

Expertise and Strategies Used by Autistics to Overcome Barriers to Participation

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1. Introduction

- Participating in and contributing to society, including through employment should be considered a right not a privilege.
- Organisations benefit from diversity e.g. high achievers prefer to work for organisations with diversity practices, policies and values.
- Both autistic people and society as a whole are disadvantaged by low education and training and employment of autistic people.
- The term autistic people will be used for everyone on the autistic spectrum.

1.1 Understandings of Autism

- There are two main understandings of autistic people: social model and neurodiversity; and medical model.
- Deficit understanding related to the medical understandings of autism are still prevalent. This also affects research.
- According to neurodiversity neurological differences lead to differences in behaviour, thinking, moving, interacting. From the social model of disability autistic people experience social, attitudinal and infrastructural barriers and frequently social exclusion.
- Non-autistic people often lack information about these differences and the barriers autistics experience.
- A social model/neurodiversity approach will be used here.

1.2 Autonomy and Self-Determination

- Traditional understandings of independence unnecessarily make autistic and other people dependent as they focus on carrying out daily living activities without support and having paid employment.
- Self-determination is about agency and making decisions. It has been linked to empowerment.
- Interdependence recognises that we are all dependent on others and that autistic people can become 'vital contributors to their communities'.

2. Questionnaire

- Part of research of An Auternative Research Project, funded by DRILL.
- Investigation of participants' good and bad experiences, strategies and suggestions for improvements in 1) diagnosis; 2) health service; 3) job search and employment; 4) benefits and 5) social interaction.
- Open questions on use of technology with service providers, employment and in social interactions.
- Personal information to check for coverage of autistic community and correlations.
- Participants could be formally or self-diagnosed or seeking a diagnosis.

3. Results: Participant Overview

- 223 responses, including eight from the initial piloting stage.
- 58% female, 33% male, 6% non-binary and 4% other. 10% trans.
- Good age distribution, but only a few participants aged 65 and older and none above 74.
- 89% white, 8% Black or mixed race, 3% other.
- 47% middle class, 37% working class, few upper class, 14% other.
- 97% mainly used speech. 19% used another communication system with speech or on its on, most frequently on a mobile device or PC.

3.1 Strategies

- The following slides illustrates strategy used in social interaction and finding a job.
- They indicate the number of different strategies as well as the types of strategies used.
- Similar strategies were used in different types of situations.
- Social interaction strategies are also relevant to the workplace, where barriers frequently related to expectations about social interaction rather than the ability to do the job.
- Subsequent slides will discuss the 'trusted person' and research and preparation strategies

Strategies Used in Social Situations	%
Hiding autistic traits	85
Presence of trusted person	82
Analysis of situation or reasoning to work it out	80
Humour	73
Using small talk from other social situations	72
Imitating other people	67
Analysing the situation or reasoning to understand emotions	66
Using your (favourite) interests	64
Stimming (repetitive body movements)	60
Using prepared social script	57
Using your personality	47
Using learnt strategies to recognise emotions	42
Identifying and using your strengths	40
Using relaxation techniques	31

Strategies Used to Try to Obtain a Job	%
Trying to hide autistic traits	55
Practising interview techniques	46
Researching a prospective employer in advance	44
Disclosing that is autistic	39
Asking for reasonable adjustments	28
Setting up own business	25
Networking	22
Using contacts in the organisation	21
Support from organisation supporting disabled people into work	18
Not used any strategy	15
Training on managing in a work environment	14
Mentoring	10

4. Trusted or Support Person

- Second most commonly used strategy in social interaction.
- Also used for accessing services and using them effectively.
- Comments were all very positive about effectiveness.
- The main problem was that this strategy cannot be implemented by an autistic person on their own.
- Participation in social activities affected by the other person's circumstances.
- At events participants preferred to interact with people they knew.

4.1 Typical Comments

- 'I went out a lot more while my best friend still lived nearby ... In family situations I won't go if my partner is not there.'
- 'If I have to go to a social event, I stay out the way until I find someone I know then I stick with them.'

4.2 Make Others Feel Better

- The presence of a trusted person was also considered to make other people feel better and the autistic person be considered more socially acceptable.
- This is counter to both social model and neurodiversity.
- It leads to autistic people using their energies to feel acceptable and takes away energy that could be used to work or otherwise creatively contribute to society.

4.3 Phone

- A phone version was also used. This showed agency in countering the barrier of services needed to be accessed by phone.
- When a trusted person was not available, services were inaccessible for some participants.
- Some participants were able to provide security information and then pass the phone to someone else.

4.4 Job Search

- Friends and relatives were used as support people in job applications to help deciphering vague application forms and understanding implicit hidden meanings.
- This shows autistic people exercising agency and self-determination to resolve problems.
- However, making application forms clearer would benefit potential employers as well as autistic (and other) job applicants.
- No mention of trusted person at interviews, but possibly useful as communication support, analogous to e.g. sign language interpreter.

4.5 Employment

- Strategies included using a 'front' person in interaction with colleagues and bosses and being accompanied everywhere.
- 'Front person' strategy is similar to one I have used when participating in high level meetings.
- This involves using an intermediary to communicate with people I do not know on organisational issues. This leaves me free to focus on the meeting.
- It would be interesting to investigate whether technology could take over in these applications.

4.6 Discussion

- Using this strategy enabled participants to engage in more social activities and overcome some of the barriers to obtaining and retaining employment.
- In employment these results provide further explanations of the value of mentors and support workers to autistic people.
- If a suitable person could be found the trusted person strategy has the potential to resolve the problems of social interaction expectations.

4.6 Discussion (ctd.)

- Further investigation is required of the interaction between the autistic and trusted person, how they briefed them and ensured misunderstandings did not occur, particularly for phone conversations.
- Although this strategy involves another person it should be considered as increasing autistic people's autonomy and self determination and showing how they can show agency to overcome barriers.

5. Research and Preparation

- Research and preparation were used to increase chances of obtaining employment and accessing services.
- Prepared social scripts or learnt small talk were also used in social interaction and the workplace.
- These strategies are used to some extent by all people. However, autistic people may use them more intensively or in contexts where non-autistic people would not.
- Examples of intense preparation include searching the internet 'excessively' and 'getting to know the rules perfectly' when claiming benefits.

5.1 Job Search

- Research and preparation were frequently used strategies in job search. They were intended to improve applications and interview performance.
- Nearly half researched prospective employers in advance and over two fifths practised interview techniques.
- Nearly two fifths of participants asked for information and interview questions to be sent in advance and some asked for photos.
- A minority of participants used training on managing in a work environment

5.2 Employability and Employment

- Participants used a wide range of strategies to increase employability skills.
- Reading body language books,
- Asking for structured meetings and preparing lists. Asking for feedback and
- Keeping notes of examples of competence and scripts on how to respond in different workplace situations. These strategies sometimes had a personal cost, with some participants 'push[ing] self even if detrimental to health'.

5.3 Learnt Small Talk and Social Scripts

- Prepared scripts were used in both the workplace and social interaction (by 57%).
- Prepared social scripts were probably more useful than learnt small talk.
- They worked best for short interactions or at the start of the interaction.
- They could reduce anxiety and sometimes gave assurances as to the direction of the conversation
- They could also break down if the other person deviated from the script.

5.4 Typical Participant Comments

- ‘I have been proactive in researching my entitlements and legal background to obtaining benefits. I spend a lot of time reading forums online about benefits advice, and official guidance and publications on DWP/HMRC policies, so that I am clear about what I need to do in order to maximise my benefit entitlement.’
- ‘Scripts can help start a conversation, but don't help much beyond that as you can't plan in advance what the other person might say.’
- ‘Using a pre-prepared script can give me a sense of security going into an interaction.’
- ‘Pre-prepared social scripts lessen anxiety, but I panic when the other person deviates.’

5.5 Discussion

- Participants used different approaches, including social scripts and finding information.
- Recognition that many situations are easier for autistic people when they know what will be happening.
- Some research and preparation strategies provided a proactive way that increased autonomy for participants to obtain advance information and reduce uncertainty.
- Research and preparation as a strategy is by no means exclusive to autistic people. However, there was some evidence that participants were more thorough and used preparation in areas non-autistic people would not.

5.5 Discussion (ctd.)

- Social scripts were used in the workplace, in face to face social interactions and on the phone.
- They worked best when used at the start or in short interactions or when there was a follow-up strategy.

6. Conclusions

- Participants used a great variety of different strategies with many participants using several strategies in each situation.
- Conceptualising these approaches as strategies rather than just run-rounds shows that autistic people use agency by taking action to overcome barriers.
- Measures to overcome barriers will still be required and we will be making recommendations.
- We hope these strategies will be both directly use and encourage autistics to develop and use their own strategies.

6. Conclusions (ctd.)

- Both the trusted person and research and preparation strategies enable autistics to participate more in social interaction, increase their chances in job search and reduce some workplace barriers.
- The trusted person strategy increases autonomy rather than leading to dependence. However, it has the disadvantage of needing to have a suitable person available.
- Participants used a variety of approaches to research and preparation, including (social) scripts, internet searches and asking for interview questions in advance.
- Participants were probably more thorough and used this approach more widely than neurotypicals.

8. Contacts and Acknowledgements

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