Representations of autism: implications for community healthcare practice

Introduction
Autism is a much researched area, with many papers discussing both its manifestations and how best to approach these in clinical practice (for example, see Wing 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. Such approaches to understanding autism generally 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 among professionals with respect to conceptualisations of autism and related classifications. The terminology used within this paper therefore 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 as 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 valuing diversity and viewing autism 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

Charlotte Brownlow PhD, BSc:
Lecturer in developmental psychology, Open University

Lindsay O'Dell PhD, BSc:
Lecturer in children and young people programme, Open University

Abstract
The work presented in this paper is part of a larger project in which online asynchronous discussion groups were employed 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 as 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 valuing diversity and viewing autism 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.

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. Within 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 this method, 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.10-12

**Method**

In 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 three months, and details about the intended research and the nature of the researchers’ presence in the online discussion groups 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. Such queries were dealt with outside of (‘off’) the public discussion groups via private individual emails to provide extra information about the proposed aims and intended use of the information collected. In addition, the project was approved by the university ethics committee, drawing on British Psychological Society guidelines for ethical research and ethical research online.14

We report examples of postings from two members of two discussion groups – referred to here as groups A and B – that were chosen due to their ownership and main contributors being people with autism. Both contributors identified themselves as AS and were contributing to discussion groups whose membership was largely comprised of people with AS. Their quotes were chosen because they provided key examples to illustrate the narrative, and are referred to in this paper with the pseudonyms ‘Ronald’ and ‘Edward’. These two particular contributors were also quite ‘vocal’ in discussing the issues in this paper. 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, seven 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. This was a term that was unfamiliar to the researchers, but which seemed to be an idea...
that had been discussed before by people with autism. These discussions arose naturally within the group following an observation that one 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 or change completely and fully immerse him or herself in the social world. This may be a role for a family member, such as a parent, but could be a specifically selected person who is independent of the family.

Intervention as a way to make individuals more ‘normal’ and less autistic was rejected by contributors to the discussion groups – and help is needed here to enable individuals to live with or negotiate 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. A social interpreter would express your worldview 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 non-social people (Ronald).

For Ronald, the social interpreter would enable him to interact with others, whether these were 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 the 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 [an] 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 and completely enter the social world, but rather to preserve his AS/non-social behaviours and maintain a way in 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 behaviour 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 and developing issues that concern the separation of ‘AS worlds’ from ‘NT worlds’ include 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. In seeking to value diversity, our work also 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: When I first heard of [high-functioning adult] 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. While 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.

Implications for practice
This research employed the use of online discussion groups to elicit information from people with AS (and in the broader study, parents and professionals). While we acknowledge that citing examples from only two individuals means that care needs to be taken about making wider generalisations, what this paper does do is provide an alternative way of representing autism, and one that needs to draw on the expertise of individuals with autism in order to gain a richer and fuller understanding.

A key implication for practice is an awareness by practitioners who work with people with AS that online discussion groups offer all stakeholders an alternative form of communication that 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.10-12 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 be supported informally 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.15 Here the focus would be moved from the individual as a source of change through professional interventions once labelled, to the individual being viewed as an important partner in any proposed solution and intervention. By including the wider views of people with autism within 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, and this 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 on 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, but it is important in practice to start from a position of acknowledging and building on 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 about valuing diversity. In doing so, it is hoped that this paper will 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 have been discussed in this paper – 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 these modes could have a central role in discussions concerning the provision and support that may be offered to them.

References
14 British Psychological Society. Ethical issues in researching online. Available at: bps.org.uk (accessed 30 April 2009).

Key points
- There is a need to value diversity, and autism spectrum and Asperger syndrome (referred together as ‘AS’) have been re-framed as differences rather than deficits.
- People with AS express alternative considerations of the goals of therapeutic interventions.
- People with autism may make important contributions to therapeutic engagements, becoming active in strategies designed to assess needs and the support offered to them.
- The internet offers potentially useful forms of communication when working with people with AS.

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