Autism, intellectual impairment and old age [chapter head]

Professor Nicola Martin and Joanna Krupa

Abstract [A head]

There is very little research about autism and intellectual impairment in later life, and it of concern to autistic people and their families that there is no obvious source of advice about high quality services dedicated to ensuring that life can be lived to the full right up until death. Advanced planning is clearly a good idea, but looking into what might be out there can feel like staring into a void and this can create anxiety for those trying to plan ahead. This anxiety is well founded as provision is limited and there seems to be little political will to change this situation, despite equalities and autism legislation which aims to improve quality of life for autistic and other disabled people throughout life. The picture is worrying for those who are formally diagnosed and there will also inevitably be ageing adults on the spectrum who never had the opportunity to access a diagnosis and the notional legal protections this may afford. Some generic information about medical, social, emotional and practical aspects of ageing may be useful, but it is essential to think specifically about what might be helpful for older autistic people with lifelong or acquired cognitive difficulties and who may also experience lifelong or acquired barriers to communication. Understanding autism from a social model perspective is important, but the emphasis must be place on individuality, so that professionals are alive to potential stereotyping, including making heteronormative assumptions. Listening to autistic people about this subject provides a good starting point, and more autistic involvement in research about what might be conducive to health and happiness in old age, and the deployment of resources to make this happen would be marvellous.

Joanna Krupa has had a long career as a social worker with adults who have intellectual impairments.

The lack of research into services to assist autistic older people has been highlighted by the National Autistic Society (NAS) and others (Barber, 2015; Bennett, 2016; McPartland *et al*, 2015; Michael, 2016). Although there is a body of research about acquired cognitive impairment alongside the development of conditions such as dementia and Alzheimer’s, there is very little which focuses on the lives of people for whom lifelong intellectual impairment has been a reality. There is even less relating to the geriatric requirements of people with autism and (acquired or lifelong) intellectual impairment together. No volume about autism and intellectual impairment in adulthood would be complete without thinking about the whole adult life span. Given the flimsy evidence base on which to draw, this article attempts to articulate some key principles and areas for future research.

We will all get old if we live long enough. This paper does not provide a numerical definition of later life because individuals experience the limitations of old age and require additional support accordingly at different stages in their life course depending on various factors including fitness, activity and levels of community participation. Attributing an arbitrary number to this would be unhelpful, although milestones such as retirement and the death of parents can be useful life course markers as they may signal points at which requirements for assistance change, and something for which advanced planning would make sense.

With ageing comes cognitive, health, physical and emotional changes which are quite individual and need to be understood by those around us and by professionals who may be delivering services on which we may come to rely. Autistic people are no exception of course, and additional considerations may need to be taken into account alongside those associated typically with later life. While an understanding of autism, from a social model perspective, will be helpful for service providers, this only creates a backdrop against which to develop an understanding of the individual with all their unique hopes, dreams and aspirations. If you have met one (older) autistic person, you have met one (older) autistic person.

The NAS’s 2013 campaign *Getting On: Growing Older with Autism* reminds us that ‘Ageing people need to be able to talk about their health’. We extend the notion to health and well-being, encompassing physical and mental health and individual interests, passions, relationships and everything else that makes life rich and fulfilling. The NAS campaign goes on to suggest that ‘If professionals learn as much as they can about the person they support, they are more likely to spot changes in behaviour or mannerisms which may signal that the person with autism is having problems’. The NAS acknowledges that ‘talk’ will not necessarily be the primary mode of communication for some autistic people, particularly those with additional intellectual impairments. Finding out about the wants and needs in old age of those for whom communication has never been easy, requires some effort and may well involve engaging with people who are close to the individual with autism or have known them for a long time.

It is possible that additional communication challenges may develop in old age as a consequence of, for example, having a stroke. It is also possible that a very elderly parent has been the conduit to communication for an individual for all their life and this is something that could come to an abrupt halt if the parent dies or acquires age-related communication difficulties themselves. Any situation which relies on a very old person caring for an old person without support is obviously not sustainable, but that does not mean that it does not happen. Reliable figures are not available as families can be below the radar, particularly if they have ‘always just managed’ and not accessed services before. It is quite possible that the autistic person is not diagnosed.

We must not fall into the trap of assuming that it is always the autistic person who is the recipient of care from another family member. Ageing autistic carers receive no research attention and we must acknowledge their existence. Autistic parents of autistic children may find themselves in this position later, and sensitive support with forward planning may be needed. Without a crystal ball it is not possible to say what sort of assistance will be out there in the future so it would be wise for researchers to engage with autistic parents right now on this subject.

We have no accurate information about how many old people are on the autism spectrum. Wallace *et al* (2016) remind us that it was not until the 1940s that the first generation of children were to receive an autism diagnosis and it is therefore only relatively recently that these individuals are moving into old age. Some will not have accessed formal schooling (D'Astous *et al*, 2014). More recently still, diagnosis in adulthood has increased and it is likely that there are many more autistic adults around who have not had access to any formal diagnostic process. Although there is some evidence of premature mortality for people with intellectual impairments (Public Health England, 2014), it is safe to assume that the majority of people with autism will live to an age at which some form of geriatric support will be required. Articulate adults on the spectrum are expressing a degree of concern about what old age might look like for them without any obvious focus on ensuring that services are designed with autistic elderly people in mind. ‘Knowing that there is such a paucity of research about supporting us as we grow older makes old age a frightening prospect’ (Michael, 2016 p515). Research into old age involving autistic people who do not communicate verbally, whether or not they have additional intellectual impairments, is almost non-existent and therefore we will have to rely on that which is informed by autistic researchers who are able to empathise with many of the experiences of those who are silent.

Much of the research which is available tends to focus on the medical and health-related aspects of ageing, rather than, for example, the psychological and social changes. Focusing on health is of course important given the higher rates of poor health and mortality of adults with learning disabilities (Public Health England, 2014). People with intellectual impairments are eligible for an annual health check from their GP, and this should help to identify health needs more promptly than has often previously been the case. There is evidence to suggest that these health checks are not always taken up (Glover *et al*, 2013). Changes to the body and physical functioning need to be considered and discussed sensitively in ways which are appropriate to the individual and inclusive of people who do not use speech. For example, McCarthy and Millard (2003) attempted to explore the concept of menopause with a group of women with intellectual impairments, from the women’s’ own perspective, rather than just as a medical phenomenon. From working with advisory groups of learning disabled women, these researchers make useful suggestions around the importance of explaining what these changes in their bodies might mean, and then following this up with regular accessible reminders, which may employ the use of pictures, symbols and other aids to communication appropriately with the individual. Professionals would benefit from training in dealing with the subject sensitively, with respect for the individual underpinned by an understanding of autism from a social model perspective. Staff working with women should be prepared for discussion about the physical aspects of ageing around and after the menopause.

Topics such as loss, bereavement and sexuality also need to be considered without automatic heteronormative assumptions being made about the individual. (Milton’s chapter on idealised normalcy in this issue unpacks the idea of normativity further. Heteronormativity is about the assumption that everyone is heterosexual). Bereavement extends beyond family relationships. An autistic person may have extremely close friends with whom their communication is largely via the internet. The death of such an important person should never be dismissed as of lesser significance because the relationship is poorly understood by service providers and others. Milton and Simms (2016) reminds us of the importance of autistic company which enables some autistic people to be themselves without trying to fit in to neurotypical ways of being. Lots of those conversations take place online.

Many older people with intellectual impairments and autism have been cared for by family members, often parents (Bibby, 2012), who will obviously themselves be growing older. Inevitably this may lead to situations where extra support needs to be provided, possibly at a time of profound grief and upheaval when a caregiver dies. Recent publicity about abusive practices in social care, for example the Panorama documentary about Winterbourne View, will continue to lead to concerns for some families about engaging with services. This is one of many reasons (Bibby, 2012) why older people and their families may find it more difficult to consider future planning, which in turn can lead to crises in support; for example, if the carer of an autistic adult with intellectual impairment who has never previously received any external support is admitted to hospital or dies suddenly. There are however also instances where the adult with autism and intellectual impairments provides care for their older relative, and again, both parties may find it hard to accept changes in this situation. Other reasons which may be a barrier to future planning include difficult relationships with professional, carers feeling there will be some loss of identity, and the obvious emotional difficulty in broaching this sensitive subject. Sometimes caring for the carer will enable families to stay together. The media occasionally highlights the sad situation of old married couples being separated when one person needs to go into residential care but it is very rare to hear about the grief and loss of identity experienced by elderly people who are removed from the person for whom they are caring, let alone the emotions which someone who does not communicate via speech may be feeling. It would be nice to imagine that the elderly carer and the person for whom they are caring could be provided with support which enables them to stay together for as long as possible while in the background someone is and empathically helping with the whole thorny issue of future planning. Waiting for a crisis and then trying to make a plan is obviously ridiculous and it is particularly important to remember that unpredictable unforeseen change is especially disruptive for autistic people.

There is some evidence to suggest that professionals have made assumptions about people from black and minority ethnic (BME) communities continuing to be supported by their extended families following the death of their parents, which has led to BME disabled people being less likely to receive services (Walker & Ward, 2013). Identity is multi-faceted, as The Equality Act (2010) reminds us. Service providers should not assume that all families originating from BME backgrounds have extended social support networks, or that everyone is heterosexual and gender conformist, or indeed that autistic people are asexual or, like Greta Garbo, just want to be alone. Stereotyping is problematic and creates barriers to getting to know the individual, their circumstances, wants, needs and passions.

It is clear that making assumptions about people’s lifestyles as they age is not useful. In fact, for the women talking about menopause, some of them were very aware of discrimination or stigma they might face, and did not want to identify themselves as ‘older’ (McCarthy & Millard, 2003). Ageing does not automatically mean a reduction in activities, and many people will wish to continue living actively and socially. In some instances, older people who are placed in ‘generic’ residential elder care because of a health or mobility crisis, end up losing their independence. Previous services or support which enabled them to pursue their activities of choice are no longer funded, homes are not sufficiently staffed to facilitate continued community access, and people’s lifestyles become more sedentary with the potential loss of skills and adverse effects on physical and mental health (Blackman, 2007).

[box]

Case study

Restricting access to the internet can severely impact on the social life of some autistic people who may have close friends who they communicate with online. As a social worker, I (Joanna) was aware, for example, of a man whose health declined, although his cognitive abilities were intact. He was therefore moved to a residential home many miles from where he had lived all his life, but close to his sister, who was also ageing. However, the home did not fund staff to accompany him on visits, and it took several years for the funding to be agreed. In the meantime, his horizons were narrowed, due in part to the limitations of the home. A long, time consuming gap between policy and good practice can, as with this illustration, have devastating effects. While we do not have space to explore here the implication that this scenario arose as a result of how older people are perceived in general, and that this might be reflected in the resourcing of social care elder services, this concern is in our minds. Harbottle and Jones (2016) discussed compassion in social care in the first volume in this series. We are big fans of the notions of compassion, respect and dignity. [box end]

End of life care merits discussion. Public Health England’s 2014 report, *Making Reasonable Adjustments to End of Life Care for People with Learning Disabilities*, including an Easy Read summary, gives useful case studies showing how agencies have worked to improve end of life care, and a comprehensive list of resources. There are also many examples of end of life plans online which can be used to ensure the wishes of autistic people and those with intellectual disabilities are carried out. Michael (2016), in the first volume of this series, discussed the use of the Mental Capacity Act (2005), and advised that professionals, including medical staff, should ensure they are familiar with the act, and use it ethically to make sure that any decisions made about a person who lacks capacity are made in their best interests. This does not just apply to end of life care. Notionally, sensitive, dignified and compassionate use of the act would contribute to preventing situations such as one I (Joanna) was aware of, where it was discovered that a man with an intellectual impairment had a ‘Do Not Resuscitate’ instruction on his hospital file, without his consent or the knowledge of his circle of support. In such cases it is difficult not to infer that judgments have previously been made about quality of life (see also the CIPOLD report (Heslop et al, 2013)). Similarly, people with intellectual impairments have been less able to access palliative care services, (Public Health England, 2014) and this inequality also needs to be challenged under the Equality Act (2010), which numbers age and disability amongst its protected characteristics.

Recommendations [A head]

Research [B head]

* More research, informed by autistic people, about the experiences, needs and wishes of people who do not use verbal communication, is essential.
* Support is required for autistic adults with intellectual impairment, their carers and families, and people working with them, in discussing and planning for the future.
* Research which identifies barriers which obstruct effective forward planning is necessary.
* Further development of services which can meet the specific requirements of older autistic people with intellectual impairments is necessary, as the current ‘generic’ model often does not meet their needs, including palliative care services. Autistic people are best placed to advise on what this might look like.

Staying active in older age [B head]

As we get older, it is more important than ever to look after ourselves. Keeping active is one of the best ways of improving our physical and mental well-being. This information will be helpful to those who are not very active at the moment or are looking for ways of doing more. It’s never too late to start making a change.  
  
Being active in later life has many benefits for older adults with autism. Everyone with autism can:

* improve their health, [well-being and independence](http://www.nhs.uk/livewell/fitness/pages/fitnesshome.aspx)
* keep in touch with their local community and friends
* learn new things, maintain interests and enjoy life
* use [physical activity](http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-older-adults.aspx) to help manage stress and anxiety.

If you are someone who supports a person with autism, physical activity will also make a difference to your quality of life as well. The benefits are there for everyone. For more information please see *A* *Practical Guide to Healthy Ageing* (NHS England & Age UK, 2015).

Health conditions and ageing [B head]

When a person has autism and any other mental or physical health condition, they are said to have a co-existing condition (e.g depression, epilepsy, obsessive compulsive disorder). As the mind and body undergo the ageing process, [co-existing conditions](http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/) can change. New conditions may develop, some of which may be related to ageing such as dementia, arthritis and osteoporosis and so on. Carers or family members  who know the person well should be alert to any changes and the possible reasons for them. This may include looking at changes in physical health, such as weight, eyesight, hearing, mobility and breathing. Changes in mood or behaviour may also signal and underlying problem. Any changes noticed should always be discussed with a GP or other health professional.

However, it is also important not to make any assumptions about physical or cognitive decline changes on the basis of age alone and to have an open mind about possible causes and reasons.  
  
Support and aids [B head]

As autistic people get older, they are likely to need more support, which could be through the help of carers or [aids](http://www.nhs.uk/conditions/social-care-and-support-guide/Pages/equipment-aids-adaptations.aspx) that can make daily tasks easier. There are many aids available now that can help with hearing, walking, sitting, turning taps on and off, reminding people to take medications and many more. Some people are starting to use assistive technology to retain their independence and promote their dignity, including apps on tablets. Not all these items will be specific to older adults with autism but a lot of them can be adapted or used in a more autism-specific way.  
  
When a person’s abilities start to decline, it is advisable to seek advice from a physiotherapist or occupational therapist to make sure that the correct equipment to meet their needs is chosen. Referrals can be made through GP’s and social services departments.

Death and bereavement [B head]

Planning for death [C head]

Calderstones Partnership NHS Foundation Trust created a document called a *Plan for When I Die* that NAS adapted for people on the autism spectrum. This plan looks at everything that needs to be considered and the decisions that will have to be made after a person with autism has died. Talking about funeral arrangements and where possessions will go can be difficult, but giving a person the chance to think about this and share their views and wishes is important. These include:

* whether the person wants to be buried or cremated
* what sort of funeral they would like
* whether they would like any specific songs played
* if they would like a religious figure to be present
* where and to whom their personal possessions should go.

Dealing with the death of someone close to you [C head]

People with [autism](http://www.autism.org.uk/about/what-is.aspx) (including [Asperger syndrome](http://www.autism.org.uk/about/what-is/asperger.aspx)) need support following the death of someone close to them, just like anyone else. If someone uses a service, a bereavement questionnaire can help staff to provide that support. The [NAS services](http://www.autism.org.uk/services.aspx) has developed a useful questionnaire which may help caregivers following a bereavement. The questionnaire looks at:

* support during bereavement
* financial and legal arrangements
* supportive relationships
* parents' and carers' wishes
* views about death.
* Useful resources for older autistic people

The NAS covers the following topics:

* [housing options for older people](http://www.autism.org.uk/about/adult-life/ageing/housing.aspx)
* [social security benefits for older people](http://www.autism.org.uk/about/adult-life/ageing/benefits.aspx)
* [social isolation](http://www.autism.org.uk/about/communication/social-isolation.aspx)
* [dental care and autism](http://www.autism.org.uk/professionals/health-workers/dentists-info.aspx)
* [managing money](http://www.autism.org.uk/about/benefits-care/managing-money.aspx)
* [age-related conditions](http://www.autism.org.uk/about/what-is/related-conditions.aspx).

References [B head]

Barber C (2015) Old age and people on the autism spectrum: a focus group perspective. *British Journal of Nursing* **24**(21).

Bennett M (2016) “What is life like in the twilight years?” A letter about the scant amount of literature on the elderly with autism spectrum disorders. *Journal of Autism and Developmental Disorders* **46**(5) 1883–1884.

Bibby R (2012) ‘I hope he goes ﬁrst’: Exploring determinants of engagement in future planning for adults with a learning disability living with ageing parents. What are the issues? A literature review. *British Journal of Learning Disabilities* **41** 94–105.

Blackman N (2007) People with learning disabilities – an ageing population. *The Journal of Adult Protection* **9** (3) 3–8.

D'Astous V, Manthorpe J, Lowton K & Glaser K (2014) Retracing the historical social care context of autism: a narrative overview. *The British Journal of Social Work* **46**(3) 789–807.

Glover G, Emerson E & Evison F (2013) The uptake of health checks for adults with learning disabilities in England: 2008/9‐2011/12. *Tizard Learning Disability Review* **18** (1) 45–49.

Harbottle C & Jones M (2016) Total attachment. A whole systems approach to safeguarding adults in care services*.* In: D Milton and N Martin (Eds) *Autism and Intellectual disability in Adults, Volume 1.* Brighton: Pavilion Publishing & Media.

Heslop P, Blair PS, Fleming PJ, Hoghton MA, Marriott AM & Russ LS (2013) *Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD): Final report.* Norah Fry Research Centre.

Howlin,P ., 2012. Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*, *57*(5), p.275.

Lever, A.G. and Geurts, H.M., 2016. Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. *Journal of autism and developmental disorders*, *46*(6), pp.1916-1930.

McCarthy M & Millard L (2003) Discussing the menopause with women with learning difficulties. *British Journal of Learning Disabilities* **31** 9–17.

McPartland JC, Law K & Dawson G (2015) Autism Spectrum Disorder. *Encyclopaedia of Mental Health*, p.124.

Michael C (2016) Why we need research about autism and ageing. *Autism* **20**(5) 515–516.

Milton D & Sims T (2016) How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability & Society* **31**(4) 520–534.

NHS England & Age UK (2015) *A Practical Guide to Healthy Ageing* [online]. Available at: <https://www.england.nhs.uk/wp-content/uploads/2015/09/hlthy-ageing-brochr.pdf> (accessed September 2017)

Piven J & Rabins P (2011) Autism spectrum disorders in older adults: toward defining a research agenda. *Journal of the American Geriatrics Society* **59**(11) 2151–2155.

Public Health England (2014) *Making Reasonable Adjustments to End of Life Care for People with Learning Disabilities [online].* Available at: <https://www.ndti.org.uk/uploads/files/RA-End_of_Life.pdf> (accessed September 2017)

Totsika, V., Felce, D., Kerr, M. and Hastings, R.P., 2010. Behavior problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without autism. *Journal of Autism and Developmental Disorders*, *40*(10), pp.1171-1178.

Walker C & Ward C (2013) Growing older together: ageing and people with learning disabilities and their family carers. *Tizard Learning Disability Review* **18** (3) 112–119.

Wallace GL, Budgett J & Charlton RA (2016) Aging and autism spectrum disorder: Evidence from the broad autism phenotype. *Autism Research* **9** (12) 1294–1303.

Additional resources [B head]

<http://www.autism.org.uk/about/adult-life/ageing.aspx>

<http://www.autism.org.uk/about/adult-life/ageing/aim-project.aspx>

NAS resources [C head]

[*Ageing With Autism - A Handbook for Care and Support Professionals*](http://www.autism.org.uk/products/core-nas-publications/ageing-with-autism.aspx)  
An in-depth guide for professionals who work with older autistic people every day. It looks at a number of issues that older people are likely to face, including physical or mental health problems; change; transition; and bereavement. It suggests ways in which these issues might be managed, with a focus on the older person's quality of life.

[*Ageing with Autism: A guide for clinicians and health professionals*](http://www.autism.org.uk/products/core-nas-publications/ageing-with-autism-ebook.aspx)  
An at-a-glance e-book guide to some of the main issues faced by older autistic people. It is aimed at professionals such as GPs and hospital staff who may come into contact with autistic people from time-to-time.