Diagnosis as a new beginning not an end: A participatory photovoice study on navigating an autism diagnosis in adulthood.

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Data availability

The data are not publicly available due them containing information that could compromise research participant privacy.

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Abstract

Autistic people diagnosed in adulthood often report that the experience can be life-changing, but there are issues with the diagnostic pathway. Few studies consider the views of people *currently* seeking diagnosis or contextualise the experience of diagnosis around developing an autistic identity. In this qualitative participatory study, we explored experiences of navigating an autism diagnosis in adulthood in the UK. We recruited six women (aged 21-46) who were seeking diagnosis, who worked with the academic researchers across four sessions to develop the study, share their experiences and analyse the themes. In one session, they completed a semi-structured interview alongside photovoice, a community-based action method, to explain and reflect on their experiences. We used reflexive thematic analysis to identify patterns, with four key themes identified: 1) "everything shattered", 2) "being seen", 3) "understanding not judgement, please" and 4) "here's a leaflet, off you go". The themes reflected a desire for change and improved support for both diagnosis and developing autistic identity. Following photovoice methodology, together we identified actions to improve adult diagnosis, including involving autistic people in making improvements to the diagnostic criteria, for key professional and community groups to listen more to autistic people, and for diagnostic support services to be flexible and appreciative of wider neurodivergence and intersectionality.

Lay abstract

Lots of people seek an autism diagnosis as an adult, and they often say that being diagnosed can be positively life-changing, but the experience of getting a diagnosis can be difficult. We often do not hear the views of people currently looking for a diagnosis, or talk to them about how diagnosis relates to their identity. In our study, we looked at experiences of people currently seeking an autism diagnosis in the UK. We used participatory methods, where six people seeking diagnosis were included as collaborators in the research. They took part in four different sessions, where they helped to shape the research, took part in interviews about their experiences, and helped to analyse the patterns in all the interviews. We also used something called photovoice during the interviews, where they could use photos to show how they felt about navigating a diagnosis. We identified four common themes: 1) everyone had experienced some form of crisis before seeking diagnosis. 2) when they realised they were autistic they felt seen, 3) the diagnostic process and criteria were not working and they felt judged by clinicians, and 4) there was limited support available after diagnosis. In another session we identified actions that need to be taken which have implications for policy and practice, including improving the diagnostic process and criteria *with* autistic people, autistic people being listened to more by people like General Practitioners and clinicians, and diagnosis services needing to be more flexible and appreciate different aspects of someone's identity and neurodivergence.

Introduction

Many autistic people make it into adulthood before receiving a diagnosis (Huang et al., 2020). Diagnostic inequalities often mean girls and women fail to be recognised as early as white cisgender males, confounding the oft-cited figure of a 4:1 male ratio (Christensen et al., 2018; Van Wijngaarden-Cremers et al., 2014), which can be further compounded by racial inequality (Jarquin et al., 2011). Diagnosticians report that assessments are "more challenging" for women and claim this is due to incongruence between diagnostic tools and "female" presentation (D'Mello et al., 2022, p.1936). While some hypothesise that women are more likely to 'mask' or 'camouflage' being autistic and therefore go unidentified (Hull et al., 2020), there has been a bias in research that focuses on cis males to the detriment of understanding of autism across genders and diagnostic processes across age (D'Mello et al., 2022; Mo et al., 2021). The process of adult diagnosis of autism is not well-studied, understood, or evaluated, partly because diagnostic processes for autism tend to be associated heavily with children and adolescents (Lewis, 2017). While there is a growing body of work on the impact of adult diagnosis, there is less about shifting identity or experiences during diagnosis (Corden et al., 2021). It is important to understand both the impact and experiences of undergoing diagnosis processes as an adult.

Academic interest in adult autism diagnosis is growing, with a scoping review identifying 82 studies on this topic (Huang et al., 2020). Many of these studies focused on co-occurring conditions, prevalence of diagnosed autistic people in the population, and pathways to diagnosis. Only 17 studies focused directly on experiences of diagnosis. These studies highlighted feelings of relief following diagnosis (e.g. Jones et al., 2014; Lewis, 2016) and enhanced self-understanding (Punshon et al., 2009; Tan, 2018). However in interviews with late-diagnosed older adults, some describe viewing being autistic negatively (Hickey et al., 2018), and feeling isolated after diagnosis (Griffith et al., 2012). In interviews with

Australian adults, Lilley et al., (2022) identified how being diagnosed helped participants make sense of past experiences, but some spoke of diagnosis as *"a blessing and a curse"* (p.1402).

The relationship between age and diagnosis for late-diagnosed autistic people should be explored in more depth, as age of diagnosis and lack of diagnosis as a child may have important implications for development, quality of life across the lifespan, and identity. Autistic adults' mixed experiences of adult diagnosis often relate to the impact diagnosis can have on identity. Late-identified autistic people often grow up feeling disconnected from peers (Cooper et al., 2021; Lilley et al., 2022) and sensing they are different (Leedham et al., 2020; Lilley et al., 2022) but do not often have the language or resources to understand these differences. They also report engaging in masking to hide differences and avoid stigma (Pearson & Rose, 2021; Perry et al., 2021). Realising they may be autistic provides a lens to view past experiences (Lilley et al., 2022), but some experience a sense of grief (Arnold et al., 2020). Corden & Cage (2021) found a positive relationship between time elapsed since diagnosis and pride in autistic identity, suggesting that as the liminality of the diagnostic process fades, people make sense of and feel more comfortable in their autistic identity. This process requires time, exploration, reflection, and developing a new autistic identity (Kelly et al., 2022; Leedham et al., 2020; Lilley et al., 2022). Yet it links to self-acceptance (Harmens et al., 2022), self-compassion (Lilley et al., 2022), and increased personal wellbeing (Leedham et al., 2020). In addition to personal identity, many may experience a shift in social identity whereby they become a part of the wider 'autistic community' (Cooper et al., 2017). Harmens et al., (2022) and Arnold et al., (2020) found that diagnosis fostered a sense of belonging within the autistic community. These communities provide a space for people to be authentically themselves and experience understanding and acceptance from others (Lilley et

al., 2022). For late diagnosed people, there may be a negative impact of not having this self-awareness (Leedham et al., 2020).

While there is a growing body of work on the impact of adult diagnosis, and despite the eventual positive impact that diagnosis could have on identity, there is very little research on adults experiences of diagnostic pathways. In the limited extant research autistic adults in the UK report mixed satisfaction with the diagnostic pathway, with satisfaction predicted by waiting time, number of referrals, and quality of information shared at diagnosis (Jones et al., 2014). An interview study including UK-based autistic adults highlighted feelings that gatekeepers to diagnosis such as General Practitioners (GPs) lacked sufficient understanding of autistic people and focused on negative aspects of being autistic (Crane et al., 2018). A survey of autistic adults in New Zealand noted some satisfaction with the assessment stages, but dissatisfaction with post-diagnosis support (Evans et al., 2022). Lack of support post-diagnosis is frequently highlighted as an issue (Huang et al., 2020) and there are challenges in accessing support from employers or social care services post-diagnosis (Kelly et al., 2022). In a UK study of clinicians and autistic adults, Wigham et al., (2022) identified characteristics deemed to constitute an 'optimal' adult autism diagnosis assessment service, including the provision of better quality information, more training for professionals, and the need for multidisciplinary teams who understand co-occurring mental health conditions.

While research is developing around diagnostic outcomes, most research has focussed on those who have already concluded the diagnostic process (Huang et al., 2020) with few studies including people who self-identify or are going through the diagnostic process (de Broize et al., 2022; Huang et al., 2022; Lewis, 2016). Thus there is a need to further explore the views of those currently seeking a diagnosis to understand what can be done to improve the experience and foster a positive sense of autistic identity. The current study aimed to address gaps in knowledge using an emancipatory, participatory approach to understanding

issues with the diagnostic process, and to provide concrete actions that would improve the diagnostic process in future based on the experiences of those currently experiencing it.

Methods

We chose to employ an adapted participatory photovoice method (which we will refer to as photovoice for brevity) because autistic people are often subjected to testimonial and epistemic injustice (Chapman & Carel, 2022) whereby their life narratives, testimony and expertise is both side-lined and erased. Photovoice is an established participatory, visual research method, and is often used to stimulate social change (Li et al., 2001; Wang & Burris, 1997). It is a collaborative process from beginning to end, where participant involvement is sought across multiple sessions (which may include for example singular or multiple photographic sessions, discussion sessions, joint data analysis), creating feedback loops that mean the end data is a culmination of rich and valuable situated knowledge that has been shaped through joint-working (Wang & Burris, 1997). Unlike traditional methods in psychology which only use participants as sources of data during collection phases of the study, in photovoice participants are collaborators who are recruited at the beginning and contribute to the design and implementation of the research. This brings together "collective identified needs and preferences", where community-collaborators take part in the process which they helped to co-create and then are involved with proper acknowledgement in the analysis and dissemination (Evans-Agnew &Rosemberg, 2016). This method fosters an emancipatory framework that is guided by the localised knowledge of a specific community, is responsive to their needs and situation, and prioritises situated knowledge in a way that non-community based participatory methods fail to capture, by drawing on collective expertise. By doing so, photovoice can foster self-efficacy of research partners and enhance engagement of communities traditionally disenfranchised from research (Israel et al., 2010).

These methods are central because they preserve and respect the voice of the community they belong to. While there can be large variation between implementation practices of photovoice, fidelity to the original concept means participants being collaborators throughout the whole process (Sutton-Brown, 2014). A review of the photovoice method has found a "surprising" lack of incorporation of collaborators voice during the analysis and publication stages of photovoice projects (Evans-Agnew & Rosemberg, 2016). This can contribute to an authoritarian research model which prioritises top-down methods and outcomes lead by researchers and for their gain (Sutton-Brown, 2014). To avoid this, we made an early decision in the process to foster methods of power-sharing in the analysis and publication process to prevent erasure of non-academic collaborators voices or work.

Community involvement

This was a participatory study, involving a mix of autistic and non-autistic academic researchers and autistic community collaborators. The academic researchers are all research psychologists, working in Scottish or English universities, with a range of different personal and professional backgrounds. We are white (but not all British), and include two women, and one trans-nonbinary person. We use the term community collaborators to describe community members who are not academics but took part in the design, analysis, and write-up of the research, as well as contributing their experiences via interviews. All collaborators were paid for their time (photovoice sessions, feedback and writing) following National Institute of Health Research guidelines (NIHR, 2022).

Recruitment:

In February 2022 the academic team advertised (via twitter, a dedicated website, and our own professional websites) to recruit people interested in collaborating on a research project about navigating autism diagnosis in adulthood. The advertisement linked to a webpage outlining the plan for the project and noted that the collaborators would contribute to the study design. Eligibility criteria stated that they had to be living in the UK and currently seeking diagnosis. Those interested completed a short form and consented to being contacted about the research. We received a high volume of interest but due to funding limitations could only involve a small group (n = 8). We read the expressions of interest and selected eight people who had diverse current circumstances (e.g. were at different life stages). We contacted these eight people, six of whom came to the first session and became involved in the entire project. We did not use purposive sampling using demographics and were unaware of participant characteristics until we met for the first time, thus it was not our intention that the final group comprised 6 white women.

Community Collaborators:

Six women on the adult autism diagnosis pathway shared their experiences. Mean age was 32.67 (*SD*=9.75, range 21-46). Five were white British and one reported another white background. Three had completed an undergraduate degree, one a National Vocational Qualification, one a postgraduate degree and the other a PhD. Two were employed full-time, two part-time, one was a student, and one had been on sick leave and only recently returned to part-time work. Four reported other diagnoses including depression (*n*=3), anxiety (*n*=2), borderline personality disorder (*n*=1), joint hypermobility syndrome (*n*=1) and chronic migraines (*n*=1). Five lived in England and one in Scotland. All were seeking autism

diagnosis via the National Health Service (NHS). Figure 1 displays where they were

positioned on the diagnostic pathway. Since our interviewees are also collaborators and some

are co-authors in this research, to protect their identities pseudonyms are used alongside

quotes. We obtained ethical approval from the Universities of Stirling and Sunderland.
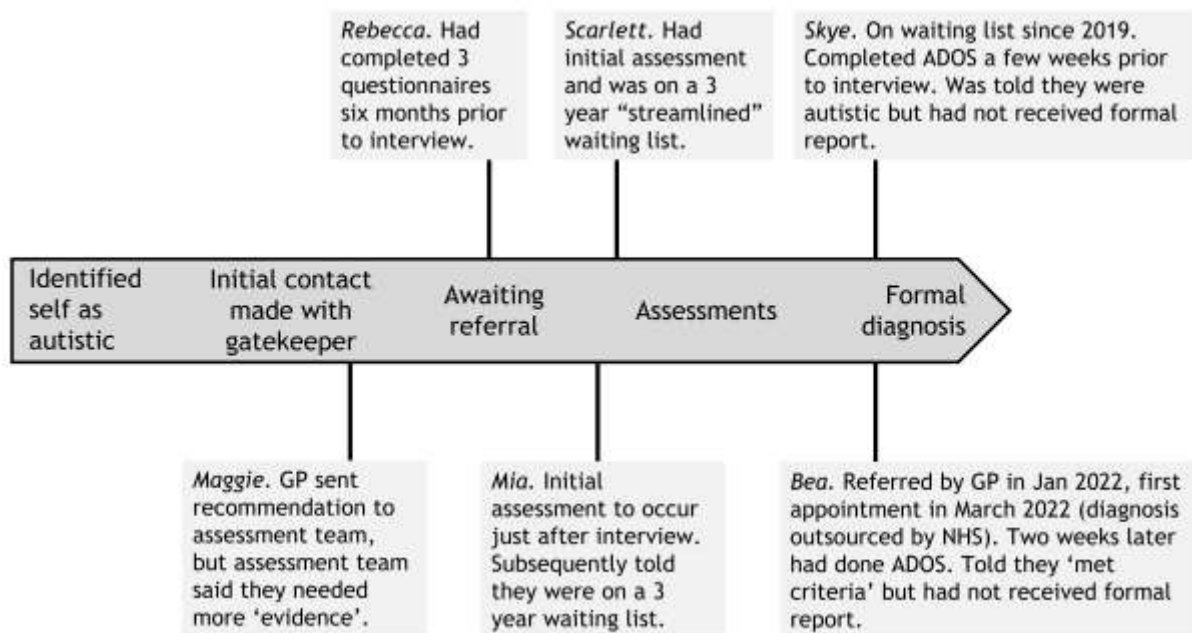

Figure 1. Diagram outlining interviewees' position within the diagnostic pathway at the time

of interview. Interviews took place in April–May 2022.

Materials and procedure

We ran four sessions (see Kolb, 2008) so that we could provide an ongoing, interactive and collaborative process whereby experiences from the previous sessions could inform the design of the next sessions. A summary diagram of the synchronous sessions, and asynchronous preparation between these sessions is available (Figure 2). The process was as follows:
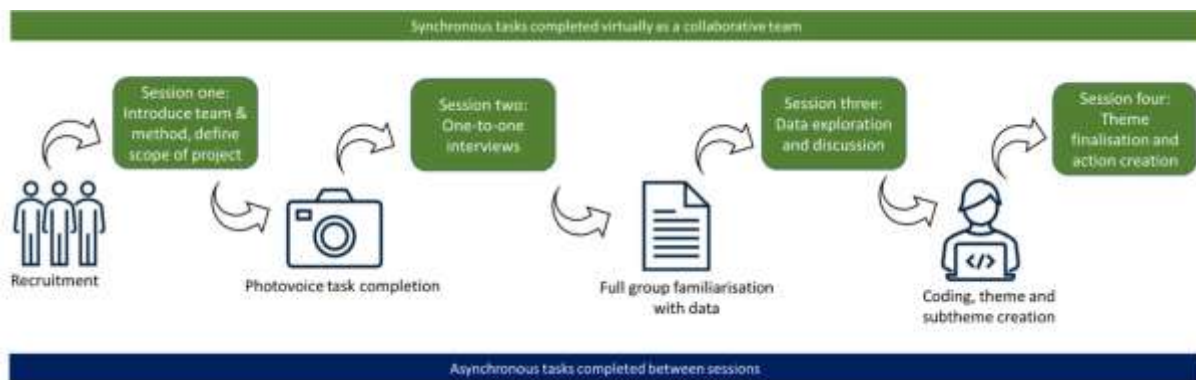

Figure 2. Diagram outlining the progression of the project, including both synchronous and asynchronous steps.

Three out of the four sessions were group sessions. We chose group sessions to facilitate co-reflection and mutual sense-making, given the community-based nature of photovoice. These sessions provided our co-researchers a space to engage with other community members who had a shared experience, which can be validating and highlights the emancipatory nature of community based participatory research. Group sessions are commonly used in photovoice, particularly at the analytic phase, acknowledging that "each image may generate many meanings" (Sutton-Brown, 2014). In the first group session (April 2022), we met via Microsoft Teams and the academics explained the general aims of the project and photovoice methodology, before gathering the group's views on this approach. We also discussed and

generated ideas for relevant questions for the semi-structured interviews in session two. Here, we used an online brainstorming tool (Padlet) where collaborators added suggestions for interview questions both during and after the session, and everyone reviewed these questions before they were finalised.

In the second session (April-May 2022), the six collaborators took part in individual interviews with the academics. Prior to interview, interviewees gave informed consent and completed a short demographic questionnaire. They were given the option to prepare images that would be used to reflect on their experiences in relation to seeking a diagnosis. As the study was conducted online (to reduce geographical and pandemic-related barriers), they collate images into a slideshow which was screen-shared during the interview. They could use personal photos or stock images, artwork or any media that would help them express themselves as opposed to photography alone. Five decided to use the photovoice method (one wrote an additional poem), one elected not to use photovoice but wrote down and read their story. Those using photovoice explained in detail what the images were showing and how they related to their experiences. The interviewer asked follow-up questions where necessary. After photovoice, we conducted semi-structured interviews, using the questions we had previously developed as a group. The questions focused on three topics (see supplementary materials): thinking about and seeking diagnosis (e.g., "what made you seek out an autism diagnosis?"), views about being autistic and autism (e.g., "how do stereotypes about autism fit with your own experiences?"), and community and identity (e.g., "have you linked into any autistic communities before or since identifying you might be autistic?"). On average, the interview took 83 minutes (range 67-100 minutes). We recorded and transcribed them using the Microsoft Teams in-built transcription software, and checked them thoroughly for inaccuracies. Afterwards, we sent transcripts back to interviewees for member-checking.

Prior to the third session (June 2022), we shared anonymised transcripts with the group so everyone could make observations about possible themes. Everyone gave permission for their transcript to be shared. In the session, the collaborators discussed any patterns they had noticed. The academic researchers then individually shared their initial thoughts on themes and asked for feedback on these. Post-session we shared a document with meeting notes and theme ideas with the group for further feedback, and one researcher revisited the transcripts, then collated updated theme names and exemplary quotes. More details on the thematic analysis are available below.

In the fourth session (July 2022), we discussed the updated themes and agreed on the theme names. As photovoice is a community-based action method (Becker et al., 2014), we discussed actions that should be taken based on our findings. We used an Padlet to gather ideas, which we summarised into action points.

Analysis

We generated themes through reflexive thematic analysis (Braun & Clarke, 2020). The academic researchers analysed the transcripts individually to familiarise themselves with the data and noted initial themes for discussion with the wider group, and present these to generate discussion. Following the group discussion (described above), one author coded the data using NVivo and developed the themes and subthemes, which were further refined alongside the full team. One researcher completed the coding based on the wider conversations of the analysis team to allow for continuity in the coding process between transcripts. We continually refined the themes, sub-themes, and codes as a team, making the analysis process iterative and collaborative. We took a critical realist approach allowing us to understand the subjectivity of experience within real-world, inflexible diagnostic processes (Botha, 2021). We embedded reflexive practice into the process by constantly considering

our roles in creating and maintaining narratives about autism as a mixed-neurotype team. From the outset, we embraced a non-traditional form of validity, aiming towards transgressive validity (Lather, 1993). In particular, catalytic validity (the incitement towards social and discourse change) and rhizomatic validity (the ability for research to be subversive and unsettling in the face of authority) were two key benchmarks. We aimed to challenge research and practice systems which alienate autistic people, and to enshrine their voices with empowering research.

Results

We identified four themes, with several sub-themes within these (Figure 3), which centred around the experience of diagnosis and exploring autistic identity. Additional quotes are available in the Supplementary Material. We have also included visual representations for each theme. It is important to note that we were not able to use some of the original photos for the manuscript as the photos that participants presented as are not available due to copyright, or were personal. Thus we chose similar photos and confirmed their use with our collaborators as representative of their intention.

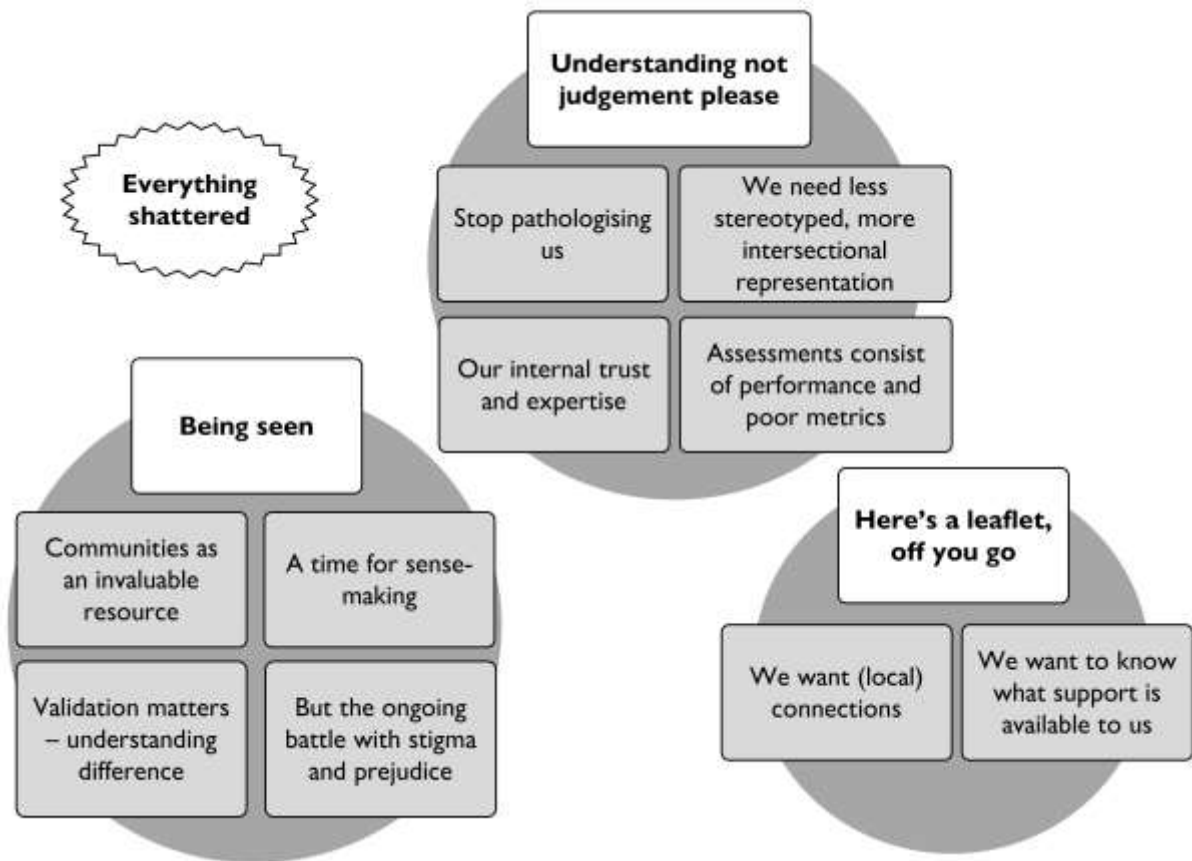**Figure 3.** Visual representation of the identified themes and sub-themes.

Theme 1: Everything shattered.

As participants reflected on their lives, for most there was a crisis point whereby everything

shattered, and they felt overwhelmed in an overwhelming world. This shattering was

typically the trigger to seek diagnosis, with this theme represented by Figure 4, an image

selected by one of the interviewees.

Figure 4. Image representing the theme 'everything shattered'. Source: 'Point of impact' by Bill Harrison is licensed under CC BY 2.0; https://www.flickr.com/photos/bill_harrison/6074633858; https://creativecommons.org/licences/by/2.0/.

Notably there was a sense that interviewees had felt 'different' throughout their lives, but a crisis point was reached which led to re-evaluation:

> *"Life got complicated, as it does when you have children, and I was just finding myself getting overwhelmed, and that's probably what the [photo with the] lady with her head in her hands is all about. It was lots and lots of things like my executive functioning was just rubbish… I've always been like it. This isn't something that was new, but it's definitely something that having kids suddenly revealed."* (Bea)

Both Skye and Mia referred specifically to "autistic burnout" as one of the key factors in prompting them to seek diagnosis, whereby they had noticed a loss in their ability to function the way that they were used to.

For some, the COVID-19 pandemic had particularly caused a change in circumstances, with lockdown providing an opportunity to "unmask" (Mia) or feel "more autistic" (Scarlett)

Theme 2: Being seen.

Despite having faced a crisis point that led to them considering diagnosis, collaborators now felt they were 'being seen' - seeing themselves more clearly, being seen by communities, but sometimes being seen in negative ways by others. Figure 5 shows an image representing this theme from the interviews. This theme is expanded across several subthemes:

Figure 5. Image representing the theme 'being seen'. Source: Image released free of copyrights under Creative Commons CC0: https://pxhere.com/en/photo/1563077.

2.1: Communities as an invaluable resource.

Community – whether online, family or friends (usually neurodivergent) – helped people to understand their experiences and find commonalities. Particularly, these communities enabled positive reflections to occur, rather than focusing on deficits. For example, one interviewee noted that:

> *"[Connecting is] useful, because it made me realise that they're really fascinating. And I'm fascinating. [...] I realised that I was really connecting with people, and it was fun and no-one was telling me that I was too much. No-one was telling me to be quiet."* (Maggie)

Communities also provided an opportunity where they could check in with others and make sense of their experiences. Social media was highlighted as both a "resource" for advice and useful information (Skye and Rebecca) and source of "validation" (Scarlett and Bea). Having like-minded others seemed invaluable when it comes to learning about and appreciating autistic identities.

2.2: Validation matters – understanding difference.

Another aspect of being seen was how interviewees saw and understood themselves better after realising they could be autistic. After a lifetime of feeling different, this was now being validated through seeing "positive representations" of autistic others (Maggie), reducing the "negative self-talk" (Scarlett") and fostering "pride" in autistic identity (Rebecca).

Some reflected on how former negative self-views had been reformulated, through being able to contextualise past experiences within an 'autistic lens'. This helped them to validate their differences which may have previously been construed as problems with themselves:

"A lot of the things that I grew up hating about myself…Had I known [I was autistic] when I was younger these things wouldn't have bothered me as much. I would have been able to say, well, actually this is nothing negative. This is who I am. And I feel like I would have been nurtured a bit more." (Scarlett)

2.3: A time for sense-making.

As they reflected on links between identity and diagnosis, some felt that seeking diagnosis was not necessarily about the formal label itself. Rather, it was seen as a time to reflect, process and understand who they are:

"What do we want this for? Is it so that you've got a rubber stamp? Something that someone says to you, why do you need this reasonable adjustment at work and go, I have my certificate here, I'm a bona fide weirdo […] This is the bit where I go - why do we want it? Why do we need it? Why is it important? And I think for me as a 41-year-old, mostly it's so I understand me." (Maggie)

However, sense making was also bittersweet. They spoke about the "struggles" they had experienced up until that point, realising that life had been hard for them which led to a "weird sadness" (Scarlett). However they also reflected that their "realisations" gave them permission to recognise what they needed and act on it (e.g. "a weighted blanket" or "saying no to going out").

2.4: But the ongoing battle with stigma and prejudice.

Despite many positives of seeking diagnosis, there were also ongoing issues that particularly related to stigma and prejudice. This was often felt from other people who could be "negative" about their autistic characteristics, or would imply that they "couldn't be autistic" which was further explained by Mia:

"Everyone there was like "oh no, I don't think you're autistic", but saying it in a sympathetic or reassuring way, as if I was meant to feel better that they thought I definitely wasn't autistic. Obviously that made it feel like they thought it was something that would be 'wrong' with me if I was. But I didn't find that really upsetting or anything, I just found it quite ignorant."

However there was also an acknowledgement by some of the 'internalised ableism' they had to contend with over the years that had made them distance themselves from the label and deny that they might be autistic. Thus 'being seen' comes not only with positives, as outlined in the other sub-themes, but also elements of risk due to the stigma attached to being autistic.

Theme 3: Understanding not judgement please.

Specific issues were highlighted in the diagnostic pathway, and how this did not seem to be working for the interviewees. Collaborators wanted to feel understood by professionals or clinicians rather than judged, as represented by the image shown in Figure 6. This theme had several sub-themes:

Figure 6. Image representing the theme 'understanding not judgement please'. Source: 'Meeting room stencil graffiti' by Richard Rutter is licensed under CC BY 2.0; https://www.flickr.com/photos/clagnut/252185030/; https://creativecommons.org/licences/by/2.0/.

3.1: Stop pathologising us.

Often interviewees felt others, typically professionals, held on to medicalised definitions of autistic people, which linked to a sense of being pathologized and felt this approach lacked empathy. They highlighted how characteristics associated with being autistic were often based on stereotypical representations and normative ideas of behaviour. They felt that some practitioners saw diagnosis as a "box-ticking" exercise against criteria, but that this varied between practitioners and the diagnostic tools they used:

"I had quite a refreshing, unexpected experience of the practitioner that was assessing me acknowledging quite openly that there were problems with the assessment process that needed to be worked around and that it's about the whole formulary. It's not just ticking boxes on a form and passing, you know, ticking boxes through the ADOS interview. I get the impression that there's a lot of clinicians who aren't yet mindful of that." (Bea)

3.2: Our internal trust and expertise.

Being trusted, trusting yourself and believing that your own experiences gave you expertise was something important, but not always appreciated by professionals, which raised questions about who or what is meant by "expertise":

"The assessment clinic keeps just saying we need more evidence before we can assess you. And I'm like, OK so where do you want me to get that evidence from? "Well, you'll need to see somebody who has expertise in autism". You are the people with that - and it's just straight back to a bit of a brick wall. [...] [There's] this wonderful quote [...] a doctor saying don't confuse Google with however many years of experience. And I get that. I think people over-Google, I think the medical field do know what they're talking about. They've done 6-7 years, it's a long time so that they can, with real evidence, be able to say stuff that they do. And I get that. But equally, we know ourselves quite well." (Maggie)

For some, receiving the formal label via diagnosis felt redundant in terms of being able to appreciate and trust themselves - that although they might not have the official diagnosis, they "knew their truth" (Skye). Others also spoke about how "invalidating" it would be to be told by a clinician "after all this time" that they didn't meet the criteria and how it would be hard to "trust their assessment".

3.3: We need less stereotyped, more intersectional representation.

Often stereotypes did not fit with interviewees' personal experiences, or they felt more intersectional representation of autistic people were lacking which had made it harder to "recognise" themselves as autistic. There was a sense among participants that media representations were often "centered around men". They felt that "diverse representations" would help them see themselves more in others, e.g. "I want to see more arts and culture autists" (Mia), but would also help clinicians recognise a broader representation of autism which might improve access to diagnosis for others:

> *"One of the reasons I definitely want to go through the assessment [...] is so that [...] there are more people who come across differently going in. Meaning that the people assessing go oh, well hang on a minute, we've seen someone a little bit like this before and you're just adding to this [...] I think that's what it is for me. You're being something that is bigger than you, so that it might help the future."* (Maggie)

3.4: Assessments consist of performance and poor metrics.

Interviewees said that diagnostic assessments (like questionnaires or the ADOS) had a performative element,. These assessments did not align with their experiences or accurately measure what they were meant to. The AQ in particular was noted as "inaccessible" due to difficulties figuring out what the questions were asking and their binary nature. Some reflected on how the tools made them question the whole diagnostic process, with multiple people noting the ADOS in particular as "weird":

> *"[The ADOS] was a bit weird. [...] This children's book, it was pretty much a picture book with minimal text about some frogs that were suddenly flying through the night.*

And it was quite entertaining. I didn't mind it. It was a bit bizarre […]. The fact that

autism is diagnosed behaviorally, it seems absurd to me." (Skye)

Skye's comments here align with Maggie's suggestion that clinicians may encounter people "masking" during the diagnostic process, limiting the utility of behavioural assessments which expect autism to be identifiable on the basis of externally visible characteristics.

Theme 4: Here's a leaflet, off you go.

There were some key concerns about life after diagnosis, with two sub-themes centred around wanting more connections and information. Figure 7 shows an image representing this theme.

Figure 7. Image representing the theme 'here's a leaflet, off you go'. Source: 'Leaflet' by Rosie Noronha is licensed under CC BY-NC 2.0;https://www.flickr.com/photos/green_lou_333/5352913258/; https:// creativecommons.org/licences/by-nc/2.0/.

4.1: We want (local) connections.

Collaborators wanted to access local or more meaningful connections – they lamented not knowing where they could find people going through the same as them nearby. Particularly there was a need for adult-appropriate support and services:

> *"I'd love to be able to go places and experience things with autistic people, because even my nephew, he's nine [...] he gets to go to where there's other autistic children. And he absolutely thrives. He gets excited to go every week. And I just… It's what, I love it, I love it so much to see him thriving in that environment and I'm a little bit jealous. I'm a little bit jealous of a 9-year-old."* (Scarlett)

Feeling few connections had an impact, leading to feelings of "loneliness". Online communities were viewed as more abundant, however "community support" and "local groups" were highlighted as essential.

4.2: We want to know what support is available to us.

Contemplating the support that could be available to them post-diagnosis, some wanted to know what was available in terms of workplace or educational adjustments. Our collaborators spoke about difficulty knowing "who to ask" or "where to go" for accommodations, finding it hard to "imagine what support there is" (Mia) or "who to go to for advice" (Bea), and where to find information about "policy" (Rebecca).

Action points

Following reviewing of themes and sub-themes, together we identified several actions based on our findings, detailed in Figure 8. These actions are organised around *"nothing about us,*

without us" - ensuring that autistic people are involved in improving diagnostic criteria and pathways, staff training and resources. Next, the actions suggested that others *"listen up!"* - that autistic people must be listened to and their experiences acknowledged and validated, by a range of different groups such as doctors, clinicians, policymakers and researchers. Finally, we identified actions related to *"flexibility and openness in services"*, with the need for readily available services with different options to enable personalisation, as well as services appreciating wider neurodivergence and intersectionality.
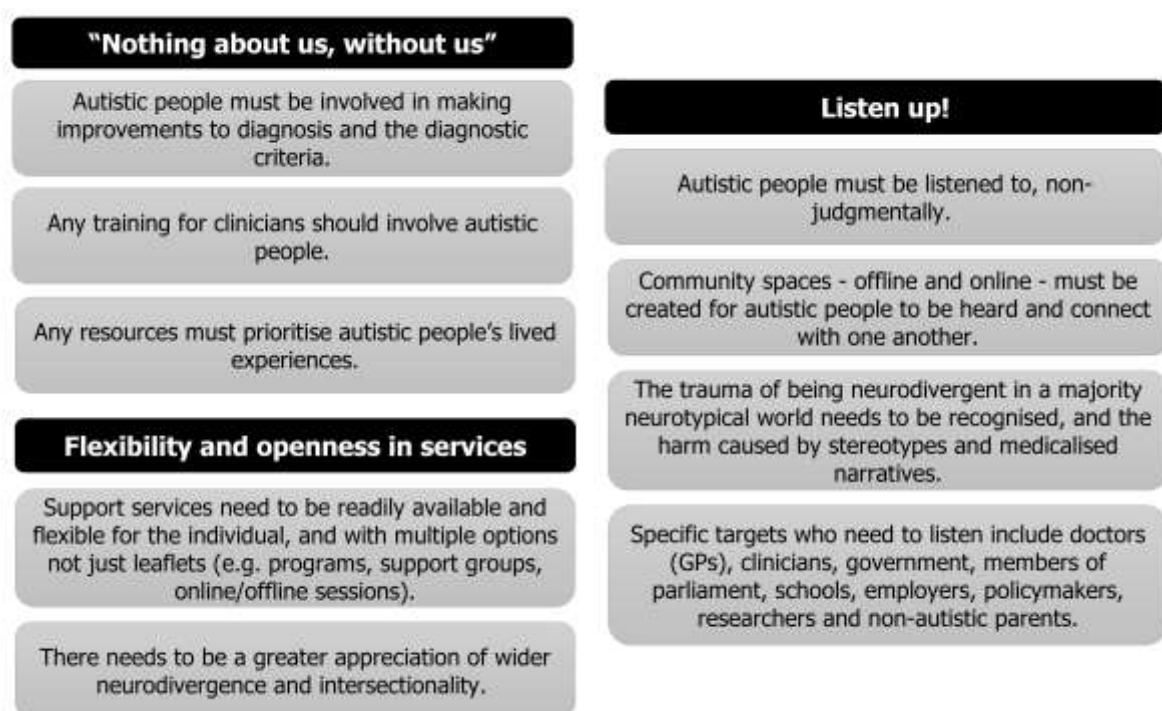
"Nothing about us, without us"

Autistic people must be involved in making improvements to diagnosis and the diagnostic criteria.

Any training for clinicians should involve autistic people.

Any resources must prioritise autistic people's lived experiences.

Flexibility and openness in services

Support services need to be readily available and flexible for the individual, and with multiple options not just leaflets (e.g. programs, support groups, online/offline sessions).

There needs to be a greater appreciation of wider neurodivergence and intersectionality.

Listen up!

Autistic people must be listened to, non-judgmentally.

Community spaces - offline and online - must be created for autistic people to be heard and connect with one another.

The trauma of being neurodivergent in a majority neurotypical world needs to be recognised, and the harm caused by stereotypes and medicalised narratives.

Specific targets who need to listen include doctors (GPs), clinicians, government, members of parliament, schools, employers, policymakers, researchers and non-autistic parents.

Figure 8. Action points identified based on our findings.

Discussion

This study uniquely obtains the perspectives of six women currently seeking an autism diagnosis as an adult in the UK. The diagnosis experience was beset with challenges, with current approaches felt to pathologise experiences, ignore intersectionality, lack validity and dismiss lived expertise. Seeking diagnosis tended to come after a crisis point, with autistic identity explored through re-evaluation of life experiences and feelings of difference. Often

these feelings were validated through communities of neurodivergent people. When considering post-diagnostic support, the need for local communities was highlighted as important. We also identified a number of actions, with a clear need for change within the adult autism diagnosis experience.

The sense that diagnosis had to be preceded by a 'breaking point' echoes previous literature (Lilley et al., 2022), and may reflect the diagnostic criteria being grounded in the need for 'significant impairment' to be present for someone to be classified as autistic. These findings relate to an ongoing debate about how autism is conceptualised (e.g., Pellicano & den Houting, 2021), given that there are likely many undiagnosed/unidentified autistic people who remain so because they have not yet reached breaking point or are living happily. Some have discussed whether autistic people who are coping (or thriving) really *need* a diagnosis (Stewart, 2017), which raises the question of what diagnosis is *for*. The utility of a diagnosis was highlighted by our interviewees, who explored the notion that whilst a formal diagnosis could be useful for accessing support, in reality few supports currently existed. For some the process served to foster self-understanding and find community. This dichotomy between how autism is currently identified (e.g., by a clinician) and confirmed (via a clinical diagnosis) has a complex relationship with what people can gain from finding out they are autistic. This suggests that we may need to rethink and redefine how we consider autism across the lifespan. One potential way of rethinking is a transdiagnostic approach, which identifies support based on personal need rather than on diagnosis (Astle et al., 2022). Exploring such approaches may be a way forward for improving diagnosis experiences.

Our interviewees highlighted the importance of clinical professionals extending trust and listening to them when they shared their experiences. Many seeking diagnosis have engaged in thorough research prior to approaching diagnostic services, and though they may not be the expert on diagnosis, they are expert on their own experiences. It is important that

GPs and clinicians are open to recognising that autistic people may not fit preconceived stereotypes of autism. However, even a clinician with a nuanced understanding of autism may be constrained by diagnostic tools (Adams & May, 2021) which rely on particular behavioural expectations and presentations (see Milton et al. 2019). There has been recent work to develop tools more suitable for women (Gale & Bradshaw, 2021) and it is important this continues, applying an intersectional lens to appreciate that individual identities and circumstances may impact on how we appear to others (Botha & Gillespie-Lynch, 2022).

Interviewees also stressed the need for better quality support during and post-diagnosis. Being given a leaflet/information pack was viewed as inadequate. Practical information (e.g. how to seek accommodations) and access to community and connections with other autistic people was crucial. These findings emphasise the importance of community connectedness (Botha et al., 2021), suggesting that diagnostic support needs to be inclusive of practical information and links to community (e.g. Crane et al., 2020), and provided earlier in the process as opposed to leaving people in limbo while they wait for clinical confirmation. Connection, positive identity, and pride is a key form of community level resilience which may buffer against the internalisation of negative messages about marginalised identities (Meyer, 2015). Participants also stressed these communities need to be local too, meaning that a reliance on global internet communities cannot replace local hubs of real-world autistic connection.

Sense-making of an autistic identity is complicated, since it involves management of how one sees themselves versus how they feel the world or society sees them. This identity management is not limited to autistic people but is a process undertaken by marginalised people more generally who face systemic exclusion, discrimination and victimisation, and the internalisation of these events can all shape the positivity and salience of identities (Bruce et al., 2015). Interviewees expressed similar sentiments, whereby their views of autism were

shaped before they got a diagnosis, having internalised negative stereotypes. This meant some had to work to understand and process their own internalised ableism when fostering an autistic identity.

Part of using photovoice is to enact social change and address community concerns (Gabrielsson et al., 2022), therefore we also identified specific future actions based on our findings. The actions first centred around *involving* autistic people, whether that was within making much-needed changes to diagnostic criteria, training for clinicians, or resources for others. Second, there was a focus on *listening* to autistic people, with the need for communities where experiences could be shared, and for those listening to acknowledge the trauma linked to living in a predominantly neurotypical world where medicalised narratives abound. Those who most need to listen included GPs, clinicians, members of parliament, schools, employers, policymakers, researchers and non-autistic parents. Finally, action was needed in transforming support services so that these are more readily *available and flexible*, with multiple options available (e.g. support groups, online/offline programs). Support must also better appreciate neurodivergence and intersectionality - how those needing support have multiple identities, some of which may be marginalised (e.g. being both Queer and autistic, or a woman and autistic) and may impact expected presentation (e.g. not fitting the stereotype of an autistic person).

Our actions have policy implications, which we apply here to the UK context. However many of the key points we highlight here would transfer to service improvement at a more international level. The ten-year (2011-2021) Scottish Strategy for Autism (Scottish Government, 2018) aimed to improve quality of diagnosis and support for adults, including funding a National Post-Diagnostic Support Programme. However, the Strategy was criticised for making little progress, and delays to diagnosis and issues with post-diagnostic support persist (Scottish Government, 2021a). The subsequent Transformation Plan (Scottish

Government, 2021b) states the Scottish Government will continue to improve post-diagnostic support and explore mandatory training for NHS staff, and they will listen to autistic people. This approach aligns well with our actions, so long as autistic people are genuinely listened to and their expertise prioritised. In England the 2021-2026 autism strategy (HM Government, 2021) acknowledges the need to improve access, reduce waiting times and improve post-diagnostic support. However, there is a focus particularly on children and young people rather than adults, with £10.5 million invested in diagnosis for children and young people, compared to £2.5 million for adults; and there is a lack commitment to involving or listening to autistic people (Pukki et al., 2022). We argue that the involvement of autistic people in decisions that affect their lives is critical.

Strengths and limitations

Our study captures the views of only six people seeking diagnosis in the UK. However, we have conducted an in-depth participatory project, involving non-researchers in multiple sessions that determined the design, interpretation of findings and action points. All were paid for their time, but this project was still constrained by funding (funded only by a small amount from our respective universities rather than an external body). Lack of funding for participatory autism research is a systemic barrier preventing autism researchers being able to engage fully in such practices (den Houting et al., 2021; Pickard et al., 2021). Other limitations include the solely white sample, given the intersectional barriers to diagnosis (see Diemer at al. 2022). Our collaborators were also at varying stages in the diagnostic process, meaning they could not all comment on the same issues (e.g. clinical tools, or clinical approach). Similarly, this is a context situated study (as is the aim of photovoice studies), meaning a potential lack of transferability of many aspects of the study outside the UK-based diagnostic pathways. We know that applied research on topics which relate to the everyday lives of autistic people are a priority for autistic people (including diagnosis; (Cage et al.,

2022), and yet these topics are funded less often than basic science (such as genetics, neuroscience) (den Houting & Pellicano, 2019; Roche et al., 2021). We hope that our study helps inform future research and funding on this topic, with a particular focus on intersectional barriers to diagnosis, and how to make the process a more respectful and collaborative experience.

Reflection and conclusion

The aim of this research was to use an action-based participatory photovoice method that disrupts medicalised, disembodied narratives of autism, and instead situates self-understanding in the context of everyday autistic lives. The whole team are all entangled in the process of creating this data, but have worked together to build commonality to achieve this goal. The narratives here, and the research process more widely, is disruptive of a culture which objectifies autistic people and rarely gives autistic people autonomy. Our themes reflect this rejection of authority whereby interviewees described a process of coming to reject how clinicians see them, with actions to enact change. Inciting system change with a single paper is complicated, but we hope to contribute to discourse and processes which should see autistic people as humans, instead of having diagnostic processes which treat autistic people as judged objects.

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