

**Exploring views on future directions of research involving nonbinary autistic people
through lived experience**
Charlotte Brooks
University of Birmingham
Master's Dissertation

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Abstract

This study aimed to capture what nonbinary autistic people think about research that involves them and how this relates to their experiences. Research questions considered views of current research, what future research should focus on and how views are informed by experiences. Interpretative phenomenological analysis (IPA) was used to analyse transcripts from interviews with 5 NBA individuals through an intersectional lens. Participants valued current research that was important and timely to NBA individuals from diverse backgrounds and focused on ways forward. They thought future research should be led by the community and had ideas about the role of education in facilitating societal change and meeting the needs of NBA people. Views were informed by foundational experiences growing up, conflict throughout their lives and newfound self-discovery and empowerment in their present day. Participants were informed by others' experiences and took an active role in shaping their communities. Further research may utilise the findings of this paper to inform research agendas, community-led research practices and educational programmes for teaching about diversity.

Exploring views on future directions of research involving nonbinary autistic people through lived experience

Autism is often viewed as an impairment relating to social, cognitive and perceptual deficits. However, the neurodiversity paradigm views autism as a neurodevelopmental difference characterised by differences in sensory experiences, communication, thinking, socializing and moving (Autistic Self Advocacy Network, 2020). In this paradigm a diversity of minds are considered as natural and valuable as other forms of human diversity (Walker, 2021). Historically, non-autistic professionals have been considered experts on autistic people. Non-autistic researchers have, therefore, led the dialogue of what autism is and what autism research should address (Catala, Faucher and Poirier, 2021). Members of the disability rights movement have highlighted this issue and argued disabled people should be authorities on issues that affect them – ‘*nothing about us, without us*’ (Charlton, 1998). This has implications for research and indicates autistic people should be involved at all stages in autism research.

The research process usually starts with a problem, issue or idea that guides a project. The autistic community should, therefore, be included in decisions on what autism research should focus upon, especially as studies have shown autistic adults may have different views on what issues are important compared to other stakeholder groups (Pellicano, Dinsmore and Charman, 2014; Fletcher-Watson *et al.*, 2019). Past research has looked at the attitudes of autistic people to current research and has sought their views on what research priorities should be. These studies have looked at: autism research in general (Pellicano, Dinsmore and Charman, 2014); early autism research (Fletcher-Watson *et al.*, 2017); sexuality and intimate relationships (Dewinter, Miesen and Holmes, 2020), transition and employment (Nicholas *et al.*, 2017; Shattuck *et al.*, 2018); and mental health (Vasa *et al.*, 2018; Benevides *et al.*, 2020).

Many autistic people also identify with having a non-binary gender - 16-17% (Cooper, Smith and Russell, 2018; Sullivan *et al.*, 2021) compared with 2.2% in general populations (Cooper, Smith and Russell, 2018). This means they identify outside, between or across the male-female gender binary. Some non-binary people also identify as being transgender, which refers to people who identify with a gender other than the one they were assigned at birth. Thus far, the views of the nonbinary autistic (NBA) population have largely been overlooked, with most studies, including those listed above, involving only male and female participants. Although non-binary identities have existed across the world throughout human existence (Herdt, 1996), to date there have been very few studies involving NBA people, and even fewer focusing on their unique viewpoints. As such, no studies have looked at the views of NBA people on research that involves them and what they believe should be priorities of research. However, research has identified the need for more research about how intersecting identities are experienced by LGBTQ autistic people more generally (Dewinter, Miesen and Holmes, 2020). Considering intersectional perspectives is important as NBA people may have different research priorities due to having experiences that are not felt by those who are not both nonbinary and autistic. When the priorities of affected communities are not considered, this may have ethical implications: funding may be directed towards projects that are not relevant or useful for the community; studies may inauthentically represent peoples' lives and experiences by not grasping the extent of issues that affect them; and research may further contribute to damaging narratives, such as those that view autism from a purely deficit-based model (Kapp *et al.*, 2013).

The Current Project

The current project seeks to address this gap by considering the following research questions:

RQ1 - What are NBA individuals' views on current research that involves them?

RQ2 - What do NBA individuals think future research involving NBA people should focus on?

RQ3 - How do views on current and future research relate to the lived experiences of NBA individuals?

After a review of the literature on research involving NBA people, the methods employed to address the questions will be outlined.

Literature Review

The literature discussed in this review has been sourced from a systematic review that will contribute to my doctoral thesis. For the review, I followed PRISMA guidelines (Page *et al.*, 2021), but the details of this process will not be reported here in full for the sake of brevity. This narrative review gives an overview, outlining what the literature says about the lives and experiences of NBA people. I reflect on the following research areas: the role of identity, including experiences of having multiple identities; autism acceptance, including relationship experiences, stimming and autistic masking; and experiences accessing healthcare and education services.

A number of studies identified by the systematic review were less helpful in contributing to our knowledge of this population. This is largely because it was not the purpose of these studies to focus on the experiences of NBA people and there were aspects of the research designs that made it not possible to glean insights on this population (see Appendix A for details). In the case of quantitative studies, some did not conduct analyses comparing genders, some combined nonbinary groups with other genders, and some excluded nonbinary groups from statistical analysis. For qualitative studies, this was mainly due to

gender labels not being included alongside data excerpts, making it not possible to identify the contributions of nonbinary participants. This highlights the need for more research focusing on the specific experiences of NBA people, developing ways to recruit representative numbers of NBA people in studies and reporting contextual information alongside qualitative excerpts. Interestingly, a greater number of studies collecting qualitative or mixed data compared with quantitative studies were more helpful at contributing to knowledge of NBA people. This was likely due to the tendency for studies collecting quantitative data to recruit few nonbinary participants and require larger numbers to conduct group analyses. As such, though the systematic search identified similar numbers of qualitative and quantitative studies, a greater number of qualitative and mixed studies are explored below.

Identity

Studies on identity have been largely qualitative, including rich extracts from NBA participants. Research has remarked on experiences of gender, sexuality, being autistic and intersections of these identities. In terms of gender, studies have referred to experiences of participants questioning their gender identity, gender dysphoria, and experiences of gender as fluid and/or changeable. Cooper *et al.* (2021) specifically aimed to understand the gender dysphoria experiences of genderdiverse autistic adults. Although gender dysphoria has historically been associated with binary transgender people, this experience of unease with one's body can also be experienced by nonbinary people (Galupo, Pulice-Farrow and Pehl, 2021). Participants in Cooper *et al.*'s study described physical characteristics that help to affirm their gender, such as broad shoulders, a frustration their body cannot transform back to how it was before puberty, and struggles with having a body that can '*never be exactly in between*' (p. 7). In terms of fluidity, Cain and Velasco (2021) explored the life of a person

who has identified as a cisgender female, as a transgender man and as a transmasculine non-binary person over the course of their life. The participant, Gray, wanted readers of the study to understand how gender identity is fluid and can change. This is also referenced in the studies by Strang et al. (2018, 2021) where genderdiverse autistic adolescents changed their gender identity over the course of the longitudinal studies. The above studies begin to highlight the complexities of gender experiences. Participants in the literature also seemed to suggest their sense of gender identity was made more complex by also being autistic.

Some suggested understanding and conceptualising their gender was made harder by being autistic (Cain and Velasco, 2021; Cooper *et al.*, 2021). A participant in the study by Cooper et al. (2021) related this to their own social difficulties and how gender '*was in the rulebook you do not get*' (p. 7). In contrast, a participant in another study (Hillier *et al.*, 2020) remarked they didn't think being autistic had affected their *understanding* of their gender identity – instead they believed being autistic had affected the very nature of their being nonbinary, and related this to a feeling of being disconnected from their body. They then went on to say that having the right language and terminology to talk about their experiences has helped them in their understanding, which was a sentiment also expressed by another in the same study. Similarly, the participant in Cain and Velasco's (2021) study felt it was important for people to understand the options out there to help them to understand their own experiences. In the literature, this was related to a sense of acceptance about participants' own identities, which was influenced by their experiences with others and in their communities. In addition to identity experiences relating to gender and being autistic, participants also spoke about their sexualities (Hillier *et al.*, 2020; Cain and Velasco, 2021) and their physical (Cain and Velasco, 2021) and mental health (Miller, Rees and Pearson, 2021). This highlights that, although the focus in this review is on NBA experiences, individuals' lives are more complex than this single intersection, and there are many aspects

that influence their identities.

Autism Acceptance

This section includes studies focusing on individuals' relationships and community; their experience of prejudice; the acceptance of autistic characteristics, such as stimming; and autistic masking.

Relationships

In terms of friendships and relationships, participants in the literature talked about struggling to make friends, miscommunication in relationships, difficulty negotiating different aspects of their lives (e.g. friends vs family), and masking as both a barrier and facilitator to friendship.

In Cain and Valasco's (2021) study, their participant spoke about their difficulties making friends and their discontent with being asked to share friends with their brother. They also talked about their experience joining communities who later had a negative impact on their life and experience of their gender. In terms of masking in friendships, a participant in one study wished they'd known how to use 'social coping strategies' sooner so they would have been more accepted by their peers (Hull *et al.*, 2017), whereas a participant in another study (Cook *et al.*, 2021) talked about how masking acted as a barrier to authenticity in their relationships with others.

These experiences with friendships and relationships were similar to autistic participants of other genders, which was reflected in the responses of male and female participants in the same studies. However, NBA participants also spoke about some experiences specific to being nonbinary and autistic. For example, they emphasised both the importance of finding a community of similar, accepting others (Hillier *et al.*, 2020; Cook *et*

al., 2021), and the additional difficulties of finding people who accept different parts of you. As one participant said, in Hillier *et al.*'s study '*if you have multiple identities, then it's very difficult to find people who understand and accept you*' (p. 103). There was also some suggestion in a study looking at the social networks of autistic adults that nonbinary participants had more friends and fewer family members in their social circles, including one participant who had no family members in their sociogram (McGhee Hassrick *et al.*, 2020). These findings highlight the importance of providing opportunities for individuals to connect with each other and recognising where they may have less support from family or friends.

Prejudice

A number of participants in the literature discussed facing prejudice for being autistic and nonbinary. One individual spoke of how others have preconceived notions of autistic people and how they were not treated as an individual if they disclosed their autism diagnosis (Frost, Bailey and Ingersoll, 2019). Another participant spoke about how others in their life denied aspects of their identity, such as being told by an ex-partner they were 'faking' being autistic (Miller, Rees and Pearson, 2021, p. 5). This is similar to the delegitimising experiences reported by other NBA people in the literature, most often in interactions with healthcare professionals (see section on Healthcare and Education).

It is likely NBA people face additional prejudice relating to their multiple identities, as both autistic and nonbinary populations are known to experience hate crime (Bachmann and Gooch, 2017; Chaplin and Mukhopadhyay, 2018). Consistent with this, a participant in one study (Hillier *et al.*, 2020) spoke about being frequently subjected to abuse as a result of being '*a highly visible walking signifier of divergence of the cultural norm*' (p. 104), suggesting they believed they were targeted for being perceived as different. Another participant from the same study spoke about not changing aspects of their appearance to

affirm their gender so they could still conceal that aspect of themselves when in hostile environments. These examples demonstrate some of the hostile treatment NBA people may face and how perpetrators of this hate may focus on traits of NBA people that separate them from cultural norms. One such trait that has faced scrutiny is stimming.

Stimming

Stimming refers to self-stimulatory behaviours autistic and other neurodivergent¹ people use to self-regulate and communicate. Stimming has also been adopted more recently as an aspect of autistic culture (Kapp *et al.*, 2019), bringing people together. Research has begun to look into stimming from the perspective of autistic people. In one study (Kim and Bottema-Beutel, 2019), explored extracts from blogs relating to stimming and the public response to a book about stimming called '*Quiet Hands*'. Extracts from NBA people in the study spoke about facing criticism from family and schools as a child for stimming. They also talked about stimming as a natural expression of their personhood and how reclaiming stimming has been empowering and helped them to embrace their autistic identity. A discussion of stimming is relevant here as encouraging others to stim freely may come from a position of privilege, and it is important to note this may be more dangerous for some groups than others to be visibly autistic (e.g. NBA people, people of colour, those who are disabled in additional ways etc.). This is also the case for the process of 'unmasking', where people try to reverse or stop masking.

Masking

Masking describes behaviours and strategies some autistic people use to suppress

¹ A term to describe those who have a neurocognitive style that diverges from culturally-determined standards and performance of neuronormativity. This includes minority neurotypes, such as autistic and ADHD people (Walker, 2021)

natural responses and adopt new ones (Pearson and Rose, 2021). Autistic nonbinary people have been involved in several studies on masking. In general, individuals have reported similar masking experiences to those of other genders, such as altering their responses and scripting (Hull *et al.*, 2017; Cook *et al.*, 2021). In qualitative studies, participants also spoke about similar negative consequences, such as it being exhausting (Hull *et al.*, 2017; Cook *et al.*, 2021) and related to suicidal behaviour and meltdowns in one individual (Miller, Rees and Pearson, 2021). There is also some suggestion this population may have unique experiences of masking as a result of their multiple identities. For example, a participant in Cooper *et al.*'s (2021) study spoke about concealing characteristics so they are treated by others in a gender-affirming way, whereas another recalled not disclosing their gender identity in unwelcoming spaces (Hillier *et al.*, 2021).

In quantitative studies, one piece of research (Hull *et al.*, 2020) has suggested the pattern of masking behaviours may be similar in NBA people as those of other genders, as NBA people showed a similar distribution of responses across factors in the development of a questionnaire for masking (Camouflaging Autistic Traits Questionnaire, CAT-Q). This suggests they may not be dissimilar from autistic people of other genders in their pattern of masking, though it is still possible all groups may mask in ways that are not captured by this tool, concealing differences. The only other quantitative study to involve NBA people utilized the same sample and looked at the relationship between scores on the CAT-Q and mental health difficulties (Hull *et al.*, 2021). Interestingly, nonbinary participants did not show a significant relationship between CAT-Q scores and mental health difficulties like autistic participants of other genders. However, this was judged to be related to small numbers of non-binary people in the study, which would mean only large effect sizes would reach levels of significance. Overall, these findings suggest masking in NBA people may share similarities with other genders, however there may be some aspects that are unique,

highlighting the need for an intersectional perspective in future masking research.

Healthcare and Education

Participants from the literature spoke frequently of their negative experiences in healthcare environments. This focus was largely due to some studies selecting participants from healthcare settings, such as gender clinics (Hillier *et al.*, 2020; Cooper *et al.*, 2021), and others with specific aims to improve healthcare experiences (Hall *et al.*, 2020; Strang *et al.*, 2021) but this theme also came up organically in other studies (Cain and Velasco, 2021). In one case, poor healthcare experiences led to dramatic consequences – the participant in Cain and Velasco’s (2021) study explained how practitioners frequently got their concentrations of Testosterone wrong, which was a contributing factor in their decision to stop identifying as a transgender man and start identifying as a transmasculine nonbinary person. Another participant from the literature remarked on the fact they would be unable to access a gender clinic due to their dependence on unsupportive family members for medical appointments (Cooper *et al.*, 2021), highlighting how family can both facilitate and act as barriers to gender-affirmative support. Individuals also spoke about difficulties finding practitioners who affirmed their identities (Hall *et al.*, 2020; Hillier *et al.*, 2020), and one reported never having seen an OB/GYN because, as an adult, they were still (inappropriately) seeing a paediatrician (Hall *et al.*, 2020). A common experience was invalidation. Participants from the literature reported professionals not believing them when they said they were both non-binary and autistic (Hall *et al.*, 2020; Hillier *et al.*, 2020), simply not referring to aspects of their identity (Cooper *et al.*, 2021) and/or thinking they couldn’t understand their own gender on account of being autistic (Hall *et al.*, 2020). Participants talked about how this got in the way of them receiving the healthcare they needed, leading to frustration and desperation (Strang *et al.*, 2021).

Participants from the literature also reported negative experiences when at school. A participant in Barnett and Maticka-Tyndale's (2015) study reported never receiving any sex education at the special education school they attended. This lack of information was compounded by the fact their parents refused to discuss sex and sexuality, highlighting how those surrounding an individual can act as barriers. Discussion of education and school settings was also apparent in Kim and Bottema-Beutel's (2019) study on stimming, where participants were told by schools to not stim or shamed for expressing themselves in this way. Although these experiences in education may not be specific to NBA people, these, alongside experiences of healthcare, highlight how aspects of environment can be disabling to autistic people (Oliver, 1990) and may be even more so to those with multiple identities, such as being non-binary and autistic.

Summary

To summarise, this review considered what current research can tell us about the lives and experiences of NBA people. I first looked at NBA experiences of autism acceptance, including relationship experiences, stimming and autistic masking, before considering service experiences in healthcare and education. This review has highlighted that NBA people may share some experiences with other autistic people, but they also have unique perspectives and experiences as a result of being nonbinary and autistic. These unique aspects justify taking an intersectional approach (Crenshaw, 1991) to the current research, as this plurality may create unique insights and outlooks from which to explore views and experiences about research. As such, the following sections will outline the implementation of this approach in regards to NBA individuals' views on current and future research and how these relate to their lived experiences.

Methodology

Approach and positionality

Interpretive phenomenological analysis (IPA; Smith, Flowers and Larkin, 2022) centres the perspectives of participants, valuing their interpretations of their own personal and social worlds. It is also highly inductive, which is beneficial for exploratory research. IPA exists at the intersection of three philosophical schools of thought: phenomenology (describing and interpreting the meaning of a lived experience), hermeneutics (interpretation) and ideography (concerned with individual perspectives). These intersecting approaches are complementary to the intersectional lens utilised in this study, which considers experiences at the intersection of multiple marginalised identities that are often erased from dominant narratives (Crenshaw, 1989). IPA allows for these meanings to be revealed through the interpretation of experiences and perspectives. IPA has been used in one previous study with nonbinary autistic people (Cooper *et al.*, 2021) and is becoming more widely used in autism research (MacLeod, 2019).

Hermeneutics inextricably involves the engagement of the researcher's own worldview. In positioning myself, I bring my own views, beliefs and assumptions - these may colour interpretations but also provide insights that may not be recognised by others. As such, my location as autistic, white, middle-class, an intersectional feminist, an ex-teacher and a member of the LGBTQ community may influence the perspective I take.

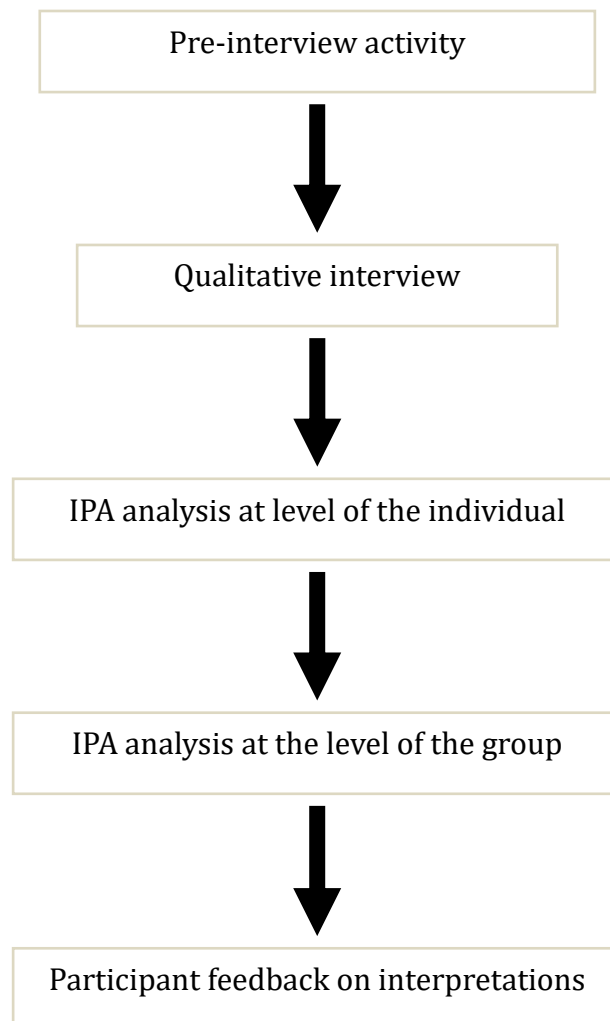
Research design

This study utilised a sequential multimethod design (see Figure 1). Participants were first asked to produce 'participant research questions' (P-RQs) as part of a pre-interview activity. The P-RQs directed the first half of qualitative interviews. The second half involved

a discussion around an activity where participants ranked statements about research in order of importance. Methods addressed different aspects of the research questions, demonstrating the complementarity of a multimethod approach (Tashakkori and Teddlie, 2010).

Figure 1

Illustration of research design



Data was collected from P-RQs, the ranking statements task and the interviews. After transcription, analysis used IPA to produce themes at the level of the individual before looking for commonalities across the group. Participants provided feedback on interpretations

made and their involvement. All steps of the design will be explored in further detail below.

Participant Selection

Initially, it was decided to identify ten NBA adult participants. After considering the time commitments of IPA, I chose to follow the guidelines for participant numbers for a Master's level IPA project (Smith, Flowers and Larkin, 2022). As such, five participants were selected opportunistically by contacting individuals directly on Twitter. Participants were identified based on their Twitter profiles (where they disclosed being autistic and nonbinary) with a focus on selecting individuals from a range of backgrounds. The sampling approach was consistent with IPA, which is interested in selecting participants who provide particular perspectives.

Potential participants were contacted on Twitter with a message introducing myself, the study and why I believed it was important (see Appendix B). They were provided with links to download the information sheet (both a written document and a video) and the consent and demographic questionnaire (see Appendix B). If individuals wished to participate, they were asked to send the completed questionnaire to my university email address to arrange an interview.

Participants

Five NBA participants took part, with almost equal numbers of those assigned male and female at birth. All use they/them pronouns. Some demographic information is displayed in Table 1. A brief description of each participant is provided below to give a fuller picture of their individual perspectives. Descriptions were informed by information participants provided in their demographic questionnaires, information from their Twitter profiles and my initial impressions. They were approved by participants during feedback.

Table 1

Table of participant characteristics

Participant	Gender	Age	Ethnicity	Nationality	Country of Residence	Autism diagnostic status (age at diagnosis)	Other neurodivergences	Physical disabilities	Interview format
Kay	Trans masculine non-binary	32	White British	British	UK	Formally identified (29), OCD	ADHD	Wears glasses, asthmatic	Online video
Rae	Non binary, transgender	44	White	North American	USA	Formally identified (41)	ADHD	Yes	Online written
Sam	Non-binary	31	Chinese (Hokkien)	Singaporean	Singapore	Formally identified (30)	ADHD	Chronic pain	Online audio
Tas	TwoSpirit, non-binary, Autigender, Indigenous woman, gender fluid	29	Native American, white, Latinx	North American	Germany	Formally identified (16)	ADHD, synesthetic, dyspraxia, hyperlexia	Yes	Online video
Lauren	Demigirl	31	White	North American	USA	Self-identified	auditory processing disorder, probably dyslexic	Yes	Online video

Note. Age was calculated using year of birth

Kay

Kay is a neuroqueer² advocate who is also researching LGBTQ autistic experiences as a postgraduate. Kay is bisexual and a new mum. They are passionate about their work as a disabled youth project leader and wheelchair basketball coach. Kay came across as knowledgeable about research involving autistic transgender people and reflective about the impact of different issues on people from all walks of life, including from the many communities they are involved in.

² A term coined by Nick Walker to describe the simultaneous queering (disrupting or subverting) of heteronormativity and neuronormativity. The term has since been adopted as a social identity to describe an individual whose identity has been shaped by engaging in these embodied practices (see Walker, 2021)

Rae

Rae describes themselves as a transgender autistic savant. Central to their identity is being a parent, their time living in Iceland and their advocacy work in Twitter Spaces where they enjoy educating people about what they know. Rae came across as passionate about inequality and had strong ideas about what they feel needs to be done to challenge systemic injustices.

Sam

Sam is a secondary school educator in Singapore with experience being involved in research. In our interview, Sam was contemplative and interested in gaining a greater understanding of issues relating to autistic experience. Sam reflected on their experiences teaching autistic students and kept in mind how issues discussed impacted the lives of their students.

Tas

Tas is a doctoral student in clinical psychology with a strong drive to help people through their work as a therapist or healer. Central to Tas' sense of self is their TwoSpirit identity and their relationship with their Native American culture and spirituality. Tas spoke powerfully about their family's forceful separation from their Native American community, abuses they have faced and their journey to their present day. Tas came across as empowered in their approach to coming to grips with these experiences and empathic to the struggles of others.

Lauren

Lauren is an early career academic who identifies as bisexual, demisexual and situationally mute. Lauren spoke about experiences that touched upon many aspects of their identity, particularly their demisexuality and family. Throughout, Lauren was reflective about their own experiences and considered how they may be viewed through the eyes of others.

Materials

Pre-interview activity

One week before the interview, participants were asked to complete an activity in the week leading up to the interview, which involved coming up with P-RQs from their daily lives. Participants were sent two supporting documents to help come up with questions and record them (see Appendix C).

Ranking statements activity

Statements describing the focus of past research involving NBA people were ranked in order of importance in the second half of the interviews. Statements were produced from a literature search, which were later shortened to reduce cognitive demand (see Appendix D). Hosted on Google Jamboard, participants' mouse movements were observed, facilitating discussion.

Interview schedule

A semi-structured interview guide generated discussion around participants' P-RQs and the ranking statements activity (see Appendix E). Questions encouraged expansive and open responses regarding participants' views and experiences. Feedback from two pilot interviews and from an online group for autistic researchers (who I asked for feedback on the guide) led to changes. These included the addition of a final question asking participants to

compare their responses to the two activities and word changes to support the participation of specific autistic profiles (see annotated interview guide in Appendix E).

To support accessibility, materials included visuals, clear wording, links to screen-reading software and an outline of the interview format (see Appendix D). Participants chose the mode for the interview (Zoom video calls, Zoom audio calls, or text-based instant messaging) and could request further accommodations.

Procedure

After participant selection, interview arrangements were made (see Appendix B). One week before, participants were sent an email with materials relating to the pre-interview task (see Materials). From the second interview, participants were also sent a copy of the ranking statements task to look at or complete. This change was after feedback from my first participant on the demands of this task. Participants were asked to send a copy of their P-RQs a few hours before the interview.

Interviews

Video and audio interviews took place on Zoom. After technical difficulties on another platform, the chat function on Zoom was used for the written interview. For visual and audio interviews, my first lasted 2.5 hours with the following three approximately 1.5 hours. The written interview was split into two parts occurring ten days apart. Collectively written sessions lasted 4 hours.

Initially, the study was re-introduced, I checked for understanding over consent and gave opportunities for participants to ask questions. I then prepared them for the types of questions I would ask and information I was looking for. Participants were first asked to consider what research meant to them in general before moving on to P-RQs. Questions

about P-RQs encouraged reflection on what made them think to ask the question and how it related to their own and others' lives. Between 3 and 6 P-RQs were discussed depending on length and depth of responses. Throughout, prompts encouraged depth and expansion.

In the second half, the ranking statements task (see Materials) was explained to three participants who had not completed it before the interview. Participants were asked if they'd like to 'think out loud' or answer questions after. All three chose to talk during the task, which was complemented with prompts and follow-up questions.

Follow-up questions asked participants about decisions around the placement of the top and bottom three statements and how these related to their lives. They were then asked to reflect on all the statements and consider how they related to the experiences of others in their communities and children or young people. Finally, I asked participants to reflect on their P-RQs and how they related to their choices in the ranking statements task.

To close, I gave a summary and checked participants were still comfortable to proceed. One person said they struggled with some of the issues we had talked about but clarified they had still been willing to talk about them. Another was concerned with being identifiable - we decided I would send them a copy of the transcript to approve to ensure no identifiable information would be included. All participants agreed to be contacted for feedback on interpretations.

Transcription and analysis

Transcription

Video and audio interviews were transcribed using Otter. Transcripts were then corrected by listening to original recordings. Transcripts were then reviewed a second time to add pauses ('...' or [long pause]), verbal emphases (underlined), nonverbal utterances (↓ - a dental click 'tut' sound) and gestures ([action]). The written interview was copied from the

Zoom ‘chat’ into a document.

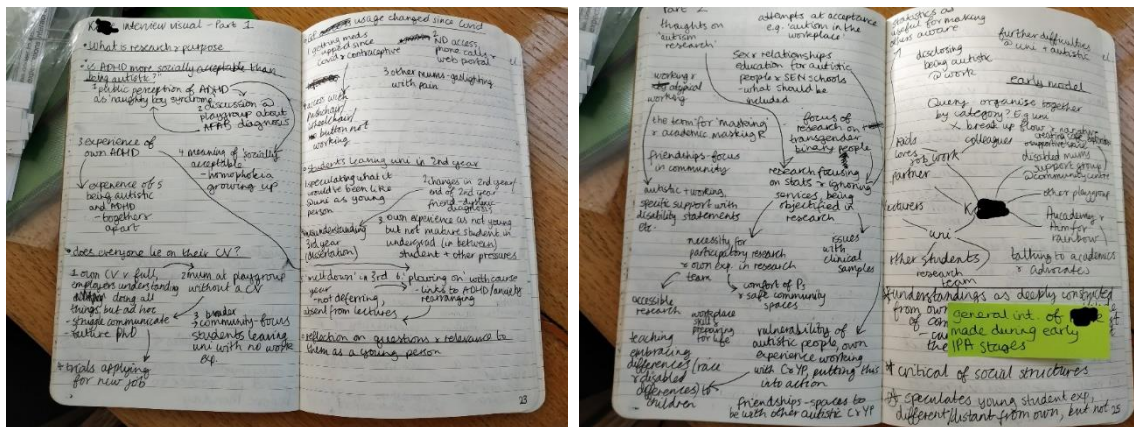
Analysis

To ensure a robust approach, I followed the steps for IPA analysis outlined by Smith, Flowers and Larkin (2022).

Step 1: Starting with the first case - reading and rereading. First, I listened to recordings of the interviews alongside the transcript until I could internalise and imagine the voice of the participant. This step immerses the researcher in the interview and centres the participant’s perspective. I then produced visuals to track the narrative through the transcript and early models to represent initial thoughts (see Figure 4).

Figure 4

Research journal notes for Step 1



Step 2: Exploratory noting. This step involved keeping an open mind to meanings emerging from the transcript with consideration of how participants made sense of their experiences. Exploratory notes included aspects that stayed close to the participant’s explicit meaning (semantic notes) and aspects that had a more interpretive focus (latent notes), a distinction borrowed from reflexive thematic analysis (Braun and Clarke, 2006). Digital and manual methods were explored (see Figures 5 and 6).

Figure 5

Digital method for exploratory noting and experiential statements

Experiential statements		Exploratory noting: semantic latent	
<p>Expectations, experiences, and challenges form a shifting landscape across an undergraduate degree</p> <p>First year of university is time for 'firsts' with low pressure and expectations</p> <p>First year of university can set false expectations about the challenges of university life, making struggles in later years more likely</p>	<p>Kay 48:36 Urm...I think because the...the two or three people I've known who've spoken about dropping out, is... ur, have, have spoken about in the <u>second</u> year. And I think they're supposed to be, and they say about it with PhD as <u>well</u>, that the second year is supposed to be like...the lull because it's the excitement of getting started. And especially with undergraduate if you're getting started, if you're moving into a new place, first time away from home, all of that kind of thing. Um, and the first year - I don't know if it's the same on a lot of courses? But, but having spoken to other people it does <u>seem</u> that way, that the first year is almost like a <u>practice</u> year. So, um, so you're still marked for things, but your markings don't <u>necessarily</u> go towards your end grade, unless you, you unless you really really bomb it like...I feel like they <u>would</u> use those in kind of more, like different circumstances. I feel like they would like, if you had to drop out for whatever reason and you needed extra credits or? Like, you had a death in the family in the third year and you totally bombed it or...whatever then they probably would. But I think more <u>typically</u> they don't tend to use it. It's like a sort of really <u>random</u> practice year.</p> <p>Kay 50:08 So, although most people are my course seem to want to do, you know, well, so yeah, <u>most</u> people my course seem to want to get the best marks they <u>could</u> do. Actually, the pressure wasn't really...on. Really, I think I think even, even if people were still putting pressure on <u>themselves</u>, which a few people did on my course. I know I did to a certain extent as well. It's not, there's, there's still a small part of you that knows that it's not, um, <u>external</u> pressure. And it's not real, and it's not <u>immediate</u>, and it's not- But I think when you come into second year...and you think, Oh, okay, we're back here again (sigh). And, you know, the workloads ramped up...but also, um, the lessons have become <u>fewer</u>...and so, your um, face to face time is less. You know, you're, um...kind of left to fend for yourself a little bit more than you</p>	<p>exp. others dropping out in second year relates to future – PhD</p> <p>2nd year as 'lull' after 'excitement...getting started'</p> <p>first year as 'practice', new place, new home</p> <p>marks carry less weight</p> <p>first year more significant if you 'really bomb it'</p> <p>meaning of first year can change in 'different circumstances'</p> <p>'most people' still wanted to do well best within ability</p> <p>self-imposed pressure not 'real' or 'immediate' [slow pace]</p> <p>workload pressure</p>	<p>reduced pressure</p> <p>'random' purposeless</p> <p>tense switching – negotiating new identity as MA st. after undergrad., closeness to uni friends? peer pressure</p> <p>difference between self-imposed and external pressure</p>

Figure 6

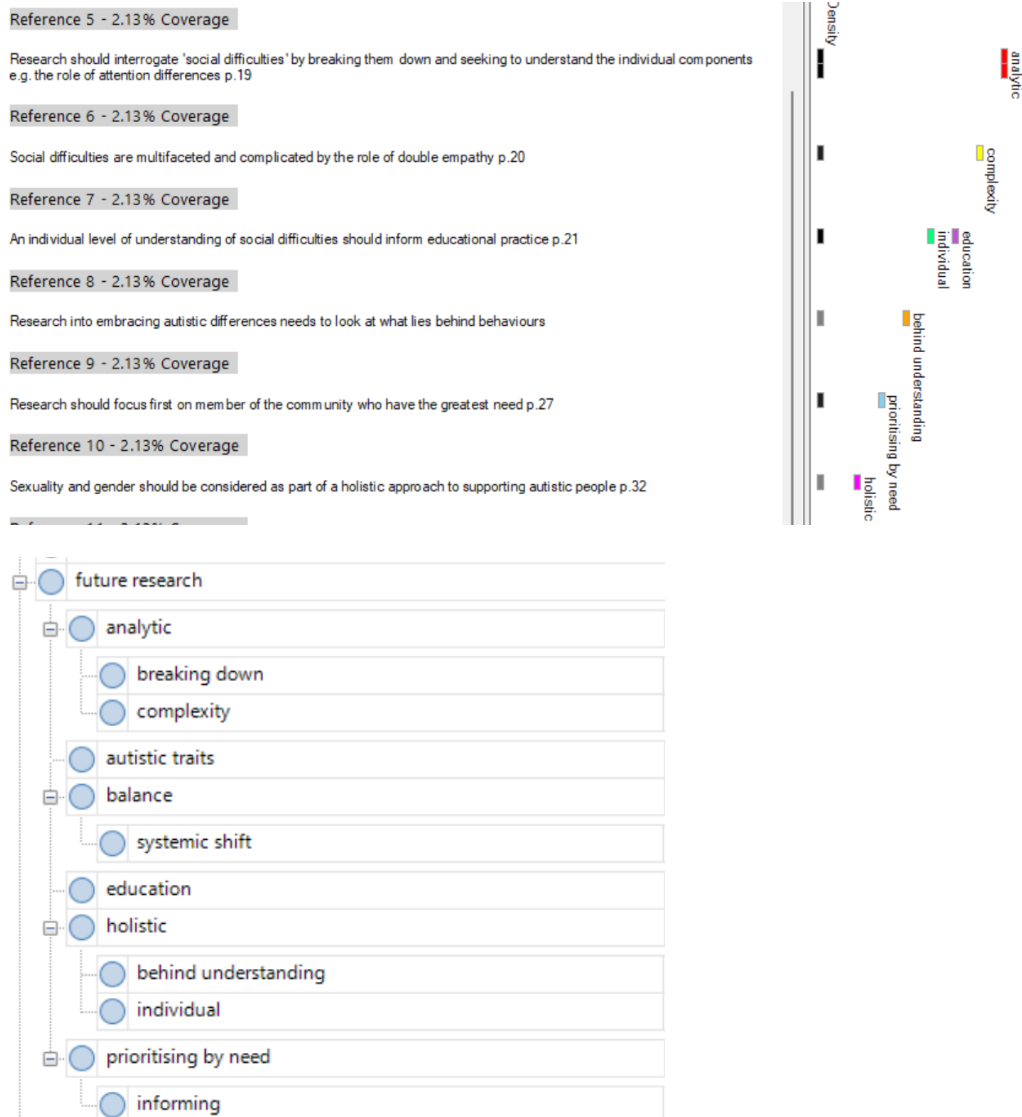
Manual method for exploratory noting and experiential statements

experiential statements	exploratory noting	
	semantic	latent
<p>moments in my life where, like, my mom would say, 'Oh, he's flirting with you.' And I was like, he's not flirting with me. I, um, or [sighs] just, don't, it's just like, all these times were just because I wasn't interested? Or I wasn't like, I just didn't see them in that way? Like, and also I'm demisexual. So it's, like, a whole can of worms. So it's like, if it's just, like, waitstaff that's flirting with me? Like, I might not pick up on that because... I don't know them. So I don't think of them like that. Um, but, uh, yeah, and my mom would say stuff like, 'Oh, you, like you make it so obvious when you don't like someone.' And I'm just like, I don't mean to, I don't know. I don't even know that they're flirting with me.</p> <p><i>L sees their demisexuality as a 'whole can of worms' that may have contributed to them missing romantic cues</i></p>	<p>Charlotte Brooks 18:54 You're just being honest [laughs]</p> <p>Lauren 18:56 Yeah... Um, and so yeah, it made me kind of think about all that stuff when I saw this movie.</p> <p>Charlotte Brooks 19:04 Yeah. Can you think back on like, a particular experience... when that happened?</p> <p>Lauren 19:10 Uh, yeah. So I, um...uh, I remember, there was this guy I would sit next to on the bus going to school. And, um... and I, I didn't even really think of us as friends. So I think that's wh- [laughs] where, where the issue really lies? Because I just, I don't know, I didn't think he was- like, we weren't in the same friend group or anything? And so I thought he- But we were in similar friend groups. He was also like nerdy. And, um... and so yeah, we would talk because we were on the bus together and we were the same grade and, um, and then, like, at one point, he grew kind of distant? And I didn't know why? And then I- and then like, when it was like, prom time or some dance time, I asked him to, to- if he wanted to go with me? Because like, we were friendly at some point, I don't know, maybe we were still friendly. And, and he was like, 'Maybe at some point, but now it's too late.' or something really dramatic. And I was, like, Okay, chill. Like I, if you, if</p>	<p>even when pointed out, L doesn't agree</p> <p>demisexuality as a cause of problems with others</p> <p>Mum critiques L's behaviours</p> <p>Mum picks up on cues L doesn't</p> <p>Reflects that they're influenced by their own perspective</p> <p>uncomfortable they may be seen as callous</p>
<p><i>L reflects on their confusion when their relationship with a boy in highschool became suddenly distant after a 'pivotal moment' they still can't identify in hindsight</i></p>	<p>didn't see as a friend even though spent a lot of time together</p> <p>didn't understand change in behaviour or severity</p> <p>some point - fixed immovable</p>	<p>may have been on different pages?</p> <p>response seemed disproportionate</p>

Step 3: Constructing experiential statements. Experiential statements summarised the most crucial exploratory notes, navigating a balance between specificity and the whole text (see left column in Figures 5 and 6). For my first transcript, I produced 211 experiential statements. I then recognised these may have remained too close to the transcript (see Figure 5). Following transcripts produced fewer experiential statements capturing a greater portion of the text (see Figure 6).

Figure 7

Digital method of coding for Step 4 shows the process for one participant for RQ2

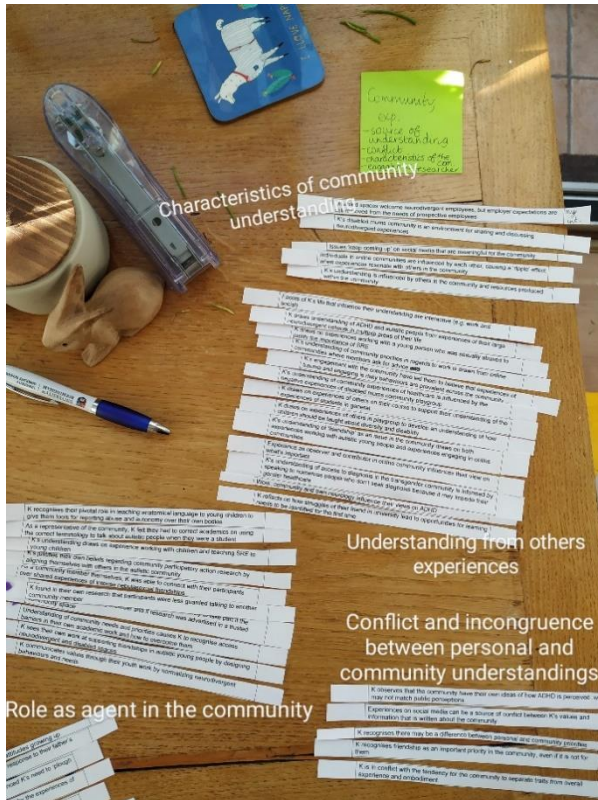


Note. Codes on the right in the first image are then organized into a structure for RQ2 in the second image

Step 4: Searching for connections across experiential statements. This step involved moving away from the original transcript and looking for patterns across experiential statements. Statements were first organised by research question. Digital and manual methods were explored (see Figures 7 and 8). Manual methods involved sorting statements into clusters. Digital methods involved coding statements on nVivo then reviewing statements with the same codes and making connections between codes.

Figure 8

Manual method of coding for Step 4



Step 5: Naming the personal experiential themes (PETs) and consolidating and organising them in a table. Step 4 clusters were brought together to create a document of PETs for each participant (see Appendix F). Documents consisted of themes and sub-themes, illustrated with experiential statements and segments of transcript that prompted them. After the first transcript, supervisors checked for the plausibility and credibility of my interpretations, considering the evidence trail. They provided points for reflection, but agreed the account was credible.

Step 6 involved repeating steps 1-5 with the following transcripts with each treated on its own terms.

Step 7: Working with PETs to develop Group Experiential Themes (GETs) across cases. GETs represent similarities between participants and the unique ways they embodied different themes. Similarities were noted in a spreadsheet (e.g. see Figure 9). Comparisons were made at all levels, starting with PETs and ending by reviewing the

original transcripts for aspects given new significance after considering the larger group.

GETs were organised into a coherent structure (see Figure 10), producing a document of GETs (see Appendix F).

Figure 9

Spreadsheet of emerging similarities between participants

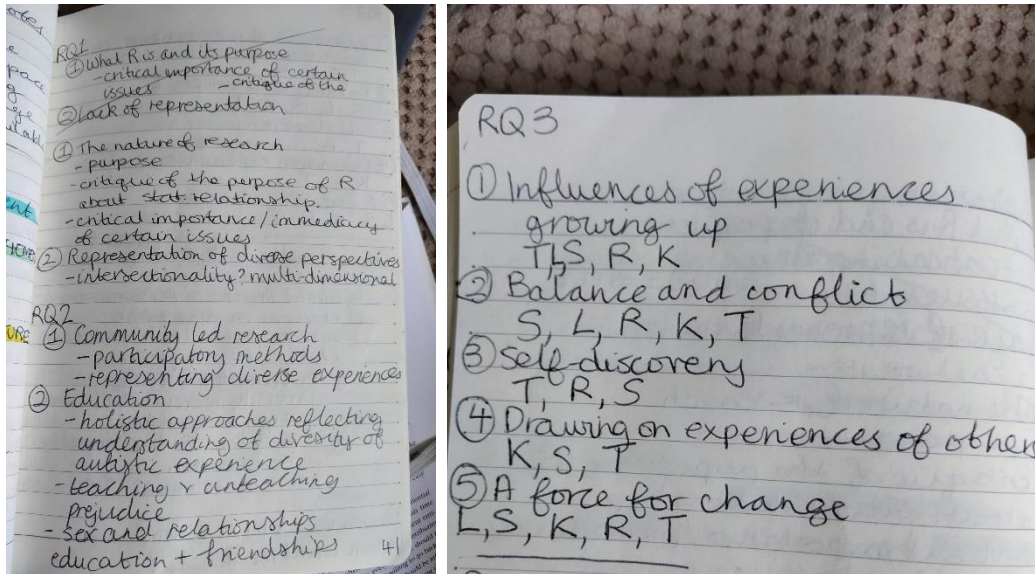
	Similarities
	Consider the role of education - K and R considers learning/unlearning prejudice, S talks about role of education in supporting autistic people
	Education should be individualised - S talks about holistic approaches generally, R talks about tailoring SRE for ND people with impulse control difficulties
	Participatory research - K talks about research being community led, R talks about paying participants for their time, L talks about importance of people picking topics
	Greater understanding of autistic experience - R thinks this should be addressed through training courses for professionals, S thinks research needs to interrogate mechanisms underlying areas such as 'social difficulties' for autistic people

GETs were sent to a supervisor for feedback on coherency and any further points.

This led to changes in the sub-theme 'Educating and supporting autistic people' to make clear disparate views. Participants were then sent an amended copy of the GETs with their contributions, information to be included in the 'Participants' section and a document with questions for feedback on interpretations and their experience being involved in the research (see Appendix H).

Figure 10

Structure for GETs



Ethics

Ethical approval was successfully sought through my supervisors by the University of Birmingham (see Appendix I).

Consent and withdrawal

Participants gave informed consent by reading or watching the information sheet and completing a digital consent form (see Appendix B). Participants were told they would be able to withdraw with no penalties up until a month after the interview. After this point they could comment on interpretations but would not be able to withdraw due to time limitations.

Confidentiality

Participants were asked to respond to the invitation to interview through my university email, so no sensitive information was disclosed on Twitter. Data was stored on secure University servers. Completed demographic and consent forms were stored separately from transcript data.

For the ranking statements activity, participants were given individualised links to

documents on Google Jamboard. After the interview, copies of the documents were removed from Google and stored with the other data. Interview recordings and copies of the chat transcript were stored locally on University servers using Zoom. This meant recordings were not stored on the Zoom cloud.

Once transcribed, recordings were deleted from the University servers and Otter, though participants were informed all services may maintain traces. When writing this paper, all identifying information was removed from transcripts with participants given pseudonyms to maintain anonymity. Inclusion of information to describe participants was chosen selectively to be unidentifiable.

Findings and discussion

Results and discussion sections are integrated so literature connections can be made alongside findings. Due to word limitations, a limited number of examples have been used to illustrate the themes. The full document of GETs can be viewed in Appendix G. The notation (...) denotes where extracts have been shortened for brevity.

RQ1 - What are participants views on current research involving nonbinary autistic people?

Themes arose from discussions around the ranking statements activity. These were: The Nature of Research and Autism Research; Representation and Issues of Critical Importance.

The nature of research and autism research

This theme addressed how participants came to understand ‘research’ and its purpose before critiquing autism research. Participants had varied views of what ‘research’ may look like:

Research could mean a lot of different things (...) peer reviewed journals, internet searching, books, history, story telling from oral traditions (Rae)

Tas highlighted research as a product of ‘*Western society*’, calling attention to traditions surrounding research and academia as an institution and how they may limit the knowledges represented (Smith, 2021).

Participants agreed research should inform and improve lives by being both ‘*timely*

and important' (Lauren). In response, they critiqued research that was pathologising or focused on negative events without considering ways forward.

Past research agrees that autism research should focus on areas of practical concern (Pellicano, Dinsmore and Charman, 2014). A tendency to focus exclusively on negative experiences is evident in the literature review for the current paper, where ways forward were rarely considered (e.g. Strang *et al.*, 2021). In their feedback, Lauren highlighted how this contributes to a pathologising narrative in wider society as '*research doesn't exist in a vacuum.*'

Representation

Participants reflected on groups that are typically under-represented in research. Sub-themes were Autistic, Transgender and Racial and Cultural Diversity, though participants' responses frequently considered how identities intersected.

Autistic. Participants thought research represented a limited range of autistic experiences. Sam reflected on the critique that research tends to focus on the views of '*more vocal*' members of the autistic community:

a lot of us are, are concerned about the people who are less able to communicate(...)But on the other hand(...)if we're not careful with, with the research that we also end up over representing certain views? Because certain people are more able or willing to communicate and take part

Some research has considered how to include those who are non-speaking or partially non-speaking. For example, Barnett and Maticka-Tyndale's (2015) study included the option

for email-based interviews, enabling the involvement of a participant who uses alternative or augmented communication (AAC). This allowed for powerful insights into their views of sex and relationship education, unique to their experiences of specialist educational provision.

Transgender. Participants critiqued the representation of nonbinary and transgender autistic people. Kay noted how even in transgender autistic research, nonbinary experiences are erased:

as you know, everything's like cis³ white boys...so that's, like, crap(...)nonbinary, autistic-specific research, like...that doesn't exist, because everything(...)is like, still very binary, like, but it's just trans binary now [laughs] (...)Where are the nonbinary folk? Like, where are the agender folk? Where are the genderfuck folk? Where are the gendervagues?

Similarly, Lauren talked about how neither nonbinary nor autistic people have a platform to express their views. It is important to consider how research can provide such a platform, but also how it has the power to misrepresent or erase experiences (Catala, Faucher and Poirier, 2021).

Racial and cultural diversity. Participants observed that research is limited to experiences of white autistic people from Anglocentric countries, erasing others' experiences. Sam reflected on this gap in research:

a lot of the research tends to be focused on white, white people(...)I suppose, like, the

³ Short for 'cisgender' referring to people who identify with the gender they were assigned at birth (i.e. are not transgender)

nature of it [†] a lot of research being English kind of just makes it that way to a large degree? But even in, like, Anglocentric countries or English-speaking countries, there's quite a large racial diversity. So I think, I think it's quite important to account for that

One explanation is that autism has long been considered culturally universal (Perepa, 2019). As this view is changing, research needs to work on representing cultural and racial diversity while considering barriers to publication faced by researchers around the world (Purwanto, 2021). Research may also benefit from insights gained. As Tas notes, Indigenous knowledges may provide alternative perspectives, whereas their erasure may limit narratives that are produced (Catala, Faucher and Poirier, 2021).

Ranking statements activity

Table 2 shows what order participants ranked the statements. It is important to note many participants saw patterns between areas and found it challenging to rank some issues as more important. As such, the table is illustrative of the range of views.

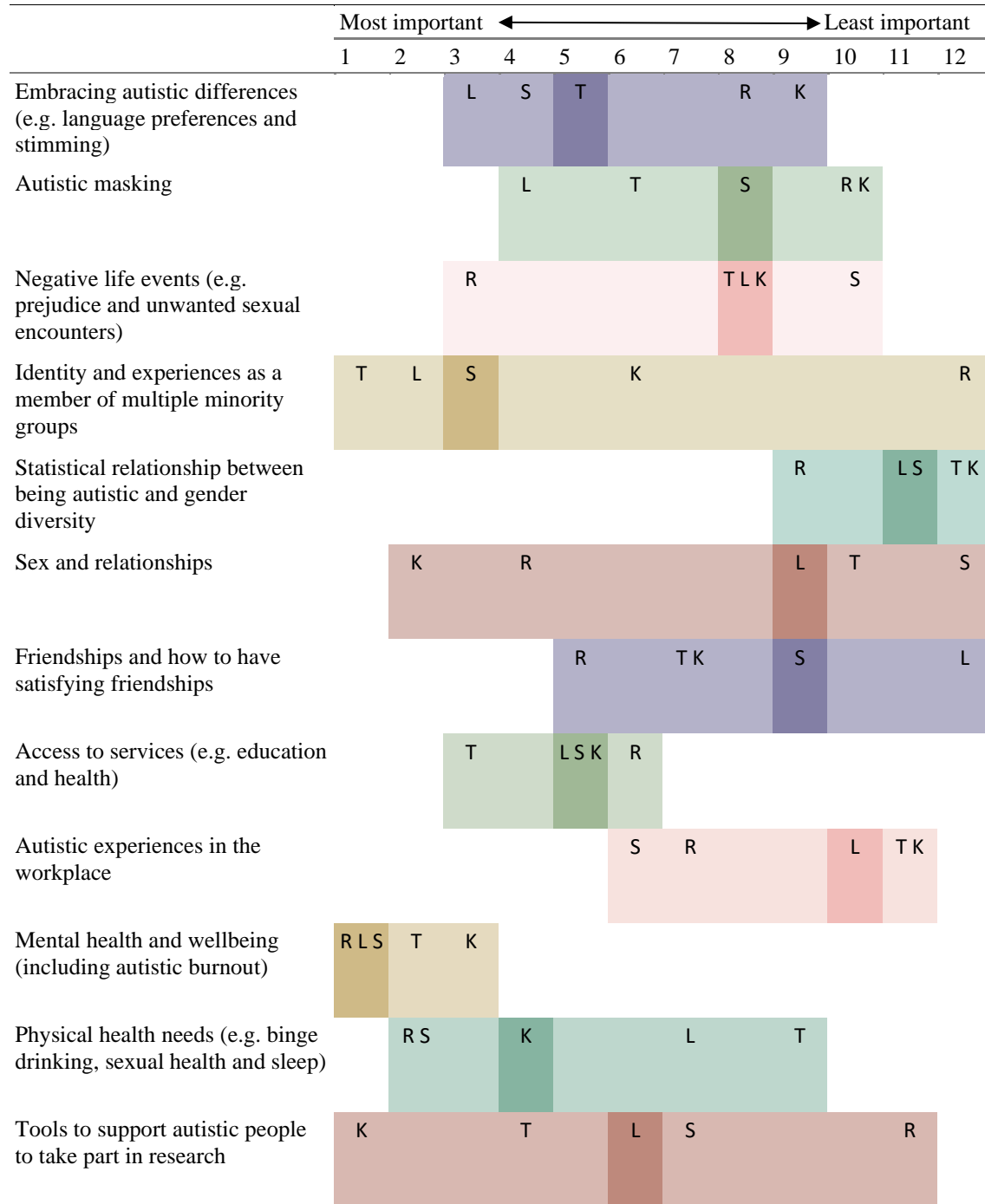
Overall, participants felt differently about many statements, indicated in the large spread. This calls into question past research that has used similar methods to generate research priorities (e.g. Frazier *et al.*, 2018). Such variability suggests there are many issues relevant to different people.

Participants ranked some statements similarly. All participants ranked ‘access to services’ and ‘mental health and wellbeing’ as important and ‘statistical relationship between being autistic and gender diversity’ as less important. These findings reflect themes expressed for this research question, especially those related to the critical importance of certain issues.

Table 2

Table illustrating the spread of how participants ranked statements from most to least

important



Note. The median is represented in a darker colour to represent the central tendency.

The table is for illustrative purposes and will not be used to make generalised statements

Critical importance of certain issues

This theme drew on how participants made sense of the ranking statements activity. Sam referenced ‘*Maslow’s hierarchy*’ and Lauren spoke about a ‘*low-level hierarchy of needs*’. However, participants had different views on which needs were most crucial, as reflected in Table 2. Kay noted how areas were connected as statements they rated higher supported other areas:

it's all wrapped up in this as well. Like, if you sort out someone's mental health needs, and their physical needs, like...work- working becomes, like, a much more viable option

The mention of basic needs and Maslow’s hierarchy suggests participants are aware that basic are not being met, speaking to a wider societal problem. If research is to have a role in reversing societal damage, it is important to consider directions for future research.

RQ2 - What do participants think future research involving nonbinary autistic people should focus on?

This question explored P-RQs (see Appendix C). Not all questions were discussed, so not all are addressed in the themes. This question also drew on discussions of the ranking statements activity as participants moved seamlessly from considering current research to future possibilities. Themes were: The Future is Community-Led and Education.

The future is community-led

Participants were knowledgeable and had strong views about community involvement

in research. This is consistent with repeated calls for greater collaboration by autistic advocates (Milton, Mills and Pellicano, 2014; den Houting *et al.*, 2021; Stark *et al.*, 2021).

Kay reflected on how participatory research may lead to societal improvements:

if the, the research found- has a foundation in actual lived experience(...)the rest of the things on this list will actually improve, like, not straightaway, not overnight. But if research underpins policy, then, then yeah, I think that's a winner

This sentiment is reflected in Pellicano *et al.*'s (2021) study who identified a theme of 'research as advocacy', demonstrating how participants viewed research as a way to enact change.

Implementing participatory research. Participants talked about representation of community members as valued and paid members of research teams. Tas had clear ideas about how collaborative and actionable research could be designed:

we could just, like, get a support group together and put, you know... twelve people together to talk about it from all these various cultures, or whatever? And it could just be like, an hour over tea? And we come up with some ideas and write it all up. And... and put it in a book

This idea echoes messages from transformative- emancipatory research, which is centred around reflexivity, community engagement, reciprocity and action (Mertens, 2010). The reference to 'over tea' situates the research in culturally familiar practices which may draw on culturally responsive ways of knowing (Smith, 2021). Such a design could be

implemented in various areas, including education.

Education

This theme was organised into three sub-themes: Educating and Supporting Autistic People, (un)Teaching Prejudice and Sex and Relationships Education.

Educating and supporting autistic people. Participants spoke about different aspects of education - schools, academic learning spaces and empowering individuals. As such, views were disparate and expressed various perspectives.

Sam talked about their belief in holistic approaches that put the individual at the centre and the challenges of implementing this as a teacher:

so that's the difficult thing of like, how do we balance out the picture for every single child(...)you're going to need a completely different set of interventions or different- a different concept of how, how do we educate this person, so that they can, you know, achieve what they want to achieve

In academia, Lauren talked about their experience of a 'hostile learning space' and what they felt were features of an 'open learning space':

like, you let people ask their questions, and you answer them and you... Like, at whatever level they're at? ...Yeah, it's meeting people where they're at. And... and listening(...)like not gatekeep knowledge

Without being specific to a particular educational context, Tas then spoke about how

autistic people should be taught and encouraged to ‘*hold space*’ for themselves and others and advocate for their needs:

like, speak for yourself and justify it? And, like, explain why you need it? (...)just, like... just unapologetically being yourself, taking up space

Collectively, these examples show that approaches need to be tailored to particular environments (i.e. school or universities) and individuals. In schools, some approaches, such as TEACHH promote an individualised perspective (Mesibov, Shea and Schopler, 2005). However, to implement this fully it may also require practitioners to alter their perspectives on autistic needs and behaviours so they can understand that person holistically. This may involve addressing prejudices and improving knowledge.

(Un)teaching prejudice. Participants saw prejudice as a learned process reinforced by society. Kay reflected on interactions between parents and children where disability is *not* spoken about as communicating wider societal prejudices and missing out on learning opportunities:

But instead of taking that opportunity to like [sighs] humanize the person that you're talking about (...)it just tells children that, you know, ‘Oh we don't talk about disability’, ‘Oh, no, it's really rude to talk about that,’ or, or that these people are unapproachable? Or don't have their own stories?

Rae spoke about ‘*human classes*’ as a way of reversing prejudice, which would be co-designed and taught by neurodivergent people on ableism and neurodivergent experience:

This class would contain anti ableism training and awareness. Trauma informed people, teaching normies how it is really for the rest of us. Anti-stigma training too.

These examples speak to different approaches. Rae believes awareness should be taught explicitly, whereas Kay's approach is more interactional. Interventions to encourage mutual understanding were also noted as a priority by autistic adults in Pellicano *et al.*'s (2014) study, and as an alternative way of improving mental health outcomes by Benevides *et al.* (2020). In terms of work with young people, it is likely implementing approaches, would also require work with '*their parents to teach them to not pass on unnecessary biases*' (Tas). Schools should, therefore, consider how to involve the whole school community in initiatives.

Sex and relationships education. Several participants spoke about experiences of sexual and relationship abuse. Kay highlighted how neurodivergent people, particularly those who receive personal care, are '*incredibly vulnerable*'. This is supported by research that reported nine out of ten autistic women as survivors of sexual violence (Cazalis *et al.*, 2022) and ten percent of autistic children and teenagers at inpatient facilities as survivors of molestation (according to reports by caregivers; Brenner *et al.*, 2018, p. 20). Effective sexuality education, including preventing sexual violence, was also identified as a priority of for future research by Dewinter, Miesen and Holmes (2020).

Both Kay and Tas believe in having candid conversations with children and answering questions in age-appropriate ways. Tas reflected on how they had approached this with their daughter:

just like, being candid from the very beginning. I, like, with my daughter, I have just, um... like, my daughter was, unfortunately, sexually abused. So I, the route I took was, I am just going to answer all of her questions as they come up, because I believe if they're asking a question, they have a need for an answer? There's a lot of, like... nuance around like finding an age appropriate answer for them?(...)Just like access to information, access to good information, access to- in particular, access to models of healthy relationships, and access to, um, understanding abusive and manipulative tactics.

These suggestions are similar to those provided by a NBA participant in Barnett and Maticka-Tyndale's (2015) study, who recommended '*using appropriate words...Not kid-words or "polite" words*', suggesting honesty and a candid approach are valued.

RQ3 – How do participants' views relate to experiences in their lives and those of their communities?

This question situates ideas discussed above in participants' experiences. Themes are Influences of Experiences Growing Up, Balance and Conflict, Self-discovery and Empowerment, Drawing on the Experiences of Others and A Force for Change.

Influences of experiences growing up

Participants drew on early life experiences to explain and reflect on their views. Tas spoke about their generational trauma and separation from their Native American roots alongside an abusive counter-culture, which lead to a sense of fragmented identities in their earlier life:

My dad was, 'scooped' (...)when in the 60s and early 70s, a bunch of Native American children were forcibly taken away from their communities and their families and adopted out to white families? And so, um, so he spent decades looking for his family, and I am now in, like, I've spent over a decade looking for them, because we still, like, I'm as close as anyone's ever been. But like, I am acutely aware, I'm Native American. I, like, m- my default is rejecting white culture [laughs] American culture. And, and like, I've always been drawn there and like (...)that's home [hand makes arch movement). I unfortunately was raised... my mom and her side of the family were very into Christianity and Catholicism. And it was hugely damaging... to my identity.

Sam's perspective as a teacher was informed by their difficulties as a teenager being overlooked:

I've always felt like, like almost like a forgotten child kind of? Like, like, um... I wasn't disruptive in class. I wasn't having any ma- major issues. Academically, I was doing okay ...um... probably fairly well, I suppose. Um... but my teenage years were very difficult

Rae also spoke about their experiences in education, where they were penalised for their 'gift' for 'years on end':

I got marked down in math for not showing my work constantly even though I had the right answers. For years on end. I was penalized for being a mathematical savant (...)made to feel badly about being gifted

Lauren recalled ‘severing’ sensory connections to avoid overstimulation:

*I would, um... [1] like, kind of sever [chopping gesture] certain... um, uh...
connections to my body, so that I wouldn't get this overstimulation or whatever?
Which led to poor interoception later on, that I'm dealing with*

Kay talked about their positive experience in their Scouts group with other neurodivergent young people and how it has informed their work as a youth worker:

*now when I look back at the scout group, I think, yeah, there wasn't, there probably
wasn't a single neurotypical⁴ one among us(...)and because of that, I got so much out
of my scout group.*

Participants used experiences to explain their journeys to their present day, the choices they made and what issues they believed to be important or thought research should address. These various experiences emphasise the individuality of participants and how this informed their unique perspectives.

Balance and conflict

Participants sought balance in their lives and frequently faced conflict and pressure from others. Sam spoke about feeling the pressure to shape themselves for other people:

*I've always felt that tension between like, 'This is who I think I need to be'? And, um,
driven entirely by social identity for that. Versus, like, the inner sense of*

⁴ Neurotypical people have a neurocognitive style that falls within dominant societal standards of ‘normal’ (Walker, 2021)

self(...)Which may not be... the more socially conventional.

Lauren also talked their asymmetrical haircut is a subject of debate in their family:

And my aunt noticed my hair(...)I said, Like, my m- but my mom doesn't like it. Um, and she- my mom said something like, 'Oh, I'm only your mother.' Like, like, I... like her opinion matters so much.

Rae talked about a sense of alienation by others in society which they attributed to ableism and prejudice:

I'm living autistic in a NT⁵ world. I experience the ableism and the prejudice first hand in my life. Dating is the worst as an autistic adult. Almost every single thing about the NT world bothers me, actually. From capitalism to politics. It's noisy, cruel, and not made for me

Kay spoke about their atypical relationship to work and negotiating societal expectations when applying for a job:

people say, 'Oh, so when did you stop doing that?' No, I haven't stopped doing that. 'Oh, so you're doing this, this, this and this, but you're also going for this job as well?' And I think some people are kind of a bit...put off by that? Um, because, I don't know, they think, like, 'Oh, well you have a baby, but you're also doing like 5 million other things.'

⁵ Abbreviation for 'neurotypical'

Tas expressed frustration about needing to get a PhD to ‘heal’ others, which would not have been necessary if they hadn’t been estranged from their culture:

at this age, I could be almost like a full-fledged practicing medicine person. But at this age, I am stuck in the Westernized context of I'm having to get a PhD, in order to get acceptance into white society(...)my PhD is a piece of paper to say, Hey, I played by your rules? And I don't like them. And so I'm going to shred them now. And I'm going to build something better.

This theme highlights how participants experienced conflict and pressure from many directions. Experiences are consistent with models of minority stress, which involves a disconnect between dominant and minority values and the resultant conflict with the social environment (Pearlin, 1989; Meyer, 1995; Mirowsky and Ross, 2017). Minority Stress has also recently been extended to the experiences of autistic (Botha and Frost, 2020) and nonbinary people (Lefevor *et al.*, 2019) whose ways of being in the world or gender expressions are subject to prejudice.

Self-discovery and empowerment

Participants experienced empowerment, self-understanding and acceptance since discovering and embracing aspects of their identity including their culture, gender and being neurodivergent.

Rae described a process of peeling back layers of trauma to understand themselves better:

I'm still unpacking my own ableism. Trauma and ableism have layers(...) Things make so much more sense than before

Tas spoke about their new understanding of themselves as unique and how this contrasted to their previous understanding of their differences:

I think that maybe someone who was raised in like a restrictive, like, situation like I was, um... might think that [unique traits] made them bad? Or might think that it made them a freak? Or they might think that it made them an outcast? Or that they're not good enough? Or that they need to change themselves? Um, which is very different from the cultural context that I have now of I... am like this for a reason, it's a gift(...)it doesn't make you infallible, it just means that, like, you've been trusted

Sam reflected on their experiences of meltdowns as a shared experience leading them to realise they were autistic and how to support their students:

actually that's how I kind of figured out I was autistic. Because I was like, looking at the kids having meltdowns, I realized, 'Oh, okay, I have meltdowns too' (...)having the self-awareness that I'm autistic has helped me to kind of, um... have more insight on how to manage and identify what's not done for myself?

Recognising they were autistic helped Lauren to consider how they could use alternative forms of communication:

especially since I've made this connection of being autistic, it has helped me, and

knowing that I actually become selectively mute when I get really depressed? Has actually... helped me realize that, like, Oh, I can use a tool to like, communicate when I'm feeling really bad. And I just never thought of that before

These extracts indicate participants felt positive about recognising aspects of their identity and the self-understanding that followed. This is consistent with research that suggests learning they are autistic can often help people to understand their differences and reframe their experiences (Humphrey and Lewis, 2008; Mogensen and Mason, 2015; Oredipe *et al.*, 2022). Research has also found, however, that some may struggle to reconcile with this view of themselves (Humphrey and Lewis, 2008; Mogensen and Mason, 2015). It is, therefore, important to consider how individuals are told they are autistic, which may influence their understanding and subsequent identity development (Riccio *et al.*, 2021).

Drawing on experiences of others

Participants made sense of their experiences and topics of research by relating to others' experiences. Kay talked about numerous people who didn't seek an autism diagnosis because it could impede gender healthcare:

is it's not like- there's enough people I've spoken to where it's not coincidental

This is consistent with past research that reported individuals not being taken seriously when disclosing they were autistic (Hall *et al.*, 2020; Hillier *et al.*, 2020; Cooper *et al.*, 2021) and highlights how individuals may draw on the experiences of others in the community to make decisions that affect their health and access to services.

Tas reflected on stories of an autistic friend who were supported in embracing their

TwoSpirit identity within their community, which allowed Tas to view their experiences from this perspective:

they, when they grew up in the culture, and when they were a child, they had a mentor, who was also... TwoSpirit, who, um, was given to them, like, was given to them by the, like, the Elders. She was an elder herself, who did a ceremony with the child to help them identify this in themselves, to help them, like, learn what it meant and, and all of these things(...)so that was like a transitional moment in their lives. They had that really young, they knew what they were, that helped guide them

This theme demonstrate how participants' understanding of others' experiences influences what they feel to be important, but also provides them with alternative perspectives on their own lives.

A force for change

Participants were highly involved in their communities. Both Sam and Lauren spoke about their roles in supporting students. Lauren talked about debriefing some PhD students they mentored about the behaviour of another academic in a reading group:

messed them later. And I was like, That is not acceptable behavior. Like this is, um, like what he did was wrong. And that's not the way academia should be

Kay spoke about their approach to their youth work and their role in normalising neurodivergent behaviours and needs:

what I do now is, you know, 'You're not the only person here,' and 'Okay, yeah, if you want to stim and flap, that's fine.' And, you know, 'We can have a bit of quiet time,' and 'This is what we're kind of generally doing today, but if we don't really get there, then it's not really a problem.' Yeah... 'I can understand why you'd have issues with that. I can help you with that'

Rae spoke about their involvement online:

I'm actually taking part in Twitter spaces now. I'm co hosting some mental health spaces and some LGBTQIA2S spaces too. We discuss all topics with those heavy experiences

Past research has emphasised the importance and difficulty of finding communities of similar and accepting others for autistic nonbinary individuals (Hillier *et al.*, 2020; Cook *et al.*, 2021). The extracts highlight how communities are co-constructed through histories of work on behalf of community members (Marx, 1887). Constructing spaces embracing nonconventional ways of being, such as those who are nonbinary and autistic, may require even further work, as such spaces involve reshaping the established '*contours of habitable or liveable space*' to create places '*queer moments*' can occur (Ahmed, 2006, p. 106). It is crucial to recognise, therefore, the personal cost to community members involve in the work. For example, Tas reflects on '*wasting my... energy on people who... won't value it*', highlighting how communities need to put support structures in place to protect the resources of its members and share this work fairly.

Feedback from interpretations

Four out of five participants provided feedback in time for the dissertation deadline with one requesting further time. In general, participants were happy with the experience of being involved and thought interpretations made sense. They reflected on future implications, such as work that may come out from this project and how they would like to see similar examples of research in the future. In response to feedback, minor word changes were made. I did not disagree with any of the suggestions so all were implemented and can be viewed in Appendix G.

Participants had mixed feedback on the activities. In coming up with P-RQs, Tas thought '*it was really good to have us come up with our own questions*' as it put participants in control. Kay, however, found it difficult coming up with questions and '*felt a little on the spot with that*' and Rae was confused about the scope of what their questions should focus on. Similarly, for the ranking statements task, Kay thought it was '*a good activity, especially as I could talk/think aloud whilst doing it*', whereas Rae found '*a lot of them overlap a bit which makes ordering them more difficult.*' The feedback illustrates how participants experienced different challenges, which has implications for considering the demands of participant-led activities and how to come up with activities and ways of explaining them that put participants in control but are not overly demanding or confusing.

In feedback on the interview, participants commented on how our dynamic felt open and relaxed, a '*pleasant and safe place to express myself openly*' (Tas). I also asked participants for feedback on being interviewed by an autistic researcher. Lauren said they didn't feel judged for '*my ideas or how I talk*'. Kay spoke about a '*shared culture, language and understanding*' and how it felt like '*doing research with neurokin⁶ as opposed to having research done to me*'. A feeling of mutual understanding was echoed in Pellicano et al.'s (2021) study where participants interviewed by an autistic researcher spoke about not feeling

⁶ A community term referring to the kinship found with others of the same neurotype

judged and felt respected and included. Other features, like being nonbinary and age or racial/ethnic background, may also impact the interviewer-interviewee relationship (e.g. Greene *et al.*, 2009). Research teams should, therefore, try to reflect a diverse range of identities and backgrounds.

Strengths and limitations

Strengths

An initial strength was the study's purpose of understanding and advising on what autistic nonbinary people want from research, in support of epistemic justice (Catala, Faucher and Poirier, 2021). This purpose was implemented using methods - P-RQs allowed participants to direct the flow of the interview towards areas most relevant to their daily lives. I also gave participants the opportunity to feedback on my interpretations. With more time and resources, I would have liked to include other NBA people as co-researchers for the analysis and interpretation. This would have benefited the project by providing multiple perspectives which could have led to additional insights.

Another strength was the use of an intersectional lens to view participants' experiences. By considering the views and experiences of participants who were both nonbinary and autistic, this encouraged multi-dimensionality, creating a fuller picture of their experiences. For example, I also considered the role of other aspects of their identity, such as cultural backgrounds and experiences growing up. This multi-dimensionality can be seen in how participants were not considered passive and instead looked at how they played an active role in co-creating their communities. In line with IPA, this created a well-rounded perspective through which to view participants' perspectives as individuals.

A final strength is the contribution of this research to the literature on what autistic people think research should focus on, particularly the fresh perspective introduced by this

study that looks more deeply into how these views are shaped by individual experiences. The implications of this will be discussed below.

Limitations

An initial limitation is related to the backgrounds of participants. Although it was not known before the start of the study, three participants had experience as researchers at postgraduate level or above and another had experience participating in research and influencing policy. In some ways this may have been beneficial because participants were able to bring this experience into the interview and reflect from their perspective as academics. However, it does mean this study may not reflect the views of those with less research experience. It is common that those with higher educational qualifications are more likely to be participants in research (Henrich, Heine and Norenzayan, 2010). I would argue, however, the perspective of NBA researchers is still novel and the prior experience of research by participants in this study does not overshadow their insights.

It is also interesting to question why almost all of those who responded to the request to take part in the study had been involved in research themselves. It may be that others felt research was not relevant to their lives or they may have been intimidated by a topic they felt they did not know much about. It would, therefore, be interesting for similar research to attempt to capture the views of those who think research is not so relevant to them to see how views and experiences differ.

A further limitation is the impact of my development as a researcher throughout the study. Before I started this project, I had no research experience as an interviewer. Although I conducted two pilot interviews, my skills still developed across the course of the project. Some later interviews may have been higher in quality than earlier ones. They were also less structured as I gained confidence to follow my intuition and the participants' lead. IPA was

also new to me. As described in the Methodology section, I trialed out different modes of conducting the analysis until I found a system that worked. Although this process may be seen as a limitation of the current study, I would argue that my reflexion and transparency are beneficial and that skill development across a project is expected by researchers at any level. These are also skills that I have developed and will be able to apply in any future studies.

Implications

The findings from this study have implications for research. The finding from the ranking statements task that participants had a range of different views suggests research should focus on many different issues. This broad scope is reflected in the priorities for research produced by Autistica (2017) which looked at questions posed by the autism community (23% autistic people, 52% family members and 25% professionals). The top ten include mental health, education, social care, supportive environments, support for family members, improving diagnosis for autistic adults and understanding autistic sensory experiences. These are similar to those produced for the ranking statements task. However, Autistica's agenda does not include a focus on identity and experiences as a member of multiple minority groups, embracing autistic differences or physical health needs, all of which were ranked highly by some participants in this study. It is important, therefore, to consider broader funding agendas, particularly those that meet the needs of marginalised groups, such as nonbinary people, within the autistic community.

Another finding was that participants valued and wanted more future research to be community-led and participatory. This has echoed repeatedly by autistic academics (Milton, Mills and Pellicano, 2014; Chown *et al.*, 2017; den Houting *et al.*, 2021). It has implications for funding more research with this focus but also in equipping researchers with the skills to utilise participatory methods effectively, which is not so widely established. Participants'

focus on representation of different groups in research is also important here, as it is crucial participatory research represents views from the whole community. This speaks to the underlying message of participatory research in representing the views of a community, which is not possible if certain groups are not included in this work.

A final implication for research is the focus on Education. Participants spoke about the role of education in reversing some of the injustices they and others in the community face. This has implications for future work in schools as it should be considered how programmes that teach about various aspects of diversity (cultural, gender, disability, neurodiversity etc.) may be combined to produce comprehensive teaching materials that offer a balanced curriculum. It should also be considered how this may be achieved for different age groups and different audiences (e.g. in schools, with parents, with professionals), as it was emphasised in this study how these lessons need to be taught more broadly to enact systemic change.

Conclusion

To my knowledge, this project has been the first to look at the research interests of NBA people. It, therefore, extends work that has looked at what research should focus on in other areas of autism research. Although participants' views differed in some areas, expressing their individual viewpoints, there were also areas where they converged. Participants were concerned current research involving autistic nonbinary people tends to focus on negative experiences, contributing to a pathologising narrative and not representing the diversity of the community. They also valued research that could make a critical difference to the lives of individuals. Participants felt future research should be led by the communities it involves and had ideas about the role of education in implementing change and better meeting the needs of NBA people.

To my knowledge, this project was also the first to look at how views related to participants' lived experiences. Participants made connections between their views on research and experiences in their own lives. This represented a journey comprising of foundational experiences growing up, experiences of conflict throughout their lives and a new chapter of self-discovery and empowerment in their present day. Participants also shaped and were shaped by others views, which was demonstrated in their tendency to draw on others experiences to frame their own and by taking on active roles in their communities. In its nature, this project is future-directed and concerned with influencing future research. The greatest contributions will, therefore, be in its future applications, including in informing my own PhD research

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