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Representations of autism: Implications for community health care practice

Abstract

The work presented in this paper is part of a larger project in which we employed the use of online asynchronous discussion groups to examine how a range of contributors including people with autism, parents of people with autism, and professionals working within the field of autism view and understand autism. In this paper we focus on the voices of people with autism. The terminology used in the paper takes its lead from the writings of people with autism, who frequently use the term 'AS' to refer to autistic spectrum and Asperger syndrome and 'NT' which refers to neurologically typical people without autism. We examine a key theme identified in the online discussion groups, the representation of individuals with autism occupying a separate world of autism. In doing so we question an apparent goal of therapeutic interventions: to bring people with autism out of their 'separate world' and integrate them into a more typically 'social world'. We present an alternative understanding of autism that argues for adopting a position of neurodiversity in which autism is viewed as a difference rather than a deficit. We will discuss some of the implications that this may have for working with people with autism in health and social care practice.

Key words: autism; internet research; diversity; AS; Social worlds; social interpreter

Introduction

Autism is a much researched area and with many papers discussing both its manifestations and how best to approach these in clinical practice (see for example Wing[1] for further discussion). Typically academic research draws on Wing's triad of impairments to understand people with autism. The first criteria of the triad focuses on the social development of the individual, the second on impairments in communication, and the third on the repertoire of behaviours expressed by the individual. Such diagnostic criteria were conceptualised by Wing as a 'triad of impairments' due to the nature of the impairments not necessarily being separate entities, but occurring together.[3] Generally such approaches to understanding autism draw on a deficit model, seeking to identify impairments and deficiencies in people with autism. Our approach is to question the focus on deficiency in understandings of autism and to understand issues from the perspective of individuals with a label of autism.

There is a varied use of terminology in the literature and amongst professionals with respect to conceptualisations of autism and related classifications. Therefore the terminology used in this paper takes its lead from the writings of people with autism who frequently use the term 'AS' to refer to autism spectrum and Asperger syndrome. The term 'NT' refers to neurologically typical and was first coined by a self-advocacy organisation run by people with autism called Autism Network International[4]. The use of the term NT to refer to people without autism removed the need to refer to this population as 'normal'. The use of NT is now commonplace within the autism community online, and is a term widely recognised by people with autism, parents and some professionals working within the field of autism.

The highlighted lack in social awareness has been an area frequently studied when research is carried out with adults with autism. Folstein[5] discusses how a lack of such social abilities can become particularly problematic around adolescence, when people with autism become increasingly aware that they are different to others and do not 'fit in'. Folstein[5] proposes that such a lack in social abilities leads to many adults with autism being under-employed relative to their measured intelligence, a premise reflected in several of the postings by people with autism to the discussion groups contributing to this current paper.

These points are echoed by Barnard et al[6] who comment that people with AS have very little choice in where they live, what work they can do, and who, if anyone, looks after them. Barnard et al[6] cite that only 2% of adults at, what they term as, the 'lower end' of the autism spectrum and only 12% of 'high functioning' adults with AS are in full time employment, with 24% not in education or employment. Barnard et al[6] further discuss that only 19% of adults in their study had access to any sort of advocacy when their future was being decided upon in order to help them express their views about their choice of care, housing and activities.

In a recent study Portway and Johnson[7] researched life stories of 25 young adults with AS and their parents. The study explored the expressed feelings of the group in that they appeared to be 'normal' but did not quite 'fit in'. The authors raised important questions concerning the reasons for this perceived 'lack of fit' – did the experience arise solely from the attitude and behaviours of others towards the young adults, or did the individual feel different regardless of the behaviour of others, or some possible interaction between the two? Portway and Johnson[7] suggest two risk types associated with the experiences of people contributing to their research, everyday and longer term risks. Everyday risks were those arising from the perception of others, and included being misunderstood, teased, ridiculed and ostracised. Longer term risks were cited as including underachievement, risks to emotional well being and over dependence on their parents.

Reflecting on the stories of parents of the young adults, Portway and Johnson[7] found that parents often felt accused by professionals of being overprotective, but felt that it was only them that understood the true extent of their offspring's dependency and vulnerability. Addressing the accusations of over protectiveness they cited their offspring's vulnerability towards exploitation from others as a primary concern in addition to an inability to cope with independence.

Increasingly literature is also turning to autobiographical accounts from people with autism in order to better understand the challenges faced by adults with autism[8]. Such personal

narratives can highlight the complexity of issues faced by people with autism and restate the individual experience of various challenges[8], rejecting the construction of people with autism as one homogenous group. The use of autobiographical accounts has led to important insights, for example, into how individuals with autism experience emotions. Barrett for example details a student, Chris, who discusses his experience of emotions. For Chris, emotional understanding was a complex issue, with some emotions being more easily understood than others. The accounts provided by Chris concerning his emotional understanding also related to his behaviour in social situations in which he experiences anxiety when he is expected to rely on cues from other people.

Similarly, emotions are highlighted as a central concern for Edgar Schneider[9] in his reflective autobiography:

> 'First, as far as being able to connect with other live human beings, male or female, I am an emotional idiot. (That last phrase is mine; the phrase commonly used in psychology is 'emotional deficit'.) It seems that, just as some people have an important physical component missing (eyes, limbs, etc.), I have an important component of the human psyche missing: the ability to connect emotionally with other human beings.' (Schneider 1999, p.25)

The richness of such autobiographical accounts and the sophisticated reflections that many make on autism make them an important resource for both people with autism and their families and professionals. Indeed, Barrett[8] proposes that the understanding of the personal experience of autism should be a key concern for professionals in their work practices. First hand accounts can also potentially play an important role in informing debate concerning the theories proposed to explain autism.

Study aims

The work presented in this paper is part of a larger project in which we employed the use of online asynchronous discussion groups to examine how a range of contributors including people with autism, parents of people with autism, and professionals working within the field of autism view and understand autism. In this paper we focus on the voices of people with autism. In this work we seek to understand autism as a *difference* rather than a *deficit*. The contributors were all members of online asynchronous discussion groups, and the topics of

discussion were participant led rather than researcher led. By using non-face to face methods such as these it was hoped that particularly people with autism would be able to voice their experiences without the additional 'complications' associated with traditional face-to-face communications, commonly framed as an impairment in social interaction. The focus is primarily on online sources due to the emerging literature that proposes the positive engagement with internet technologies by people with autism and the possibilities to develop more empowering identities online.[10,11, 12]

Method

When approaching this study, careful consideration was given to ethical issues when conducting qualitative research with online communities[13] . The discussion groups were asked for permission to join them for an agreed upon period of 3 months, and details about the intended research and the nature of the researchers' membership in the online discussions were shared in an introductory post to the group. Other than this initial communication, no further postings were made by the researchers. However, members were encouraged to voice any concerns that they may have had with the proposed research, and such queries were dealt with off the discussion groups via private individual e-mails to provide extra information about the proposed aims and intended use of the information collected. In addition, the project was approved by an ethics committee, drawing on the British Psychological Society's guidelines for ethical research and ethical research online.[14]

The data contributing to this paper forms part of a larger scale research project in which four online discussion groups were joined. The membership to the groups comprised of people with AS, parents of people with AS and professionals working within the field of AS. In this paper we report examples of postings from members of discussion groups A and B. Both contributors identified themselves as AS and were contributing to discussion groups whose membership was largely comprised of people with AS. The groups varied in terms of the numbers of postings made and how many of the group members were active contributors. In group A, to which Ronald posted, there were 12 members, 7 of whom regularly contributed to discussions. In group B, to which Edward posted, there were between 39 and 49 group

members, 23 of whom were regular contributors. All quotes that appear in this paper are reported verbatim and have permission from their creators for use in the write up of the research.

Analysis

A key theme identified in the thematic analysis of the discussion group postings and selected for presentation here is that which reflects discussions of an 'AS world'. In the group discussions this was linked to a rejection of the goal of 'normalising' people with autism through therapeutic intervention. One apparent goal of therapy is to bring people with autism out of their AS 'other' world, into the 'normal' world. Achievement of this would constitute a positive result for therapists and parents working within a normalising therapeutic intervention model.

A common discussion thread reflected a rejection by people with AS to fully immerse themselves into the NT social world. While it is recognised in the discussions that there are profound differences between people with AS, the main focus of discussions by people with AS in the groups was that of differences between AS and NT people. The contributors to the discussion groups were largely positive about the possibility of employing a 'social interpreter' to negotiate between the two worlds. These discussions arose naturally within the group following an observation that a member had used a social interpreter. The role of a social interpreter was conceived as facilitating interaction with others, but the onus of change is not placed solely on the individual with autism as in a traditional therapeutic environment. A social interpreter would act as a mediator to the social world, hence not requiring the person with autism to adapt/change completely and fully immerse him or herself in the social world. This may be a role for a family member (for example a parent), but could be a specifically selected person who is independent of the family.

Intervention as a means of making individuals more 'normal' and less autistic is therefore rejected by contributors to the discussion groups, and help here is to enable individuals to live with/negotiate a difference. The role of such an interpreter is quite clearly defined, but may

differ depending on the need of each person. For example Ronald offered rich and interesting insight into the concept of social interpreters. He explained his vision for social interpreters and the role they might have in both helping him to understand the world of others and others to understand his world:

> My vision of a social interpreter is someone who will allow me to communicate with other adults with autism.
>
> The difference between a social interpreter and a social worker is social worker presupposes that you have social abilities and a social interpreter would not. A social worker helps you fit in. As social interpreter would express your world view to others and explain their world in ways that you understand.
>
> I don't want to live in a high social world all the time----I can't take it in fast enough. I want to experience some of that through the eyes of an interpreter and I want to share some of the experience with other social and nonsocial people.

For Ronald, the social interpreter would enable him to interact with others, whether these are AS or NT people, without needing to attempt to fit in to a world that he finds difficult. In his discussion he draws parallels between his situation and with people who are blind and deaf and their use of interpreters: 'They are required by law to provide interpreters for the visually and hearing impaired.' Therefore the point is made that it is the disabling world that can be changed to facilitate the participation of people with a whole range of disabilities. This echoes debates within disability studies and the importance of the social model of disability to challenge disabling practices[15].

The important links between therapeutic intervention and the AS world are eloquently reflected in the following quote:

> If you are Adult with Autism Diagnosis you have to have experience with medicine. Applied Behavior Analysis is a way to bring you completely into the social world and I do not want to go. I want to stay in my world and just visit the social world.
> Ronald.

This individual does not want to change through Applied behavioural Analysis (ABA) and completely enter the social world, but rather preserve his AS/non-social behaviours and at the same time maintain a way with which to mediate with the social world. The goal of professional therapeutic intervention is therefore presented as removing the individual from

the AS world and changing their behaviours in order to make them a full member of the social world. Such a change rejects the positive embracement of AS traits in favour of more dominant NT traits.

Further developing issues concerning the separation of 'AS worlds' from 'NT worlds' is the applied example of the position of adults with autism within the workplace. In our research we have successfully demonstrated, for example in the quotes above, that there is the possibility for some people with autism to have sophisticated conversations with others in an online environment. Also in seeking to value diversity, our work examines the positive attributes associated with autism as presented by some of the contributors to the online discussion lists, which are traditionally considered in a negative light, for example a keen attention to detail, and a lack of concern with social matters. For example:

> "When I first heard of HFA[1] and AS unemployment I almost didn't believe that. I thought, why would people with such unusual talents and abilities have to suffer such a fate?"
> Edward

Autism traits can therefore be valued and channelled into important employment and lifestyle opportunities for people with autism if they wish, providing that the wider ethos of society generally and the workplace specifically values diversity and difference. Whilst we recognise that there are many structural inequalities experienced by people with AS, we would argue that with adequate supports people with AS may be able to use their unique skills effectively and make important contributions to the workforce. This has been shown by employers such as Goldman Sachs, who have formalised a programme for workers with autism, where positions do not require a focus on communication skills, and the importance of working as a team.[16] Such programmes value the specialist knowledge that autistic individuals may have in a narrow range of fields, and address the issues faced at the interview, which frequently rely on a competence in social skills in addition to competencies in the key skills demanded of the job.

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[1] HFA is a term commonly used to refer to high functioning autism

Implications for practice

This research employed the use on online discussion groups to provide information from people with AS (and in the broader study, parents and professionals). A key implication for practice is an awareness that online discussion groups offer all stakeholders an alternative form of communication which can be very enabling for people with AS. Our experience of working with people with AS online is similar to previous key authors who discuss the successful use of the internet by people with autism[10,11,12]. In our study we found that using internet technologies facilitated effective communication, which has important implications for health and social care practice. For example it may be possible for practitioners to work with a child or adult with AS via online communication, which may reduce some of the difficulties experienced in more direct face-to-face social interactions. Another form of communication that may be beneficial when working with people with AS is through drawing on the expertise of a social interpreter. The role of a social interpreter was presented as a potentially important resource for people with autism. This role may informally be supported by parents of people with AS, but contributors called for a more formalised role.

A second implication for practice is in terms of alternative views of 'autistic impairments', which can feed into a more enabling vision of practice[17]. Here the focus of the individual would be moved from a source of change through professional interventions once labelled, to the individual being viewed as an important partner in any solution and intervention proposed. By including the wider views of people with autism in professional representations a less negative and less stigmatised view of autism can be presented. By including alternative representations of autism in health and social care practice ideas the voice of individuals with direct experience of autism can be accessed, which may provide a new agenda with which to discuss autism.

The work presented above focuses attention on valuing the skills of children and adults with AS and listening to the voices of people with AS, both of which have important implications for practice. Autism spectrum disorders represent a broad range of issues and capabilities. When working with people with AS it is important to value these differences and to be aware

of the person's unique skills and attributes. This position is not to deny that there are difficulties for people with AS, however we feel that it is important in practice to start from a position of acknowledging capability (in whatever form that may take) rather than deficit.

Conclusion

The work presented here begins a dialogue between practitioners and people with autism, which involves considering autism in an alternative and more positive light, and seeks to open up debates around valuing diversity. In doing so the work hopes to inform alternative understandings of autism and encourage practitioners to reflect upon their own practices and engagements with people with AS. Two distinct alternative forms of communication were discussed: interactions that make effective use of computer mediated communication and the use of a social interpreter in order to facilitate engagement in social interactions. The work presented here has demonstrated that some people with autism can have sophisticated communications through these media.. Through employing alternative modes of interaction people with AS could play an active role in strategies designed to assess their needs, and be a central role in discussions concerning the provision and support that may be offered to them.

Key Points

- The need for a focus on valuing diversity

- Re-framing autism as a *difference* rather than a *deficit*

- An alternative consideration of the goals of therapeutic interventions

- Valuing the important contributions that some people with autism may make to therapeutic engagements, becoming active in strategies designed to assess needs and the support that may be offered to them

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