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Researching Autism as a Non-autistic person: A reflection

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Keywords: *Autism, participatory research methods, barriers*

When I started my PhD in 2021, I felt confident that the aims and approach of my research reflected my desire to make a positive contribution to our understanding of autism. However, I was not aware of *participatory research methods*, and subsequently did not include this in my research practice. Participatory research involves collaborating with community members throughout the research process, and therefore recognises the value of lived experiences (e.g., Macaulay, 2017). In the case of autism research, this means giving autistic individuals an active role in shaping the research aims and methodology, interpretation of results, and dissemination of findings. This therefore ensures that research is respectful, accessible and socially relevant (Raymaker & Nicolaidis, 2013).

When looking back, I recognised that my approach only included autistic people as passive study participants. This was an uncomfortable realisation for me, which felt entirely at odds with my intentions. Anyone can apply core aspects of their identity to recognise the value of participatory research methods. I was recently provided with a powerful analogy. That is, would I be cautious in accepting findings from a research project investigating “what it is like to be a woman” if the research team was exclusively male? Would I not feel that they cannot truly *know* what it is like to identify as female, and as such, their interpretation of results might be skewed by bias or a lack of lived experience? The answer – of course – is yes.

Understanding Participatory Research

Over the last few years, I have attended several institutional and conference-based workshops which have promoted the value of participatory research methods. Key messages from these events included that, firstly, the people who are affected by research should get to have a say in it. This is the case when identifying the most important topics, constructing the aims of the research, and tailoring the methodology to the specific needs of the group. Community members can also provide a unique perspective – different to those in

academia. This can be on a small scale, such as advising on which language choices might be confusing or harmful. Alternatively, they can work within a much broader scope, such as aiding in the interpretation of results by contextualising research findings within their subjective experiences.

I have also sought out resources which have expanded my knowledge of implementing this in practice. In particular, the report published by Fletcher-Watson et al. (2019) following the *Shaping Autism Research* seminar series outlines a helpful framework for participatory autism research which was co-produced by autistic and non-autistic individuals with academic, clinical, and lived expertise. Similarly, the AASPIRE guidelines for including autistic people as co-researchers can also be used to inform best-practice (Nicolaidis et al., 2019).

Lessons that I have learnt from these resources include the significance of being transparent about the goals of community collaborations, as well as clearly defining their role in the research process (Nicolaidis et al., 2019). Having structured decision-making processes can also facilitate effective communication and power-sharing between individuals with a wide range of needs (Nicolaidis et al., 2019). In future projects, I will aim to outline key elements of collaborative meetings in advance, including the formality, frequency, method (e.g., online or in-person) and level of preparation needed. Furthermore, individuals will be able to engage via a range of methods, and information will be provided in a variety of mediums (e.g., written, video, Q&A sessions), to maximise accessibility.

Importantly, the theme of *respect* is central to participatory research. This includes ensuring that autistic community members feel that their voices are being heard, and that their opinions are being taken seriously (Fletcher-Watson et al., 2019). In my future work, I would like to implement participatory research methods from the outset – before a grant application is written – to create a fully co-designed project which is driven and informed by the autistic community. However, this may be difficult to achieve before securing funding as Nicolaidis et al. (2019) also suggest that fairly compensating autistic people for their contributions is an essential way of demonstrating respect – thereby explicitly recognising the value of their expertise. Going forward, I will also need to navigate the administrative challenges of paying contributors, including being able to flexibly offer a variety of payment options.

Tokenism

A key issue associated with participatory research is the inherent power imbalance that exists between researchers and community members. As such, building a sense of trust, and establishing shared goals, is essential for facilitating authentic relationships which empower autistic individuals (Fletcher-Watson et al., 2019; Nicolaidis et al., 2019).

My concern is how to ensure that collaboration with community members is not perceived as tokenistic – merely a ‘tick-box’ exercise to secure funding or ethical approval. Fletcher-Watson et al. (2019) suggest that establishing an open dialogue with community representatives, which is not constrained by a specific research agenda, is a good starting point. In my future work, I will aim to spend time with autistic people – meeting them in their safe, community spaces – in order to learn from their experiences. This will create a foundation for research which is truly shaped by the autistic community.

Furthermore, the use of research passports will also facilitate relationship-building in my future work. Here, each member of the team (researchers and community members) can complete a document which includes personal information, such as their likes and dislikes, their chosen methods of communication and self-regulation, and what their typical week might involve. Asking all project collaborators to complete this form will create equality within the team, thereby redressing any perceived power imbalance. By outlining the preferences and expertise of each community member, research passports can also be used to shape all interactions to the specific needs of the individual.

Diverging Stakeholder Opinions & Child Participants

As a developmental psychologist, I believe that there are unique barriers to conducting participatory research with autistic *children*. These include addressing the conflicting views or priorities of different groups (children, their parents, teachers, and organisations), and the practical considerations associated with eliciting opinions from children.

Due to the heterogeneity of autistic experiences, and the range of perspectives from stakeholders within the broader autistic community, I fear that it might be challenging to manage disagreements between and within groups. However, it is also important to remember that the goal of consultation with community members is not to force a consensus, but rather to gain a balanced understanding of all perspectives (Fletcher-Watson et al., 2019). This means that we need to ensure that groups who are often overlooked in autism research, such as those who are minimally-speaking or have intellectual disabilities, are also involved in these discussions. As such, it is important to be mindful of the cognitive and communication demands of participation which may act as a barrier to inclusion.

Furthermore, the principles of participatory methods should also be applied to research with *children*, alongside careful consideration of how to effectively elicit their opinions or feedback (Kleine, Pearson, & Poveda, 2016). Visual methods, which often have low linguistic requirements, can facilitate joint knowledge production between children and adults (Kleine, et al., 2016). Other strategies, such as photo-elicitation or card-sort tasks,

have also been found to be effective tools for understanding the subjective experiences of autistic children (Lewis, Hamilton, & Vincent, 2023). In the future, I will therefore employ creative methods to capture the perspectives of autistic children, such as through art, storytelling, or photography.

Going Forward

Reflecting on this topic has empowered me to recognise my role as an ally and advocate for the autism community. In my future work, I intend to include autistic voices and expertise at each stage of the research process. Overall, my goal is to champion the role of participatory methods in formulating and conducting studies *with* autistic people, not *on* them, and therefore producing research where we learn *from* autistic people, not *for* them.

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