from in-person support, a similar thing. Just some place where I could speak to and meet other autistic people"* – Participant 7 (F, 43)].

Though research has shown the benefits of community engagement for autistic people, no participants mentioned being told this during the diagnostic process.

Theme 2: Community Connection

The second theme focussed on community connection. Following their diagnosis, participants felt that they wanted to connect and engage with a new community of people, build connections with others who may have similar experiences to them, and that this may increase self-acceptance in being autistic.

Subtheme 1: Building Connections

Participants felt that after receiving an autism diagnosis, building connections with like-minded peers, and feeling part of a community was particularly important. Participants said that relationships with other autistic people felt easier and more comfortable than relationships with non-autistic people, and that they experienced feelings of similarity and connection with them. Participants felt that they were more able to create authentic connections with other autistic people because they had a reduced need to mask their natural autistic behaviours [*"It is great to have people who don't need an explanation... you don't need to hide your autistic traits...you know there is no need to worry with them."* – Participant 7 (F, 43)]. This communicative ease and mutual understanding may create a comfortable and supportive environment for peer support following diagnosis, and more so than support provided by non-autistic people.

"Autistic (peer support) would be the most beneficial. Just because you can never explain to someone who has never been othered, you can never explain what that feels like from birth. The level of personal reflection, doubt, fear, that that brings, whatever intersection you belong to. If you don't belong to any, you can't explain what that feels like, and the effect it has 30 years down the line, you know" – Participant 10 (F, 33).

"It just helps to have a group of fellow travellers who understand" – Participant 8 (F, 46).

Subtheme 2: Identity and Visibility

Many participants reported that it took some time to overcome embedded internalised stigma, and that it was difficult to come to terms with some aspects of being autistic that they struggled with.

In the past I really would have beaten myself up about it thinking... 'I need to go to these things' and then I would go along to it, probably have to leave early and then feel like I had disappointed everybody and people would be angry with me and I would be angry with myself. So... I now think understanding that my brain works a bit differently in certain aspects is ok. And it is ok to be me and that I should not criticise myself for being me. – Participant 1 (F, 54).

Participants felt that being around other autistic people, sharing mutual experiences and discussing challenges helped enhance their self-understanding and reduce internalised stigma. Peer support may provide a space where autistic adults can be comfortable in who they are, and discuss things they struggle with, with peers who have similar experiences.

"Just having some people to say 'this happens to me, is this normal? What do you do about this?' is so important" – Participant 11 (F, 39).

Subtheme 3: Community Diversity

While participants generally found interacting with autistic people more comfortable than interacting with non-autistic people, this is not a universal experience. All autistic people are different, and it cannot be assumed that all autistic people will experience similarities or have easier communication on the basis that they are autistic.

"*I think it is untrue, the idea that all autistic people get along with each other. They don't. There is a heck of a lot of arguing going on on twitter amongst autistic people...All autistic people are different, even if there are some similarities by virtue of having the same diagnosis, and there will be some people who you get along with and some people you don't"* – Participant 1 (F, 54).

Autistic people are not solely defined by being autistic and for peer support to be successful, participants felt it was important to take into account other aspects of their backgrounds [*"I find I am just as defined as being a carer for my husband and being a mother to my children than I am my autistic diagnosis. So those other roles need to be there, for them to truly understand."* – Participant 10 (F, 33)]. It is also important to consider compatibility (or incompatibility) of communication styles and preferences of group members.

> *"Just kind of finding compatible people. There is quite a few people who are very similar to me. We get on really well. Cause we are all quite quiet. We will talk if we are interested in something. But we won't just talk and talk and talk and we will all be fine in a group. But as soon as you introduce someone who is louder, they kind of take over the whole group. Or somebody who can't control the volume of their voice or whatever. Then you might get people going 'shut up'. People who are more outspoken than me will then get annoyed and it will turn up into just a big barny, or argument and I am just like fleeing this issue. So it is hard to kind of . . . having that empathy for understanding people can't help how they are."* Participant 3 (F, 31).

Theme 3: Flexible and Personalised Support

The third theme focussed on the need for flexible and personalised support. Participants reported needing a variety of support following the diagnosis, focussing on different areas, with different support intensity and length. Participants felt that peer support may offer the flexibility needed to improve their post-diagnostic experience.

Subtheme 1: Focus of Support

Peer support offers a flexible way to meet the needs of autistic people, which may vary both between people and over time. Participants reported that peer support could have a number of purposes, including sharing skills and strategies, providing a space to talk and socialise, or engaging in shared activities.

> *"I suppose it is what they struggle with in particular. So some people really struggle with anxiety and depression and other people might struggle with socialising, someone else might struggle with sensory things. So there is different things that we struggle with. So maybe thinking about what area they would need support with."* – Participant 2 (NB, 48).

Participants felt it was important that the focus of support should be led by those engaging with the peer support group at any given time, and so peer support frameworks should be flexible and responsive to the needs of group members.

Subtheme 2: Practicalities of Support

Preferences regarding the structure of peer support varied between participants, reflecting a variety of opinions. Peer support facilitators should be sensitive to the preferences of group members regarding group size (i.e., 1:1, group support, or mentoring), frequency of support (weekly, fortnightly, or monthly), and location (online or offline, and if online, the type of space used).

Peer support facilitators should ensure accessibility of spaces for autistic people, including considering the sensory environment, including photos and bios of facilitators, and a clear explanation of the roles of peer support facilitators.

> *"In my area there is. . . another adult who I know through a friend, who is autistic, has said 'oh there is this pub meet up for kind of Asperger's type people'. It is like going to a pub to meet a load of people you don't know, is like my worst nightmare. So I have never done it. It is just ironic, there is support there, but in order to access it you have to do the thing that is really difficult."* – Participant 11 (F, 39).

> *"Trust would be the biggest barrier to overcome for me. I would say that maybe a 'get to know the mentors coffee morning' so you can see which ones you get along with or maybe, an online bio and a photo, so you get a better grasp of who they are and what they are about, before you start trusting in people. Because post diagnosis you are very raw. . . well I was, and quite guarded about 'well everybody has failed me', not that that was true, but that was what it felt like."* – Participant 10 (F, 33).

Theme 4: Sustainability of Support

The final theme focussed on the sustainability of support. Participants expressed a need for peer support to be manageable and sustainable in the long term. Some participants expressed distress that they had engaged with formal or informal peer support groups, and had found that the group had been discontinued due to a lack of funding, space, or someone to co-ordinate.

> *"I went to a sort of support group. Run by our local. . . psychiatric hospital, run by a chap from there. Which I already knew about and which I joined in as much as I could. But that has collapsed. . .because of funding"* – Participant 12 (M, 66).

Subtheme 1: Supporting Peer Support Facilitators

Simply being autistic does not provide someone with the knowledge and skills to be a peer support co-ordinator. Participants felt that peer support coordinators or mentors needed to have some training or experience, otherwise peer support may not function.

> *"some kind of training on how. . . how to make sure [peer support coordinators] are communicating effectively to the particular person that they are mentoring. . .you need someone who can communicate with you in a way you respond to positively. Otherwise you are just going to feel even more alientated: here I am with this new diagnosis and even other "Aspys" or people on the spectrum don't get me either"* – Participant 5 (M, 50).

Participants stated that peer support coordinators require training and support in order to be able to run a peer support service that meets the needs of a wide range of autistic adults.

> *"If you are going to mentor someone you would need to tell them what other support is available. Training on what they are entitled to, what issues they might experience, where to get help, that sort of thing. And where to get help if they are having mental health problems or bullying at work, or anything like that. Some kind of psychological training or coaching because you don't want to say the wrong thing"* – Participant 7 (F, 43).

"Because they [peer support coordinators] are offering psychological support, they will need training before doing it." – Participant 8 (F, 46).

"Training on group dynamics if they are not managed well, if there is a personality clash or something like that, places of inclusion can become quite exclusive" Participant 9 (M, 36).

"*Some awareness of being a parent or carer…and I don't know if they would have to go on a course to educate themselves but there are other things that non-white autistic people are party to that white autistic people wont understand…little bits of racism"* – Participant 10 (F, 33).

Additionally, participants reported that facilitators should have professional supervision to reduce the risk of burnout, and to enhance resilience and confidence.

I think kind of like the supervision model is always a really good one. If you are being the person that is taking an emotional burden from somebody then you need somewhere to put it as well. So I think kind of having a forum where I would then be able to… either I had a mentor or there was some sort of group where mentors were able to chat stuff through and put stuff down, something like that would be really useful. – Participant 11 (F, 39).

"Being a peer support worker, there needs to be thoughts about workplace mental health, stress at work, how that affects you, the boundaries of it…I guess proper like supervision, where you were able to talk about these specific issues, that would be a massive part of it" – Participant 6 (F, 30).

Subtheme 2: Providing Sustainable Infrastructure

Participants reported that long-term secure funding was essential for providing a stable environment for them to feel comfortable in the peer support relationship. Some participants had engaged with peer support or autistic-led support after their diagnosis, but a lack of sustainable funding had resulted in anxiety around whether support would be available to them beyond the short-term.

Providing administrative support to organise and host peer support is essential to ensure smoothly-run and consistent support: *"…it should be properly constituted, and perhaps even having some sort of professional workers there as facilitators who are there just to… you know manage the group and maybe the admin and booking rooms and things like that"* – Participant 9 (M, 36).

Subtheme 3: Working With Other Specialist Services

Many participants reported that following a diagnosis of autism, services were less likely to offer them support or be willing to provide them with care.

"All of a sudden… IAPT and local community mental health services wouldn't actually take a referral because they said it wasn't within their expertise and that I should access the specialist service. But the specialist service was only a diagnostic service, not a general health and wellbeing and ongoing support service. So it actually closed things off." – Participant 9 (M, 36).

Additionally, some services did not consider the autism diagnosis and gave advice that was difficult to understand or apply.

"One thing I have found with my chronic fatigue syndrome for example, some of the things I am expected to do for that are completely at 180 degrees from the things I am supposed to do to manage my depression, so it is very difficult to know what to do. Then when you add autism into the mix as well. It is just a further complication…that has been very, very frustrating and there has been absolutely no support at any level, from the state sector, the NHS, or from the third sector, on trying to figure that out." – Participant 5 (M, 50).

Participants noted the importance of recognising the boundaries and limitations of peer support, and acknowledged that autistic adults may require support from other healthcare providers. This may include accessing mental health care from specialist providers. Peer support frameworks should not be used in place of specialist support: it should work alongside specialist teams to ensure that autistic adults can access the support that best suits their needs.

DISCUSSION

In general, participants were very positive about the concept of post-diagnostic peer support. They felt it offered unique opportunities to engage with other autistic people, learn more about autism, and understand how their new diagnosis applied to their lives in a more meaningful way than the facts-based information that had been provided to them at their diagnosis. Participants liked the flexible nature of peer support and the opportunity to focus on a wide range of topics from an autistic perspective. Participants provided key insights into what peer support should focus on, how it should be run, and the specific benefits it may offer. According to these findings, maximising the potential of peer support will involve sustained funding, engaging with other specialist services, and training and support for facilitators. These findings are a crucial step in future studies that may examine the efficacy of a post-diagnostic peer support intervention for autistic adults.

Many of the findings of this research are supported by recent literature. One of the benefits of peer support indicated by this study is the relational and emotional benefits of autistic-autistic interaction. Being with other autistic people may act as a buffer to the effects of minority stress (Botha, 2020), and being around other autistic people in the post-diagnostic period may be especially beneficial (Crane et al., 2020). Alongside lived experience, autistic adults have fairly high levels of scientifically-based knowledge of autism (Gillespie-Lynch et al., 2017), and frame autism in a way that is embodied and positive (Welch et al., 2020). The need for post-diagnostic support that meets emotional and relational needs (as well as informational) has been also emphasised in the literature, though in the context of supporting parents after a child's diagnosis (Legg and Tickle, 2019). Our results suggested similarly that a relational and emotional approach can be beneficial for autistic adults to help them re-frame their past experiences and work out where an autism diagnosis fits into their life. Providing a space for autistic people to interact and support one another in a comfortable way may also help build resilience to

manage everyday life in a world that is designed for the non-autistic majority (Crompton et al., 2020a). This manuscript is among the first to explicitly examine how post-diagnostic peer support may function for autistic adults, exploring the views, preferences, and priorities of autistic adults relating to post-diagnostic peer support. Currently, many health and support services do not know what autistic people need (Doherty et al., 2020). This manuscript provides key insights from autistic people and paves the way for their voices to be centred in creating services that meet the needs of autistic people. By examining what the function and focus of peer support should be, future studies may in turn be able to focus on the efficacy of a post-diagnostic support intervention that is informed by these views.

Practical Implications and Peer Support Design

It is essential for autistic people to be integrally involved with creating, designing, and implementing supports to ensure that they meet their needs (Monahan et al., 2021), and this study provides key grounding in post-diagnostic peer support design. Firstly, good communication is essential to providing peer support. Many participants were not able to access support due to inaccessible referral routes, poor communication while support was provided, or support starting or stopping with short or no notice. When accessing any new support, flexible communication is crucially important and this is no different for peer support. Participants stated a preference for support that focuses on progressing and re-framing during the post-diagnosis phase, rather than being based on facts about autism. While learning about autism was important, participants felt that it would be most helpful to have a chance to contextualise that information, and reflect on how their new diagnosis fit with their past experiences. Participants also stated that peer support facilitators require training in order to run a peer support service that meets the needs of a wide range of autistic adults, and that facilitators require ongoing support and supervision. To ensure that peer support is accessible, participants felt it was important that peer support frameworks take into account the diversity of the autistic population, the intersectionality of autism with other identities, and the communication preferences of group members. Participants felt it was essential that peer support infrastructure was sustainable with steady, long-term funding, and that engaging with other specialist services (for example mental health services) was well supported. They felt these actions creates a peer support space that feels safe and comfortable for autistic people to engage with.

Strengths and Limitations

This study has some limitations. First, the sample included 12 autistic adults. The number of participants for this study was selected before commencing the study and is in line with similar studies in this area (see Cresswell et al., 2019), and based on prior research suggesting this sample size is sufficient to achieve saturation (Guest et al., 2006; Hennink and Kaiser, 2021). While a moderate sample size is standard in qualitative research in order to allow for an in-depth exploration of individual experience, findings may not apply to all autistic people diagnosed in adulthood. We cannot be sure from these data that all autistic people will equally want or benefit from the same kind of peer support. For example, not all newly diagnosed autistic people will accept or openly identify with their "new identity" as an autistic person, and it is important to ensure that autistic people can access the post-diagnosis support that best suits their needs at that time. While our sample had good diversity in terms of gender, age, and length of time since diagnosis, all participants were White British or European. It is important to consider that the views of autistic people from other ethnic backgrounds may differ, and they may have specific support needs and preferences (Jones et al., 2020). Additionally, all participants were based in the United Kingdom: their experiences of services may be shaped by United Kingdom norms and findings may not apply to autistic people living outside the United Kingdom. Participants had a variety of prior exposure to peer support: some had no experience, some had experienced informal peer support, and some had engaged with formal peer support. While this variety of experiences meant a range of views were represented, it did mean that the participant sample was not consistent in whether they were speaking from experience or speaking speculatively about peer support. We used a range of options for engaging with interviews to diversify the participant sample, including face-to-face, online messaging, video calls and phone calls. However, the sample is, of course, self-selecting and we may have over-representation of participants with an interest in autistic community and peer engagement.

CONCLUSION

This study found that peer support may be a useful mechanism to support autistic adults after their diagnosis. Autistic adults were generally positive about the concept of peer support and the opportunity it provides to interact with others in a comfortable way, and to discuss difficulties with empathetic and understanding others. Peer support offers unique opportunities not available through other support channels, and can run alongside other specialist support if required. Peer support may be a sustainable and low cost option to fill the much-needed post-diagnostic support gap currently faced by autistic adults; however, careful planning, ongoing support and training for peer support facilitators, and centring the voices of autistic adults is essential to ensure the success of peer support programmes.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because of the potentially identifiable nature of the raw qualitative interview data. Requests to access the datasets should be directed to CC, catherine.crompton@ed.ac.uk.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Edinburgh Moray House School of Education Research Ethics Committee. The participants provided written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

CC: conceptualisation, funding acquisition, data collection and curation, formal analysis, project administration, and writing-original draft preparation. SH: formal analysis and writing-review and editing. CM: writing-original draft preparation. AS and SF-W: conceptualisation, funding acquisition, supervision, and writing-review and editing. All authors contributed to the article and approved the submitted version.

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PERSPECTIVE
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Perspective: Presuming Autistic Communication Competence and Reframing Facilitated Communication

Melanie Heyworth[1,2]*, *Timothy Chan*[1,3] *and Wenn Lawson*[2,4]

[1]*Reframing Autism, Sydney, NSW, Australia,* [2]*Macquarie School of Education, Macquarie University, Sydney, NSW, Australia,* [3]*School of Arts and Education, Australian Catholic University, Melbourne, VIC, Australia,* [4]*Department of Education, University of Birmingham, Birmingham, United Kingdom*

Debate surrounding the validity of the method of supported typing known as facilitated communication (FC) has been continuous since its inception in the 1990s. Views are polarized on whether FC can be considered an authenticated method for use by people with complex communication needs (CCN) or significant challenges in speech, language, and communication. This perspective article presents an analysis of the research arguing for—and against—the use of FC, combined with the lived experience knowledge of autistic adults who utilize FC, to rehabilitate its current standing as discredited and unevidenced. By considering extant qualitative and quantitative studies, as well as personal accounts of the use of this particular Augmentative and Alternative Communication (AAC) method, the authors argue that the current dismissal of FC is rooted in ableist and outdated approaches. FC research should be reconsidered and reconducted using current best practice autism research approaches, including coproduction and a presumption of autistic communication competence, to assess its validity as a potential AAC method for autistic individuals.

Keywords: facilitated communication, rapid prompting method, complex communication needs, epistemological violence, communication competence

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****Correspondence:***
Melanie Heyworth
melanie@reframingautism.org.au

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INTRODUCTION

Autistic individuals with complex communication needs (CCN) are often required to rely upon Augmentative and Alternative Communication (AAC) methods for functional communication. Within the available range of AAC methods, support can be necessary to enable typing on electronic and non-electronic devices for those autistic individuals presenting with co-occurring motoric and planning/coordination challenges. Two such supported communication methods, Facilitated Communication (FC) and Rapid Prompting Method (RPM), were developed to provide greater scope and flexibility for self-expression by end-users (Crossley, 1994).

Despite an initial proliferation in the use of FC after its popularization in the 1990s, such mediated communication methods soon attracted significant debate (Green, 1994; Stock, 2011). In the decades following its inception, FC has repeatedly been decried as controversial, and discredited as unevidenced. This reaction has led to a ban on its use, echoed across peak

bodies, academia, and medical and allied health professionals (e.g., American Psychological Association, 2003; International Society for Alternative and Augmentative Communication, 2014; American Speech-Language-Hearing Association, 2018).

The uncompromising dismissal of FC largely rests on the quantitative research conducted predominantly in the 1990s, when FC was in its infancy. Following the evolutionary trajectory of autism research (O'Reilly et al., 2019), the 1990s FC research was undoubtedly colored by the prevailing deficits-based ideological framework surrounding autism at the time. Three decades later, with co-production and neurodiversity beginning to shape autism research questions, design and research priorities, it is time to reassess. It is time to challenge the potential impact of research bias underpinned by ableist assumptions toward nonspeaking autistic people on our current perceptions of FC and supported communication methods.

Indeed, alongside lived experience testimonies, robust and peer-reviewed research exists to challenge a categorical anti-FC position, although, strikingly, the presence of such research has rarely been acknowledged by those who adhere to an anti-FC stance. In this Perspective piece, we argue for a re-assessment of FC. Given advances in autism research and understood within a human rights frame, all individuals have an inalienable and basic human right to self-expression through all forms of communication. That individuals are entitled to utilize their preferred means of communication is set out in the Universal Declaration of Human Rights (Article 19, UDHR; United Nations General Assembly, 1948) and the Convention of the Rights of Persons with Disability (Article 21; CRPD, United Nations General Assembly, 2008). Hence, we argue that accessing preferred means of communication for individuals with CCN should be upheld as an important avenue to self-expression and empowerment. Without this avenue, such individuals might be denied their voice and a means to achieving communicative competence for participation and autonomy.

A BACKGROUND TO FC RESEARCH

Facilitated communication is a process of communication utilized by the nonspeaking disabled population, in which the communicator is supported or assisted physically by a facilitator, or communication partner (Biklen, 1990, 2000). FC was introduced initially by Crossley (1994) who described a communication partner using physical support to assist the communicator to point to pictures, words, letters, and/or numbers on a range of communication aids. Such physical assistance varies considerably depending on the FC-user's needs, but might involve stabilizing support at the hand, wrist, forearm, elbow, or underarm, or touch or pressure on the shoulder or back, or even simply physical co-presence with no actual touching occurring. Crossley (1997) argued that with familiarization with and practice of FC, physical support could be withdrawn as appropriate to match increasing communicator proficiency. The original aim of FC, then, was to encourage individuals toward independent communication, fading physical support as soon as appropriate, not unlike the process of prompt fading that is used in other autism interventions (Cengher et al., 2018).

In model of Crossley (1994), the communication partner would ensure the necessary physical support to stabilize the user's movement, inhibit impulsive typing, and/or to encourage the initiation of typing or pointing. Importantly, the communication partner would also give emotional, attentional, and regulatory support to encourage communication and assist the user in focusing on the keyboard, pictures, letters, or words during the communicative process. The quality of relationship between the communicator and their communication partner was paramount to the success of the communication.

Many disabled and autistic individuals with CCN received FC positively, as a new AAC method with the potential to increase their communicative competence *via* an effective and flexible communication method. Yet FC was not received so optimistically by all. Early in its development, vocal detractors raised concerns about the method's validity. Specifically, critics questioned whether it was the user/typist or the facilitator/communication partner who authored the typed output (Schlosser et al., 2014). In the decades since, these arguments have remained ongoing, with increasing polarization between pro- and anti-FC positions (Cardinal and Falvey, 2014; Hemsley et al., 2018).

Throughout the 1990s, several published studies emerged to challenge the authenticity and authorship of communication produced through FC (e.g., Eberlin et al., 1993; Green, 1994; Bebko et al., 1996). These studies followed strict experimental procedures of message passing, a process in a controlled environment to ascertain agency under different exposure conditions, in which researchers used an object, instruction, or question prompt to solicit a response from the FC-user alone, and, separately, from the FC-user and their communication partner or facilitator. In the absence of positive results validating FC with message passing protocols, findings were interpreted as indicating the undue influence of the communication partner on the typed output, and the authorship of the output and the communication competence of the FC user were questioned. Based on the conclusion that FC messages are authored by the communication partner rather than the autistic or disabled individual themselves, FC was—and continues to be—deemed invalid and the call to prohibit its use loudly voiced (Schlosser et al., 2014; Hemsley et al., 2018).

However, naturalistic peer-reviewed journal articles, which supported FC and argued the validity of its authorship, also proliferated in the 1990s. In contrast to the comparatively few quantitative studies published in peer-reviewed journals after 1996 (Cardinal and Robledo, 2012), these have continued to be published over time. Indeed, peer-reviewed studies confirming autistic or disabled authorship of FC messages number over a hundred from the 1990s to the present (Cardinal and Falvey, 2014), and use varied methodologies including text analysis (Bernardi and Tuzzi, 2011), naturally occurring message passing (Biklen et al., 1995; Weiss et al., 1996), intensive video analysis (Emerson et al., 2001), inductive analysis (Broderick and Kasa-Hendrickson, 2001), and linguistic structural analysis (Niemi and Karna-Lin, 2002). This body of evidence speaks to the

need to reassess FC, given that its validity and efficacy are not so unproblematically dismissed (Williams, 2020).

Autistic adults with CCN who utilize FC are increasingly attesting to the FC as their chosen AAC method for developing communicative competence in people with CCN (e.g., Chan and Chan, 2019; Peña, 2019). The methodology of FC is evolving to address the controversy, with a focus on the systemic development of best practice in effective use and improved techniques (Broderick and Kasa-Hendrickson, 2001; Rubin et al., 2001). Such qualitative evidence is underpinned by more quantitative approaches, including video eye-tracking. Studying an FC user's eye gaze to verify that the autistic or disabled individual has targeted letters or letter series prior to making a hand movement toward that target, has been instrumental in providing additional support for the validity of FC-authorship (Grayson et al., 2012).

A recent naturalistic investigation utilizing sophisticated video-based eye-tracking technology, considered the real-world communication experiences of nine nonspeaking autistics who communicated by letterboard in the presence of a trained communication partner (Jaswal et al., 2020). This study authenticated the authorship of the autistic user/typist. Measuring the speed, accuracy, timing, and pattern of eye gaze fixation, the autistic participants (the letterboard users) were found to be actively typing their own thoughts, and the results negated cueing from their communication partner.

Another recent quantitative study using accelerometry, or measures of finger movement, has also provided additional evidence to confirm the authorship of autistic or disabled user/typist, signifying FC as a valid potential method of communication for non-speakers (Faure et al., 2021). In this study, the index finger of both communicator and communication partner were measured for fine motor events in typing speed, time, and acceleration produced during keystrokes. Results indicated that with a variety of physical supports, the autistic typist was found to be contributing actively to the typed output in motion acceleration toward the letters which preceded the facilitator.

Similar support has come from linguistic analysis of typed messages that reveal the communicators' unique use of language (Zanobini and Scopesi, 2001; Niemi and Karna-Lin, 2002; Tuzzi, 2009). The body of evidence in favor of FC is thus substantive enough to warrant a reassessment of FC, with new research designs like that of Jaswal et al. (2020) and Faure et al. (2021) to utilize not only significant technological advancements to evaluate FC authorship, but also which are framed by contemporary research approaches to autism as a neurodevelopmental condition (Pellicano and den Houting, 2021) and to inclusive autism research (Fletcher-Watson et al., 2021).

STUDY DESIGN IN FC RESEARCH

In FC research, as elsewhere, the perspective exists that quantitative research designs are superior (both more reliable and valid) to qualitative, interpretive, or other methodological approaches (Schlosser et al., 2014; Travers et al., 2014; Hemsley et al., 2018; Williams, 2020), resulting in a skewed picture of FC research. For example, Schlosser et al. (2014) set strict hierarchical criteria, which effectively excluded all quantitative descriptive and qualitative data from their review, resulting in "overwhelming … evidence for facilitator control" (p. 363) from the peer-reviewed, experimental, conditional design studies that the authors deemed appropriate for consideration. A 2018 review by Hemsley et al. (2018) similarly dismissed (or missed) studies that validated FC, by concluding that sufficient prior scientific evidence exists from studies prior to 2014 to prove FC is ineffectual and unauthenticated, and to support a position banning its use.

While peer-reviewed, experimental, conditional design studies have undeniable scientific validity, the authors of this Perspective argue that dismissing descriptive quantitative, qualitative and, indeed, testimonial first-person evidence ignores the imperative to understand communication holistically, within an interpersonal, social pragmatic viewpoint (Kecskes, 2010). Reducing communication to clinically measurable message passing is reductive and discounts the very real benefits that embracing a more socio-cognitive approach to communication might offer Autistics with CCN.

Importantly, when research designs have taken into consideration autistic participants' anxiety, hypersensitivities, and related issues, and have proactively worked to alleviate those compounding factors, FC authorship has been more likely to be authenticated (Cardinal et al., 1996; Sheehan and Matuozzi, 1996; Weiss et al., 1996). The experimental designs and methodology used for investigating FC make an immense difference to the results obtained. Quantitative methods which employ strict experimental conditions in message passing, by and large, have not supported validity. Conversely, qualitative studies, and those quantitative studies, the design of which allows for the effects of environmental and participant factors, or which utilize progressive digital technology, have indicated support for authenticity and authorship of typists/users. This is unsurprising given that empirical positivist approaches, which privilege experimental, quantitative, and statistical analysis studies, in general have less explanatory power than more qualitative, interpretive approaches, which recognize the role and impact of subjectivity and intersubjectivity on what is known or assumed (Torbert, 2021).

Perhaps most disturbingly, many critiques of FC employ an antagonistic tone, which undermines "healthy scholarly engagement and … other ways of knowing" (Connor, 2019) and makes it difficult for researchers and Autistic individuals alike to engage in the kinds of robust dialog that might examine, for example, researcher bias, implicit bias, ableism, and unwillingness to embrace a presumption of communication competence (Lester, 2015). For instance, FC has been termed "pseudoscience" (Jacobson et al., 1995; Travers et al., 2014) and deemed totally without merit as a communication tool for those with CCN (Simpson and Myles, 1995; Myles et al., 1996; Travers et al., 2014). Such antipathy makes respectful debate framed by contemporary best practice approaches to

autism research (Fletcher-Watson et al., 2019, 2021; den Houting et al., 2021; Keating, 2021) unlikely.

THE ISSUE OF RESEARCH BIAS

As noted, quantitative methodologies are often privileged as more scientifically valid (Mahoney and Goertz, 2006) in reviews of FC evidence, since they tend toward objective, neutral, and generalizable findings. However, we—as researchers—are (or should be) becoming more aware of the deep impact of implicit and unspoken biases (the "isms," like racism, sexism, and ableism) on all findings and interpretations of findings. Any claims of "scientific objectivity" and "neutrality" should be thoroughly interrogated and challenged (Evans, 2002; Stanovich and West, 2008; Teo, 2010; Williams, 2020).

In FC research, we argue, it should at least be entertained that strict experimental quantitative research reflects *myside bias* (Evans, 2002; Stanovich and West, 2008). *Myside bias* refers to evidence generated from experimental designs, with data evaluated, tested, and analyzed in ways that reflect preconceptions derived from researchers' own beliefs, opinions, and attitudes (Stanovich et al., 2013).

Facilitated communication research that suffers from *myside bias* is designed—consciously or not—to invalidate FC by adopting purely deterministic paradigms and experimental designs with a singular focus on the ability of participants to pass messages (Eberlin et al., 1993; Wheeler et al., 1993; Green, 1994; Simpson and Myles, 1995; Bebko et al., 1996; Saloviita, 2018; Vyse et al., 2019). Many FC researchers have proposed that the experimental tasks of message-passing should be the only proof required for the validity/invalidity of FC (Saloviita, 2018). This position ignores or dismisses the interpersonal pragmatic dimension of communication, and the humanity of those communicating. In so doing, many FC researchers project *myside bias* into their research design and review analysis by consistently disregarding contrary research authenticating authorship of FC users which adopts more comprehensive and naturalistic data collection methods.

Such *myside bias* is evident in the dismissal by some researchers of autistic communicators using FC who can also independently write or type (e.g., Higashida, 2013; Mukhopadhyay, 2021) or who have in time become independent of physical support (e.g., Kedar, 2012; Rubin, 2021; Sequenzia, 2021). It strikes the authors of this Perspective, that such summary rejection of the lived experience knowledge and testimonies of independent FC users is indicative not only of research bias but also perpetuates the routine silencing of the autistic "voice" in autism research (Milton and Moon, 2012).

Perhaps most importantly, many FC studies have ignored the unique developmental trajectory of nonspeaking autistics, as well as the potentially significant challenges autistic individuals with CCN might experience in clinical, experimental environments. Such challenges include high anxiety levels, hypersensitivities and sensory overload, and performance stress under unfamiliar testing conditions and in unfamiliar environments (see, Jaswal et al., 2020). Rigorous empirical evidence emerging from the 1990s onward, incorporating findings from the fields of psychoneuroimmunology (PNI), epigenetics, and bioenergetics (Segerstrom, 2012), has indicated that environmental factors, stress, and other mental states have significant negative effects on the communicative performances of nonspeaking autistics (Cardinal and Falvey, 2014). Unsurprisingly, then, studies that take such unique challenges into account and are designed to recognize communication as complex systems incorporating many elements of social interaction, are more likely to validate FC communication (Emerson et al., 2001).

DISCUSSION: PRESUMPTION OF COMMUNICATION INCOMPETENCE

Epistemology is the study of the nature and production of knowledge. Knowledge produced through empirical research comprises both research data and their interpretations according to theoretical frameworks. Various interpretations are possible in examination of data according to the types of theories used, and "knowledge" is invariably socially constructed within associated normative and cultural contexts (Teo, 2010).

Take, for example, a presumption of incompetence associated with cognitive impairment in nonspeaking autistic children, which is commonplace (e.g., Simmons et al., 2021). The communicative (in)competence and/or cognitive impairment of research participants are not inherent in data but are socially constructed in the interpretations of data according to frames of references. We would argue that these data are too often skewed by biased frames (of presumed incompetence) that distort and misrepresent individuals with CCN and exclude their perspectives. This argument is sustained by research that shows conventional measures for intelligence (e.g., WISC test batteries) generally underestimate the ability of nonspeaking autistics (Courchesne et al., 2015; Nadar et al., 2016; Akhtar and Jaswal, 2019). When individuals with CCN, who were identified as having Intellectual Disability using language-based measures, were reassessed using more appropriate non-language-based instruments that employ visual spatial tasks, a significant proportion were found to be within or above the expected IQ range (Dawson et al., 2007; Barbeau et al., 2013; Courchesne et al., 2015; Crossley and Zimmerman, 2019). The conflation of not speaking, and not having anything to say, then, is a product of neuronormative and ableist perspectives that privilege verbal communication and construct hierarchies of communication competence.

Such issues pertain to epistemological violence which emerges when interpretive knowledge is accepted as "truth," despite the interpretative process being grounded in assumptions of inferiority and "othering" (Teo, 2010). Epistemological violence is experienced disproportionately by nonspeaking autistics because researchers and professionals claim the authority and prestige of expertise (Willis, 2020), and nonspeaking autistics are very often multiply marginalized, not least because of their CCN.

It is an unfortunate reality that there exists a prevalent presumption of incompetence affecting so called "low functioning" or "severe" autistic individuals with CCN, that is accompanied by a presumed lack of ability, desire, and capacity to communicate. Thus, some researchers and professionals accept as self-evident that, given the low level of language development of a nonspeaking autistic, any typed communication *via* FC/RPM demonstrating typical or above normal linguistic competence, cannot possibly be that individual's output (Jacobson et al., 1995; Konstantareas and Gravelle, 1998; Simmons et al., 2021). Framed by such ableist assumptions, the voices of individuals with CCN, some of whom are independent typists, have consistently been ignored or dismissed.

Epistemological violence is evident when researchers insist that facilitator influence is the only way to account for FC/RPM users who failed message passing tasks under strict experimental conditions. This interpretation of data, we would argue, presupposes that autistic individuals with CCN lack the ability to communicate (rather than the ability to speak), although as we have noted, communicative performance is inevitably impacted by autistic challenges like anxiety, hypersensitivities, motoric differences, and being confronted with an unfamiliar environment and novel task requirements (e.g., Shoener et al., 2008).

Epistemological violence is inherent in denying the autistic "voice" authenticity of *all* output from FC users, even those who have become independent typists/writers (Vyse et al., 2019; Simmons et al., 2021). Such sweeping assertions "others" not only the FC/RPM users themselves, but also their social network, including parents and facilitators with no desire to gain from manipulating those they support (e.g., Kedar, 2012, 2018; Mukhopadhyay, 2021; Rubin, 2021).

Fundamentally, it is epistemological violence to deny nonspeaking autistics the right to self-expression and to silence their voices by denying their right to explore supported AAC (Woodfield and Ashby, 2016). It is usually claimed that the use of FC/RPM should be banned because individuals with CCN have the basic right not to be manipulated by facilitators (e.g., Simmons et al., 2021). But given that a reductive dismissal of FC has been contested by both research and nonspeaking autistics themselves, it seems prudent to re-evaluate the received position on FC so that we do not—albeit inadvertently—commit an even greater rights violation. At the very least, as researchers, we have a duty of care to acknowledge and listen to the voices of FC/RPM users who have become independent of physical support and who have irrefutably demonstrated cognitive and communicative competence (e.g., Kedar, 2012, 2018; Higashida, 2013; Mukhopadhyay, 2021; Rubin, 2021; Sequenzia, 2021).

CONCLUSION

The debate surrounding the validity of FC has continued since its inception with polarized positions on FC as a valid method for communication by individuals with CCN. The existing quantitative studies (approximately 40) unsupportive of FC, identify facilitator influence within typed output, and were mostly undertaken in the 1990s. Conversely, over 100 peer-reviewed articles validate FC, and other evidence authenticating authorship exists to support the validity and efficacy of FC for autistic individuals with CCN. Perhaps most importantly, in personal narrative information using autoethnographic approaches (Ellis et al., 2011), communicative competence, agency and autonomy has been established by many nonspeaking autistic individuals, including those who once used FC.

The authors of this Perspective argue that given this evidence, our developing understanding of communication as complex processes of interpersonal, socio-cognitive, and pragmatic bidirectional exchange, moves within autism research to embrace coproduced, participatory research. Our evolving understanding of autism within a biopsychosocial model of disability and a neurodiversity framework behoves us to reconsider the standard, accepted position which dismisses and invalidates FC communications. We must consider the possibility that assisted typing is valid and offers a flexible communication tool for self-expression for certain individuals. This is not to say, of course, that all autistic individuals with CCN will benefit from FC/RPM, but that it is an inalienable human right to have the choice to access supported AAC if it is indicated for any individual.

AUTHOR CONTRIBUTIONS

TC, an FC-user, conceived the Perspective and researched with the support and guidance of WL and MH. TC wrote a broad argument. MH revised and prepared this Perspective, based on TC's arguments, with iterative input from TC and WL. All authors contributed to the article and approved the submitted version.

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EDITED BY
Amy Pearson,
University of Sunderland,
United Kingdom

REVIEWED BY
Steven Stagg,
Anglia Ruskin University,
United Kingdom
Zachary J. Williams,
Vanderbilt University,
United States

*CORRESPONDENCE
Amanda Roestorf
amanda.roestorf@autistica.org.uk

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Ageing and autism: A longitudinal follow-up study of mental health and quality of life in autistic adults

Amanda Roestorf[1]*, Patricia Howlin[2] and Dermot M. Bowler[1]

[1]Autism Research Group (ARG), Department of Psychology, City, University of London, London, United Kingdom, [2]Department of Clinical Psychology, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, United Kingdom

Background: Poor mental health is known to adversely affect functional abilities, social isolation, and quality of life (QoL). It is, therefore, crucial to consider the long-term impacts of mental health conditions as autistic adults grow older.

Objectives: To explore, in a group of community-based autistic adults, the extent of: (i) autistic traits, co-occurring physical and mental health conditions; (ii) age-related differences in those conditions, and changes over time; and (iii) their impact on everyday living and QoL.

Method: About Sixty-eight autistic adults (aged 19–80years) participated in the first study (T1); 49 participants from T1 took part in a follow-up at T2 (mean retest interval 2.4years). Standardised self-report measures of autistic traits, mental health, and QoL were completed at both time points.

Results: Over two-thirds (71%) of autistic adult participants experienced at least one co-occurring condition, and over a third (37%) met the criteria for three or more co-occurring conditions. Mental and physical health difficulties were related to autistic traits and difficulties in everyday life and were consistent predictors of poor QoL at T1 and T2.

Conclusion: Mental health difficulties in autism persisted into older age and did not improve over time. These findings have important implications for mental health provision for autistic adults in older age.

KEYWORDS

autism, ageing, mental health, quality of life, follow-up studies

Introduction

There is an increasing drive for support of older adults in the general population, related to cognitive change, well-being, social isolation, and physical healthcare (e.g., Wright et al., 2016; Kelly et al., 2017; Wu, 2020). Studies in gerontology provide insights into the selective challenges of ageing, and the strategies that enable older adults to maintain cognitive functions (e.g., Salthouse, 2004), social integration, and

better quality of life (QoL; Hornby-Turner et al., 2017). There are various definitions of QoL and Subjective well-being (SWB) but both concepts encompass domains of physical, psychological, environmental, and social well-being. The World Health Organization (2002), in their report on *Active Ageing* suggests that 60 years of age should be a marker of "older" adulthood, but caution that:

> *"chronological age is not a precise marker for the changes that accompany ageing… [since] There are dramatic variations in health status, participation and levels of independence among older people of the same age"*

Autism spectrum disorder (henceforth "autism"[1]) is a lifelong neurodevelopmental condition that is estimated to occur in at least 1% of the general population (American Psychiatric Association, 2013; Lord et al., 2020). Autism is characterized by a specific yet diverse profile of characteristics that include differences in social communication and social interactions; a strong need for routine and sameness that includes differences in information processing and thinking, specific patterns of interests, and sensory sensitivities (Lord et al., 2018). In turn, these differences can affect everyday functioning and autonomy, social relationships, mental health, and QoL (Shattuck et al., 2011; Geurts and Vissers, 2012; Howlin et al., 2013; Fortuna et al., 2015; Lever and Geurts, 2016). In addition, recent evidence suggests that increased difficulties related to depression, sleep quality, and general psychological well-being are also determinants of poor QoL (Lawson et al., 2020).

There has been relatively little systematic research into the impact of ageing among autistic adults, whether diagnosed in childhood or later life (Mason et al., 2022; and see Magiati et al., 2014; Steinhausen et al., 2016, for systematic reviews). Information on the prevalence or persistence of mental health difficulties in older autistic adults is particularly limited; similarly, little is known about QoL changes in older age or the degree to which autism-related difficulties and mental health affect QoL (e.g., Howlin and Taylor, 2015; Roestorf and Bowler, 2016; Wise et al., 2017; Mason et al., 2018). However, there is evidence that autistic adults experience more physical and mental health difficulties than age-matched non-autistic peers (Croen et al., 2015; Hirvikoski et al., 2016; Zerbo et al., 2019; but see Lever and Geurts, 2016), with approximately 70–80% of autistic individuals having co-occurring physical and/or mental health conditions (e.g., Bishop-Fitzpatrick and Rubenstein, 2019; Hand et al., 2020). These difficulties are exacerbated by the lack of access to appropriate services in adulthood and across the lifespan (Parr, 2016; Wright et al., 2016; Robison, 2019). Some recent research suggests a generally poorer QoL in older autistic adults (e.g., Van Heijst and Geurts, 2015; Bishop-Fitzpatrick et al., 2016; Roestorf and Bowler, 2016; Mason et al., 2018; Yarar Zivrali et al., in press; and see Ayres et al., 2017 for a meta-analysis) although findings are inconsistent (see Chiang and Wineman, 2014 for a review). Factors related to social support, long-term relationships, engaging in meaningful employment, and lifestyle autonomy have been linked to positive mental health and improved QoL (e.g., Ratto and Mesibov, 2015; Van Heijst and Geurts, 2015; Lever and Geurts, 2016; Mason et al., 2018; Park et al., 2019). However, the cumulative effects of long-term, co-occurring, physical or psychiatric conditions on everyday functioning and QoL are largely unknown (Howlin and Moss, 2012; Howlin et al., 2013; Kats et al., 2013). Similarly, little is known about the availability or effectiveness of health, care and social support services to accommodate the individual differences of older autistic adults who may need continued support related to autistic traits, mental/physical health difficulties, or daily living skills (Mason et al., 2019; Charlton et al., 2021, 2022; Lord et al., 2021; Oakley et al., 2021). Thus, more longitudinal research is needed to evaluate the effects of long-term co-occurring conditions and their relation to QoL in older age (Michael, 2016; Oakley et al., 2021). Stress and anxiety-related difficulties have substantial implications for the social functioning, cognitive abilities, and adaptive behaviours of autistic individuals (Maisel et al., 2016; Wallace et al., 2016; South et al., 2017), and are further compounded by intolerance of uncertainty, and aversiveness to emotional experiences whilst simultaneously experiencing difficulties identifying and interpreting emotions (e.g., Maisel et al., 2016). Because of the complex associations between the clinical features of anxiety and autism, it remains important for clinicians to dissociate core autistic symptoms from mental health conditions and physical health, when considering the primary care and service needs of autistic people across the lifespan (Roestorf et al., 2019; Oakley et al., 2021). A critical evaluation is needed of individualised long-term support needs, alongside physical and mental health as an autistic person grows older (e.g., Charlton et al., 2022).

The present study focuses primarily on depression and anxiety symptoms since these are the most common mental health conditions in autism (e.g., Maisel et al., 2016; Hollocks et al., 2019). The negative effects of depression are far-reaching in terms of cognitive, social and psychological functioning, reduced QoL, increased disability, and premature mortality (McClintock et al., 2010; Khanna et al., 2014; Mason et al., 2019; Lawson et al., 2020), and these effects may be exacerbated in individuals with co-occurring intellectual disability and/or neurodevelopmental conditions including autism (e.g., Coppus, 2013; Ratto and

1 The term autism is used in this manuscript to reflect the general profile of autistic features related to Autism spectrum disorder. We acknowledge that while there is still ongoing discussion in the autistic and scientific communities about the preferred terminology when referring to diagnosed individuals, the present paper has used 'identity-first' language (i.e., autistic individual; autistic adult) as this was identified as the preferred terminology for autistic people involved in our study (and see Kenny et al., 2016; Bottema-Beutel et al., 2021).

Mesibov, 2015). Long-term mental health difficulties, such as depression, are associated with increased risk of neurocognitive disorders (i.e., dementia; Bauman, 2010), although whether this is increased for autistic individuals is unknown (e.g., Hategan et al., 2017).

Background to the present study

As part of a larger programme of work on ageing in autism, participants completed a wide range of assessments including measures of autism symptomatology, social and behavioural adaptive skills, mental health, quality of life, cognitive, language and memory, and a range of executive functions (see Roestorf and Bowler, 2016; Roestorf, 2018 and section "Measures" below). One part of the programme focused on age-related comparisons between autistic and non-autistic adults (see Roestorf and Bowler, 2016 and Roestorf, 2018); in the present paper, we describe findings from (i) a cross sectional comparison of younger and older autistic adults aged 19–80 years and (ii) a short-term longitudinal study of change over time. Our main aim was to identify any factors that might be related to adverse mental health (Schwartz and Meyer, 2010) and reduced quality of life of autistic people (McConachie et al., 2018; Mason et al., 2019; Lawson et al., 2020).

Study aims

Study 1 [First time-point (T1); cross-sectional]

At T1, the study set out to explore (i) the extent of autistic traits and co-occurring physical and mental health difficulties in autistic adults; (ii) age-related *differences* in these areas through comparisons between younger and older autistic adults; and (iii) how these factors are associated with daily living and QoL.

Study 2 [Second time-point (T2); follow-up]

At T2, we followed-up participants from the T1 study. In addition to replicating the aims of Study 1, the principal aim at T2 was (i) to evaluate the profile of potential age-related *changes* over time in younger and older autistic adults, related to autistic traits, co-occurring mental health conditions, and QoL. Regression analyses explored (ii) how these factors were associated with QoL over time.

Materials and methods

Ethics

Ethical approval was obtained from the City, University of London Psychology Department Research Ethics Committee PSYETH (UPTD) 13/14 28, for the research project titled: *Age-Related Effects on Cognition and Quality of Life in Adults with Autism Spectrum Disorder*, published as part of the programme of work submitted for the first author's PhD Thesis (Roestorf, 2018).

Participants

Procedure for participant selection and recruitment

The study was advertised *via* the United Kingdom National Autistic Society website and online *via* the Twitter network of the first author. We aimed to recruit older adults and autistic women as these groups are greatly underrepresented in most autism research. Participants from the research databases at the Autism Research Group and online research recruitment portal at City, University of London were also invited to take part in the study. Informed consent was obtained from all participants prior to enrolment in the study and they were informed of their right to withdraw from the study at any time, without being disadvantaged. Participants were offered £25 as a gratuity for taking part in the research at each time point and received full reimbursement of travel expenses.

The relative lack of studies on ageing in autism means there is no consensus on the definition of 'older' age in this group. For the purpose of the present study, we included autistic adults across a wide age range, with 'older' adults being defined as those aged ≥50 years and 'younger' adults as those aged 18–49 years. Participants were assigned to 'younger' and 'older' age groups at T1 and remained assigned to those same groups at T2 follow-up.

To ensure that participants were able fully to understand all the task requirements English language proficiency was assessed using the Comprehensive Receptive and Expressive Vocabulary Test–Third Edition (CREVT-3; Wallace and Hammill, 2013). Two participants were excluded at this stage as they did not meet the standardised assessment criteria for English fluency (CREVT-3 overall language score > 70; population mean 100, SD 15; see Appendix 1 in Supplementary material).

Sample characteristics

Participants at T1 comprised 68 autistic adults aged 19–80 years (mean 44.1 years, SD 15.5 years), including 37 younger (mean 31.9 years, 10 female) and 31 older adults (mean 58.6 years; seven female). All participants had a formal diagnosis of autism, confirmed by a copy of clinical diagnostic reports obtained at enrolment. Age groups were matched on gender ratio (reported as male and female in this study, no participants identified as transgender or non-binary), years of formal education and general intellectual ability (IQ; measured by Wechsler Adult Intelligence Scales–Fourth Edition; WAIS-IV; Wechsler, 2008; see Table 1 for data, and see Appendix 1 in Supplementary material). Following the T1 study, participants were asked if they would be willing to take part in a subsequent follow-up study (T2).

A total of 49 individuals (72.1% of the T1 sample) agreed to take part at T2. Their ages ranged from 24 to 74 years (Mean 48.4 years), including 25 younger (mean 36.2 years; five female) and 24 older adults (mean 60.9 years; five female; for details see Table 2).

Reasons for non-participation at T2 ($n = 19$, 28% of the T1 sample) were: chronic or terminal illness ($n = 7$), or death ($n = 2$); lost to follow-up, moved to different town, city or country ($n = 2$); work commitments, personal difficulties, or family commitments ($n = 5$); administrative reasons, or self-exclusion or withdrawal from the project for other reasons ($n = 3$).

Community involvement

Participant well-being was central to all stages of the research. During the study scoping and design, advice was sought from autistic peer researchers in co-creation discussion forums. Participants were consulted throughout the data collection about any adaptations they might require to the study procedures and materials, and every effort was made to incorporate adaptations to meet their individual needs. These adaptations included easy read formats for information about study aims and task instructions, changes to sensory stimuli in the research laboratory, e.g., noise reduction and soft lighting, and frequent breaks between tasks as needed. Every effort was made to ensure that these adaptations did not compromise the methodology or quality of the data.

Procedure

Difficulties related to autistic traits, mental health, and QoL were compared at two time-points: Study 1 focused on T1 cross-sectional comparisons between younger and older groups; Study 2 followed the same participants who took part in T1 and applied the same procedures regarding ethics, sample selection, materials, and assessment. The mean follow-up interval was 2.4 years. At each time point, the measures were conducted face to face in a single session.

Measures

Assessments of IQ, autistic traits, mental health (anxiety, depression), daily functional difficulties, and QoL were carried out at T1 (see Table 1) and repeated at T2 follow-up.

In addition to the measures described below, participants provided information on co-occurring physical and mental health conditions, difficulties related to everyday skills (e.g., self-care, household management, employment, and managing finances), social interaction difficulties, loneliness and isolation, sensory sensitivities, and stress responses experienced as meltdowns and/or shutdowns and related cognitive difficulties in everyday life. This information was captured through semi-structured questions, using the Passport to Individual Autism Support (PIAS), developed by the National Autistic Society (2012).

Intellectual ability profiles

The Wechsler Adult Intelligence Scales–Fourth Edition (WAIS-IV) was administered at T1 and T2 follow-up. The WAIS-IV is a widely used standardised measure to assess intellectual ability profiles in adults aged 16–90 years (Wechsler, 2008). It comprises 10 core and five supplemental subtests, providing Index scores for Verbal Comprehension (VCI), Perceptual Reasoning (PRI), Working Memory (WMI) and Processing Speed (PSI), and a composite Full-Scale IQ (FSIQ) score.

Autistic traits

At T1, clinical reports confirmed autism diagnosis (see the section Sample Characteristics). Since those reports incorporated a variety of measures, the Autism Diagnostic

TABLE 1 T1 characteristics of younger and older adults.

Measure	Age group ($N = 68$)		Statistics		
	Younger ($n = 37$) Mean (SD)	Older ($n = 31$) Mean (SD)	*t(66)*	*p*	*Cohen's d*
Age (yrs)	31.89 (8.02)	58.61 (7.36)	**−14.07**	**<0.001**	**−3.43**
YFE[a]	14.80 (2.38)	14.36 (2.90)	<1.00	0.69	0.17
FSIQ[b]	108.89 (14.91)	112.19 (18.95)	<−1.00	0.07	−0.19
VCI[b]	111.14 (15.71)	115.87 (16.49)	−1.21	0.36	−0.29
PRI[b]	110.49 (16.79)	111.16 (14.18)	<−1.00	0.17	−0.04
WMI[b]	87.50 (14.10)	91.92 (22.66)	<−1.00	0.07	−0.23
PSI[b]	94.68 (19.51)	101.27 (16.86)	−1.10	0.22	−0.31

[a]YFE, Years of Formal Education.
[b]FSIQ, Full-Scale IQ; Index Scores: VCI, Verbal Comprehension; PRI, Perceptual Reasoning; WMI, Working Memory; and PSI, Processing Speed.
Bold values are significant at $p < 0.05$.

TABLE 2 T2 age-group comparisons of autistic traits, mental health, and QoL.

Measure	Age groups ($N = 49$)		Statistics		
	Younger ($n = 25$) Mean (SD)	Older ($n = 24$) Mean (SD)	$t(47)$	p	*Cohen's d*
Age	**36.23 (7.64)**	**60.94 (6.85)**	**−11.86**	**<0.001**	**−3.39**
FSIQ[a]	111.18 (18.86)	116.05 (17.35)	−0.81	0.43	−0.27
VCI[a]	113.06 (14.64)	116.47 (14.25)	−0.71	0.48	−0.24
PRI[a]	110.12 (19.41)	114.21 (16.82)	−0.68	0.50	−0.23
WMI[a]	109.00 (18.26)	116.44 (16.13)	−1.28	0.21	−0.43
PSI[a]	101.71 (21.52)	106.39 (12.57)	−0.79	0.43	−0.27
Autistic traits					
SRS-2 Total	71.36 (10.63)	68.71 (12.61)	0.75	0.46	0.23
SRS-2 SCI	70.05 (10.60)	69.00 (12.74)	0.29	0.77	0.09
SRS-2 RRB	69.14 (11.08)	68.24 (12.36)	0.25	0.80	0.08
Mental health					
Anxiety	15.65 (11.01)	11.46 (9.49)	1.09	0.28	0.12
Depression	17.24 (11.50)	14.50 (12.12)	0.88	0.39	0.23
Somatoform disorder	0.22 (0.43)	09 (0.30)	0.89	0.38	0.35
Major depressive syndrome	0.22 (0.43)	0.18 (0.40)	0.25	0.80	0.10
Other depressive syndrome	0.17 (0.38)	09 (0.30)	0.56	0.58	−0.97
Panic syndrome	0.17 (0.38)	0.18 (0.40)	−0.10	0.92	−0.05
Other anxiety syndrome	0.28 (0.46)	0.18 (0.40)	0.57	0.57	0.22
Bulimia Nervosa	0.06 (0.24)	-	0.78	0.44	0.33
Binge eating Disorder	0.11 (0.32)	0.09 (0.30)	0.74	0.87	0.06
Alcohol abuse	0.06 (0.24)	0.18 (0.40)	−1.07	0.30	−0.38
Extent of daily difficulties	1.00 (0.84)	0.73 (0.65)	0.92	0.37	0.36
Quality of life					
PWI outcome variables					
Subjective Well-being	**34.04 (12.88)**	**43.24 (10.43)**	**−2.59**	**0.013**	**−0.79**
Global Life Satisfaction	46.96 (17.69)	57.14 (24.73)	−1.58	0.12	−0.47
WHOQOL-BREF outcome variables					
Overall-QoL	**51.25 (17.16)**	**66.67 (21.41)**	**−2.54**	**0.015**	**−0.79**
Health-QoL	46.25 (26.00)	55.95 (29.48)	−1.12	0.27	−0.35
Support received	46.43 (26.73)	43.75 (30.96)	0.26	0.80	−0.09
Physical-QoL	58.90 (19.18)	62.29 (17.47)	−0.59	0.56	−0.18
Psychological-QoL	**48.45 (17.55)**	**62.29 (17.47)**	**−2.09**	**0.044**	**−0.65**
Social-QoL	**40.60 (18.84)**	**55.00 (16.99)**	**−2.57**	**0.014**	**−0.80**
Environmental-QoL	60.75 (18.31)	70.05 (11.29)	−1.97	0.056	−0.61

[a]FSIQ, Full-Scale IQ; Index Scores: VCI, Verbal Comprehension; PRI, Perceptual Reasoning; WMI, Working Memory; and PSI, Processing Speed.
Bold values are significant at $p < 0.05$.

Observation Schedule–2nd Edition (ADOS-2; Lord et al., 2012) and the Social Responsiveness Scale–2nd Edition (SRS-2; Constantino and Gruber, 2012) were administered to confirm diagnostic reports. The Module 4 (adult) ADOS assessment is reported to have sensitivity of 0.61 (Bastiaansen et al., 2011; de Bildt et al., 2016); specificity is between 0.50 and 0.84 (Maddox et al., 2017). The first author was trained in ADOS-2 administration to 0.89 reliability and overseen by a certified ADOS trainer. The ADOS-2 was administered to 50 participants (74%) who consented to complete this assessment. Over a third (37.2%) of assessments in this study were double-coded for inter-rater reliability which was maintained at 0.84 or above. We note that subsequent development of calibrated severity scores (CSS; Hus and Lord, 2014) are now more commonly used as more sensitive measures of autism symptom severity in adults. However, because the CSS algorithm was not available when the present study data were collected, the ADOS data reported here are according to the algorithm in Lord et al. (2012).

The SRS-2 is a self-rated measure of autism-related traits and difficulties based on the DSM-5 (American Psychiatric Association, 2013) criteria for autism. It provides a Total score

and separate domain index scores (T-scores; range 30 to >90, mean 50, SD 10) for Social Communication, Social Motivation, Restricted Interests and Repetitive Behaviours (RRBs), Social Awareness, and Social Cognitive functioning. Studies with autistic adults have reported sensitivity and specificity of 0.85 and 0.83, respectively (Bölte, 2012). The SRS-2 was administered at T1 and T2 explore possible age-related changes over time.

Physical and mental health

Passport to individual autism support

The PIAS was designed by the National Autistic Society to assist autistic individuals who have difficulties advocating for themselves when accessing health and social care services. The resulting information (see Appendix 3 in Supplementary material; Figure 1) provides a summary of co-occurring conditions and other self-reported difficulties associated with autism, such as sensory sensitivities, limited motor function, and difficulties related to cognitive processing and social interactions (National Autistic Society, 2012).

Patient health questionnaire–9-item

The PHQ is a standardised assessment based on DSM-IV (American Psychiatric Association, 1994) diagnostic classifications for psychiatric conditions. The PHQ is a self-rated questionnaire comprising core items designed to screen for depression and other conditions, including anxiety and panic syndrome, somatoform symptoms (e.g., pain and digestive problems), risk of eating disorders and alcohol abuse. A single item reflects everyday functional difficulties: *"How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?"* Scores determine clinical diagnostic thresholds for anxiety- and depression-related conditions, indicated by a minimum number of symptoms, yielding accuracy of 0.85, sensitivity of 0.75, and specificity of 0.90 (Spitzer et al., 1999). Participants completed the PHQ at T1 and T2, based on symptoms experienced during the previous 4-week (major depression, panic/other anxiety syndromes); 2 weeks (other depressive syndrome); 3 months (eating disorders); or 6 months (alcohol abuse). Additionally, a single item question evaluated the degree of everyday difficulty experienced from any reported symptoms. Reliability in the present sample was excellent, with Cronbach's α 0.93 (Spitzer et al., 1999).

Beck anxiety inventory–second edition

The BAI-II is a 21-item self-rated standardised measure that captures the physical symptoms associated with anxiety that cannot be explained by biological reasons (e.g., hypoglycaemia; peripheral neuropathy, or other non-anxiety factors). Item scores, rated on a scale from 0 ("not at all") to 3 ("severely"), provide a Total anxiety score (0–63) and clinical cut-offs indicating the severity of anxiety symptoms, yielding 0.92 reliability, and 0.75 test–retest reliability (Beck and Steer, 1993). The BAI-II was administered at T1 and T2. In the present sample, reliability was good, with Cronbach's α 0.88 (Beck and Steer, 1993).

Beck depression inventory–second edition

The BDI-II is a 21-item self-rated standardised measure, based on DSM-IV-TR (American Psychiatric Association, 1994) diagnostic criteria, that is widely used to screen for depression and related physical and psychological symptoms, e.g., suicidal ideation, rumination, sleep disturbances, weight loss, and change in appetite in adolescents and adults. Item scores, rated on a scale from 0 ("not at all") to 3 ("severely") provide a Total depression score (0–63), and clinical cut-offs indicating the severity of depression symptoms, yielding 0.86 reliability and 0.90 test–retest reliability (Beck et al., 1996). The BDI-II was administered at T1 and T2. In the present sample reliability was excellent, with Cronbach's α 0.94 (Beck et al., 1996).

Quality of life and subjective well-being

At the time this study began, very few investigations had evaluated QoL in autism and even fewer had explored QoL in older autistic adults (e.g., Geurts and Vissers, 2012). Accordingly, two QoL measures were used (see below); these are designed to capture similar domains but use different methods of calculating outcome scores. Thus, a conversion formula (see International Well-being Group, 2013) was applied to the World Health Organisation Quality of Life–Short Form (WHOQOL-BREF) scores for Overall-QoL, Health-QoL, and degree of Support received, for comparable reporting in relation to the PWI-A scores. Both the WHOQOL-BREF and the PWI-A were administered at T1 and T2 to evaluate any (positive or negative) change in quality of life and well-being.

World health organisation quality of life–short form

The WHOQOL-BREF assesses the effects of physical and cognitive difficulties on everyday living and QoL. Items are self-rated on a Likert-type scale from 1 ("worst") to 5 ("best"). The measure provides a Total score and four domains outcome scores (all 0–100; mean 50), namely: Physical-QoL (e.g., activities of daily living, sleep, pain, and illness), Psychological-QoL (e.g., negative/positive feelings and memory/concentration), Social-QoL (e.g., relationships and social support), and Environmental-QoL (e.g., financial status, living arrangements, and access to and quality of social care). Three additional questions provide measures of Overall-QoL, Health-QoL, and degree of Support received from others. One of the benefits of the WHOQOL-BREF is that it asks about the individual's satisfaction with life-domains rather than being based on normative assumptions about what constitutes a "good" quality of life (e.g., having a range of friends). In the present sample, reliability was good, with Cronbach's α 0.85 (Skevington et al., 2004).

Personal well-being index, adult

The PWI is a self-rated standardised measure of quality of life that focuses on *subjective* well-being (SWB) and global life satisfaction (GLS). It has good index reliability (Cronbach alpha 0.70–0.85; International Well-being Group, 2013), and 0.84 test–retest reliability

Co-occurring conditions* **long-term medication use*	Sensory sensitivity (under- / over-sensitive)	Sensori-moto functions	Cognitive functions	Social functions
• Sleep: irregular patterns, disturbances • Other diagnosed e.g., depression, anxiety, obsessive compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD) • Cancer(s) • Irritable bowel syndrome • Other digestive problems (reflux, constipation, food intolerances), • Menopause • Prostate (enlarged, other) • Hypertension • High Cholesterol • Diabetes • Seizures	• Light / vision • Sound / Hearing • Smell • Taste • Touch / texture	• Balance • Speed of responding • Co-ordination • Multi-tasking • Sense of direction	• Concentration • Short term memory • Time management • Following complicated or multi-part instructions • Filling in forms • Planning ahead and changes to plans • Information processing	• Social conversations • Understanding body language • Interpreting metaphors • Understanding social nuances • Ability to be brief • Being bullied • Eating in public Stress and/or anxiety related to: • Busy and/or noisy places • Social interactions (including small talk) • Changes in routine and/or plans

Autonomy and daily activities
- Restricted modes of communication (e.g., written text / postal / emails preferred over telephone)
- Independent travel
- Maladaptive stress responses (e.g., physical and/or verbal outbursts or aggression [meltdown]; passive and/or non-verbal responses [shutdown])

Supports required during stress response (e.g., quiet time, being left alone, dim lighting in quiet space)

FIGURE 1
Self-reports of difficulties experienced by autistic adults, reported on the Passport to Individual Autism Support (PIAS, National Autistic Society, 2012).

(Cummins and Law, 2005; Lau and Cummins, 2005). Seven core items evaluate "health," "standard of living," "relationships," "safety," "achievement," "future prospects," and "community," with scores averaged to provide a measure of SWB. Two optional questions evaluate GLS (item-1: "Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?") and Religion (item-8: "How satisfied are you with your spirituality or religion?"). Each item is rated from 0 to 10 (0 = "no satisfaction at all," 10 = "completely satisfied"). Because almost half the participants (42%, $n = 29$) did not answer the optional item about religion, data for this item were excluded from the overall analysis. In the present sample, reliability was good, with Cronbach's α 0.88 (International Well-being Group, 2013).

Statistical analysis

T1 and T2 cross-sectional comparisons were carried out with *t*-tests between younger and older groups. Statistical significance (alpha, $p < 0.05$) and effect sizes (d) are reported for between-group contrasts. A secondary analysis was carried out using Bonferroni corrections for multiple comparisons ($p < 0.001$). At the time of this study, there was no precedence for evaluating analysis of change in autistic adults. The general ageing literature was consulted to inform the analytic approaches to the data reported here. In our study, analysis of change (Table 3) was calculated using individual change scores for each participant, followed by a SD method of variance between T1 and T2 scores for each participant to establish a reliable change index (RCI; see Jacobson and Truax, 1991; Frerichs and Tuokko, 2005), using the formula: X2-X1/SD, where X2 represents the individual score at T2 (averaged for each Age Group) and X1 represents the individual score at T1 (averaged for each Age Group), and SD is the T1 standard deviation of the mean for each Age Group. The RCI scores +1 indicate change; scores >+1SD indicate improved change, whereas scores <−1 SD indicate deterioration (Frerichs and Tuokko, 2005, p. 324). A detailed description of the method is provided in Supplementary material (Appendix 4). Additionally, to check the above calculation outcomes, paired *t*-tests were run to confirm any group differences between T1 and T2 scores (see Table 3).

At T1 and T2, multivariate linear regression analyses were carried out to determine Overall-QoL and Health-QoL as outcome variables, using a stepwise regression method for autistic traits and mental and physical health conditions as independent variables. Stepwise backward regression analysis was used to assess which factors were predictors of Health and Overall QoL outcomes. This method was used since the data were exploratory and no prior theoretical basis for selecting particular variables as predictors over other variables. Furthermore, the stepwise backward method controls for suppression effects in analysing the relative contribution of each variable to the regression model. The following variables were significant predictors and were subsequently included in a second regression using the Enter method: age, processing speed, self-report autistic traits, self-report RRBs, anxiety, depression, Somatic complaints, and difficulties in daily living. At the time this study was conducted, this statistical approach was a recommended method (e.g., Howell, 2002) for the exploratory investigation in this study. Alternative approaches have subsequently been suggested (e.g., Smith, 2018), but these statistical guidelines were not available at the time the present study was conducted.

Missing data analysis

In the typical ageing literature, longitudinal studies of this nature report participant attrition between 10 and 32% depending on the age and gender of participants (Young et al., 2006), the duration of the study and intervals between follow-up assessments (Saiepour et al., 2019). In the present study, every effort was made to collect completed data sets for all participants. However, where background information or test data were not available (e.g., ADOS), these are reported as missing data [Little's MCAR test: χ^2 (632) = 555.06, $p = 0.99$; see Appendix 2 in Supplementary material].

Study 1: T1 cross-sectional

Results of T1 study

Sample characteristics

Table 1 describes the sample characteristics at T1. Given the study design, younger ($n = 37$) and older ($n = 31$) groups differed

TABLE 3 Change scores between T1 and T2.

Measure	Follow-up sample ($n = 49$)				Statistics		
	T1 Mean (SD)	T2 Mean (SD)	CI 95%	RCI[†]	$t(47)$	p	Cohen's d
Autistic traits[a]							
SRS-Total	70.01 (11.58)	70.08 (11.81)	66.51–73.96	−0.04	1.50	0.14	−0.01
SRS-SCI	69.53 (11.56)	70.85 (12.90)	65.74–75.96	−1.33	0.00	1.00	−0.11
SRS-RRB	68.70 (11.59)	72.52 (12.85)	65.13–77.60	0.13	**2.22**	**0.03**	**−0.31**
Mental health[b]							
Anxiety	13.40 (8.92)	13.83 (10.42)	9.94–17.73	−0.34	0.26	0.80	−0.04
Depression	16.39 (13.35)	16.00 (11.66)	11.72–20.45	−0.34	0.18	0.85	0.03
Quality of life[c]							
PWI outcome variables							
Support	45.00 (27.39)	48.28 (26.67)	34.77–58.42	0.04	−0.21	0.83	−0.12
SWB	38.43 (12.53)	38.90 (13.41)	33.79–44.00	−1.02	−1.07	0.29	−0.04
GLS	51.82 (21.70)	54.14 (19.91)	45.22–61.71	−0.49	−0.57	0.57	−0.11
WHOQOL-BREF outcome							
Overall	59.15 (20.73)	60.00 (20.34)	52–40–67.60	−0.62	−1.07	0.29	−0.04
Health	51.22 (27.92)	52.50 (24.87)	42.41–61.79	−0.38	−0.57	0.57	−0.05
Physical	60.63 (18.17)	58.33 (16.63)	52.12–66.37	−0.83	1.47	0.15	0.13
Psychological	54.49 (18.83)	52.17 (16.62)	41.94–58.37	−0.73	0.17	0.84	0.13
Social	47.98 (19.13)	44.40 (19.45)	37.14–54.01	−0.68	−0.20	0.84	0.19
Environmental	65.51 (15.66)	63.83 (16.04)	57.84–70.45	−1.00	0.31	0.76	0.11

[†]RCI is the Reliable Change Index score calculated as the difference between T1 and T2 scores.
[a]Autistic traits (SRS-2): Total and index (T-scores) for Social Communication (SCI) and Restricted Interests and Repetitive Behaviours (RRBs) are reported (range 30 to ≥90), where higher scores indicate greater related difficulties.
[b]Mental health total scores reported for Anxiety (BAI-II, range 0–63), and Depression (BDI-II, range 0–63), where higher scores indicates greater related difficulties.
[c]Quality of life scores (PWI and WHOQOL-BREF, range 0–100) are reported for Subjective well-being (SWB), Global life satisfaction (GLS), Support received from others, and quality of life (QoL) domains related to Overall-QoL, Health-QoL, Physical-QoL, Psychological-QoL, Social-QoL, and Environmental-QoL, where higher scores indicate better quality of life or support.
Cohen's d effect sizes indicate small ($d = 0.20$–0.49) effect of change scores. See Supplementary material for detailed description of change analysis (Appendix 4).

significantly on chronological age. Groups did not differ on years of formal education, despite five older adults holding fewer. There were also no group differences in gender [$\chi^2(1) = 0.005$, $p = 0.94$], or any IQ scale scores (see Table 1).

Table 4 summarises autistic profile scores for younger and older adults. There were no age group differences in ADOS-2 or SRS-2 scores (Table 4). As previously mentioned, all participants had existing clinical diagnoses of an autism spectrum condition. Although 12 participants (younger, $n = 7$; older, $n = 5$) did not meet the cut-off for ADOS-2 Total scores for 'Autism Spectrum' (≥7), they did meet or exceeded the cut-off for both index scores (Communication ≥2; Social Interaction ≥4). These findings are consistent with variable sensitivity and specificity of the ADOS for adults who also have co-occurring mental health conditions (Maddox et al., 2017).

Physical and mental health

Figure 2 summarises the PIAS self-reported data related to everyday difficulties with social skills, mental and physical health indicated high rate of co-occurring conditions in younger and older adults. Overall, participants reported high rates of symptoms related to anxiety ($n = 50$ [74%]) and depression ($n = 47$ [69%]), and related difficulties in identifying and describing emotions (alexithymia, $n = 28$ [41%]; for further information see Appendix 3 in Supplementary material; Figure 1). Sleep disturbances (e.g., difficulty falling asleep; frequent waking) were common in more than half to two-thirds of adults ($n = 48$ [71%]) as were sensory hypersensitivities ($n = 58$ [85%]). Conditions related to sensory sensitivities (e.g., visual, auditory, touch, taste/texture, and olfactory, $n = 27$ [40%]) were reported more by younger than older adults, whilst only five adults (younger, $n = 1$; older, $n = 4$) reported hyposensitivity or sensory-seeking. Social difficulties and stresses were related to social conversation ($n = 26$ [39%]), social anxiety ($n = 28$ [42%]), and loneliness or social isolation ($n = 26$ [39%]). Additionally, somatic conditions that presented greatest difficulties were related to neurophysiological symptoms (heart racing, $n = 10$ [14%]; shortness of breath, $n = 14$ [21%]); digestive problems (bowel, $n = 14$ [21%]; indigestion, $n = 28$ [41%]); and pain (stomach, $n = 19$ [28%]; back, $n = 10$ [14%]; and joints or limbs, $n = 28$ [41%]).

Figure 3 summarises the percentage of adults who met the threshold for at least one co-occurring condition (measured by PHQ) and experienced everyday difficulties related to those conditions. Overall, at T1 59% of the younger ($n = 22$) and 30% of older adults ($n = 9$) met the criteria for at least one other condition. The number of co-occurring mental health conditions ranged from 0 to 4, with almost half (46%) of all autistic adults having multiple co-occurring conditions. Although there were no significant differences between younger and older adults on any mental health measures (Table 5), 37% of younger ($n = 14$) and 22% of older adults ($n = 7$) met the criteria for three or more co-occurring mental health conditions. Both groups reported being on multiple pharmacological treatments for those conditions, which aligns with the self-report background data collected (using the PIAS; see Appendix 3 in Supplementary material).

The most common conditions reported by younger adults were Anxiety (27%; of which 16.2% other Anxiety syndromes; 10.8% Panic syndrome), Major Depressive syndrome (21.6%), Eating disorders (21.6%; of which 18.9% Binge Eating; 2.7% Bulimia Nervosa), Somatic disorders (16.2%, e.g., bodily pain), and Alcohol abuse (8.1%). For older adults, the most common conditions were Depression (15.6%; of which 12.5% Major Depressive syndrome; 3.1% other Depression syndrome), Binge Eating disorder (12.5%), Anxiety (9.4%; of which 6.3% other Anxiety syndromes; 3.1% Panic syndrome); Alcohol abuse (6.3%), and Somatic disorders (3.1%).

TABLE 4 T1 comparisons of autistic traits in younger and older adults.

Measure	Age Group		Statistics		
	Younger ($n = 25$) Mean (SD)	Older ($n = 25$) Mean (SD)	$t(48)$	p	Cohen's d
Autistic traits					
ADOS-2 Total[a]	8.44 (2.83)	9.76 (3.83)	−1.39	0.17	−0.39
ADOS-2 Comm.[a]	2.88 (1.48)	3.48 (1.33)	−1.51	0.14	−0.43
ADOS-2 Social Int.[a]	5.56 (2.16)	6.28 (2.77)	−1.01	0.32	−0.29
ADOS-2 RRB[a]	1.41 (1.30)	0.95 (0.95)	1.33	0.19	−0.17
	Younger ($n = 33$) Mean (SD)	**Older ($n = 27$) Mean (SD)**	$t(58)$	p	Cohen's d
SRS-2 Total[b]	72.61 (9.60)	69.00 (12.79)	1.25	0.22	0.32
SRS-2 SCI[b]	71.36 (9.68)	69.41 (12.48)	0.68	0.50	0.17
SRS-2 RRB[b]	71.39 (10.27)	68.96 (12.48)	0.83	0.41	0.21

[a]ADOS-2 indices (threshold scores): Total (≥7); Comm, Communication (≥2); Social Int, Social Interaction (≥4); and RRB, Restricted interests and repetitive behaviours (≥1).
[b]SRS-2 T-index scores (threshold ≥ 57): Total; SCI, Social Communication Index. RRB, Restricted Interests and Repetitive Behaviours.

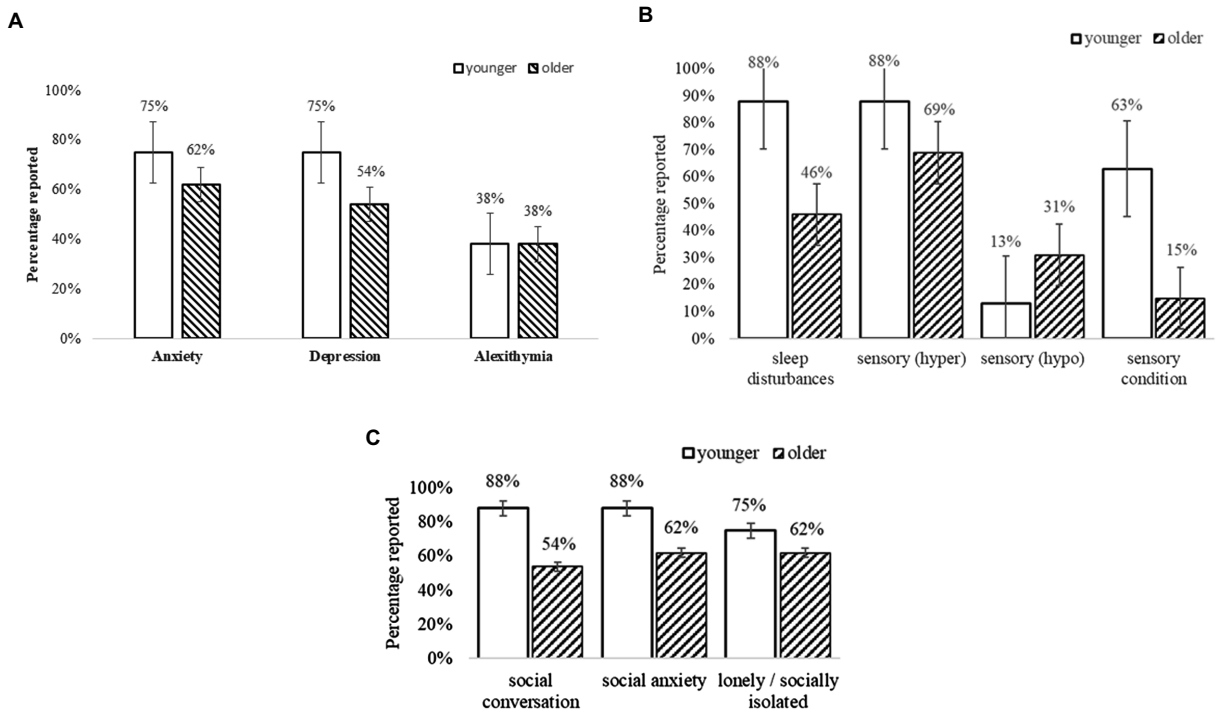

FIGURE 2
(A) Self-reported mental health conditions. Error bars indicate 1 SE. **(B)** Self-reported sensory and sleep conditions. Error bars indicate 1 SE. **(C)** Self-reported social difficulties. Error bars indicate 1 SE.

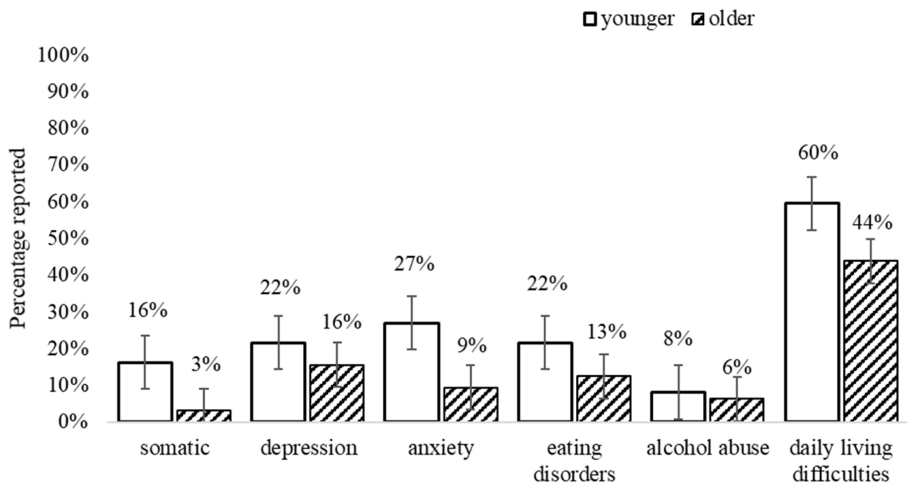

FIGURE 3
Co-existing conditions and everyday difficulties (measured by PHQ). Error bars indicate 1 SE.

Moreover, both groups reported difficulties in everyday functioning (e.g., doing housework, employment, and social relationships), as "somewhat" to "very difficult," related to these conditions.

Table 5 summarises the statistical analyses for T1 comparisons between younger and older adults, on the standardised assessments of mental health and quality of life. Although the standardised measures captured a lower rate of mental health concerns than those self-reported in background descriptive information (using the PIAS), these were nevertheless still predominant for the majority of adults, indicating at least "moderate anxiety" symptoms (as measured by BAI-II), and "mild mood disorder" to "borderline clinical

TABLE 5 T1 comparisons of mental health and QoL in younger and older adults.

Measure	Age group		Statistics		
	Younger ($n = 29$) Mean (SD)	Older ($n = 25$) Mean (SD)	$t(52)$	p	*Cohen's d*
Mental health					
Anxiety[a]	16.28 (9.12)	12.24 (8.93)	1.63	0.11	0.45
Depression[b]	19.11 (12.54)	14.08 (13.76)	1.41	0.17	0.38
Somatoform disorder[c]	0.22 (0.42)	0.04 (0.21)	1.84	0.07	0.54
Major depressive syndrome[c]	0.30 (0.47)	0.17 (0.39)	1.00	0.32	0.45
Other depressive syndromes[c]	0.00 (0.00)	0.04 (0.21)	−1.09	0.28	−0.30
Panic syndrome[c]	0.15 (0.36)	0.04 (0.21)	1.22	0.23	0.35
Other anxiety syndrome[c]	0.22 (0.42)	0.09 (0.29)	1.30	0.20	0.37
Bulimia nervosa[c]	0.04 (0.19)	0.00 (0.00)	0.92	0.36	0.27
Binge Eating disorder[c]	0.26 (0.45)	0.17 (0.39)	0.72	0.48	0.20
Alcohol abuse[c]	0.11 (0.32)	0.09 (0.29)	0.28	0.78	0.08
Extent of daily difficulties[c]	**1.44 (0.83)**	**1.01 (0.83)**	**2.33**	**0.024**	**0.67**
Quality of life					
PWI outcome variables					
Subjective Well-being[d]	**35.10 (12.36)**	**42.08 (11.72)**	**−2.11**	**0.04**	**−0.58**
Global life satisfaction[d]	50.67 (20.50)	57.08 (24.93)	−1.04	0.30	−0.28
WHOQOL-BREF outcome variables					
Overall-QoL[e]	**52.38 (17.51)**	**65.22 (22.28)**	**−2.11**	**0.04**	**−0.64**
Health-QoL[e]	46.43 (25.35)	57.61 (29.61)	1.34	0.19	−0.41
Support[e]	46.43 (23.73)	43.75 (30.96)	0.26	0.80	0.10
Physical-QoL[e]	57.35 (18.93)	62.30 (17.56)	−1.19	0.24	−0.34
Psychological-QoL[e]	**47.85 (17.67)**	**60.25 (18.27)**	**−2.40**	**0.02**	−0.68
Social-QoL[e]	47.46 (19.49)	53.33 (17.01)	−1.71	0.09	−0.32
Environmental-QoL[e]	62.15 (17.97)	69.08 (14.44)	−1.50	0.14	−0.43

[a]Anxiety (BAI-II) calculated for Total score (range 0–63); clinical cut-off scores: 0–7, "Minimal"; 8–15, "Mild"; 16–25, "Moderate"; and 26–63, "Severe."
[b]Depression (BDI-II) calculated for Total score (range 0–63); clinical cut-off scores: 1–10, "normal ups-and-downs"; 11–16, "Mild mood disturbance"; 17–20, "Borderline clinical depression"; 21–30, "Moderate depression"; 31–40, "Severe depression"; and >40, "Extreme depression."
[c]Clinically significant mental health conditions (PHQ). Daily difficulties: 0 = "not difficult at all"; 1 = "somewhat difficult"; 2 = "very difficult"; 3 = "extremely difficult."
[d]Subjective well-being and Global life satisfaction (PWI). Scores range from 0 to 100 (mean = 50, SD = 15).
[e]Quality of Life domains and Support received from others (WHOQOL-BREF). Scores range from 0–100 (mean = 50, SD = 15).
Bold values are significant at $p < 0.05$.

depression" symptoms (as measured by BDI-II), which were also observed on the PHQ (reported in Table 5).

Quality of life and subjective well-being

As set out in Table 5, scores across SWB and QoL domains were, overall, poor for both younger and older adults, indicated by below-average scores (<50; scale 0–100) on the PWI and WHOQOL-BREF scales, respectively (see Roestorf and Bowler, 2016; Roestorf, 2018 for reports of significant lower QoL for autistic adults compared to non-autistic groups). Moreover, both groups reported low degree of Support received for their everyday needs. The most common indicators of low SWB were related to lack of Personal Relationships and feeling isolated from the Community; lack of Achievement; and concerns about Health and Future. Scores for these factors were also below normative population mean scores of 70–80 points (see Cummins et al., 2003; International Well-being Group, 2013). Standard of Living and feeling safe (Safety) were amongst the highest SWB indicators.

Predictors of quality of life at T1

Table 6 sets out the main predictors of QoL domains across all participants. Age was not consistently related to QoL [all $r(44) < 0.17$, all $p > 0.25$] as low QoL scores, across domains, were observed across the lifespan. The only exceptions to this were Overall QoL and Social QoL domains, for which older adults reported greater satisfaction. Overall, depression and anxiety symptoms (as measured by BDI-II and PHQ, and the BAI-II, respectively) were the strongest consistent predictors of Global Life Satisfaction and Subjective Well-being, and most QoL domains including Overall-QoL, Health-QoL, Physical-QoL, Psychological-QoL, and Environmental-QoL. However, these symptoms did not predict Social-QoL scores [$R^2 = 0.07$; $F(2,46) = 1.83$, $p > 0.05$].

Difficulties related to autistic traits (as measured by SRS-2 Total scores), predicted Subjective Well-Being, and to a much lesser extent Overall QoL, Global Life Satisfaction, Psychological-QoL, and Environmental-QoL.

By contrast, factors related to age, gender, and autistic traits (as measured by ADOS-2 and SRS-2 Communication and RRB scores) did not predict any QoL or SWB outcomes [all $F(8,30) < 1.60$, all $p > 0.05$].

Discussion of T1 results

At T1, there were no age group differences in autistic traits (Table 4) or mental health (Table 5). Although older adults reported slightly better Social-QoL and Overall-QoL, in general QoL was low in both groups. Poor QoL was strongly linked to depression symptoms, anxiety, and autistic features, and was associated with difficulties in everyday functioning (e.g., autonomy, self-care, doing housework, holding employment, and maintaining social relationships; and *cf.* Park et al., 2019). The high rates of co-occurring physical and mental health conditions identified in the present study concur with many recent reports of everyday difficulties and poorer QoL in younger and older autistic adults (e.g., Khanna et al., 2014; Bishop-Fitzpatrick et al., 2016; Mason et al., 2018; Lawson et al., 2020). The findings replicate observations of recent studies that outline comparisons between older autistic and non-autistic adults (see Yarar Zivrali et al. (in press); and see Van Heijst and Geurts, 2015; Ayres et al., 2017 for reviews).

Study 2: T2 longitudinal follow-up

Results of T2 study

Sample characteristics

Table 2 summarises the characteristics T2 participants (25 younger and 24 older adults). The mean interval between T1 and T2 assessments was 2.4 years (range 1.2–3.8 years) and was not significantly different between age groups [$t(25) < 1.00$, $p > 0.05$]. Comparisons of the profiles of participants who continued to the T2 follow-up with those who did not, revealed significantly greater T1 depression symptoms in the non-continuing group [$t(36) = 2.33$, $p = 0.03$, $d = 0.78$], but no other differences in T1-derived cognitive or health profiles.

Autistic traits profiles (as measured by the SRS-2; Constantino and Gruber, 2012) were re-assessed in younger and older participants. As at T1, there were no age-related group differences at T2.

Mental health

As indicated in Table 2, there were no significant Age Group differences in anxiety or depression symptoms (measured by the BAI-II and BDI-II, respectively). Nor were there any differences in PHQ-measured symptoms of somatic complaints (e.g., bodily pain), or eating disorders, or alcohol abuse. Once again, daily difficulties related to co-occurring conditions were rated by both groups as "somewhat" to "very difficult."

Quality of life and subjective well-being

Table 2 summarises the T2 QoL scores. As at T1, QoL at T2 was low across domains. The T2 data followed a similar pattern to T1 observations, with older adults once again reporting greater satisfaction in Subjective Well-being, Overall-QoL, and Social-QoL. However, in contrast to T1 data, older adults also reported greater Psychological-QoL than younger adults.

Analysis of change over time

Table 3 indicates the change in T1-T2 scores that were assessed by comparing individual scores for autistic traits, mental health (anxiety, depression), and QoL, following the procedure set out earlier (see section "Statistical analysis"). There were no significant differences between T1 and T2 scores on any mental health or QoL domain scores [all $t(26) < 1.96$, all $p > 0.05$]. Regarding autistic traits, only RRBs showed significant change presented as increased at T2

TABLE 6 T1 predictors of quality of life.

Measure	*B*	*SE*	Beta	*t(52)*	*p*
PWI outcome variables					
Subjective well–being					
Depression	−0.53	0.11	−0.60	**−4.70**	**0.003**
Anxiety	−11.05	4.69	−0.30	**−2.36**	**0.025**
Social Responsiveness Scale – Total	−0.54	0.12	−0.53	**−4.33**	**<0.001**
Global Life Satisfaction					
Depression	−1.22	0.17	−7.21	**−7.27**	**<0.001**
Social Responsiveness Scale – Total	−0.56	0.26	−0.30	**−2.19**	**0.033**
WHOQOL-BREF outcome variables					
Overall-QoL					
Depression	−0.65	−26	−0.44	**−2.55**	**0.017**
Social Responsiveness – Total	−0.56	0.25	−0.33	**−2.22**	**0.032**
Health-QoL					
Depression	−0.75	0.34	−0.36	**−2.22**	**0.03**

Bold values are significant at $p < 0.05$.

[$t(26) = 2.22$, $p < 0.04$]. However, the analysis was not significant after applying Bonferroni corrections ($p < 0.001$) for multiple analysis ($p = 0.16$, $\eta_p^2 = 0.13$).

Predictors of quality of life at T2

Table 7 summarises the main predictors of T2 QoL for all autistic adults. Once again, Age did not predict any QoL outcomes, across domains [all $r(29) \leq 0.17$, all $p \geq 0.18$], which followed the pattern observed at T1. However, Age at T2 was significantly correlated with Subjective well-being [$r(29) = 0.40$, $p = 0.015$] and Global Life Satisfaction [all $r(29) = 0.34$, $p = 0.036$], which was explained by higher satisfaction in these domains reported by older autistic adults (see Table 2).

Autistic traits were significantly negatively correlated with all QoL domains, except for Health-QoL, (all $r(29) \geq 0.32$, all $p < 0.05$). Given the marginal increase in autistic traits observed at T2, these were also explored in relation to QoL outcomes. RRBs, but not social communication or total scores (measured by SRS-2), were a significant predictor of Subjective Well-being ($R^2 = 0.14$, $F(1,27) = 4.43$, $p < 0.05$), Physical-QoL ($R^2 = 0.2$, $F(1,27) = 4.35$, $p = 0.05$), and Environmental-QoL ($R^2 = 0.14$, $F(1,28) = 4.62$, $p < 0.05$).

Difficulties related to anxiety, depression, and eating disorders were consistent predictors of Health-QoL [$R^2 = 0.60$, $F(3,22) = 11.16$, $p < 0.001$], Physical-QoL [$R^2 = 0.65$, $F(3,22) = 13.34$, $p < 0.001$; Table 7]. Whilst depression alone predicted Overall-QoL [$R^2 = 0.51$, $F(2,23) = 12.16$, $p < 0.001$], and anxiety and difficulty in everyday living predicted Psychological-QoL [$R^2 = 0.50$, $F(2,23) = 11.42$, $p < 0.001$]. Social-QoL, however was predicted by multiple factors including anxiety, depression, and autistic traits difficulties related to social communication, and difficulty with everyday living [$R^2 = 0.71$, $F(6,19) = 7.80$, $p = 0.005$]. The significant predictors of respective QoL outcomes are presented in Table 7.

Discussion of T2 results

There were no overall changes in autistic traits over time (as measured by SRS-2). In relation to quality of life outcomes, although older autistic adults reported significantly elevated satisfaction, compared to younger adults, in domains of Subjective Well-being, Overall-QoL, Psychological-QoL, and Social-QoL, statistical comparisons between T1 and T2 outcomes showed no general improvement in QoL, over time. Similarly, there were no changes in mental health, again reflecting continuing difficulties in this group, and poor QoL across domains (*cf.* also Mason et al., 2018; Lai et al., 2019). Furthermore, co-occurring depression symptoms at T2 were a consistent significant predictor of all QoL outcomes. Overall, these findings mirror the pattern of associations observed at T1 (Table 6).

General discussion

In the present study, we set out to describe the patterns of autism traits and well-being in the context of ageing, by exploring age-related differences between younger and older autistic adults. We also explored changes that occurred over a short follow-up (approximately 2 years) period. This paper describes our findings related to general ability, autistic traits, mental and physical health, and several quality of life domains. The present findings concur with emerging literature that highlights how increased difficulties related to autistic traits and mental health (e.g., anxiety, depression; Lawson et al., 2020; Oakley et al., 2021; Mason et al., 2022) are strong predictors of poor quality of life in autistic adults. The results highlight specific areas of concern for autistic adults, as well as domains that may contribute toward a more positive QoL in older age.

Overall, existing data from cross-sectional and longitudinal studies suggest that the core features of autism remain relatively stable over time (e.g., Magiati et al., 2014; Gotham et al., 2015; Lever and Geurts, 2016; Steinhausen et al., 2016), including up to middle age (Howlin et al., 2013). However, low well-being and poor QoL outcomes are frequently reported for autistic people, particularly in adulthood (e.g., Ayres et al., 2017; Mason et al., 2018; Lai et al., 2019; Lawson et al., 2020). Poor mental health is also known to have adverse effects on cognitive abilities, social isolation, and QoL (e.g., McClintock et al., 2010; and see Lai et al., 2019; Mason et al., 2019), whereas increased facilitation of social integration is linked to higher QoL and fewer anxiety and depression symptoms (Lever and Geurts, 2016; McConachie et al., 2018; Mason et al., 2018) but this is not well understood in older autistic adults (Mason et al., 2019). Therefore, accounting for individual differences is an important consideration for future autism ageing studies.

The pattern of findings in the present study broadly reflects the findings in previous studies. In our study, no age-related changes were observed for most outcome measures. Regarding autistic traits, social communication difficulties remained generally stable, although there was some increase in restricted interests and repetitive behaviours (RRBs) from T1 to T2.

Restricted Interests and Repetitive Behaviours were also a significant predictor of QoL outcomes related to Subjective Well-being, Global Life Satisfaction, and Environmental-QoL. The underlying causes of these associations are unknown but it may be that continuing difficulties associated with RRBs could adversely impact environmental autonomy, related to the home environment, access to and quality of health and social care, and participation in community activities or opportunities for leisure and recreation (e.g., Oakley et al., 2021; and see Park et al., 2019).

Similarly, age-neutral outcomes were observed across mental health and QoL domains, over time. Thus, whilst there were no further significant declines, overall, in these domains, nor were there any improvements. At T1, around two-thirds

TABLE 7 T2 Predictors of quality of life.

Measure	B	*SE*	Beta	*t*(47)	*p*
PWI outcome variables					
Subjective Well-being					
Depression	−0.38	0.18	−0.38	**−2.12**	**0.044**
Anxiety	−0.44	0.20	−0.39	**−2.22**	**0.036**
Autistic traits RRBs	−0.97	0.31	−0.88	**−3.18**	**0.005**
Difficulty in daily living	−6.55	2.90	−0.44	**−2.26**	**0.035**
Global life satisfaction					
Depression	−0.58	0.24	−0.39	**−2.40**	**0.027**
Autistic traits RRBs	2.00	0.98	1.14	**2.05**	**0.05**
WHOQOL-BREF outcome variables					
Overall-QoL					
Depression	−0.04	0.01	−0.53	**−3.22**	**0.004**
Health-QoL					
Anxiety	−0.04	0.02	−0.39	**−2.55**	**0.018**
Depression	−0.04	0.01	−0.49	**−3.24**	**0.004**
Eating disorder	1.58	0.71	0.31	**2.24**	**0.036**
Physical-QoL					
Anxiety	−0.85	0.25	−0.50	**−3.43**	**0.002**
Depression	−0.59	0.22	−0.40	**−2.74**	**0.012**
Autistic traits RRBs	0.63	0.30	0.46	**2.09**	**0.05**
Eating disorder	34.31	11.44	0.39	**3.00**	**0.007**
Psychological-QoL					
Anxiety	−0.59	0.25	−0.36	**−2.36**	**0.027**
Depression	−0.73	0.24	−0.51	**−3.08**	**0.005**
Difficulty in daily living	−12.43	3.69	−0.52	**−3.37**	**0.003**
Social-QoL					
Anxiety	−0.84	0.34	−0.46	**−2.47**	**0.023**
Autistic traits Social Communication	−14.68	4.52	−0.55	**−3.25**	**0.004**
Difficulty in daily living	4.81	2.00	2.84	**2.41**	**0.026**
Environmental-QoL					
Anxiety	−0.57	0.23	−0.43	**−2.53**	**0.021**
Depression	−11.80	5.03	−0.32	**−2.35**	**0.030**
Autistic traits RRBs	−0.49	0.23	−0.38	**−2.15**	**0.040**
Eating disorder	−20.01	5.60	−0.49	**−3.58**	**0.002**

Bold values are significant at $p < 0.05$.

of participants reported co-occurring physical and mental health conditions which were associated with poorer QoL. Anxiety and depression were experienced by more than two-thirds of the autistic adults in the study and difficulties related to both of these conditions were significant predictors of poor QoL at T1 and T2. Mental health difficulties were also strongly associated with everyday difficulties (e.g., housework, employment, social relationships; and *cf.* Gotham et al., 2015; Mason et al., 2018; Park et al., 2019). Accordingly, the findings at both time points suggest that anxiety and depression have a widespread impact on many aspects of everyday life, including participation in social activities (see Park et al., 2019 for similar findings in and adolescent-young adult sample). In the present study, reliability across the mental health and quality of life measures used was good (>0.85) to excellent (0.94). These findings concur with previous reports of sustained difficulties related to mental health and QoL (see Roestorf and Bowler, 2016; Roestorf, 2018; Yarar Zivrali et al., in press, for cross-sectional comparisons with non-autistic groups; and see, e.g., Gotham et al., 2015; Van Heijst and Geurts, 2015; Lever and Geurts, 2016; McConachie et al., 2018).

Given that these difficulties still remained significant at T2, the findings raise important issues about the mental health and well-being needs of autistic adults in the context of ageing. However, the direction of any association is unknown and the underlying causes and exacerbating factors related to these difficulties need to be systematically explored in future research

(see Lord et al., 2021 for current review and future-focused recommendations).

Study limitations and future directions

The main limitation of the present study relates to the generalisability of the findings to the wider autistic community. In common with most other research that directly includes autistic people (i.e., not *via* proxy reports), the data are based on relatively small volunteer groups of participants with average to above-average cognitive skills. The ADOS is not designed to account for age-related differences or trajectories over time and revised ADOS CSS algorithm (Hus and Lord, 2014) were not available at the time. There is emerging literature to suggest the revised algorithm can provide a more robust evaluation of differences in symptom profiles and behavioural outcomes. However, there is still little evidence to support its use and sensitivity in the context of ageing and autism (Morrier et al., 2017). Moreover, we do not know if the same associations would be found in participants with more severe autistic or psychiatric conditions, or by those less able to share their own experiences and difficulties, or engage social participation without individual supports (e.g., Charlton et al., 2022). Similarly, whether the pattern of results reported here would be mirrored in a more intellectually disabled sample, particularly in low-middle income countries where resources for post-diagnostic support and health care are more scarce is an open question (e.g., McCauley et al., 2020; Frankish and Horton, 2021).

The findings are also limited by a lack of detailed information on variables such as socioeconomic status. Whilst we did record years of education, measures of income, employment status, and residence were not systematically collected, and this further compromises the generalisability of these findings to autistic adults living in different circumstances. The inclusion of non-standardised measure of physical health status was primarily due to the lack of an autism-specific measure in this area, but again is a methodological concern that should be considered when interpreting these findings. Although the measures selected to assess mental health and well-being were based on the best available at the time, that had also been used in previous autism research, more autism-specific measures have since been developed, such as for assessing anxiety (e.g., Rodgers et al., 2020) and Quality of Life (e.g., ASQOL; McConachie et al., 2018 but see Williams and Gotham, 2021 for caution on interpreting the ASQoL composite score). The present study did not report the internal consistency of the standardised general population measures that were used with an autistic community sample. Therefore, caution should be exercised in interpreting the present study findings, subject to future replication. However, we note that more recent literature has validated the use of measures, such as the BDI-II (Williams et al., 2021) and PHQ (Arnold et al., 2020) with good construct validity and reliability, respectively, in autistic adult samples.

In the present study, only around two-thirds of participants at T1 went on to complete the T2 follow-up. This was primarily because of participant ill-health or death, life commitments, or withdrawal from the larger research programme. It is possible that the demands of ongoing research participation may have been too challenging for some adults with greater cognitive, functional or mental health difficulties, or that poorer health, or lower Socio-Economic Status may have affected the ability or means to take part in the follow-up study (e.g., Howlin et al., 2014; Van Heijst and Geurts, 2015).

A third limitation centres on gender. Like the majority of other autism studies, most of our participants were male. Although some recent studies on gender differences suggest that masking of autism-related symptoms by autistic females may underpin more pronounced mental health difficulties (e.g., Mandy, 2019). Fombonne (2020) highlights the poor methodological quality of much research in this area (and see Williams et al., 2021). Therefore, better representation of autistic women in the context of ageing research is needed.

A fourth limitation is the statistical analyses used in the present study. Given the present study is one of the few longitudinal studies of autistic adults, there was little precedent for the exploratory investigation of change in this study. Furthermore, there is still little consensus in the general ageing literature on the "right" reliability of change analysis, since change scores are influenced by the type of assessment, cognitive and mental "health" of participants at baseline compared to follow up, and the duration the of interval between test and retest, and the heterogeneity of the participant group (Ivnik et al., 2000; Maassen, 2001; Frerichs and Tuokko, 2005). To evaluate the predictors of quality of life, stepwise regression was used based on a review of the literature available at the time of this study. Whilst alternative approaches have subsequently been suggested (e.g., Smith, 2018), these guidelines were not available at the time the present study was completed. Moreover, while the present study did not demonstrate significant age effects over time, the validation of "age-neutral" outcomes is required from replication studies. The findings should therefore be interpreted with caution and subject to replication in future studies using alternative statistical analyses.

A final limitation is the short time between the T1 and T2 assessments, which may have reduced the chances of detecting significant patterns of change. This coupled with the problems of attrition noted above, points to the need for greater attention to be paid to reducing attrition rates especially in the context of longer follow-up studies.

Strengths and contributions of the present study

The present findings provide new and important insights into health and well-being outcomes for autistic adults as they grow older. The majority of existing autism research

relies on cross-sectional studies between autistic and non-autistic comparison groups (Raz et al., 2005). However, it is only in longitudinal evaluations that true *changes* over time can be observed (Salthouse, 2004).

In the present study, both cross-sectional and longitudinal methods were used to assess age related changes across a wide range of standardised and self-report measures of autistic traits, health and well-being. This comprehensive approach enabled us to identify and evaluate the factors that are associated with ageing and autism to a better understanding of well-being outcomes for autistic adults as they grow older.

Conclusion

To our knowledge, the present study is among the first to combine cross-sectional and longitudinal methodologies, across a breadth of measures, to assess mental health and quality of life in a community-based sample of younger and older autistic adults. The findings highlight the adverse effects of co-occurring physical and mental health conditions on everyday living and quality of life over time. Thus, the present research contributes to furthering our understanding of the specific challenges that may be associated with ageing and autism. However, more work is needed on larger, more representative cohorts, with sustained longitudinal follow-ups at multiple time points. Only through continued efforts can we understand the potential factors that may help or hinder transitions across the lifespan (Roestorf and Lambrechts, pre-print; https://osf.io/ygkw5/) and support autistic individuals to lead longer, healthier, and happier lives.

Data availability statement

The datasets presented in this article are not readily available because the raw data supporting the conclusions of this article are governed by General Data Protection Regulations (2008) in the EU and UK. Accordingly, no data, whether anonymised or identifiable, may be made shared without the express written consent of participants involved in this research. Requests to access the datasets should be directed to amanda.roestorf.2@city.ac.uk.

Ethics statement

The studies involving human participants were reviewed and approved by City, University of London Psychology Department Research Ethics Committee PSYETH(UPTD) 13/14 28. The patients/participants provided their written informed consent to participate in this study.

Author contributions

DB and PH were involved in obtaining research funding and providing supervision to AR during the programme of work, and reviewed and advised on the research protocol, analysis, and results and contributed to editing the manuscript. AR designed all studies and conducted all data collection, diagnostic assessment, and analysis and writing of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary materials for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.741213/full#supplementary-material

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EDITED BY
Amy Pearson,
University of Sunderland,
United Kingdom

REVIEWED BY
Georgia Pavlopoulou,
University College London,
United Kingdom
Emma Gowen,
The University of Manchester,
United Kingdom

*CORRESPONDENCE
Jacquiline den Houting
jac.denhouting@mq.edu.au

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From ivory tower to inclusion: Stakeholders' experiences of community engagement in Australian autism research

Jacquiline den Houting[1,2]*, Julianne Higgins[3,4], Kathy Isaacs[2,5], Joanne Mahony[1,3] and Elizabeth Pellicano[1,2,6]

[1]Macquarie School of Education, Macquarie University, Sydney, NSW, Australia, [2]Cooperative Research Centre for Living With Autism (Autism CRC), Brisbane, QLD, Australia, [3]Sylvia Rodger Academy, Cooperative Research Centre for Living With Autism (Autism CRC), Brisbane, QLD, Australia, [4]Department of Developmental Disability Neuropsychiatry (3DN), University of New South Wales, Sydney, NSW, Australia, [5]The Autistic Realm Australia, Inc., Adelaide, SA, Australia, [6]Department of Clinical, Educational and Health Psychology, University College London, London, United Kingdom

Autistic people, and other community stakeholders, are gaining increasing recognition as valuable contributors to autism research, resulting in a growing corpus of participatory autism research. Yet, we know little about the ways in which stakeholders practice and experience community engagement in autism research. In this study, we interviewed 20 stakeholders (academics, autistic people, family members/careers, research students, and service providers) regarding their experiences of community engagement in Australian autism research. Through reflexive thematic analysis of interview data, we generated four themes. First, our participants perceived academia as an "ivory tower," disconnected from community members' lives and priorities. Second, our participants identified that different stakeholders tended to hold different roles within their research projects: academics typically retained power and control, while community members' roles tended toward tokenism. Third, our participants spoke of the need to "bridge the gap" between academia and the community, highlighting communication, accessibility, and planning as key to conducting effective participatory research. Lastly, participants emphasized the changing nature of autism research, describing participatory research as "the way of the future." Our findings reflect both the progress achieved to date, and the challenges that lie ahead, as the field advances toward genuine co-production of autism research.

KEYWORDS

patient and public involvement, autism, community engagement, participatory research, co-production

Introduction

Over the past decade, there has been increasing recognition of the value of community engagement in autism research. As recently as 2014, examples of participatory research were rare in the autism literature (Jivraj et al., 2014). Following trends in health research and a range of other fields, however, a growing body of participatory autism research has

developed since that time (see Crane et al., 2019; Fletcher-Watson et al., 2019; Nicolaidis et al., 2019; Benevides et al., 2020 and Keating, 2021, for further discussion and examples).

The term *participatory research* refers to research conducted with meaningful input from members of the relevant community/ies during the research process. In autism research, this typically involves academics (research professionals and/or research students) working together with community members (autistic people; their families, friends, and carers; service providers; and other stakeholders) to produce research. Ideally, community members will be involved across all stages of the research process, sharing power and control as equal partners in a research team—a participatory approach known as *co-production* (Filipe et al., 2017; Roper et al., 2018; Redman et al., 2021).

In Australia, the Cooperative Research Centre for Living with Autism (Autism CRC) has contributed a considerable proportion (approximately 45%) of national autism research funding since its establishment in 2013 (den Houting and Pellicano, 2019). Autism CRC is the world's first national, cooperative research effort focused on autism, and comprises a collaborative network of more than 50 participant and partner organizations, including universities, autism service providers, autistic and other advocacy organizations, industry entities, and government departments (Autism CRC, 2021). Autism CRC promotes inclusive and community-engaged research practices, with a strong focus on research co-production. Autism CRC has established a range of initiatives to promote and incentivize participatory research including, for example, the Participatory and Inclusive Autism Research Practice Guides (den Houting, 2021), which provide information and guidance regarding the conduct of participatory autism research; the Co-Production Partner Initiative, which recognizes organizations that show a commitment to sustainable research co-production (Autism CRC, 2022a); and the Sylvia Rodger Academy Research Program, which provides training to equip researchers and autistic adults with the skills needed to co-produce autism research (Autism CRC, 2022b). In previous research, we examined the extent and nature of community engagement in research commissioned by Autism CRC (den Houting et al., 2021), using an online survey. We identified that, while Autism CRC stakeholders expressed strong support for community engagement in research, these positive attitudes often failed to translate into participatory research practices. Our findings suggested that there remain barriers— in particular, systemic constraints and knowledge gaps regarding participatory research—limiting the conduct of high-quality participatory autism research in Australia.

While community engagement in autism research continues to increase, our understanding of the attitudes and beliefs informing such engagement remains limited. To our knowledge, the first investigation of attitudes toward community engagement in autism research was conducted by Pellicano et al. (2014), who gathered both researcher and community views. Overall, researchers reported engaging with the autism community to a moderate extent, while community members reported significantly lower levels of engagement. Researchers held varied opinions regarding the value of community engagement, with some believing that community input should be central to the research process, while others felt that research should remain in the hands of scientists. Researchers were concerned that there is a lack of diversity among the community members who are most frequently engaged in research, and felt that autistic characteristics can make it difficult to work with autistic people. Community members, in contrast, felt that their contributions to research were often undervalued. Some described a lack of opportunities for engagement; others described one-sided engagement during which they were "treated like guinea pigs" (Pellicano et al., 2014, p. 7). As a result, community members found that research findings were often inaccessible, and lacked relevance to their daily lives.

More recently, both Hollin and Pearce (2019) and Pickard et al. (2022) elicited autism researchers' attitudes toward community engagement in research. In both studies, participants reported the belief that community insights are valuable, but also voiced a range of concerns. Hollin and Pearce's participants described challenges they encountered when working with autistic people and tended to attribute these challenges to autistic characteristics; for example, stating that disagreements between autistic and academic stakeholders arose due to autistic people's perceived impairments in perspective-taking. Pickard et al.'s participants noted similar communication challenges, which they attributed as resulting both from autistic characteristics and community members' unfamiliarity with research. Participants in both studies were concerned that the autistic people who contribute most frequently to participatory research may not fully represent the diversity of the autistic community. At the same time, though, participants expressed confusion regarding how to respond to the at-times conflicting views held by different autistic stakeholders. Additionally, while Pickard et al.'s participants believed that participatory approaches are becoming more common in autism research, they noted that this shift toward increased community engagement may be hindered by considerable systemic barriers and a confusing lack of clarity surrounding participatory research terminology and practices.

To examine experiences of participatory research from the perspective of research participants, Pellicano et al. (2022) interviewed autistic adults who had taken part in the Hidden Histories project, an oral history research project co-produced by a team of autistic and non-autistic researchers. Almost universally, participants in the Hidden Histories project felt that the involvement of autistic researchers had improved their experience as participants. Indeed, for some participants, the co-produced nature of the project was a key factor in their decision to take part, as it provided reassurance that the research ethos was aligned with participants' own values and priorities. Participants described feeling supported by the research team throughout the study, and were able to form connections with the autistic researchers (who conducted the oral history interviews) that would be less likely to develop with a non-autistic researcher. As a result, participants felt

safe and comfortable sharing their stories, despite the often-confronting content of their narratives.

These studies have provided preliminary insights into stakeholders' perceptions and experiences of participatory autism research. With the growing trend toward participatory research in this field, though, deeper understanding will be vital in informing future community engagement. In this study, we focused on the practicalities of participants' involvement in participatory research, to elucidate the factors they perceive to have most shaped these experiences. We examined (1) how stakeholders practiced and experienced participatory research within Autism CRC research projects; (2) why participatory research was practiced and experienced in this way; and (3) how we might improve participatory autism research going forward.

Materials and methods

Participants

Participants in this study comprised a sub-sample of participants from a previous online survey study examining perceptions of participatory autism research in Australia (den Houting et al., 2021). Recruitment was initiated by Autism CRC, who contacted all Autism CRC Project Leaders with a request to nominate current and previous members of their research team/s (including both academic and community stakeholders) for participation in the online survey. Project Leaders and nominated team members were invited to complete an online survey, with the option to participate in a follow-up interview. Of the 79 participants who completed the survey, 25 consented to being contacted for participation in a follow-up interview. Of those 25, 20 participants (80%) took part in the interview (four did not respond to email invitations and one declined to participate).

Each participant completed a brief demographic questionnaire prior to interview (see Table 1). Sixteen participants (80%) were women, three (15%) were men, and one reported non-binary gender. Participants' ages ranged from 24 to 72 years ($M = 45.15$, $SD = 13.69$). All reported some tertiary education, with more than half (55%) holding a PhD or Doctoral degree, and most (70%) engaged in full-time employment or study. Most participants (70%) reported a white European racial background. Participants identified their various (often multiple) roles within the autism community, with 15 identifying as an autism researcher; six as a family member or carer of an autistic person; four as an autistic person; four as service providers; and three as research students studying autism.

Interviews

Each participant took part in one semi-structured interview, either via Zoom (n = 17) or face-to-face (n = 3). All interviews were conducted by the first author, an autistic early-career academic. Interviews ranged from 38 to 77 min in length (M = 54 min). Nineteen interviews were audio recorded, using Zoom's inbuilt recording function and/or a digital voice recorder, and transcribed by a professional transcription service. One participant did not consent to being recorded, and the interviewer took notes by hand during this interview. All transcripts were returned to participants for review and correction prior to analysis. Community stakeholders were offered a AUD$20 gift card for their participation (participants employed in paid roles in autism research did not receive gift cards).

During the semi-structured interview, we asked participants to describe their own personal and professional experience with autism and, specifically, autism research. We asked them to describe their understanding of participatory research, and how participatory research differs from more traditional research. Next, we asked participants to bring to mind their experience of one specific Autism CRC research project of their choosing, and to describe this research process. We asked them to explain whether and how community members were involved in their research process, to describe the relationships between different stakeholders in their research process, and to describe the outcomes of their research process. We also asked about the benefits and challenges of community engagement within their specific research project, and how community engagement impacted their research project. Lastly, we asked participants to talk about autism research more generally. We asked questions about historical and current perceptions of autism research, perceptions of autistic people's roles in research, and ways to improve meaningful community engagement in autism research (see Supplementary material).

Data analysis

Data were analyzed using reflexive thematic analysis. We approached analysis through an interpretivist/constructivist perspective, recognizing that individuals create meaning, with each person's individual reality influenced by their social context. In so doing, we approached analysis with the understanding that, just as our data reflected participants' contextually situated experiences, our analyses reflect our own contextually bound interpretations of the data. The community of autism researchers in Australia is relatively small and well-connected, meaning that many of our participants were acquainted with the interviewer prior to taking part in this study. Our findings should be considered within this immediate interview context, as well as broader academic and social contexts. We adopted an experiential orientation, with language (and therefore our data) assumed to accurately reflect participants' constructions of their experiences and realities (Braun and Clarke, 2021).

The first author is an autistic early-career researcher and activist, with expertise and experience in participatory autism research. This author led analysis, working through Braun and

TABLE 1 Participants' demographic characteristics.

Participant ID	Gender	Age	Education	Occupation	Role/s in autism community
01-R	Woman	33	PhD/Doctorate	Full-time employment	Researcher studying autism
02-A	Man	69	VET*, Diploma, or Associate Degree	Retired	Autistic person
03-StF	Woman	40	Master's Degree or Postgraduate Diploma	Full-time study	Student studying autism; family member/carer of autistic person
04-R	Woman	54	PhD/Doctorate	Full-time employment	Researcher studying autism
05-StF	Woman	24	Bachelor's Degree	Full-time study	Student studying autism; family member/carer of autistic person
06-RSp	Woman	36	PhD/Doctorate	Full-time employment	Researcher studying autism; service provider
07-AR	Woman	35	Master's Degree or Postgraduate Diploma	Part-time employment	Autistic person; researcher studying autism
08-R	Woman	35	PhD/Doctorate	Full-time employment	Researcher studying autism
09-RSp	Woman	59	PhD/Doctorate	Full-time employment	Researcher studying autism; service provider
10-F	Woman	49	Bachelor's Degree	Full-time carer/domestic duties	Family member/carer of autistic person
11-R	Man	54	PhD/Doctorate	Full-time employment	Researcher studying autism
12-R	Man	38	PhD/Doctorate	Full-time employment	Researcher studying autism
13-ARSp	Woman	31	Bachelor's Degree	Full-time employment	Autistic person; researcher studying autism; service provider
14-RF	Woman	46	PhD/Doctorate	Part-time/casual employment	Researcher studying autism; family member/carer of autistic person
15-AR	Non-binary	72	Bachelor's Degree	Part-time/casual employment	Autistic person; researcher studying autism
16-StSp	Woman	28	Bachelor's Degree	Full-time study & part-time employment	Student studying autism; service provider
17-RF	Woman	40	Bachelor's Degree	Part-time employment & part-time study	Researcher studying autism; family member/carer of autistic person
18-RSp	Woman	63	PhD/Doctorate	Full-time employment	Researcher studying autism; service provider
19-RF	Woman	55	PhD/Doctorate	Full-time employment	Researcher studying autism; family member/carer of autistic person
20-R	Woman	42	PhD/Doctorate	Full-time employment	Researcher studying autism

*Vocational education and training.

Clarke's six-phase reflexive approach: (1) familiarization with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing potential themes; (5) defining and naming themes; and (6) producing the manuscript (Braun and Clarke, 2012, 2019; Braun et al., 2019). Because many of our participants identified with multiple roles in the autism community, it was not possible to create distinct participant groups (e.g., academics versus community members); therefore, data from all participants were analyzed collectively.

After familiarizing themselves with the data, the first author generated and applied codes to each transcript using NVivo version 12. In line with our experiential orientation, we coded the data at the semantic level, based on the explicit meanings of the data. We coded data inductively, aiming to construct codes from the data, rather than from pre-existing knowledge or theories. After coding all transcripts, the first author developed preliminary themes by collating similar codes and discarding codes that did not appear relevant to the research questions. This process produced 12 candidate themes, which were explored through thematic mapping. Through re-engaging with the data coded within each candidate theme, the preliminary themes were revised and a thematic structure consisting of five themes and nine subthemes was constructed. Next, the first author selected data extracts to illustrate each subtheme, and sought participants' approval to publish the relevant de-identified extracts from their interview transcripts in this manuscript. The first author then generated descriptive names for each theme and subtheme.

With input from the last author, an experienced non-autistic researcher with expertise and experience in participatory autism research, the first author produced a draft of this manuscript. During the writing process, it became clear that one of the five themes was better conceptualized as a subtheme within one of the other themes. The themes were revised accordingly, resulting in the current thematic structure of four themes and ten subthemes (Figure 1).

Community engagement in this study

Members of the autistic community were engaged throughout the process of this research project. The project plan (including funding application) for this study was developed by the last author, in consultation with the first author. An Autistic Advisory Group, consisting of five autistic adults with experience as both peer researchers and research participants, was established during the early stages of this project. The Advisory Group acted as consultants throughout this study, providing input via web conferencing and email.

The semi-structured interview template was initially developed by the first author, with input from the last author. This template was then revised based on feedback from the Advisory Group. The first author led participant recruitment, conducted all interviews, and led data analysis. Members of the Advisory Group contributed to this manuscript and are credited as authors, where appropriate. Advisory Group members were paid for the time they spent consulting on this project.

Results

We developed four themes that addressed our research questions, described below. Quotes from individual participants are identified by participant number and the participant's role/s in the autism community (R = researcher; A = autistic person; F = family member/carer; Sp = service provider; St = student).

Theme 1: Academia is an ivory tower

Autism research is out-of-touch with the "real" world

Participants, including researchers, described the field of autism research as being largely out-of-touch with the realities of autistic people's lives. They spoke of autism research as failing to address the autistic community's priorities, instead being "more focused on things like genetics, or parent stress, that are quite stigmatising or… not vital to their day-to-day functioning" (06-RSp), or "addressing stuff that just does not matter. It's just irrelevant. It just does not matter" (04-R). Participants felt that autism research often failed to improve the lives of autistic participants, who were "just… contributing their information, contributing their experiences to studies that… would never help them, in the end" (05-StF).

Academics themselves were described as similarly out-of-touch with autistic people's experiences: "I mistakenly thought that researchers would know a lot about autism, but they know a lot about autism research and that does not mean to say they know

FIGURE 1
Participatory autism research practices and experiences: themes and subthemes.

a lot about autism, the lived experience" (15-AR). Beyond autism itself, academics were perceived as disconnected from the community more generally. As one autistic person noted, "they are very much steeped in academia" (02-A). This participant described how,

> You learn nothing more because all the conversation revolves around is the academia… Now, I can understand living in that sort of research type environment, it's a bit like being an archeologist and wanting to be going away and scraping away in a trench all day long, oblivious of time and everything, because you can immerse yourself in it… They're living their life through academia. (02-A)

Some researchers shared this sentiment:

> It's easy to get lost in the data, the ethics applications, the measures, the validity and the reliability, but actually constantly being reminded that these are people with real lives… If that's not constantly reminded to you, it's easy to get lost in that rabbit hole of academia. (01-R)

For one participant working in a basic science setting, it was important to introduce a sense of humanity into his team's work:

> There were people that… would deal with the samples and do the biological research, that would have no interaction whatsoever with that family. I try to instil into some of the research staff and students that work on these projects, that when you're talking about the cells, you're talking about… these are Peter's cells, Peter is eight years old, he loves cars. You try and add that personal touch to it. This is actually a person that we're working with. (11-R)

Some participants also noted the downfalls that can arise when an awareness of the real-world context is lacking in research. One participant, for example, perceived this to limit the utility of research outputs in community settings:

> A lot of things developed in universities, they've used a lot of exclusion criteria and they've excluded all the people with challenges… they have communication difficulties or learning difficulties or whatever… So, we often end up having to adapt what universities have produced because it's not meeting the needs of the people that come to us. Or we have to develop our own anyway. (18-RSp)

Academic priorities are at odds with community priorities

Participants often faced difficulties conducting research that met community needs, while also meeting academic expectations regarding scientific rigor: "There were certain rigidities around methodology, and certain rigidities in the classroom around curriculum and what has to be done, so there was a bit of negotiation having to happen to get those two things to work together" (14-RF). One participant was frustrated that rigid ideas around research methodology overshadowed the value of her work:

> I keep getting feedback that, 'Well, you didn't do a randomized controlled trial'. Well, that's not what this is about. This is about people being able to express what's important to them, so how can I possibly do a randomized controlled trial? It's really about individuals and what's meaningful to them, so I can't compare one person to another. There's nothing standardized about it. (18-RSp)

Another participant described a similar experience:

> With the focus being on something real-world and actually useful, I think the challenge as an academic is that it's probably going to result in one paper that we're probably going to have a hard time publishing because it's real-world data, it's messy, there's missing data, sample sizes maybe aren't perfect, it's not a randomized controlled trial but… We've learnt a lot, and we've really tried to make it very real-world, and it's been [difficult] trying to balance that with the demands of, you know, the whole 'publish or perish' and so on. (06-RSp)

Disparities between university priorities and the priorities of community organizations were highlighted as a particular challenge, with universities described as "all about the thesis and the student and… not terribly good at working with community organizations and thinking that you have anything to offer" (18-RSp), and community organizations perceived as being "unaware… of the processes and the checks that we had to go through for the PhD student at the university, those requirements from the university" (04-R). As one participant explained,

> There were also competing priorities within the organization at the other end, because at a university level, you are here to do that research project, or you are teaching your research and that's it. Whereas if you are a not-for-profit organization and you are running multiple research projects, plus all of the other things that you do, there's a lot more priorities going on at one time. (16-StSp).

On an individual level, researchers felt that community members had "a very different sense of what research can be" (20-R), which led to difficulties in "getting the stakeholders to really understand what rules we, they, need to abide by" (04-R). Others, though, felt that it was academics' responsibility to ensure scientific rigor in participatory research projects:

> Sometimes you might need to be trying to explain to one of the advisors why… advice might not be able to work because of the context of the research methodology and things like

> this. I think that's part of working together as a team. That's what the researchers will bring – is that deeper understanding of methodologies and approaches to the science. That's one of the skills of the researcher groups. (12-R)

Academic systems are not built for participatory research

Participants consistently reported that academic systems pose major barriers to the conduct of participatory research. One researcher spoke about academic processes as being "in opposition… to participatory research," describing how they have to "figure out how to make [participatory research] fit within the existing protocols and systems" (04-R). Another participant agreed, stating,

> I think organizational structures don't reward that, too. Like if you're thinking about what universities want on the time and space they provide, it's really hard… They have structures around what people can and can't do. So it's often harder to engage in collaboration where you've got organizational rules about what can and can't happen. (16-StSp)

Participants highlighted funding and time constraints: "I guess it's still limited by issues like funding, just time constraints. The pressure… for people to just constantly publish to justify funding… those constraints make it difficult" (05-StF). More specifically, participants were concerned that the academic funding system lacks adequate provisions to ensure that community members—particularly autistic people—are paid appropriately for their work "right at the stage of writing the grant" (12-R). As one researcher noted,

> If an autistic person is going to come in and contribute, they absolutely deserve to be paid for their time… it's part of the challenge… how to work that within an institution and a funding model and a grant and all of that sort of thing. (17-RF)

Theme 2: Stakeholders have different roles in research

Academics retained power

Perhaps unsurprisingly, participants reported that researchers typically retained the majority of power within their research projects. As one participant described, "the decisions sat with the academic research team, really. Even though that should not have been the case, that's how it worked… that power imbalance is definitely there, at the end of the day, if everyone's honest" (01-R). One community member clearly described this power imbalance:

> I admire all the credentials of those people and that, but it's a question of whether you feel like you can contribute to that group, because it seems like there's two levels. You know, you've got the researchers who are dominant, and you've got perhaps a few others that have had a lot of life experiences and are certainly far from unintelligent… but are unable to meet on the same plane. (02-A)

Often, power dynamics followed a hierarchical structure, with Chief Investigators holding the balance of power, "I think the head of the project definitely had the majority of the power. Most people were kind of just looking to her to say, okay, well, what do we need to do next?" (08-R). Some participants felt that this was necessary to ensure projects ran efficiently, "Of course, at the end of the day the leader—the research team needs to make… those decisions" (20-R), noting that such decisions would involve a "negotiation process" (20-R) with community members.

Some participants were aware that the existing power dynamics are not in line with best practices for participatory research, "the power exchanges, because it's collaborative and it's genuinely – well, it should be, I'll clarify that – should be a genuine power sharing. So, there should not be, 'well, the academics hold more power because they came up with the initiative'" (16-StSp). Despite acknowledging that "you have to let go of control" (04-R), however, some researchers held concerns about the practicalities of sharing power:

> Letting go of control is one thing, but how much control do you need to let go of and how much do you still need to maintain? Because sometimes when you get too participatory, nothing ever happens. There's too many voices, they never come to a decision. (04-R)

Importantly, participants expressed the belief that, within autism research, there are some "academics who are incredibly resistant and do not want to change things at all… who do not want to let go of their power. They like things done a certain way, and they like the way things work right now and the current reward structures" (06-RSp).

Community members' roles were unclear and tokenistic

Some participants expressed a lack of clarity regarding community members' intended roles within their various research projects. Community members, in particular, were uncertain of how they were expected to contribute to research: "What are we supposed to be doing? Are we advisors or are we actually providing the material [data] that you can use?" (02-A). They were even unclear about the nature of the research that they were involved in:

> I did one [advisory role] and then I think one of those may have merged into something else, I think. So, I think it was two [projects]… I think it was somebody's PhD. I think it was her – I'm almost certain it was her PhD research. (10-F)

Community members typically held advisory or ancillary roles and were perceived by researchers as "external collaborators rather than project team members" (14-RF). This perception was consistent with community members' own experiences, "I would not say that I felt a part of a team. Definitely not, and I would have liked to" (10-F). Community members described working in isolation from other project stakeholders, "I do not know anyone who was involved in it… I only know them by their name, but they could just—they could walk past me now, I would not know" (10-F), often performing their roles "via the computer… through emails and transfer of documents" (02-A). Some participants felt that community members were not given "the opportunity… to really influence or change how the project worked in any way" (16-StSp), and community members agreed that they "definitely would have liked… probably a stronger input or influence" (10-F). The lack of clarity regarding one participant's role, and lack of engagement with the wider project team, left him "feeling sometimes that it is almost like I am the token autistic person that is not involved, like all the others, in research professionally" (02-A).

Consistent with the ancillary roles that community members often played, some participants questioned whether attempts at community engagement were genuine:

> I feel like each time they say 'we need to ask the autistic community', it's… 'oh, we have to do this, or else we might get in trouble'. It feels like… we're only doing it because we're being told we have to do it. (03-StF)

Another participant felt that community members were engaged "when it suited the organization's aims to look participatory," noting that there wasn't "a genuine acknowledgement across the board that these people brought expertise to the project, that could have been used in a lot of different ways" (16-StSp). An autistic researcher described this *ad hoc* consultation as a common experience, "'Oh, can you just read the survey and make sure that autistic people are not going to get upset about my language?' It's like, 'Yeah, I can do a lot more than that'" (13-ARSp).

Community input is valuable and valued

In contrast, many researchers reported that they highly valued community members' input. Participants felt that community input assisted them in "understanding the needs of individuals" (11-R), and "brings in a whole new perspective [that has] been extraordinarily valuable to what we do. It makes the team think about how we go about doing research, and about our priorities" (09-RSp). Some autistic participants shared these positive perceptions, feeling that their "input was valued and that it was a genuine part in shaping the research" (07-AR).

In particular, participants described community engagement as having beneficial impacts on research findings, outputs, and outcomes. One participant stated, "I wished that they were brought in earlier, to help me with the process, just because I thought they were so valuable to my interpretations in the end" (05-StF), while others felt that input from community members had "really made a big impact on the findings" (12-R), "helped to ensure that the study that I'm doing is worth it" (03-StF), and demonstrated "how much better outcomes and results you can get… when you do get involved with a bigger range of stakeholders" (17-RF).

In some cases, community members were engaged due to having a particular skillset relevant to a research project, and therefore "contributed to the areas that they were most passionate about and… actually drove a lot of those areas… that was a great benefit to have that in the project" (06-RSp). In other cases, community members' insights into the lived experience of autism were an asset that academics prized:

> I think there's perception, potentially, from them that they have to have some sort of skillset related [to research]; they have to be able to read academically or write academically… it's like, maybe some people don't actually know the value that their experience of day to day, that's actually invaluable to us and that's exactly what we're trying to get at. It's not about whether you can read an academic paper or not or whether you might understand the statistical approach. (01-R)

Despite these generally positive attitudes toward participatory autism research, some participants felt that there remains "room for improvement" (18-RSp), with "steps to be made in making sure participation is even more valued and has even more, kind of, concrete contributions" (17-RF). One participant noted that this is not unique to autism research, but extends across the broader disability community: "[we need] almost an attitudinal shift about the value of people with disabilities' voices… we are not very good at that, if you look across any of the disability groupings, we do not value [their voices]" (16-StSp).

Theme 3: Bridging the gap between academia and the community

"More than anything, it's about working with people"

For some participants, the diversity of academic and community perspectives was managed by simply working together as people. Participants described the processes of communication and relationship-building that took place between different stakeholders in their research projects, noting that "really open communication was key" (17-RF), and that "there's no shortcut to building trust in good relationships" (07-AR). For some participants, developing a positive working relationship with other stakeholders was relatively easy, "We've had really good rapport I think… [I] got to know the team there, I think, pretty well and had no hesitation… I think we built up a pretty good relationship" (06-RSp). Some participants connected over shared experiences,

"I feel real empathy for her and with what maybe she is going through… we were in tune together, which was nice" (02-A). Others were able to work together to build strong and meaningful partnerships over time:

> I think that we actually work well as a team… we're able to be upfront with each other and also we were able to support each other through it… We've got the opportunity to learn from each other, you know, and we do appreciate each other's strengths. (15-AR)

One research student described benefitting from her team's established relationships with community members, which facilitated open communication and collaboration:

> It was good that there was already an established network of advisors… there's already a relationship between the [research] team and them, so the communication felt open, almost in some cases very friendly and conversational… they weren't afraid of making suggestions, because they already knew the team would be open to them… it was a strong relationship between the team and the advisors, and that paved the way for it to be more of a collaborative thing. (05-StF).

For many participants, though, communication between stakeholders was a source of tension. Occasionally there were difficulties with communication across neurotypes, "there are some challenges with communication obviously on the autistic side, but also on that neurotypical side of things, people—they have their own communication quirks and it does not always work" (13-ARSp). One autistic participant described his academic peers' communication as overly "formal… rigid… just, bloody get on with it" (02-A). These challenges were not limited to communication between autistic and non-autistic stakeholders, however, with participants equally often describing tensions arising between non-autistic team members from different academic and/or community organizations. Participants felt that these conflicts reflected "a problem of perspective" (04-R) due to different professionals "not understanding each other's ways" (09-RSp):

> I think that [relationships were] an ongoing challenge and struggle as well, because I think there was definitely a perception of very differing aims from different departments… then add on top of that, different personalities, just of the human kind, which really did influence the politics of working through some of these projects. (01-R)

Accessibility facilitates engagement

Accessibility was frequently highlighted as a priority for research involving autistic people as team members or consultants. One autistic participant noted that the process of community engagement should be approached with as much care as the research process itself: "The projects themselves are very important, but there should be equal amount of thought put into the actual community meetings or the input of individuals… the mechanics if you like, need to be really looked at" (02-A). Another participant spoke of her annoyance upon witnessing meetings conducted without necessary accommodations for autistic team members:

> I think it's just good meeting practice to make sure it's inclusive of who's in a space… some of those things didn't happen, which then actively excluded or made it difficult for the people on the spectrum to participate… I found it frustrating to be in a room where we weren't setting things up for people to actually be part of the process. (16-StSp)

Encouragingly, many researchers spoke about the strategies in place within their projects to facilitate accessibility for community members, and autistic people in particular. Participants described a wide range of strategies, including accommodations for sensory processing differences ("Somebody says it's too bright or it's too noisy, there were adjustments. 'Can I wear ear plugs?' 'Yes, of course you can wear ear plugs, can we buy them for you?' So we get some noise cancelling ear plugs"; 09-RSp); preferences regarding social interaction ("One of our advisors – maybe more than one – has actually commented that they actually prefer not having a group interaction situation… They're quite happy to provide their feedback individually to researchers working on the project"; 12-R); executive functioning difficulties ("doing things like sending a reminder the day before"; RSp-06); and differing levels of education and cognitive ability ("We put together a template of how you might present the results [to community members] … You'd still include potentially the table of numbers, but then under it would be a blurb written in not necessarily strict academic writing"; 01-R). Regarding which specific strategies to implement, participants noted the importance of being "flexible, and understanding that every autistic person… will have different preferences for the way that they engage with the project… being aware of that and changing your approach" (12-R).

Setting up for success

Participants explained that, to conduct effective participatory research, community engagement needs to occur "right from the beginning" (04-R) of a research project. Processes for community engagement must be deliberately planned as a core component of the research,

> I think you have to build it in from the get-go. You can't retro fit it. You can't add it on as something that looks good or meets a requirement because neither of those are going to be genuine and they're not going to work… You need to plan in the power structures and the power sharing, so that that's actually intentionally done, rather than just kind of ad hoc approaching things. (16-StSp)

This planning process should involve all relevant stakeholder groups, and take into account the research context and the individual needs of each stakeholder, "establishing early on how, when, why the engagement is going to happen and how people want the engagement to happen, both the autistic individuals and the researchers… it's got to be individual to every project and every person" (12-R).

Participants acknowledged that conducting high-quality participatory research can require considerable effort but felt that investment was justified by the potential benefits: "when the academics are willing, you can really see the effort they put in… it becomes a smoother process. Just that willingness to bridge that gap makes a huge difference" (05-StF). Some found benefit in departing from typical research processes to engage creatively with different stakeholders: "What this project has shown is, if you do think creatively about ways that people can express themselves in different ways… then they can be a lot more involved, actively involved" (18-RSp). One participant explained the importance of planning and sustained effort for facilitating inclusion:

> If the structures are right, anybody can participate at any time, but it has to be set up for people to be successful… You take little steps, and you keep trying and you keep doing more, and you keep building skills and capacity, and then eventually, you'll get there. (16-StSp)

Theme 4: Autism research is changing

Participants overwhelmingly agreed that "autism research is really in a changing space" (16-StSp), describing "a huge amount of change in our knowledge in the field, and how we look at autistic people" (04-R). Participants agreed that this change is a positive development in the field. They acknowledged that "if you go back far enough, you can see why there's very good reasons to have skepticism and concerns around research that was done" (12-R). They also noted that "you do not get changes in research trajectories quickly" (16-StSp), but felt that the field is "slowly improving" (07-AR), and that the current shift is "a change in the right direction" (05-StF).

Participatory research is "the way of the future"

As well as identifying a broad environment of change within the autism research field, participants identified a specific shift toward participatory research and increased involvement of autistic people in research: "I think it's definitely shifting towards more involvement and more in every area, research priorities being set by autistic adults… being involved in the project from beginning to end rather than just as that participant" (17-RF). Participants believed that there exists "a growing body of researchers that do acknowledge the benefits and the value of participatory methods" (01-R), and felt that, despite some initial resistance (see subtheme 2.3) "some researchers might be realizing that they might be running out of a choice not to be inclusive" (12-R).

Participants attributed this shift toward participatory research to "a combination of [autistic people] pushing more and researchers finally realizing, 'oh, maybe we should get their opinion on this'. I think that's been making autistic individuals more involved in the research that's supposedly being done for them" (05-StF). Another participant noted: "There's just a lot more recognition of including the community in research, I think… autistic adults saying, 'well, hang on a minute. You cannot do all this research without including us and asking us what we want'" (08-R).

Some participants had witnessed or contributed to increased community engagement within their own organizations, which is "very formalized now rather than being hap-hazard" (RSp-09); "my involvement in the project was part of that transformation of [the organization] moving from that tokenistic, 'hey, look, we are training an autistic to be a researcher', into that genuine respect and recognition and inclusion" (13-ARSp). Others noted a similar shift across the process of a research project, describing how "the participatory side of [the project], if anything, has continued to grow and increase and is actually a solid part of the project now" (01-R). Participants were confident that this evolution will continue, with one participant speaking optimistically about the future of community engagement in autism research:

> I think that, going forward, every research project will have a participatory element. I think it is the way of the future and I think, in another 10 years' time, to think that people used to do research projects to groups of people and those people were not involved, will just be a little bit absurd. Let us hope, anyway (01-R).

Discussion

How did stakeholders practice and experience participatory research within Autism CRC research projects?

In this study, we sought to understand the varied ways in which stakeholders practice and experience participatory research within projects supported by Australia's Autism CRC. Consistent with previous research (Pellicano et al., 2014; Hollin and Pearce, 2019; Pickard et al., 2022), many of our academic participants spoke about the benefits of participatory research and believed that community members had made valuable contributions to their work. Like previous findings, and in line with evidence regarding participatory research beyond the autism field (Brett et al., 2014; Forsythe et al., 2019), community members' insights were perceived to improve research outcomes and inform research findings that are more relevant to the autism community.

Yet, almost universally, participants' experiences reflected community engagement consistent with a consultation approach, as opposed to the co-production approach endorsed by the Autism CRC. As with our own previous work (den Houting et al., 2021), community members were frequently described—both by academics and by community members themselves—as "advisors" who provided "feedback" to research teams, rather than as

members of those research teams. In some cases, autistic people were employed as Research Assistants, which afforded community representation within research teams, albeit in subordinate roles. Academics largely retained decision-making power and control over the research process itself, and also over processes for community engagement, including decisions regarding how and when community members' input was sought. Unsurprisingly, then, some community members felt that they had little or no influence over research processes and perceived their engagement as tokenistic. This finding echoes the sentiments of community members in Pellicano et al.'s study, who asked, "Whatever we say, is that really going to influence anyone?" (Pellicano et al., 2014, p. 4).

Consistent with previous research (Pellicano et al., 2014; Hollin and Pearce, 2019; Pickard et al., 2022), some of our participants faced challenges in communicating across different stakeholder groups, describing incidents of conflict and misunderstanding. In contrast to previous reports, though, our participants spoke of communication challenges occurring across a range of (autistic and non-autistic) stakeholder groups, and therefore tended not to attribute these difficulties to communication deficits on the part of autistic stakeholders. Instead, our participants perceived these communication challenges as arising from the varied experiences and perspectives that different stakeholders brought to the research process. In their Guidelines for the inclusion of autistic adults in research, Nicolaidis et al. (2019) warn against pathologizing autistic community members in instances of disagreement, noting that such challenges are usual in academic-community partnerships beyond the autism field. We echo this warning, and put forward our findings here as evidence that communication challenges in participatory autism research stem from factors far more complex and diverse than presumed autistic communicative "deficits."

Discussion of the need for diversity in community representation is a theme consistently raised in previous relevant work (Pellicano et al., 2014; Hollin and Pearce, 2019; Pickard et al., 2022). In previous work, this emphasis on diversity perhaps stems from the perception that autistic people's primary role in research is that of participant, with diversity and representativeness favorable within a participant group. When autistic people are instead engaged as research co-producers, however, there may be a tendency to erroneously apply these same expectations of diversity and representativeness. This is despite the striking lack of diversity evident among researchers—in our participant group, for example, a considerable majority of academic participants were white women. In our data, a focus on diversity was notably absent. Instead, many of our participants emphasized the importance of making research involvement accessible for community members, describing a range of different strategies that their research teams had implemented to facilitate the engagement of stakeholders with varying skills and expertise relevant to the particular research project. This finding signals an important distinction in how our participants approached the issue of diversity. Rather than implicitly placing the onus on the autistic and autism communities to make available a diverse range of representatives, this framing suggests that academics hold responsibility for providing a research environment that is accessible and welcoming to a range of collaborators (see Cascio et al., 2020 and Gowen et al., 2019, for discussion). The development of strong, trusting relationships between researchers and autistic community members should help to ensure that the accessibility needs of all team members are met.

Barriers to access, though, extend beyond the sensory processing differences, executive functioning difficulties, and other accessibility considerations discussed by our participants. In the autism field, the substance of research itself can serve as a considerable barrier to engagement by autistic people. Our participants spoke of autism research as being stigmatizing, irrelevant, alienating, and even harmful to autistic people. In writing about their experience as an autistic academic and activist, Botha (2021) describes regularly encountering dehumanizing, objectifying, and violent content and attitudes. Other autistic academics (Yergeau, 2013; Raymaker, 2019; Dwyer et al., 2021) have similarly described how the harmful and ableist nature of autism research has detrimentally impacted their experiences of academia, an experience that the first author of this manuscript shares. The autism research field is permeated by systemic violence against autistic people, ranging from ableist language (Bottema-Beutel et al., 2021) to efforts to prevent autism (e.g., Qiu et al., 2022). As oppressive as this is, autistic academics have the benefit of familiarity with the academic system, allowing us to engage with such content and attitudes from a position of relative privilege. For lay autistic people, engaging with such accounts may prove even more confronting. It is vital, therefore, that academics support their lay collaborators to safely engage with research and minimize exposure to offensive content, while at the same time working to enact systemic change to ensure that autism research can be safely accessed by all stakeholders.

Why was participatory research practiced and experienced in these ways?

Within the academic setting, there exists an inherent power imbalance between researchers—who are typically highly educated, familiar with academic systems and structures, and perceived as "experts"—and lay community members, who may have few or none of these attributes. Also, community members in participatory research are often members of minority groups with little social power (e.g., Nicolaidis and Raymaker, 2015; McFarlane et al., 2022), an added complexity that may serve to exacerbate the power imbalance. One key aspect of participatory research is an epistemological shift—the ability to change the way we perceive community members and see them as experiential experts and equals, rather than as research participants or otherwise subordinate (Cargo and Mercer, 2008; Ocloo and Matthews, 2016).

Several of our themes and subthemes highlight the persistence of conventional perceptions regarding academics, academic systems, and the respective roles that researchers and community members can and should play within the research process; perceptions that are largely incompatible with meaningful community engagement. Participants across various stakeholder groups described the academic context, and academics themselves, as "out-of-touch" with the community. Participants described the priorities of the academic system as being disconnected from community priorities, and even as hindering efforts to ensure research has real-world applications. This finding mirrors closely the experiences of community members in Pellicano et al.'s (2014) study, who described research—and researchers—as "isolated" and "detached" (Pellicano et al., 2014, p. 9) from the practical issues faced by the autism community. This enduring perception of academia as an "ivory tower," reported by both researchers and community members, is likely to reinforce existing power structures and serve as a barrier to meaningful community engagement in research.

Encouragingly, our participants often problematized the academic system, recognizing the limitations the "ivory tower" imposed. Even so, participants tended to accept current academic processes—including rigid protocols and tight constraints on time and funding—as inexorable and even necessary elements of the research process. Rather than highlighting the need for systemic change, participants spoke of adjusting participatory research processes to "fit" within the confines of academia, in some cases even suggesting that community members must also conform to these rigid academic standards if they are to contribute to knowledge production.

While participants expressed frustration with the academic orthodoxy, this orthodoxy was nonetheless evident in the roles that different stakeholders played within research processes. Some participants spoke candidly about the power imbalances that existed within their research teams and acknowledged these as inconsistent with best practices for participatory research. Lay community members' roles were, at best, described as valuable but peripheral to the core research team; and, at worst, as disingenuous and tokenistic. Given this finding, it is evident that there remains a perception of community members—particularly autistic people, who have historically been limited to the role of participants in research—as less-than-equal contributors to research.

The establishment of strong working relationships between stakeholders is key in mitigating power imbalances. Current perceptions of community members may hinder the development of these relationships. Academics may be less motivated to build relationships with stakeholders who they perceive as being subordinate or ancillary to a research team, and reluctant to place trust in these stakeholders. Similarly, community members may have difficulty relating to and trusting "out-of-touch" academics, who they perceive as having limited understanding of the reality of lived experience. This may be particularly true for autistic community members, who have—as our participants noted—good reason to be wary of placing their trust in researchers. While these dynamics persist, participatory autism research teams will likely struggle to establish effective strategies for mitigating power imbalances. As a result, efforts to achieve genuine co-production of research may be hampered.

It is worth noting that several of our participants described research projects in which the only community members involved were autistic people employed as Research Assistants. Though participants typically perceived the employment of these Research Assistants as constituting community engagement, their descriptions suggested that these individuals' roles might be more accurately framed as that of insider-researchers; that is, research staff (or students) who share an identity with the researched. Insider-researchers can bring considerable value to participatory research teams, occupying a "middle-ground" with access to both community and academic experiences, knowledge, and resources (Muhammad et al., 2015). There are, though, at least some aspects of a community member's role that an insider-researcher will not typically be well-placed to undertake—for example, making judgements regarding accessibility for lay participants. Additionally, and crucially, a Research Assistant's role ordinarily exists within a hierarchical academic team, with team members working under the supervision of a (most often non-autistic) Principal Investigator. Such a hierarchy inherently dictates the distribution of decision-making power and control within the academic team, with Research Assistants typically afforded relatively little of this power; equitable power sharing between the academy and the community is likely unachievable in these circumstances. It is vital, then, that participatory research teams do not rely solely on the expertise of insider-researchers, but include lay community members as equal partners in the research process.

How might we improve participatory autism research going forward?

Consistent with previous research (Pickard et al., 2022), our participants described the autism research field as being in the midst of a broad shift in terms of attitudes toward autism and autistic people, with increasing recognition of autistic people as key stakeholders in the production of knowledge about autism. Although they often found participatory research challenging in practice, participants invariably expressed positive attitudes regarding community engagement in autism research. This context of attitudinal change toward autistic people and widespread support for community engagement provides a rich opportunity to advance participatory autism research.

To move toward a more participatory future in autism research, it is important also to recognize the historical and ongoing epistemic injustice practiced against autistic people. Broadly, epistemic injustice refers to a range of injustices carried out against a person in their capacity as a knower or a producer of knowledge; see Catala et al. (2021) for a detailed discussion of the many types of epistemic injustice autistic people face. In short, autistic people face both testimonial injustice, in which biases against autistic people serve to diminish their credibility as epistemic agents; and hermeneutical injustice, in which the epistemic resources (e.g., concepts and language) necessary for autistic people to understand and articulate their experiences are lacking (Fricker, 2007; Catala et al., 2021; Dinishak, 2021). Addressing this epistemic injustice is both a necessary precondition for, and a likely result of, effective participatory autism research. Autistic people must be recognized as credible producers of knowledge if they are to contribute to participatory research; that is, testimonial injustice must be addressed. At the same time, autism research produced by and/or with autistic people will likely be better placed to produce the epistemic resources needed to overcome hermeneutical injustice. This is evidenced by, for example, Milton's Double Empathy Problem (Milton, 2012), and recent co-produced and autistic-led work on autistic burnout (Raymaker et al., 2020; Higgins et al., 2021) and autistic inertia (Buckle et al., 2021; Phung et al., 2021), all of which have introduced to the academic literature new epistemic resources for understanding autistic experiences.

As discussed above, our participants predominantly adopted a consultative approach to community engagement in research. While this approach lacks the power-sharing that is central to more genuinely participatory work, it can nonetheless serve as a key foundational step in establishing an equitable co-production partnership. Consultation between academics and community members can provide a valuable opportunity to establish working relationships and identify shared values and interests. To move beyond consultation, it will be critical to build upon these incipient relationships, working over time to establish effective communication and mutual trust.

As our participants explained, effective participatory research must be "set up for success," with community engagement intentionally established as core to the research from the earliest stages of a project. We suggest that, to be most beneficial, community engagement can be established even earlier. Rather than approaching community engagement as subsumed within a particular research project, we encourage researchers to consider community engagement as an independent—but equally important—process. Ideally, stakeholders could first work to establish trusting relationships, open communication, and processes for power-sharing, before collaboratively identifying research topics of mutual interest and beginning the process of research co-production. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) is an example of a long-term participatory partnership that has successfully followed this approach (Nicolaidis et al., 2011, 2019).

Establishing and maintaining participatory partnerships of this type can require considerable resourcing. As our participants observed, existing academic systems are often designed to facilitate conventional research processes, and lack the flexibility to accommodate participatory research. To foster meaningful community engagement in research, then, change is needed at the systemic level. Our participants noted three elements of current academic systems that serve as barriers to participatory research: academic protocols and rules; time pressures; and funding constraints. We suggest that two overarching changes within academic systems are necessary to mitigate these barriers. First, greater flexibility and responsivity within the academy, allowing for the tailoring of protocols, timelines, and budgets to better accommodate a range of research processes and stakeholders. Second, cultural change, promoting greater recognition of the value of community engagement in research, and ensuring that the additional labor inherent in such work is acknowledged and rewarded.

Limitations

While this study provides valuable insights into stakeholders' experiences of community engagement in Australian autism research, these findings must be considered in the context of the study's limitations. First, participation in this study was open to any stakeholder involved in producing Autism CRC-funded research, regardless of their level of experience with participatory research. It is therefore possible that our participants were motivated to take part due to a particular interest in the topic of participatory research, which may be reflected in our findings. As a result, the extent and nature of the challenges identified herein may well be an *underestimate* of those experienced in autism research more broadly.

Second, although we did not specifically recruit participants for their participatory research experience, we asked each participant to identify and describe a participatory autism research project in which they had been involved. While every participant was able to identify and discuss a project they perceived as participatory, some participants noted that they felt their projects were not "good" examples of participatory research, and others described projects with minimal or no community engagement in the research process. Consistent with our previous work (den Houting et al., 2021), participants in this study had varied understandings of what constitutes participatory research, which did not always align with accepted definitions. As a result, the findings presented here describe participants' experiences of research that they perceived as participatory, some of which appeared to lack meaningful community engagement.

Third, our recruitment process relied on Autism CRC Project Leaders to nominate members of their project team/s as

potential participants. To encourage the nomination of a range of different stakeholders, we specified that project teams may comprise both academic and community members, in paid or unpaid roles, including advisors and consultants. Despite such encouragement, most nominated participants were academics (see den Houting et al., 2021). Only two of the current participants held exclusively non-academic roles in the autism community (02-A, an autistic person; and 10-F, a family member/career); the remaining 18 participants all held academic roles, either exclusively or in addition to non-academic roles. As a result, our findings provide only limited insight into lay community members' experiences of participatory autism research. In addition, most participants were women, white, highly educated, and engaged in full-time employment or study. Given that previous findings indicate considerable disparity between academic and community experiences of autism research (Pellicano et al., 2014), future studies should make additional efforts to ensure that the perspectives of non-academic community members, particularly those from marginalized communities, are represented.

Conclusion

The findings presented here paint a picture of a field in flux, facing a shift from the "normal science" (Pellicano and den Houting, 2022) of the ivory tower to a more inclusive, real-world paradigm with community members valued as key agents in knowledge production. It is clear, though, that much remains to be done if the field of autism research is to achieve epistemic justice for all stakeholders. At an individual level, we must continue working to forge meaningful, sustainable academic–community partnerships to facilitate the power-sharing that is key to genuine research co-production. At a systemic level, considerable change is needed to eliminate the barriers that hinder community engagement in research. By moving forward with such changes, we may indeed find that participatory research is "the way of the future."

Data availability statement

The datasets presented in this article are not readily available because the data reported in this study are qualitative interview data. The raw data include details that could identify participants. Participants did not consent to sharing of identifiable data beyond the current research team. Requests to access the datasets should be directed to jac.denhouting@mq.edu.au.

Ethics statement

This study received ethical approval from Macquarie University Human Research Ethics Committee (Project ID 3300). Written informed consent was obtained from all participants for their participation in this study.

Author contributions

JH, KI, and JM contributed to the conception and design of the study. EP contributed to the conception, design, and data analysis. JdH contributed to the conception and design, conducted all interviews, led data analysis, and wrote the first draft of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.876990/full#supplementary-material

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