

Neurodiversity: accepting autistic difference

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Abstract

'Insider' descriptions of living with autism in a world where most people are not autistic may at the same time inform and challenge a professional approach to what can be termed as 'autistic behaviour'. This article draws on the perspectives of the 'neurodiversity' movement, people who themselves have diagnoses on the autistic spectrum but reject that autism is a disorder, choosing instead to fight for their right to be autistic. The authors include a case study to explore how such descriptions and perspectives can be applied to services supporting an autistic service user. They conclude that, regardless of whether autism is seen as a difference or a disorder, care staff providing services to autistic service users may need to examine their assumptions carefully if they are to avoid discriminatory practices.

Introduction

Autism, including Asperger syndrome, is generally perceived as a disorder. But over the past two decades, helped by the emergence of the internet (Sinclair 2010), autistic self-advocates have been cultivating the idea of autism as a neurological difference. Referring to this movement called the 'autism rights' or 'neurodiversity' movement, French researcher Brigitte Chamak writes: 'If the disability movement is considered as the latest generation of social movements, the action of autistic persons can be viewed as the latest generation of the disability movements' (Chamak 2008).

British autism researcher Simon Baron-Cohen (2012) also commented in a recent talk that looking at the neurobiology of autism there is not much evidence for dysfunction, but a lot of evidence that people on the autistic spectrum are simply different.

Although autism can present in combination with a range of impairments, such as epilepsy or intellectual disability, many autistic self-advocates reject that their

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autism in itself is a disorder. They claim that, apart from differences such as race, gender and sexual orientation, people are also born with different minds. Autistic self-advocates consider themselves as a neurological minority, and regard autism as a difference to be respected, not a deficiency to be 'repaired' or counteracted (Silberman 2010).

This view is also reflected in how these self-advocates refer to themselves in that they prefer to be called 'autistic people', not 'people with autism'. American self-advocate Jim Sinclair explains this position: 'Autism is a way of being. It is not possible to separate the autism from the person – and if it were possible, the person you would have left would not be the same person you started with' (Sinclair 1993).

Only when someone had decided that the characteristic being referred to is negative, he adds, would they want to separate it from the person. But to Sinclair and other self-advocates, autism is not negative. In one of the classic texts of the neurodiversity movement, where Sinclair explains why he dislikes what is termed 'people-first language', he states: 'I know that autism is not a terrible thing, and that it does not make me any less of a person' (Sinclair 1999). This is one of the fundamental tenets of the neurodiversity movement and out of respect for it, the authors use the form 'autistic people' not 'people with autism' when referring to people with diagnoses on the autistic spectrum.

The internet portal Aspies for Freedom (AFF) is one of many forums run by autistic people for autistic people. At present, AFF has 90,000 members and, since 2004, members have generated more than half a million forum posts. This online activity gives an indication of the number of autistic people who are engaging with autistic self-advocacy.

Reflecting on the claims of the neurodiversity movement, Jaarsma and Welin (2012) conclude that such an approach makes sense, but primarily for 'high-functioning' autistic people including, for example, those who have verbal language.

This article presents examples of experiential knowledge from autistic self-advocates and research studies that have examined how adult autistic persons themselves describe their own situation.

The authors refer to definitions of disability and to equality guidelines. In light of this, a case study in which aspects of services received by an autistic service user labelled as 'low functioning', has been included on page 34. The name of the service user has been changed to preserve her anonymity. The authors' aim is first to show that a neurodiversity approach may also be viable in relation to 'low-functioning' autistic service users, and, second, how an insufficient respect for autistic difference may lead care staff and professionals to uphold practices that can be characterised as discriminatory under current equality guidelines.

Disability rights

To American autistic self-advocate Ari Ne'eman, being autistic is a fundamental part of who he is. He has no desire to become less autistic. On the contrary, he is keen for autistic people to have their differences recognised as a part of human diversity, and for society to provide better adaptations for autistic citizens. Society's main approach, he claims, is still: 'How do we make people with autism behave more normally? How do we get them to increase eye contact and make small talk while suppressing hand-flapping and other self-stimulatory behaviour?' (Silberman 2010).

Mr Ne'eman is president and co-founder of the Autistic Self Advocacy Network (ASAN), an organisation that rejects normality as a measure of human dignity. The organisation's aim is a world in which autistic people have the same access, rights, and opportunities as all other citizens, that is the non-autistic majority.

From a traditional perspective of disability – known as the 'medical model' – such an aim will seem illogical. The opportunities autistic people lack will be perceived to be an unfortunate, but highly natural, result of their autism. But whether autism is seen as a disorder or a difference, this perception is untenable in the face of current international disability rights.

The United Nation's (UN) Convention on the Rights of Persons with Disabilities, which the UK has ratified, draws a line between impairment and disability, stating that disability results from the interaction between people with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (UN 2006). The UN's statement means that participation can be improved by reducing environmental barriers just as effectively as by strengthening the individual's capabilities.

The classic example of being disabled by environmental barriers is when a person in a wheelchair is confronted by a staircase. The problem is not caused by the impairment because the person was doing fine until encountering the stairs. The problem is an environment that favours people who walk and excludes those who need to use wheels. When the problem is described in this manner it becomes evident that many of the difficulties that face people who use wheelchairs, such as staircases, narrow doorways and out-of-reach shop shelves, can be met only through addressing environmental factors.

The aim, therefore, should be to create a physical environment that is accessible to everyone. This principle, called 'universal design' is also part of the Convention on the Rights of Persons with Disabilities and is supported by the UK Equality Act 2010. The aim is to reduce barriers created by society and to

prevent new ones from arising. Therefore, ASAN's seemingly 'illogical' aim is thoroughly aligned with current international policies.

When it comes to autistic citizens, environmental barriers are not related to staircases, doorways or shop shelves. Yet, because of a number of sensory issues and hypersensitivities common among autistic people (Caldwell 2006, Bogdashina 2010), the physical environment may have a profound effect on their participation. For example, among 237 autistic people who took part in a study carried out in the UK in 2007, 60 reported that sensory issues and/or overcrowding made it difficult to use public transport.

Six participants found it impossible. Enduring sounds made by other passengers such as conversations, crying children, electronic games, mobile phones, and smells such as perfume and smoke were especially taxing (Beardon and Edmonds 2007). Other studies highlight crowds, sounds and smells as obstacles to autistic people's participation in society on an equal basis with others (Ryan and Räisänen 2008, Madriaga 2010). This means that public transport can be said to function in an indirectly discriminatory manner towards autistic citizens, in that it adopts practices that apply to everyone but disadvantage some people in particular (Government Equalities Office 2010).

Case Study

Sally lives in a care home with five other adults with autism and intellectual disability. Ann, a second-year learning disability nursing student, is on placement in this care home. One of the requirements of the placement is a written assignment. Ann wants to write about Sally. To fulfil the assignment, she has to explore a particular area of Sally's life, going beyond what the staff can tell her.

After some thought, Ann ends up with the research question: 'What activities does Sally like?' Ann's conclusion, after weeks of interviews, observations and trying out activities, is that most of what Sally likes happens outdoors. She likes to watch bunting move in the wind and to stand in the wind, holding pieces of cloth and watching them flap. When invited, she is happy to participate in cutting and decorating bunting, which she can later take outside. Sally likes to look at rain and feel raindrops falling on her hands. She also likes to pull on branches and watch them move, and to pat small puddles on rocks after rainfall.

Ann has an overall positive impression of the way the staff team works. Their skills and knowledge show in their communication with Sally. The staff work hard to create daily routines that meet Sally's need for predictability and structure. In most situations they seem to respect her choices.

However, as Ann gets to know Sally better, she grows more uncomfortable with how staff members behave when going for walks with Sally. She frequently stops by flag poles, bushes, trees and puddles, to watch, pull and pat, often quite repetitiously. But, even if they are in no hurry, staff members rarely give Sally time to ponder and explore the things that catch her eye. After a few seconds, they invariably ask Sally to move on, and sometimes they pull her by the arm. Evidently, to the staff, 'going for a walk' means walking continuously to a specific place and returning home in the same manner – perhaps to 'activate' Sally at home and 'motivate' her to engage in various activities there. However, Sally rarely shows any motivation for activities at home. To Ann, it is obvious that Sally is already engaged and motivated – just not in or by the things that staff expect.

Ann's supervisor asks her if Sally's behaviour might be perceived as compulsive, perhaps a sign of obsessional compulsive disorder (OCD). If so, the actions of the staff could be considered as a way of helping Sally out of a situation where she is stuck? Ann reads up on OCD, and discovers that for repetitive behaviour to be considered a sign of OCD, it must be something the person seems not to wish to do – for example, if it results in the person not being on time for activities he or she likes (Deb et al 2001). But Ann's observations indicate clearly that this is not the case with Sally. Ann's supervisor is satisfied and approves Ann's request for trying to go for walks with Sally on Sally's terms.

Such walks take time. Sally can stop for up to 20 minutes at a time, but Ann finds that Sally eventually takes the initiative to move on when she is done with whatever has caught her eye. Going for walks in this manner makes Sally very pleased. It also seems that after such walks it is easier to motivate Sally to participate in chores and activities at home.

For Ann, going for walks in this way is unfamiliar. The looks that some passersby give them can make Ann feel uncomfortable. However, Ann accepts the challenge because she sees the difference this makes for Sally and because she realises that this is a concrete way of showing respect for Sally and for Sally's rights.

However, for many autistic people, the greatest environmental barriers are to be found in social interaction, especially interaction with 'neurotypicals', the term devised by the neurodiversity movement to describe persons who are not autistic, or the 'normal' majority. In their 2007 study, Beardon and Edmonds found that 83 per cent of participants said they felt strongly or very strongly that many of the problems they faced were a result of neurotypical people failing to understand their needs or behaviour.

One of the participants said: 'Neurotypicals need to stop thinking they are better than us. They should accept us for who we are instead of only accepting us if we try to be like them, and rejecting us and being mean if we make a mistake or get confused or stressed, or just don't always want to socialise' (Beardon and Edmonds 2007). Such experiences may be characterised as encounters with attitudinal barriers. Other autistic people note that neurotypical people can be good allies (Sinclair 2010). A participant in a study by Hurlbutt and Chalmers (2002) said: 'One of my friends divides neurotypicals into two categories: high functioning, such as yourself, and low functioning, who do not understand us.'

Ne'eman (2010) writes: 'When addressing autistic traits such as categorisation and sequencing behaviour, lack of eye contact and a departure from social norms, we should give serious thought to whether the problem lies with the behaviour itself or the social stigma that surrounds it.'

But, one may ask, why is neurotypical society so preoccupied with getting autistic people to make eye contact, when it is obvious that so many do not like it, or find it too intense and distracting? It may simply be basic human nature, faced with what seems unfamiliar and strange, we will often – almost instinctively – react by trying to make it less strange if in a position to do so (Lorentzen 2003).

As part of an ethnographic research project, researcher Nancy Bagatell attended a support group organised by autistic people for autistic people. She found it strange to see people talking without making eye contact, but to the group participants it was a relief not to have to make eye contact. She describes conversations without small talk, in a setting where members were free to flap their hands as they wished, without risking reproach. Bagatell (2010) also describes how members could be sociable without words.

On one occasion, Bagatell observed two members sitting in adjacent chairs, one tapping his fingers rhythmically, the other swaying backwards and forwards. It took her several minutes to realise that they were moving in step, almost as if in a ballet (Bagatell 2010).

In 2010, US president Obama appointed Mr Ne'eman to the country's National Council on Disability. Mr Ne'eman has said he wishes to be a spokesperson for all autistic people, lobbying also for better support for families with autistic children and more inclusive services to autistic adults in need of support. He calls himself lucky for being able to do things other autistic people cannot. He can participate in politics on neurotypical people's terms. He can make eye contact with them, which they seem to need him to do before they can feel at ease with him and take him seriously. But, he points out, this participation never has been, or will be, easy for him. He does it to help create a better world for autistic people.

One of Mr Ne'eman's strategies for replenishing his strength is attending social events organised by autistic people for autistic people, where he can be himself and socialise on his own terms (Silberman 2010). One such event is Autreat, a US annual 'retreat-style conference run by and for autistic people to accommodate autistic people as much as possible' (Sinclair 2010). A similar annual British event, inspired by Autreat, is Autscape.

Different sensory reality

Not all autistic people have Mr Ne'eman's opportunities and choices, however. For a start, not everyone has verbal language. American autistic self-advocate Amanda Baggs writes that many people might perceive her as 'low functioning', based on her movements and the fact that she seldom speaks (Savarese et al 2010). However, when assisted by technology, Ms Baggs can be eloquent (Baggs 2007). In 2007, as a protest against the underestimation of autistic people, Ms Baggs made the video, *In My Language*, and uploaded it to YouTube, where to date it has been viewed 1.2 million times.

The first part of the video shows Ms Baggs doing a series of movements that many might perceive as 'typical autistic self-stimulation'. In the second part of the video, called 'A Translation', Ms Baggs explains, via speech synthesis and text, that the first part was in her 'native language' and that these movements are the way she interacts with her physical environment. 'Ironically, the way that I move when responding to everything around me is described as "being in a world of my own",' she says. 'It is only when I type something in your language that you refer to me as having communication' (Baggs 2007, Wolman 2008).

Tito Mukhopadyay, born in India in 1989, has no verbal language. Like Ms Baggs, he needs support on a daily basis, and, similarly is in danger of being perceived as 'low functioning'. He was not allowed to attend school, but received extensive and intensive home schooling from his mother. She read him literature and poetry from around the world, and taught him to write, first with a pencil, then with a keyboard. Author of three books, some of Mr Mukhopadyay's poetry has been published in the *Disability Studies Quarterly* (Mukhopadyay 2010).

Mr Mukhopadyay's writing conveys a sensory reality far from typical. He describes his strong sense of connection with the physical world around him, and how he finds himself merging with the wind, a rain cloud, a stone, a pen on a table and a tree.

Even though his autism complicates his life, Mr Mukhopadyay does not consider it as a disorder. Rather, he invites neurotypical people to explore their own limitations – for example, their rather limited ability to accept that others, such as

autistic people, may have different needs, wishes and priorities (Savarese 2010a, 2010b).

Regarding the case study about the staff who did not see the point of letting Sally stop to explore her surroundings when out walking, the insights offered by Ms Bagatell, Ms Baggs, Mr Ne'eman and Mr Mukhopadyay have a seductive, explanatory power. Bagatell (2010) tells us that autistic people relate to their surroundings in different ways from other people and that for them, hand-flapping, tapping and swaying can be a natural part of social interaction.

Rights and equality

Mr Ne'eman reminds us that autistic citizens should have the same access, rights and opportunities as all other citizens without having to emulate the neurotypical majority and that 'normality' is not a good measure of human dignity (Ne'eman 2010). Ms Baggs shows us how unusual movements and behaviour in autistic people can be a form of communion between the person and the physical aspect of their surroundings. Mr Mukhopadyay suggests there is more to such activities than meets the neurotypical eye.

Sally's caregivers struggle to see bunting-watching, branch-pulling and puddle-patting as meaningful leisure activities. Their conception of going for a walk leads them to prompt Sally to move on when she stops. But 'insider descriptions' of autism may have the potential to change how care staff understand the needs and behaviour of autistic service users. Perhaps such descriptions may change staff's perception of certain forms of behaviour, from dismissing it as annoying 'unwanted behaviour' to a recognition that for these autistic people and service users, the behaviour is a part of living a fulfilling life.

Whether autism is seen as a difference or a disorder, being autistic can be considered as a minority position. In a society where the majority of people are neurotypical, there is a likelihood that the services that some autistic people need, for example because they also have intellectual disability, will be delivered by neurotypical care staff. From this arise some challenges for the staff.

In the example described in the case study, Sally's caregivers' conception of going for a walk leads them to prompt Sally to move on when she stops. Yet, the care standards that regulate the services supporting Sally specify that staff shall 'respect service users' right to make decisions' and that service users shall be 'encouraged and supported to pursue their own interests and hobbies'. In general, staff members should offer 'sensitive and flexible personal support' to 'maximise service users' independence and control over their lives'. They have an important role 'in supporting service users to live fulfilling lives outside as well as in the home'

(Department of Health 2003). This suggests that one of the challenges facing care staff who work with service users who are different from themselves, is that their personal experiences and understandings, which serve them well in their own lives, may not be good guidelines for their choices of action at work.

As the case study shows, the preconceptions that staff members bring to the situation seem to make it harder for them to recognise and acknowledge Sally's branch-pulling as a pursuit of 'interests and hobbies'. If they are like most neurotypical people, such activities have no great part in making their own lives fulfilling. Sally is dependent on extensive support in daily life. But if this support contributes to a daily life modelled on what Sally's staff find fulfilling in their lives but that fails to fulfil Sally herself, it does not amount to giving her control over her own life. Similarly, there is a risk that Sally's right to make decisions may become restricted to decisions that make sense to her support staff.

The uncritical use of 'neurotypical standards' as guidelines on, for example, what behaviours are meaningful and what interests are considered legitimate when designing services for autistic service users, may bring staff into the territory of indirect discrimination.

Indirect discrimination can happen 'when there is a rule, a policy or even a practice that applies to everyone but which disadvantages people with a particular disability' (Government Equality Offices 2010). Therefore, for staff to pressure someone in their care to refrain from what is for them natural ways of self-expression may qualify as indirect discrimination – as might a failure to respect wishes, choices and interests that in themselves cause no harm, purely on the grounds of them being unusual. This means that to provide non-discriminatory services, staff may need to accept leisure activities that they do not see the meaning of and support choices that they do not understand – because they realise that these activities and choices somehow are important to the service users in question.

A third aspect of this concerns what is called 'challenging behaviour'. Based on the testimony of autistic people with verbal language, Beardon and Edmonds (2007), Madriaga (2010) and Ryan and Räisänen (2008) point to the fact that in many cases, sensory conditions that most people would consider normal and acceptable, can be difficult or even unbearable to some autistic people. There is no reason to believe that this does not also apply to autistic people who lack verbal language.

According to Caldwell (2006), many different forms of repetitive behaviour by people with autism can be understood as coping strategies, ways of reducing stress in environments that threaten to overload them with sensory stimuli. Sometimes,

challenging behaviour in people with autism and intellectual disability can be explained as fight-or-flight responses, attempts to avoid the pain that can result from sensory overload. Consequently, in preventing challenging behaviour the first step should be to look at environmental factors (Caldwell 2006, McDonnell 2010).

A final challenge to care staff who provide services to autistic service users may therefore be to accept and take account of the fact that the service user may perceive a situation differently from how staff perceive it. Insisting that someone endures an environment that overloads them with painful sensory stimuli would qualify as discrimination.

Implications for practice

Care staff engaged in service provision to autistic citizens should ask themselves:

- 1) *Do our services contribute as far as possible to daily lives on users' own terms and values?*
- 2) *Where our choices and actions limit the choices and actions of autistic service users, do these limitations spring from a need to protect other people's boundaries and uphold fundamental societal values?*
- 3) *Or do they first and foremost spring from our own need to make what is unfamiliar to us less unfamiliar, what seems strange less strange?*

Ideal answers are 'yes', 'yes' and 'no'.

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Learn more

Aspies for Freedom: www.aspiesforfreedom.com

Autscope: www.autscope.org

Autistic Self Advocacy Network: www.autisticadvocacy.org

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