Old age and people on the autism spectrum: a focus group perspective

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Abstract

Until recently, the focus of many within the 'autism service industry' has been on children and young adults who are on the autism spectrum where 'service transition' usually refers specifically to the transition from children to adult service provision. This article explores 'service transition' from the opposite end of the age scale, that of old age, and incorporates the views of older adults who are on the autism spectrum. In order to design and provide a service that is 'fit for purpose', training of health professionals and consulting with people on the autism spectrum is crucial.

Key words: Elderly care ■ Autism spectrum conditions ■ Nursing education and training ■ Service user views

In her foreword to a recent National Autistic Society (NAS) policy report on old age and people on the autism spectrum Baroness Greengross suggests that:

> **'Only in the past four or five years has any real attention been paid to adults, and the needs of older adults with autism are yet to get a real look-in.' (NAS, 2013: 4)**

Given a possible greater emphasis in research and policy guidelines on children and young adults who are on the autism spectrum, it seems that older adults are a neglected group who receive little attention in policy, research or service design and provision. As an example, 'service transition' for people on the autism spectrum usually refers to transition from child to adult services and from school to college, university or work. Other age-related issues such as retirement or elderly care, let alone end-of-life care and support, appear to be ignored. Indeed, the NAS suggests that a review of the literature reveals the paucity of research into autism in older age—as also highlighted by Piven and Rabins (2011) and Perkins and Berkman (2012)—and that it appears that clinicians working in age-related specialties often have a poor understanding of autism and believe that autism is not a condition that affects older people (NAS, 2013: 17).

This article seeks to explore the meanings of autism spectrum conditions and old age and will highlight existing elderly care services and gaps in such services for people who are on the autism spectrum and what they would like as they grow into old age.

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Research methodology

Background

The author, a registered learning disability nurse and visiting nurse lecturer, was diagnosed in November 2008 with Asperger's syndrome/high-functioning autism at the age of 49. As he is now in his mid-50s, he became aware of the lack of any real research into and interest about old age and autism spectrum conditions in terms of service design and provision, an awareness that caused him some concern. Indeed, such a lack of interest on the part of service commissioners and providers was confirmed during a recent meeting of a local autism partnership board of which the author was a member. The author became aware that other 'older adults' on the autism spectrum may also be concerned by a lack of appropriately researched service design and provision. Consequently, this article was driven by 'self-interest' and was not as a result of, for example, a postgraduate research initiative. However, that is not to say that in-depth research by doctoral candidates into appropriate elderly care service design and provision for people on the autism spectrum on the part of service commissioners, designers, providers and users would not bear much useful fruit for those likely to be affected by such services.

Method

In order to gain an insight into current research into old age and people on the autism spectrum a search of online research databases was conducted (British Nursing Index, CINAHL, Social Policy and Practice) along with a review of literature through the NAS website. Given that a lack of research into this issue has been highlighted, it was not surprising that only three or four useful pieces of research were uncovered, the main documents being the NAS report and guidelines produced in 2013, Perkins and Berkman (2012) and Piven and Rabins (2011).

The author decided to explore the views of people on the autism spectrum who were middle-aged or elderly regarding elderly-care service design and provision, through face-to-face discussion. Four focus group participants were personally invited to take part on the basis of autism diagnosis and age, although in hindsight a general invitation might have brought together people who may not have been known to the author and with differing views. The participants were all known to the author from a variety of autism groups and all shared his concerns regarding the apparent lack of genuine interest in service design and provision for people on the autism spectrum and who were elderly. The discussions, in an informal setting and atmosphere, were structured by means of questions focusing on certain aspects of service provision and therefore the comments were thematically linked.

Data analysis

Discussion notes were read and comments that were either different from or common to all the participants were listed. The recorded comments were then compared and contrasted with those recorded by the NAS (2013), Perkins and Berkman (2012) and Piven and Rabins (2011).

The presentation of the recorded conversations was shown to the participants for confirmation of accuracy and their approval.

Ethics

This article was a personal project driven by a personal interest and concern regarding elderly care services for people on the autism spectrum. However, as much of the information for the article was gathered from people who were on the autism spectrum as well as from published sources, those who were invited and who subsequently agreed to take part in informal discussions were given the following information:

- The purpose of the discussions
- Guarantee of anonymity (pseudonyms are used in this article)
- Their right to withdraw from the discussions at any time
- Their right to refuse inclusion of their contribution.

Their communication and social needs were recognised and appropriately met and safeguarded, as was any sense of vulnerability owing to their autism. All participants gave their free consent to both the informal discussions that took place and the publication of the comments with a view to improving service design and provision.

What is autism?

Often, when people think of autism, the film *Rainman* springs to mind. However, the film offers a rather simplistic caricature of what autism is. What, then, is autism?

First, a short note on the use of terminology. Autism is not a static condition but a spectrum of conditions ranging from 'classic autism' to Asperger's syndrome and high-functioning autism. People with 'classic autism' are more likely to have additional learning disabilities and will therefore be more likely to be known to learning disability services. People on the other end of the spectrum, those with Asperger's syndrome or high-functioning autism, are likely to have average to high IQ levels. Again, some use the term 'autism spectrum disorder' while others reject the word 'disorder', believing that the word 'disorder' carries with it unhelpful and even harmful historical baggage. Instead they use the term 'condition' (autism spectrum condition). Autism is not simply a childhood condition but is a life-span condition; increasing numbers of middle-aged adults are being diagnosed as being on the autism spectrum.

It is estimated that around 1% of the UK population is on the autism spectrum (Brugha et al, 2012) which gives a UK 'autistic population' of around 600 000, of which 80% are male. Seeing autism from a 'denotative' perspective, the key features of autism spectrum conditions are differences or difficulties in social communication, social interaction and social imagination. These are often called the 'triad of autistic impairments'. This was formulated by Lorna Wing and Judith Gould (1979) and affects people with an autism spectrum condition in different ways and to different levels. Sensitivity to sensory stimuli is often seen as being a fourth key feature by which people on the autism spectrum may be either hypersensitive or hyposensitive to sensory stimuli such as sound, smell, taste, vision, touch or movement. However, Lawson (2015: 16) collapses this triad and sensory issues down into two specific domains (*Box 1*).

Box 1: Key characteristics of autism spectrum conditions

'Triad of autistic impairments' (Wing and Gould, 1979)

Difficulties in:

- Social communication
- Social interaction
- Social imagination

As described by Lawson (2015)

- Difficulties with social and communication skills
- Difficulties owing to a restricted repetitive interest and behaviour

What is old age?

It is only relatively recently that the possibility that people on the autism spectrum are just as likely to grow old as their 'neurotypical' peers, and therefore may need access to specific autism-friendly elderly care and support, has occurred to service commissioners, designers and providers.

It could be suggested that old age is very much a 'moveable feast', a state of mind, with those who have reached the state pension age of 66 considering themselves or are considered to be moving into old age. It must be remembered that state pension age (the age at which someone receives a state pension and free bus pass) is not the same as retirement age. Retirement age is open-ended and employers cannot discriminate against employees wishing to work beyond their state pension age.

Many people who are in their 70s and beyond still consider themselves to be 'middle aged' or youthful, at least in spirit. One has only to look at the current Pope—who was 76 when elected—and the main characters in the TV comedy *Last of the Summer Wine*' Is there a mismatch between what a person's body is telling them and what their mind, their spirit, their soul, is telling them? For the sake of expediency, the current state pension age will be taken as marking the ending of middle age and the start of old age. However, as the state pension age is set to rise, so should the start of 'old age'.

Views of people on the spectrum

It could be suggested that unless one listens to the views of those on the autism spectrum regarding what they consider to be appropriate services and appropriate alterations to existing services then such services are unlikely to be of any real future value. Is it appropriate for 'neurotypical' service designers to guess what people on the spectrum are likely to need once they move into old age? Therefore the views of four people on the autism spectrum were gained as to the services for those who have reached state pension age.

'I would like diagnostic services that are age appropriate.' (Steve, 62)

While it is likely that the core criteria for diagnosing autism spectrum conditions will be the same regardless of the age of the person seeking a diagnosis, the language throughout the diagnostic assessments used must respect and promote the dignity of the person and not seek to infantilise them.

'I would like to be asked what services I would need once I enter into old age.' (Bill, 64)

Such seeking of views must be specific. Instead of just asking Bill what his views are on elderly care services, clear information regarding how old age is likely to affect Bill physically, emotionally and psychologically must be presented to Bill in ways that he can understand and process and Bill's views gained based on this information.

'I understand that I may become physically frail, that my eyesight and hearing may get worse and that I may develop Alzheimer's and that I may need extra support in order to deal with these. The options that are available to me in terms of support at home, moving into supported living or moving into a care home must be presented clearly and simply in whatever form of communication that I am comfortable using.' (Ruth, 59)

Such communication forms may not necessarily be verbal but may be written or pictorial, depending on the person's communication preferences and ability. Furthermore, Lawson (2015: 20-2) suggested that regardless of where people live, they are likely to need support specific to those with an autism spectrum condition.

'I need an environment where I am treated as a person, as a human being, rather than as the "autistic".' (Bill, 64)

Services need to be human sized and shaped, to safeguard the dignity and respect of the individual, rather than expecting the individual to lose their individuality and identity within a large and anonymous elderly-care service.

'I need a service that recognises that I am likely to interact differently with the environment and the people within that environment because of my Asperger's and to tailor service design and provision accordingly.' (Ruth, 59)

Such differences in interaction could be argued to be at the core of the 'autistic triad' of Wing and Gould (1979).

'I would like care staff, be they in community health teams, GP practices or care and nursing homes to have a firm grasp of autism and what it means to be on the autism spectrum.' (John, 56)

Such a need for care staff and service designers and providers to receive in-depth autism training (Department of Health (DH), 2010a; 2010b) was voiced by John, Ruth, Bill and Steve. Such training needs to cover what autism means, 'normal ageing processes', differences in the 'autistic ageing process' and how these differences manifest themselves (Lawson, 2015), service design and provision from an 'autistic perspective' and achievable and simple alterations to existing service design and provision. However, such training is likely to be expensive in terms of resources and must include the contributions of people who are elderly or middle-aged and on the autism spectrum. Without such contribution, service designers and providers will likely end up guessing what people on the autism spectrum will need. At all costs, the following comment that was overheard after a training session must be avoided:

'I have attended a one-day course on autism. I know everything that there is to know about autism.'

While one comment—which was echoed by John, Bill and Ruth—may well be 'obvious', its realisation remains to be seen:

'However the service is designed and provided, it must be deliverable, fit for purpose and cost effective.' (Steve, 62)

Gaps in service provision

Just as there are many examples of good service design and provision, there are gaps in knowledge on the part of health and social care professionals around autism in general and the interactions between autism and the ageing process in particular and service design and provision. Many of the gaps previously identified (*Box 2*) echo the suggestions given by John, Ruth, Steve and Bill.

The NAS (2013) suggested that DH should make sure that older people who are on the autism spectrum are represented in its autism strategy review engagement work, particularly focus groups and online engagement. However, it could be suggested that only people who are 'computer literate' or have reasonably good communication skills will engage; those who are on the autism spectrum but who have severe communication difficulties may remain unheard, and if unheard their views will not be acted upon.

It appears that there are a number of issues and limitations around existing research on adults ageing with an autism spectrum condition. There is apparently a lack of a coherent age-related research framework and focus. Given that everyone, regardless of age, is at some point in the ageing process and will experience this process in varying ways and degrees, do researchers concentrate on adults over the age of 30, over the age of 40 or indeed over the age of 70? Do researchers ask the right questions or even know the right questions to ask? Consequently, researchers need to be clear as to what they mean by ageing and autism. The bulk of research on autism spectrum conditions appears to focus on children, adolescents and young adults, with very few studies concentrating on adults and more specifically older adults (Piven and Rabins, 2011). As professor Francesca Happe suggested:

'We simply do not know what autism spectrum conditions look like in older age. We don't know whether particular sorts of physical health problems are greatly raised … We don't know how best to diagnose in the very elderly, we don't know how dementia looks overlaid on top of autism. We don't know what the potential is for new insights both into autism and into ageing itself.' (NAS, 2013: 14)

This lack of knowledge has an impact on service design and delivery (NAS, 2013).

The changes in services for people on the autism spectrum make it difficult to compare the experiences of those from previous generations as they get older. While the key 'triad of autistic impairments' (Wing and Gould 1979) may have remained relatively stable and unchanged over the decades, the diagnostic criteria used by the various diagnostic tools may have changed. Again, it appears that, in common with all adults who are on the autism spectrum, older adults reported lengthy waits for diagnostic assessments. Consequently, the condition that may have been originally diagnosed some 30 years ago may not be the exact same condition that is being diagnosed today. Therefore service design and provision is likely to have changed over the years to reflect changes in diagnostic criteria. Such changes may be made more complex given the philosophical move from institutionalised care to enabling care and citizenship. The NAS (2013:12) suggested that even when adults with autism are receiving support, such support is likely to be as a result of a co-occurring learning disability. Hence, people without a learning disability are far less likely to receive appropriate support.

Box 2. Gaps in knowledge regarding older people and autism spectrum conditions

- Appropriate diagnostic tools to diagnose and assess the needs of adults who are in their 60s and over—see also NICE CG 142 (National Collaborating Centre for Mental Health, 2012: 107-8)
- In-depth description and evaluation of existing service and support networks
- Longitudinal studies that cover the entirety of people's lifespan trajectories
- Studies into the interaction between ageing, autism and health conditions
- Studies into the intervention with older adults with an autism spectrum condition
- Models to support training on ageing in relation to people who are on the autism spectrum

Source: Piven and Rabins, 2011

Suggestions for future improvements

It would be wrong to focus on gaps in needs research and service design and delivery based on this research without suggesting possible

Box 3. Recommendations for national health organisations and local/regional commissioning bodies

- Ensure that any guidance on older people applies to people on the autism spectrum
- Investigate ways to overcome challenges posed by diagnosing adults who are in their 50s–70s
- Present examples of best practice for local authorities and healthcare providers on planning the transition into elderly care services
- Ensure that the voices of people who are on the spectrum and who may require the input of elderly care services either now or in the near future are heard and acted upon

Source: NAS, 2013: 30-3

Box 4. Recommendations for local authorities and local commissioning bodies

- Train staff working in older peoples services
- Follow the NICE guidelines on autism in adults (National Collaborating Centre for Mental Health, 2012)
- Gather information on the number of people over 65 who are on the autism spectrum living in their areas
- Such information must include the services that are both needed by them and designed and provided for them
- Ensure that they are developing post-diagnostic support that is relevant and appropriate to the needs of people on the autism spectrum who are in their 50s and over

Source: NAS 2013: 30-3

ways of 'filling' these gaps and removing barriers that prevent the needs of people on the autism spectrum being met. Indeed, the NAS (2013: 30-3) made a number of such suggestions for future work involving the English DH, its Welsh, Scottish and Northern Irish counterparts, and regional and local commissioning bodies (*Box 3*). Locally, the NAS (2013: 30-33) suggested that local authorities and commissioning groups should include the suggestions given in *Box 4*.

Discovering the numbers of people who are elderly and on the autism spectrum alone is unlikely to be useful and the focus must be on how these numbers are used. Commissioning groups and local authorities are just as likely to need information around existing service design and provision both for those who are elderly and those who are on the autism spectrum. Given that it will not be appropriate to graft services that are designed more for young adults who are in their 20s onto the needs of those who are post-retirement, it may be helpful to engage in conversations with those who are in their 50s and 60s. Such conversations can take place within the context of local focus groups. However, a problem exists in that those who are likely to engage in focus groups are those who are relatively articulate and comfortable engaging with other people. People who are severely autistic or who have additional learning disabilities may be unable to engage in such groups and will therefore go unheard.

Service designers and providers must be appropriately and adequately resourced in order to meet the healthcare needs of people on the autism spectrum. There is very little point in tasking service designers and providers with providing appropriate services and information for people on the autism spectrum who are elderly, be it at strategic or local user levels, without giving them the necessary resources in terms of time, manpower and money to do so. This is likely to be a funding and therefore a political issue, but it is an issue that needs to be engaged with.

However, there may be existing services for the 'neurotypical' elderly (those who are not on the autism spectrum) that may require little more than tweaking to make them 'autism friendly'. For example, sensory levels (specifically lighting and sound levels and room decor) in care and nursing homes or community day centres may need to be changed so as to be non-threatening to people on the autism spectrum. Replacing flickering fluorescent strip lighting, which is known to cause physical distress and headaches in many people on the autism spectrum, with ordinary light bulbs or natural lighting would be a simple and cheap alteration to a care or nursing home environment. Alerting care staff about the distress that some forms of light physical touch can cause to people on the autism spectrum can also be useful.

Conclusion

'As I get older, I worry about what is going to happen to me … the sensory overload, the social demands and the difficulty with communicating with healthcare people, are frightening and overwhelming.' ('Neil', as recorded by the NAS (2013: 17))

The NAS suggests that in current and future service design and provision, government leadership is needed (NAS, 2013: 8). However, providing appropriate support and care for people who are autistic and who are approaching or journeying through old age is also the responsibility of nurses working in the community, in care and nursing homes and even in hospitals. The personal nature of, approach towards, and reason for this article should not deter readers from such an engagement. Not to engage fully with this responsibility risks denying people on the autism spectrum a dignified old age. This cannot be allowed to happen. BJN

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KEY POINTS

- The majority of autism transition service design and provision involves children and young people who are on the autism spectrum rather than older adults or those who are elderly
- Those on the spectrum who are elderly need to have a service that is fit for purpose with service information that is accessible and can be processed by those on the spectrum with differing communication needs
- Thorough knowledge and understanding of autism and its interaction with the ageing process seems to be the key to designing and delivering care services for an ageing population
- Those who are on the autism spectrum must be consulted with and involved in staff training and service design in order to make such service design and delivery fit for purpose.