



Navigating an autism diagnosis and autistic identity: A participatory photovoice study

Eilidh Cage¹, Amy Pearson², Monique Botha¹, Lynsey McDevitt¹, Karis King, Liz Biscoe, Kirsty Tucker

¹University of Stirling ²University of Sunderland

Corresponding author: eilidh.cage@stir.ac.uk

Introduction

Adults are increasingly seeking autism diagnoses, although often report issues with the diagnostic pathway. Few studies consider the views of people *currently* looking for a diagnosis, or within the context of identity - even though diagnosis is likely to have an impact on identity.

Methodology

This was a participatory study, involving autistic & non-autistic researchers and autistic non-researcher collaborators. The collaborators (six females, all seeking diagnosis in the UK) were involved throughout the research process, taking part in four different sessions, one of which involved sharing their experiences in semi-structured interviews with photovoice. Interviews were analysed using reflexive thematic analysis.

Aims

(1) To identify what improvements could be made to the adult autism diagnosis experience.(2) To understand how we can support positive autistic identity development after an adult autism diagnosis.

Photovoice

The interviewees could prepare photos to reflect on their experiences so far in relation to seeking a diagnosis and realising their autistic identity. Photovoice is a community-based action method, therefore in one session after themes had been identified we also discussed specific actions that should be taken based on our findings.

Themes

Everything shattered

"The thing that really spurred me on to seek a diagnosis recently was the burnout of going back to uni after the lockdown [...] And I guess that was probably a massive period of unmasking [...] and nothing has ever really felt the same since"

Understanding not judgement, please

Stop pathologising us

We need less stereotyped, more intersectional representation

Our internal trust and expertise

Assessments consist of performance and poor metrics

"The way that a lot of the diagnosis seems to go is a lot of box checking. Which doesn't really work, and I understand that's how you have to get that [diagnosis...] They sort of focus too much on what the DSM says, like if you can make eye contact, you mustn't be autistic, but you'll get sort of removed."

"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"

"That wait for the official assessment, in a sense, by now, it doesn't really matter so much because I know myself. I know my truth now. [Diagnosis] would have been much more helpful a year in"

"[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 fly[ing] through the night [...] The fact that autism is diagnosed behaviorally, it seems absurd to me."

Being seen

Communities as an invaluable resource

A time for sense-making

Validation matters - understanding difference

But the ongoing battle with stigma and prejudice

Here's a leaflet, off you go

We want (local) connections

We want to know what support is available to us

"[Connecting with others is] useful, because it made me realise that they're really fascinating. And I'm fascinating. [...] But also, just so much more than useful, because actually 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."

"Finally realising that yeah, there is something different... It was never just me being crazy or sort of quirky and stuff like that. But then it brings this weird sort of sadness almost, that you've struggled up until this point."

"I saw some of these things spelt out and, and somebody saying no, it's OK to be like that as well. And that was like a massive, big relief, you know the first time, that somebody said no, the way you are is OK."

"Back then, if somebody had said 'you're autistic', I had quite a lot of internalized ableism, I guess. And my own prejudices about what that means. And I think if somebody had labelled, I had quite a lot of like, can I do it, can't I do it, about going to [university] and it might have tipped the balance towards no, I can't do it."

"I'd love to be able to go places and experience things with autistic people because even my nephew, like he's nine and he goes to... [...] somewhere where there's other autistic children. And he absolutely thrives. [...] 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"

"I don't know what support is available. I guess that it would be helpful to know and then I would be able to assess whether I thought it would be useful."

Action points

(1) Autistic people must be involved in making improvements to diagnosis and the diagnostic criteria. (2) Autistic people must be listened to non-judgmentally. Specific groups who need to listen include doctors, clinicians, government, schools, employers, policymakers, researchers and non-autistic parents. (3) Support services need to be available and flexible for the individual, with multiple options. (4) We need greater appreciation of wider neurodivergence and intersectionality.

Conclusion

Diagnosis should be a new beginning, not an end. The current approach to autism diagnosis for adults (in the UK) appears to be incompatible with supporting positive autistic identity development. Systemic, multilevel changes are needed to improve the adult autism diagnosis experience. When is that change going to happen?