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BRIEF REPORTS

Empowering Voices: Fostering Reflective Dialogue and Redefining Research Dynamics in Participatory Approaches With the Autistic Community

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Within this brief report, the authors, who are mostly neurodivergent and a majority autistic, outline some of the challenges and historical failings of participatory research with the autistic community. There is an urgent need to explore creative ways to ensure that research engages with autistic people in an active, meaningful, and valuable way (Den Houting et al., 2021; Fletcher-Watson et al., 2019; Garfield & Yudell, 2019). The authors detail the process of using reflective dialogue to explore the participatory research group's personal experiences of mental health at a university. The participatory group later presented their experiences at a webinar attended by more than 200 strategic and supporting staff from UK universities. The group found reflective dialogue to be useful in addressing many of the failings of participatory research with the autistic community, such as redressing power imbalances and finding it to be personally beneficial and validating. The authors detail how this might be implemented and argue that this approach has valuable applications within autism research and beyond and should be explored further.

Background to Participatory Research with the Autistic Community

The autistic community has historically lacked representation in participatory research, compared to learning disability and healthcare communities (Den Houting et al., 2021; Fletcher-Watson et al., 2019) and other scientific areas outside of autism (Pellicano et al., 2022). Concerningly, studies show that even when researchers employ participatory methods to research autistic people's views and experiences, family members or professionals are usually participants rather than the autistic individual (Roche et al., 2021). A systematic review of research considering a participatory framework with the autistic community reported engagement involved principally family members or professionals, with only 9% involving autistic people (Roche et al., 2021).

Clear attempts are being made to increase participatory research with the autistic community. However, there are methodological issues. When participatory approaches are used, they often lack the meaningful involvement of autistic people (Den Houting et al., 2021; Fletcher-Watson et al., 2019). A meaningful approach to measuring participation utilizes Arnstein's Ladder of Participation (Arnstein, 1969). This model is relevant here as it measures participation in relation to decision-making power, a privilege historically shown to be lacking in research in the autistic community (Fletcher-Watson et al., 2019). The eight-rung ladder has had significant influence across many disciplines in providing a tool to measure and categorize citizen participation (Gaber, 2020) and allows practitioners and researchers to measure the level of a group's participation, moving up the ladder with greater involvement. Participation is split into three domains, with manipulation at the bottom, tokenism in the middle, and citizen power at the top. The top domain is what participatory approaches should aspire to reach. Participatory research with the autistic community often sits in the lower half of the Participatory Ladder and is tokenistic at best (Fletcher-Watson et al., 2019). Den Houting et al. (2021) reconceptualize the ladder for application within academic settings, renaming the three domains "doing to" at the bottom, "doing for" in the middle, and "doing with" at the top. The top of the ladder shows increasing community power while increasing academic power is a feature of participatory approaches at the bottom of the ladder.

This lack of representation is surprising given the rise in autism diagnoses and the growing strength of the autism community. The autistic community has expressed its wish to be involved in research and that "their views are typically misrepresented, misinterpreted and misused by the wider community, especially neurotypical researchers" (Haas et al., 2016, p. 1803). Botha and Cage (2022) argue that the very concept of autism has been created and researched by neurotypical researchers and is often dehumanizing, objectifying, and alienating. There is a growing number of researchers adopting neuroaffirmative approaches that embrace and support neurodiversity, and some autistic researchers are reclaiming the space (for example, Cullingham et al., 2023). However, autism researchers within the Psychology field have typically been trained in Eurocentric approaches to ensure that Psychology is both empiricist and objective (Botha, 2021). Participatory research is often not considered to have the necessary scientific rigor. It is also argued that autism research is deficit-focused (Pellicano & den Houting, 2022) and ableist, which has led to the development of stigmatizing autism discourses (Bottema-Beutel et al., 2023).

Lack of participation in autism research is thought to stem from a misconception that the autistic community does not want to be or cannot be meaningfully involved in research (D. Milton & Bracher, 2013), as explained by Bertilsdotter Rosqvist et al. (2023), "The problem is that individual accounts are not recognized as stories about autism because individual autistics are either 'too autistic' to be heard or 'not autistic enough' to have anything to tell" (p. 1236). Researchers often base this misconception on key challenges for autistic people such as difficulties with social and communication skills, sensory needs, and mental health challenges (MacLeod et al., 2014) or due to an assumption that autistic people may find it hard to understand others (Greathead et al., 2016). However, Milton (2012), in his theory of the Double Empathy problem, argues that this misunderstanding is bi-directional and that differences in the norms and realities of autistic and neurotypical people may create barriers to effective research collaboration. The cause is likely to be multi-dimensional but there is a consensus that this lack of participation has resulted in services for autistic people being developed around neurotypical perceptions of what they need, rather than what they *actually* need (Rudd & Hwang, 2021). Ultimately, this leads to a misalignment of support and needs, creating wider gaps.

Background to Autistic Student Mental Health

The need to improve the quality of participatory research was imperative when planning a project to examine the mental health experiences of autistic undergraduate university students. The mental health of the wider university student population has attracted worthy attention due to increased numbers of students reporting mental health issues in recent years (Office for students, 2023). Research demonstrates the increased prevalence of mental health issues within the autistic community (Lever & Geurts, 2016) and growing numbers of autistic students are going to university (Office for students, 2023; Taylor & Seltzer, 2010). Autistic students are one of the most at-risk groups for experiencing mental health difficulties at university (Campbell et al., 2022) and bespoke approaches are needed to address the mental health of autistic students as the risks and triggers may be unique for this community (Cassidy et al., 2018; Purkis et al., 2016). According to Rauchberg (2022), medicine and psychiatry have a long tradition of enforcing “aspects of cure and rehabilitation, reinstating centuries of the medical and psychiatric-industrial complex’s violence and harm against disabled people” (p. 371). Mental health support services traditionally exert power over autistic people, viewing them as a problem to solve through medication or therapy, and providing privileges to neurotypical people (Rauchberg, 2022, p. 379). For example, Williams and Gilbert (2020) highlight the hyperfixation of research attempting to “fix” perceived social deficits in autistic people, ignoring the discrimination that autistic people typically face in society, such as that described within Milton’s (2012) Double Empathy Problem. Rauchberg (2022) argues that instead of “searching for a cure, we should ensure that the lived experience of the neuroqueer community, defined as anyone from a neurodivergent community who disidentifies with the concept of heteronormativity or neurotypicality, are firmly rooted within the research process.”

Therefore, adopting PAR approaches is essential in informing sensitive, bespoke support that meets the needs of autistic students. However, this area has been under-researched with few projects adopting participatory methods. To follow Rudd and Hwang’s (2021) assertion around autistic services being designed following neurotypical perceptions of what they need, this is likely to result in university approaches to mental health for autistic students being based on what works for neurotypical students, despite research suggesting the need for bespoke approaches as outlined above (Cassidy et al., 2018; Purkis et al., 2016). Gunin et al. (2021) call for research in this area to take a participatory approach to address these challenges.

Addressing the Power Imbalances and Lack of Participation of the Autistic Community through Reflective Dialogue

To address this lack of representation in participatory research, it is of utmost importance that researchers adopt novel ways to engage with the autistic community at all stages of the research process (Den Houting et al., 2021; Garfield & Yudell, 2019). This involves a cultural shift, moving away from the perception of autistic people as subjects to fulfilling the role of active co-researchers, playing an equal and meaningful role within the research process (Fletcher-Watson et al., 2019). Appropriate methods and strategies should be adopted and researchers should look for creative ways to turn traditional notions of research on its head. "... our methods should support, not undermine, our overall aims of empowerment and social justice" (Foster-Fishman et al., 2005, p. 275).

Within participatory research, power imbalances between the researcher and the "researched" are well documented and important to address (Fletcher-Watson et al., 2019) with traditional approaches deeming the researcher as a person of knowledge and the researched as subjects (Doyle & Timonen, 2010). Researchers argue that addressing this power imbalance requires skills beyond those needed within traditional research (Dewar, 2005; Stoeker, 1999; Tetley & Hanson, 2000). May (2024) argues that principles from critical pedagogy — namely the work of Paulo Friere — can be usefully applied to participatory action research. Critical pedagogy is an educational approach that aims to cultivate critical thinking, empowerment, and social transformation and addresses power structures and inequalities through dialogue, inquiry, and reflection. Freire emphasized the importance of dialogue as a transformative tool for education, social change, and research and emphasized the importance of "praxis," which involves a cyclical process of reflection and action and can be usefully applied in participatory action research with disabled people to ensure that participants can reflect on their lived experience and change their realities (May, 2024). The use of dialogue has been highlighted as an appropriate method to redress power imbalances within social science disciplines (Kindon et al., 2007), but to the authors' knowledge, has not been explored within the autism field. Autistic narratives are often re-interpreted by neurotypicals (Bertilsdotter Rosqvist et al., 2023) and this method challenges traditional qualitative approaches where the researcher decides on questions to ask the "subjects" and then interprets the data by categorizing themes. Kindon et al. (2007) argue that the use of dialogue has the advantage of shared learning, knowledge, and flexibility and allows the researcher to relinquish control and take on a facilitation role.

The Process of Using Reflective Dialogue to Elicit the Experiences of Autistic University Students

In this PhD project, a participatory group of autistic students and recent graduates (PAR group) was established to ensure the research was informed and led by autistic students' experiences, that it was accessible and met the needs of the autistic population. The lead author was keen to explore new and creative ways at all stages of the research process to address some of the common challenges associated with participatory research. It was also important for the research to be true to the principles of participatory action research (Kemmis et al., 2014), which builds on and furthers participatory research where autistic people simply co-create the research process but is likely to restrict participation to not achieving full community power when applying Den Houting et al.'s (2021) reconceptualization of Arnstein's ladder. Participatory action research involves learning and stimulating transformations (May, 2024). Therefore, after identifying and discussing the mental health experiences faced by PAR group members, it was important for findings to be disseminated and lead to behavioral and/or strategic transformation. This approach gives power to the PAR group members to stimulate change in how universities respond to mental health for autistic students, providing opportunities for "doing with" (Den Houting et al., 2021) and increasing community power.

With that in mind, the authors (which included seven members of the participatory group and the PhD researcher) planned a webinar. The webinar, which took place in June 2023, aimed to inform more than 200 attendee practitioners, strategic leaders, and teaching staff within UK universities of the experiences of autistic students and to explore the support and strategies that help in addressing these unique challenges. Additionally, it aimed to provide an update of preliminary results of a Qualtrics survey as part of the wider PhD research. A smaller second webinar took place shortly after, aimed at an audience of autistic participants who gave their views and experiences of mental health at university in an online survey. This webinar focused on the discussion of support and strategies that members of the participatory group found useful throughout university to promote mental well-being.

To identify the key issues and mental health experiences of the participatory group to present at the webinars, a collaborative, reflective dialogue approach was adopted (Kindon et al., 2007). Reflective dialogue is an iterative process and often involves multiple rounds of conversation, allowing for deeper exploration and refinement of ideas over time. Over a four-month period, five meetings leading up to the webinars were held via Teams. Each meeting lasted approximately one hour. The Teams platform was found to be the most preferable and accessible way to meet, given the different geographical locations of members. Providing necessary accommodations to optimize full involvement is essential in participatory action research to ensure meaningful participation (Schwartz et al., 2020).

The autistic community is heterogeneous, with considerable variation in strengths, challenges, and needs. It was therefore essential that we practiced "bending towards the [PAR group members] skills set" (Rauchberg, 2022, p. 380) rather than attempting to assimilate them into neurotypical conceptions of how the meetings should progress. Therefore, in the initial PAR group meetings as well as during every contact, individual adjustments such as extra time to process information or the use of captions and recording sessions were discussed and implemented. This ensured members had the opportunity to participate using their chosen means, in addition to providing additional time to process information, as delayed processing is common for autistic people (Pang, 2020). Members were able to switch off cameras/microphones if they felt more comfortable doing this. This approach rejected the tendency to assume spoken word as the optimal form of communication (Rauchberg, 2022) by providing the option to contribute viewpoints via typing into the Teams chat during or after meetings or through email outside of the meetings. Payment for participants has been highlighted as important in addressing power imbalances (Den Houting et al., 2021) as well as ensuring that participants' contributions were valued. Participants were given vouchers for their attendance in pre-meetings, as well as for their time at the webinar.

Reflective dialogue involves conversations between pairs or groups of individuals, enabling them to reflect and offer their perspectives and experiences. Participatory group members could raise any theme or question pertinent to their experiences and open this up to comments and discussion with the wider group. This enables the gathering of valuable insights into experiences, values, situations, and beliefs (Rarieya, 2005), as well as identifying useful support and strategies. As is typical within reflective dialogue, discussions were mutually supportive and collaborative.

PAR group members had previously been involved in coproducing the webinar, so were aware of the aims of the reflective discussions. Initially, members were asked to identify themes that embody their mental health experiences at university and the support they found to be useful. The first theme was generated by a PAR group member who opened discussions with, "It is important for universities to understand the bigger picture for autistic students" (Anonymous). The first theme therefore became "Seeing the bigger picture" and the rest of the group engaged in reflective dialogue around this and subsequent themes, sharing similar or contrasting experiences. Group members were free to direct discussions in any direction they thought relevant, so were organic and fluid in nature. During and after each meeting, the researcher clarified themes with group members. Minutes and a recording of the Teams meeting were available and circulated to the group and members could contribute their experiences through other means such as email, if they preferred or were not in attendance at the meeting.

During reflective discussions, the researcher adopted a facilitation role, probing with open-ended questions to help clarify and deepen responses rather than leading and guiding discussions. When evaluating participation using Den Houting et al.'s (2021) reconceptualization of Arnstein's ladder, the highest level of community power is where "community partners assume control of the research process, and academic partners provide consultation and guidance only" (p.149). Where PAR group members engaged in dialogue but had not identified an overarching theme, the researcher suggested themes based on the frequency of a topic's discussion and opened this to group discussions to check that this was an accurate theme to embody their experiences. Some themes identified throughout the meetings were amalgamated into one — for example, the additional theme "a range of learning options" was originally identified, but sat within the wider theme of reasonable adjustments, so was discussed with the group and agreed to combine. In the final meeting before the webinar, ten themes were discussed, clarified, finalized, and used as a structure for discussions to present at the webinar. The webinar was recorded and transcribed, and the researcher then circulated a transcript of all discussions and themes to group members. Group members, along with the researcher, were then involved in editing their own dialogue and deciding on the relevant parts to include within a journal article. This counteracts the research tradition of "extracting data from participants with otherwise limited engagement" (May, 2024, p. 14). The researcher and PAR group members discussed roles to take in composing the article. Drafts were then uploaded to a shared drive so all members could access, comment, edit, and review. Flexibility in this process meant that members contributed according to their perceived skills, areas of interest, and the time that they had available.

Participatory Group Members' Experiences of Participation

In addition to ensuring that our methods promote the full and meaningful participation of the autistic community, it is of paramount importance to consider the effects of the methods we use on the people who participate (Foster-Fishman et al., 2005). Our means of collecting data should be empowering (Rappaport, 1990). The use of active reflection can be beneficial and empowering for participants (Foster-Fishman et al., 2005; Keiffer, 1984). This was reflected by a participatory group member who commented:

> The participatory research has been excellent to be a part of. Being part of the research group has allowed my thoughts and opinions to be heard from within the group and the wider audience that we have presented to at webinars. (Max)

Participants reported that the sessions were supportive and validating and enabled them to make sense of their mental health experiences and share what works for them:

> I found the reflective discussions very useful in various ways. For example, sometimes it is difficult to verbalize or even recognize some of the experiences we have.

> For a number of reasons, it can be very confusing to understand what it is we feel or whether what is happening is okay or not.
>
> ... Reflective discussions help explore mental health, understand the experience, talk about it, share it, and ask for support.
>
> It is also comforting sometimes to know that you are not alone, others have similar experiences at times. To learn about how others cope with it or what solutions they have developed. (Anita)

Another member found reflective discussion to be a useful tool in promoting self understanding

> Being within the group has also highlighted new symptoms of autism that have resonated with me and allowed me to understand myself more than I previously had. (Max)

Along with the personal benefits of self understanding, empowerment, and feeling heard, Max also mentioned the benefits of presenting the issues at webinars to motivate community action, an essential feature of participatory action research (May, 2024). This is presented as an advantage, in addition to facilitating communication, relationships, shared knowledge, and awareness by Foster-Fishman et al. (2005).

To maximize the benefits of this approach, it is important to foster a safe and supportive environment where participatory group members feel happy to share, which has previously been found challenging (Foster-Fishman et al., 2005). Participatory group members and the lead researcher had met on several occasions previous to these discussions and established a relationship, which helped in fostering a trusting, safe, non-judgemental, and supportive environment, along with the implementation of individual adjustments (discussed above).

Reflection

Reflective dialogue, therefore, has the potential to facilitate a cultural shift within autism research by turning the traditional process of research on its head and ensuring that research is led by autistic people who identify the themes first, rather than the researcher deciding this after data analysis. This approach addresses power imbalances that are often inherent and deeply embedded within the research process. It also addresses some of the barriers that occur when research is led by neurotypical researchers, such as the reinterpretation of autistic voices (Bertilsdotter Rosqvist et al., 2023) or the Double Empathy problem, described by Milton (2012). As autistic people decide on themes meaningful to them and engage in group discussions, this method addresses potential misunderstandings or misrepresentations evident within other traditional qualitative research methods such as during interviews or focus groups. The tendency to interpret autism and autistic people according to deeply ingrained notions of normality and ableism can influence research results and lead to confirmation bias (Bottema-Beutel et al., 2023). This method ensures that experiences are described and interpreted through an autistic lens rather than interpreting using ableist or societal notions of "normality," thus eliminating researchers' confirmation bias. Reflective dialogue also proved to be a useful method in addressing some of the challenges that information processing delay may present with other data collection methods because participants could read transcripts and add to the data collected over a four-month period. Furthermore, and crucially, reflective discussions can be validating and useful for the autistic people who participate, an issue we must consider when collecting data. Finally, the research tradition of "extracting data from participants with otherwise limited engagement" (May, 2024, p. 14), can be counteracted through participants sharing results and co-authoring reports or journals (May, 2024) as was the case within this project.

Using Arnstein's ladder of participation or Den Houting's reconceptualization for academic settings as an assessment tool, reflective dialogue has the power to propel participatory research with the autistic community from merely increased academic power, as previously found to be common in research with the autistic community (Fletcher-Watson et al., 2019), to the aspirational community power and "doing with" (Den Houting, 2021) or citizen power (Arnstein, 1969).

Conclusion

Although this paper has focused specifically on the use of reflective dialogue with the autistic community, this method could also prove to be a useful tool with communities that have traditionally been excluded from research and/or when they have been included.

When researching autistic students' mental health, it is imperative that autistic students are involved throughout the research process so that services and support are shaped and led by their actual needs, rather than by neurotypical and ableist assumptions of what is assumed to be needed. As outlined above, research that is led by autistic people into the effectiveness of mental health support is essential, with a focus on the environment or interventions to meet the needs of autistic students rather than fixating on ways to cure or modify autistic people and their behavior. The future of autism research should without doubt adopt neuroaffirmative, participatory approaches and there is an urgent need for time and resources to be invested into higher quality participatory research expanding the use of appropriate methodologies, such as reflective dialogue. This could address neurotypical researchers' ableist and historical trends in excluding the very people who hold the key to us learning about the experiences and realities of being autistic.

This PhD project continues to engage with the PAR group to develop creative ways to collect qualitative and quantitative longitudinal data to ensure that autistic students' experiences inform and shape PhD research into the mental health experiences of autistic university students. For example, PAR group members recently developed research questions based on the themes derived from a Qualtrics survey through a shared Padlet, online platform, where they were able to contribute in their own time. We plan to continue publishing our findings as well as further innovative and creative developments which will offer opportunities for meaningful participation of autistic people in research and service planning.

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