Reflections on An Auternative: An Innovative Co-Production Approach to Research with Autistic People

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Abstract

This paper reflects briefly on the recent An Auternative Project which investigated the barriers experienced in domains such as employment, access to health and other services and social interaction, and the strategies used by autistic people. The research highlighted the wide range of strategies used by autistic people to overcome barriers and to participate in the community, the fact that autistic people do show agency rather than just responding to others, and the importance of respect and valuing diversity. The research is original in using co-production and being autistic led, having an underlying theoretical framework of the social model of disability/neurodiversity, autonomy and empowerment and focusing on the voices of autistic people rather than professionals and family members.

Keywords: Autistic people; Neurodiversity; Non-disabled people; Social interaction; Post-school education

Introduction to the Project

Autistic people are about 0.62% of the world's population though there are considerable differences between countries [1]. In the UK, where the project data was obtained, the figure is about 1%. Research highlights that many autistic people have a poor quality of life, experiences and expectations. For instance, only about 16% are in full time paid employment, compared to 47% of disabled people and 80% of non-disabled people [2] and only 25% of young autistic adults have any post-school education or training [3], though these figures may be underestimated. Autistic people also have higher mortality and suicide rates [4]. We use the term autistic people and autistics for everyone on the autistic spectrum, as the terms preferred by the autistic community [5]. Existing research is largely biomedical rather than focusing on improving autistics' experiences and life chances [6]. Various barriers exclude autistics from decision making, control over their own lives and participation in all aspects of the community.

The project idea came out of a Scottish Autism Research Group seminar in 2017 and concerns by several autistic participants about the over-focus on 'interventions' which showed a lack of understanding of real autistic lived experiences and objectified autistic people rather than treating than as the subjects of their own experiences. The project was funded by Disability Research for Independent Living and Learning (DRILL).

The two research questions covered the barriers experienced by autistic people to participation and the strategies used to understand social situations and other people's reactions and in interactions with bureaucracy and to empower themselves. The mixed methods approach used questionnaires, interviews and a diary exercise and drew on the expertise and lived experiences of the autistic led project team to obtain a combination of qualitative and quantitative data. The project highlighted process as well as outcomes. This has included developing ways of communicating and working that involve and validate all participants' diverse accessibility and other requirements. The underlying theoretical framework was based on the social model of disability [7] and the compatible neurodiversity model [8], autonomy and empowerment. This results in the need to overcome social, attitudinal and infrastructural barriers and social exclusion [9] resulting from not valuing and taking into account autistic differences in thinking, moving, interacting, and sensory and cognitive processing. Autonomy involves being able to 'make meaningful decisions about [one's] life and have also them happen' [10].

Brief Overview of Project Results

The results differ from those of most other studies in being from an autistic perspective and focusing on the expertise and strategies used by autistic people rather than deficits. Our results show the extent of the barriers experienced and the great ingenuity of autistics in devising strategies to overcome them.

Participants experienced a number of different types of barriers. Several of them resulted from expectations and assumptions about behaviour leading to difficulties for those who behave differently, as well as assumptions and misperceptions of what it means to be autistic. In particular, this included expectations of phone use and lack of other options whereas many autistic people require written non-synchronous communication to reduce stress. They also included frequent assumptions that autistic people were totally incapable, resulting in many autistic people experiencing difficulties in being accepted as autistic and sometimes in obtaining a diagnosis. For instance, Anne was told she was 'putting on' her symptoms, George was congratulated on how 'articulate' he was and how well he was communicating, but his distress was not taken seriously, and Sophie experienced difficulties in being referred for a diagnosis as she was not listened to or taken seriously. Anne, George and Sophie and any subsequent names are participant aliases.

Differences in communication and social interaction styles of autistic and non-autistic people could lead to bullying, stereotyping, marginalisation, finding social interaction exhausting and difficulties in obtaining employment due to not 'fitting in' socially. Anne sometimes 'struggle[d] with unclear expectations' at work and Crawshay felt there were 'arbitrary rules'. Bullying and harassment were major problems experienced by many participants. They commented on being 'intimidated', 'forced out' or 'bullied'. Factors such as unreasonable and damaging expectations or being made to feel inadequate had resulted in difficulties with families, including total lack of contact. For instance, Diva, Anne and Ohona were estranged from their families. Sam experienced expectations which were impossible to meet, resulting in a total lack of self-confidence as an adult. Max's and Betamax's (step) mothers did not accept they could be autistic.

Support and resources for autistic people are still lacking, though this may be part of the wider austerity agenda and low prioritisation of the needs of disabled people, rather than something aimed specifically at autistics. Noise and other sensory issues were another barrier resulting from design for the majority rather than design for all to consider the needs of the whole population. In particular, noisy crowded waiting rooms affected access to health care and the ability to communicate with professionals, possibly a contributory factor to autistics' poor health outcomes. Noise and crowds also made social interaction more difficult.

Positive experiences and areas of good practice were also identified, though considerably less frequent than barriers. For instance, in diagnosis they related to acceptance, person centered approaches and good relationships with professionals. This involved supporting the person to make sense of their experiences and develop a way forward rather than a medicalized focus on 'symptoms' and deficits which could have a negative impact on self-image.

We will now briefly discuss the wide range of strategies [11] participants used to overcome barriers, increase participation and empower themselves. The two most commonly used strategies were a trusted or support person and masking and imitation. The trusted person's roles included providing moral support, advocacy, accompanying the person to meetings, speaking or phoning for them, intervening in difficult situations, acting as intermediaries and helping them complete forms. It was used in social interaction and to support service access, job search and employment. The use of a trusted person as a strategy indicates an autistic person taking an active role, investigating and identifying barriers and identifying and implementing solutions. This contributes to their autonomy and empowerment and is distinct from an autistic person being dependent on someone else.

Masking, which involves putting on a 'persona' or mask to present yourself in a particular way and constantly monitoring and, if necessary, modifying behaviour, was a frequently used strategy, both in the workplace and in social interaction. Many participants found it essential, though there were also concerns about burn-out and exhaustion. It is the main strategy recognised in the literature, though most of the literature on it is recent, and has also been extensively criticized [12] on account of its costs, such as exhaustion, damage to mental health and sometimes burnout. On balance our participants' views were more positive than those in the literature and considered the costs worth the benefits.

Other strategies included research, preparation and planning; technology use; managing disclosure; analysis and reflection and employment and social interaction strategies and strategies to manage energy and sensory issues. Most participants used research and preparation. While these are strategies also used by non-autistic people, participants often used them both differently and more intensely than non-autistic people. For instance, preparation included preparing notes, lists and scripts for doctors' visits, preparing social scripts and small talk for different situations and reading body language books as well as preparing answers to possible interview questions. Using prepared scripts could reduce anxiety, but other people generally soon deviated from the script, which could cause panic. Participants used a variety of technologies, particularly email, text, Internet, online chat, WhatsApp, Facebook and Skype, to contact services, order online, socialize and keep in touch with people. Many participants enjoyed online games and other means of socialising online.

Additional social interaction strategies included maintaining control, particularly of when they could leave, by the use of excuses and having their own transport. Several participants used low tech communication aids, including note cards to write on and a 'traffic light' system to indicate whether or not they wanted to interact. Other communication strategies included asking (doctors) to repeat things and writing them down.

We also obtained evidence that participation in the project had some positive impacts on the lives of some of the participants. Several participants had learnt about strategies from the project, including recognising their own use of strategies and the value of these strategies and were working on better strategies. Some participants had learnt to communicate need, which can be a major issue for autistic people. Other lessons from the research included workplace strategies, the value of diagnosis and the advantages of disclosing rather than hiding being autistic. Two participants had been motivated to get better support and reasonable adjustments in the workplace and with health professionals. Some participants had developed greater understanding, including continuing to use their experiences to help others. Several participants were trying to improve their self-images.

Analysis of the results was used to generate a large number of recommendations, aimed at government and other decision makers, service providers and employers. Many of them focused on the need to treat autistic people as actors entitled to control their own destiny, rather than objects to be acted on by others. This included the need to treat all autistic people with respect, be proactive in consulting autistic people and involving them in decision making and autistic people having a significant role in research about themselves. Communication was another important theme, including listening to what autistic people say and not reinterpreting it, communicating clearly and unambiguously, clearly stating roles and expectations and speaking directly to autistic people not talking to their companions about them. A related recommendation is careful and responsible reporting of stories about autistic people to avoid further contributing to stereotypes.

Governments should set up working groups of autistic and other neurodivergent people to produce clear information and disseminate it widely. Training of service providers, employers and decision makers is also important and should be provided by autistic people. This will require government and/or local authority funding to train autistic people to do this. One of the innovative aspects of the recommendations is their evidence base, including for claims by autistic advocates and community groups for the involvement of autistic people and that autistic people are able to show agency.

Conclusion

The results showed that autistic people have a wide range of strategies to overcome barriers and increase their autonomy. The use of strategies shows agency and autistic people taking control of their lives. However, the extent to which strategies were used and the types of strategies were often indicative of a response to a problem rather than solely a means of managing situations more effectively.

Many of the barriers resulted from lack of understanding of and respect of difference. Where positive experiences and areas of good practice were mentioned they frequently resulted from the converse of this i.e., acceptance and person centred approaches. The strategies are then ways to function in a society that does not value diversity. This includes using human support (a trusted person) and or technology as an intermediary to avoid problems or as a way to try to make sense of and function within confusing situations. It also includes attempts to try to minimize difference. The recommendations largely relate to different ways of recognizing and valuing difference, planning for diversity and acting proactively to consult with autistic people, involve them in decision making and remove the barriers to them showing agency.

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