

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

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## 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.

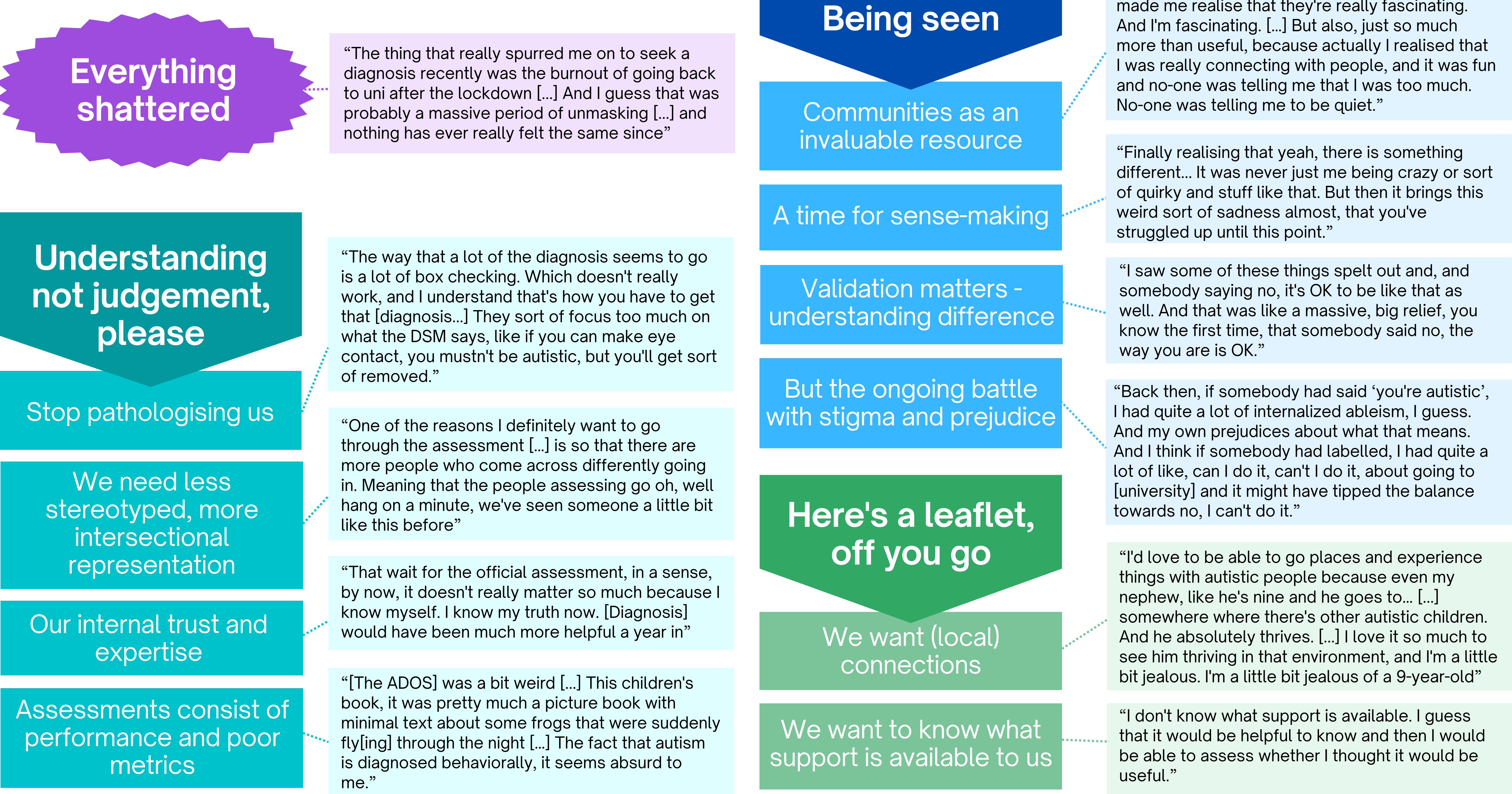
## Aims

- (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



## 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, multi-level changes are needed to improve the adult autism diagnosis experience. When is that change going to happen?