

Summary

Examining the barriers faced by autistic people

About the DRILL Programme

DRILL (Disability Research on Independent Living and Learning) was an innovative 5 year, UK wide programme led by disabled people, for disabled people and funded by the National Lottery Community Fund.

Launched in 2015, the programme was managed by a partnership of Disability Action Northern Ireland, Disability Rights UK, Disability Wales and Inclusion Scotland.

The aim of the programme was to build better evidence about approaches which enable disabled people to achieve independent living. The findings from the projects it funded can be used to inform future provision across a wide range of policy areas, and give a greater voice to disabled people in decisions which affect them.

This is one of a series of summaries of the project supported by DRILL. Final reports, toolkits and summaries of all the projects are available from the DRILL website at www.drilluk.org.uk.

Overview of the project

This project explored the barriers to participation and issues around stereotypes and misconceptions about autistic people.

It also looked at the strategies used by autistic people to overcome these barriers, and how to increase independent living options and promote full participation for them.

Approach

The project produced two questionnaires and received 223 useable responses. Interviews were also conducted with 21 of the respondents as a follow up to their questionnaire.

An additional questionnaire looked at the impacts of the research on the project team members and received 21 responses.

Findings

Autistic people commonly used a trusted or support person, such as a family member, partner, friend or support worker. This included moral support, advocacy, making phone calls, booking appointments and providing practical support such as taking them to appointments.

Masking and imitation were often used, where an individual constantly monitors and corrects behaviour and facial expressions. This can lead to exhaustion or burnout.

Strategies to obtain a diagnosis included self-referral, identifying a not-for-profit firm that did diagnosis and saving up for a private diagnosis.

To manage energy and sensory issues participants spoke about taking breaks in quiet areas, using de-stressing strategies such as exercise or contact with animals or using distraction strategies such as reading or listening to music.

Participants experienced communication barriers. They were not being listened to or taken seriously; ambiguous and imprecise language was being used and they were often misunderstood.

In employment, participants were often bullied, excluded or made to feel bad about the way they had interacted with others.

Few of the participants had their needs fully and appropriately met. This was often due to a lack of resources and/or a misunderstanding of their needs.

Participants had a number of internal barriers, such as low self-esteem and anxiety.

Findings (continued)

There was often a lack of information about a diagnosis. An NHS diagnosis was not always available or only available to people with additional conditions. There were often long waiting lists and, sometimes, people were getting lost in the system.

Autistic people often received poor quality advice or struggled with badly designed forms when trying to obtain benefits.

Often feedback on unsuccessful job applications was difficult to obtain.

Several participants experienced major difficulties with their families. Sometimes this included being estranged from them.

Recommendations

The project outlined many recommendations, some of which are listed here. All recommendations are included in the full report, which is linked below.

- Autistic people should be consulted and given a major role in creating and implementing policy
- All communications by service providers and other organisations should be clearly expressed and not ambiguous
- Autistic people should be spoken to, not about, even if a person answers on their behalf
- There must be careful and responsible reporting of stories involving autistic people
- Government must set up working groups of autistic and other neurodivergent people to produce clear information
- Autism equality training should be carried out by autistic people for service providers
- A proactive approach must be taken to reasonable adjustments by employers
- Research about autistic people should involve autistic researchers
- Funders of autism research should engage more directly with autistic researchers.

Final report

[Examining the barriers faced by autistic people](#)

Please click on report name to read the full report.

Project partners

University of Glasgow

