

## **Priorities for research on Autism and Ageing: A roundtable discussion**

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### **Introduction**

The majority of autistic people are adults, yet diagnostic inequalities persist for older autistic adults, those with high support needs (including learning disabilities), ethnic minorities, and women or gender diverse individuals.<sup>1</sup> Despite growing research interest in older autistic adults,<sup>2-6</sup> most published research focuses on children and young people, and there remain inequalities in representation in research.<sup>7</sup>

In this paper we share a roundtable discussion on gaps and priorities for research on autistic experience and ageing. The roundtable was convened by Professor Mary Stewart BSc MSc PhD, Professor Hanna Bertilsdotter Rosqvist PhD, Dr Anna Day PhD DClinPsy, and Dr Joe Long PhD who identified topics for discussion and invited contributors. Roundtable contributors were autistic researchers and advocates who work in the areas of autism, ageing, and care: Cos Michael BSc, an autism and ageing consultant and trainer, Dr Aimee Grant PhD, an Autistic and disabled academic, Dr Mary Doherty MB, PhD, a consultant anaesthetist and autism researcher, and founder of Autistic Doctors International, Dr Cecilia Ingard PhD, autistic academic with a focus on ageing and neurodiversity, Dr Marion Hersh MA, MSc PhD, CEng, CMath, academic, autistic with intersectional characteristics, activist, and campaigner, and Dr Wenn Lawson PhD, autistic academic and campaigner. As specialists in the field, the group were able to share insights from their own research and advocacy work as well as identifying gaps and areas for future exploration from their own lived experience.

Convenors used four initial topics to prompt discussion: i) gaps and priorities in research with autistic people as they age; ii) the impact of ageing for autistic individuals, their friends, and family; iii) successful ageing – what it looks like and what is required; and iv) life course inequalities in autistic biographies. These topics were shared with the roundtable contributors ahead of the discussion. In relation to the final topic, participants emphasised the need to address intersecting forms of marginalisation such as ethnicity and gender.

The roundtable was a forum in which participants could respond to each other's points and develop topics and themes, which are reflected in the discussion

presented here. Two online meetings took place, with opportunities to reflect on the topics and the content after each meeting and during the writing process, where participants reviewed the transcripts. Two participants (MH and WL) were unable to join the live discussions but added their contributions to the written transcripts as they were circulated, adding an asynchronous element to the discussions.

We highlight the importance of recognising both the commonalities and differences in autistic experiences and acknowledge the considerable diversity within the autistic community.

**Professor Mary Stewart:** Our contributors have engaged in different ways, in online meetings, and in writing, meaning that some points were made in an online conversation, some asynchronously, and some during editing and after reflection. The roundtable contributors are all autistic and as such we, as the convenors, aimed as much as possible to ensure that our roundtable was accessible. Our discussion started with the question: **What are the gaps and priorities in research for autistic people as they age?**

**Dr Marion Hersh:** Most of the very limited literature with older autistic adults focuses on mental and physical health conditions and cognitive impairments, in which there can be a focus on comparisons with older non-autistic people or younger autistic people. There is very limited research on older autistic people's lives, their living and working situations, leisure and social activities, use of technology, and how these change with increasing age.

**Dr Aimee Grant:** Quality of life and improving services are consistently identified as high priority areas for research by autistic people.<sup>8</sup> We need to apply that throughout the life course.

**Dr Mary Doherty:** One of the biggest problems is that there's an almost complete lack of awareness of autism in the fields of geriatrics and older age psychiatry – but these are the professionals that are commonly referring older people for residential care or deciding on living arrangements for older autistic people. If they don't realize that they're dealing with autistic people, then there's very little chance that our needs might be met effectively.

**Cos Michael:** You become an adult and then you get stuck in stone because from the age of 25 to the day you die, you are just referred to as an autistic adult. Until we're included in policy as a life stage with its transitions to retirement, death, bereavement, moving into accommodation (if we need to), then there is no imperative for anybody to commission anything.

### **Research methods**

**Prof Mary Stewart:** Thank you everyone for highlighting these critical gaps. Given the challenges you've identified, from the lack of research on everyday lived experiences to the absence of autism awareness among key professionals, do you think there would be any need for methodological advancement to bring autistic people more into the research? Is there anybody else that we think should come into that discussion?

**Dr Aimee Grant:** I think participatory and truly co-productive methods are really important. I've made a real effort with my Autism from Menstruation to Menopause project.<sup>9</sup> A community council of 11 autistic people ran the project with me. I worked with some community leaders to get truly lay autistic people so it wasn't just the really highly educated people who may also be researchers, but my project included representation from people with learning disabilities, and non-speaking autistic

people. Because autistic older people aren't involved much in research and policy-making we don't know what suits them best. To me that implies a need for Participatory Action Research (PAR) or Community-Based Participatory Research (CBPR) with Autistic older people really involved in co-designing the studies, so we can hear the issues from them.

**Dr Cecilia Ingard:** In my PhD thesis I explored elderly care with people with dementia. During interviews with relatives, the participants brought photos with them that they took together with their relatives with dementia.<sup>10,11</sup> The photos showed places or environments in the nursing home that facilitated their health or that was a barrier for their health. People who may traditionally have less power have the opportunity to feedback to managers their opinions and influence the nursing home, the manager, and the policies.

**Dr Wenn Lawson:** We used the same sort of method and PhotoVoice when we did our work with older adults and mental health research.

**Dr Marion Hersh:** Development of the Calm Spaces Forum and website for older autistic people was carried out using a co-production process involving a team of three older autistic academic and community-based researchers supported by an advisory committee of three older autistic people.<sup>3</sup> We are now developing a community of older autistic people through the forum. This will contribute to providing support and advice and could have a role in combating loneliness.

**Dr Mary Doherty:** I totally agree about participatory research, although I sometimes look at it from the other perspective, we always think of participatory research in terms of including community members and often don't think about the professionals who are on the other side of the equation and dealing with autistic people. I think

sometimes that can be quite helpful. I would love to see some research done with geriatricians to explore their experiences. I think that could certainly address some of the knowledge gaps and capitalize on this growing awareness and thirst for information that I'm perceiving from the professional community.

### **Navigating Ageing, Change and Loss**

**Prof Mary Stewart:** The approaches you've outlined, from community councils to PhotoVoice to engaging professionals, provide valuable frameworks for conducting research with older autistic people. Building on this foundation, what do you think we need to consider when supporting older autistic people to navigate ageing, change, and loss? Aimee, your research focuses on menopause – would you like to start by discussing the impact of menopause?

**Dr Aimee Grant:** My recent review assessed the experiences of autistic people during the menopause transition, we find that they're juggling a lot and they've been on the edge of burnout for a really long time.<sup>12</sup> They've got significant caring responsibilities, and then during the menopause transition, they're suddenly not able to cope with everything anymore, losing skills and struggling, sometimes having to stop working. Part of this is also because there's been so much difficulty throughout the life course.

We have evidence that, during menopause, the number of meltdowns people experience increases, can become more severe, and even self-injurious. But when they go to the doctor and ask for menopause support, they often don't get it. There is very little written about autistic people's experiences of using Hormone Replacement Therapy (HRT) - which is the gold standard for reducing menopause symptoms.<sup>13</sup>

**Dr Marion Hersh:** Menopause is also not a horrendous experience for all autistic people, so we need research on what makes the difference: what makes the menopause a non-event for some autistic people and horrendous for others? And what can autistic people do and what support is required to make this a better experience?

**Prof Hanna Bertilsdotter Rosqvist:** I think about these problems across the life course, autistic women being misdiagnosed when they are in their teens or twenties when their hormones were changing in the adolescent phase.<sup>14, 15</sup> It could be comparable at menopause.

**Prof Mary Stewart:** We can see a similar pattern across the life-course, that there can be, for instance, diagnostic overshadowing, where there can be a misattribution of symptoms and challenges to being autistic, rather than perhaps anxiety, depression, or changes in, for instance, hearing and sight. In addition, autistic people's experiences, biographies, and needs are often homogenised rather than recognised as diverse.

**Dr Cecilia Ingard:** Older people who may be autistic might be seeking psychiatric care, but professionals may respond with answers like, "No, you might have dementia instead".<sup>16</sup>

## **Employment and Retirement**

**Prof Mary Stewart:** That's a crucial point about misdiagnosis in healthcare settings. I'd like to shift our focus now to another important area – that of employment and also changes associated with retirement. What issues do we need to consider for older autistic people?

**Cos Michael:** Employment is important - we don't know the percentage of autistic people in work, as the older people who are working are probably mostly undiagnosed and have masked all their lives.

**Dr Marion Hersh:** My research shows that older autistic people have varied patterns of employment and retirement.<sup>17</sup> A few participants were happy with their jobs, but dissatisfaction was more common. Several would have liked to retire or reduce their hours but could not afford to. Others wanted to work, but support was not available or felt they would not be able to work even with support. The lack of care had also reduced choices, with several participants full time unpaid carers. There were also instances of underemployment, sometimes in multiple jobs, and 'retirees' who were still working. As well as income, there can be a variety of social and other benefits associated with employment. Being unemployed or under-employed also impacts financial security, restricts care options, and affects overall wellbeing.

### **Social Connection, Isolation, and Community Participation**

**Prof Mary Stewart:** Those are really important points about the varied employment experiences and the knock-on effects for financial security and wellbeing. I'm conscious that employment often provides not just income, but also social connection and routine. This brings us to a related but distinct challenge – social isolation in older age. What particular barriers do older autistic people face when it comes to social connection and community participation?

**Dr Cecilia Ingard:** I think it's hard when you have special interests such as running or something that also gives you calm and mindfulness, and then you can't do that as you get older. It's hard to find a new special interest. The special interest can also

bring you to a social community and that's your community and if you can't exercise or something, you can't meet your friends.

**Cos Michael:** Personally, I don't like small talk, but we're told we're more likely to get dementia if we don't participate, which frightens me. Yet I can't cope with the things organised for older people, like knit and natter and lunch clubs. But because older autistic people are so scattered within communities, we don't have networks. I don't have older autistic friends locally. There is a monthly adult autistic meetup at the library, but nearly everybody is young. They talk about their life stage, not mine. I think that that social isolation is sort of imposed by our isolation as older autistic people within our own communities because we don't have peer networking.

### **Physical Changes and Ageing**

**Prof Mary Stewart:** Those are really important insights about how social isolation is reinforced by the lack of autistic peer networks and inappropriate mainstream social provision. I'm struck by how physical changes keep emerging in this discussion – Cecilia mentioning the challenge of continuing special interests like running, and Cos talking about the loss of walking as thinking time. This seems like a natural point to explore the physical changes of ageing more explicitly. How do these changes intersect with being autistic in ways that might be different or particularly significant?

**Dr Mary Doherty:** I'm thinking about how the physical changes of ageing intersect with being autistic and how that's different for us. For instance, how joint hypermobility interacts with arthritis and how our sensory needs change as we age. To give context, I was noticing that my sensitivity to light has increased rapidly over the last couple of years. And it took me a while to realize that that is linked to age-

related changes in my eyes. So now I need reading glasses, my eyes just don't accommodate in the way that they used to, which is a standard age-related change for everybody. But that significantly impacts my sensory experience. Also, as my hearing has deteriorated - age related hearing loss, my sensitivity to sound has changed, which is a welcome change except for the fact that I cannot bear anything touching my ears. Therefore, I haven't been able to use hearing aids, which I do need. And that's purely because I can't tolerate the sensory input from wearing or anything around my ears. There's all these sorts of things that there's just no discussion of really in terms of ageing and sensory needs. So, there's lots need to be done there.

**Cos Michael:** Absolutely agree. I jump at the slightest sound these days. I have false teeth, they are difficult to live with. I have arthritis, which means I can't walk very far and that is impacting my quality of life because that was my thinking time. I used to go for very long walks, and it cleared my mind, and I can't do that now. And I think that all the accoutrements, the hearing aids, glasses, false teeth, the walking frames, all of those things which occupational therapists tend to be there to help you deal with in your own home, they really need to be included in research and need to be understood how they impact the person and their wellbeing.

**Dr Aimee Grant:** And to add - joint hypermobility is hormone mediated, so may change during menopause.<sup>18</sup>

**Dr Cecilia Ingard:** I think about the special interests as we age, because I need to run or cross-county skiing every day. I really need that to concentrate. And when I get older then probably, I can't do that. It becomes more difficult to take part in your special interest.

**Dr Mary Doherty:** Age-related changes impact our stimming. For example, arthritis in hands and you stim with your hands, or knee arthritis stopping you from walking, climbing, running, that sort of thing, that's going to have a massive impact on quality of life. My own mum was undoubtedly autistic, stimmed with her hands and ended up with joint replacements in her thumbs in both hands. And as I look back, undoubtedly because of a lifetime, a lifetime of stimming and not recognized.

**Dr Aimee Grant:** Some of the isolation that older autistic people face could be because of all of these bodily changes, changes to sensory sensitivity which can then have a negative impact on our quality of life.<sup>19</sup> So, it's thinking about how we can maintain networks including using the internet. I very rarely leave my house but I don't feel isolated. I had a really bad burnout around the time of perimenopause starting and my legs have never started working again. I used to run long distances and now I'm a wheelchair user. These impacts on our lives can be really big and extreme. And I think it's important that we're thinking about how we can replace some of the things that are filling our cups in a positive way when we need to start doing them differently because of ageing.

**Cos Michael:** Thinking about health - I also think about the self-medication that autistic people practice throughout the lifetime, which may be self-harm, drugs, alcohol - stress and ageing related health conditions may mean that this is exacerbated. So, if you overeat all your life, you are likely to get heart conditions, stroke, diabetes. Although we know that lifestyle is linked to health – it would be important to consider how being autistic and self-medicating affects health across the lifespan.

**Relationships – family relationships, bereavement, and caring responsibilities**

**Prof Mary Stewart:** Thank you. The physical changes of ageing clearly create unique challenges for autistic people, particularly around sensory needs and the ability to maintain essential activities for wellbeing and self-regulation. These physical limitations also impact relationships and independence. Let's explore the relational dimensions more fully – family relationships, bereavement, and caring responsibilities. What issues do older autistic people face in these areas?

**Cos Michael:** We also need to consider family - a huge amount of autistic people are supported by their parents although again there is a paucity of research that discusses the rates and impact.<sup>20</sup> Parents fear what will happen to their autistic adult offspring. So what happens if a parent dies, leaving an autistic adult, possibly 50, 60, even 70 years old themselves, with the loss of the person who cooks for them, makes sure that they're clean, that their buttons are sewn on, who helps support them financially, possibly provides them with their home and who deals with any paperwork? Their whole social and support network may have been managed by their parents and suddenly they're adrift. As well as this, they're grieving.

**Dr Mary Doherty:** It is important to consider grieving, what's different for us about how we grieve? Do we need more research on that? Do we need to look at that differently because losing loved ones, losing a spouse, losing a parent, that could be potentially very different for us in the way that we experience that. And maybe the support that we need around those major life changes might be different to what non-autistic people might need. And I am not sure if there is much work on that at all.

**Dr Marion Hersh:** Another related issue is funeral ceremonies and mourning rituals. More traditional ceremonies may include an element at the end where attendees approach the main mourners to 'comfort' them. Being approached by people they may not know and possibly being expected to submit to being hugged and engaging in meaningless platitudes with them can be really difficult for (older) autistic people, particularly at a time when they are already upset. However, other family members may object if they opt out of this.

**Dr Aimee Grant:** The need to be an advocate for neurodivergent children is definitely an issue. There is a particular impact on women and people Assigned Female At Birth (AFAB) - they're doing all of that emotional labour within their family. They may well have a neurodivergent partner who struggles with that stuff. So, as the supports get less available, and support needs to be fought for, there is additional labour on autistic parents, which will impact them as they get older.

**Cecilia Ingard:** There is a lot of stigma surrounding autistic parenting. Additionally, as part of the myths regarding autism and parenting, some people still discuss autism as if it were grounded in bad parenting.<sup>21</sup>

**Dr Aimee Grant:** We also see quite a lot of changing relationships with partners, family and friends, needing to rely on them more as carers or giving over some of the things that have typically been done. Menopause transition is a time that's really difficult for relationships for autistic AFAB people. This includes relationship breakdown because things that have been tolerated in the past can no longer be tolerated. Alexithymia increases for some autistic AFAB people at menopause. So, it might just all be a big ball of rage and fury with big impacts on family and partners.<sup>12</sup>

**Dr Mary Doherty:** Another thing I've seen is autistic people really struggling to deal with their own ageing parents and the changes that brings – that needs addressing.

### **Accessing Healthcare**

**Prof Mary Stewart:** These are crucial points about family dynamics, caring responsibilities, and bereavement – from the difficulties with traditional mourning rituals to the impact of being advocates for neurodivergent children throughout life, to relationship changes and supporting ageing parents. All of these situations may require healthcare or professional support at some point.

**Let's turn now to accessing healthcare. What are the key issues here?**

**Dr Mary Doherty:** Thinking about healthcare professionals' involvement in age related health issues and unwanted social interaction, I was asked by a group of physiotherapists to speak to them about how to manage elderly patients who've had strokes. They're trying to do rehab and they're expected to go to the person's home but they're not being let in. And I can really understand that. I would hate to have unwanted professionals in my life, in my home interfering with how I want to live my life, and strangers in my life. Yet there is an acknowledgement that help is needed. I don't know what the solution to that is, but rehabilitation from a stroke can be negatively impacted by the health professionals not understanding how to work with autistic people. That can have a huge impact on quality of life and rehabilitation - training is just so important there.

**Cos Michael:** I think there's a sort of expectation for each life stage in the way people treat you and the way you are supposed to respond to that treatment. And again, professionals aren't trained to work with older people. At the dentist's, I have to tell the nurse "please don't stroke my arm. Please don't touch me". I'm managing

the fact that the dentist is touching me, if something else touches me, it's too much for me – and that makes me the problem. I have to tell them in advance, I'm autistic, I have a sensory need. I don't expect to be touched. It doesn't soothe me or calm me. All professionals need to understand how to work with older autistic people – ambulance workers, emergency services, and other professionals.

**Dr Mary Doherty:** One point I've found really useful is highlighting the differences between autistic and non-autistic people to help staff in health and social care understand our needs. It's much more aversive to be touched. It's much more difficult for us to have a break in routine. Maybe non-autistic people mightn't like it, but they're not going to refuse the healthcare because of it. Whereas for us it is an absolute barrier sometimes. (see <sup>22-24</sup>)

**Dr Marion Hersh:** Asking for their needs to be met was one of the strategies used by my research participants who also noted that 'minor irritations for neurotypical people aren't minor irritations for me'.<sup>17</sup> Other strategies included asking for the first appointment to avoid waiting and the associated sensory overwhelm, a quiet space to retreat to, going round buildings on outside to avoid sensory issues, asking for GP's email address to communicate asynchronously in writing, noise protection and sunglasses and a variety of calming strategies. Success varied and was likely to be greater if the action was not dependent on other people.

**Dr Aimee Grant:** Choice and autonomy are really important. Being able to do things in the way that works for you and that just being accepted by the system and those around you. So, I guess being UK-centric, bringing in something like the Equality Act (2010) and saying actually we really do have the legal right to have services and things in the way that meet our needs and this is a legal requirement.

## **Care homes, residential settings, and care at home**

**Prof Mary Stewart:** Thank you all. These points really highlight how healthcare professionals often lack understanding of autistic needs – from unwanted touch to the need for different communication approaches and environmental adjustments. Aimee, you've emphasised the importance of choice, autonomy, and legal rights to have services meet our needs. This brings us to another critical area of care and support – care homes, residential settings, and care at home. What are the key issues for older autistic people?

**Dr Marion Hersh:** All the research shows that older people want to stay in their own homes rather than move.<sup>25</sup> This is probably even more the case for older autistic people. Research on support and caring needs of older autistic people and how best they can be met would be useful. The provision of more appropriate support will likely have associated costs but there will also be savings as well as improvements in quality of life.

**Dr Aimee Grant:** There's no way I would cope with going into any kind of residential care home. I will just have to keep on working so I can get all of the supports in my home that meet my needs.

**Dr Mary Doherty:** I think if I had sort of a box where I could just look out at nature and I was isolated from all other residents and what I needed was delivered to my door, I could be perfectly happy in that sort of a setting. But it's the enforced socialization that I absolutely couldn't cope with.

**Dr Cecilia Ingard:** My thesis work was about nursing homes.<sup>26</sup> Nursing homes are not adjusted for neurodivergent people, to enable that, staff need knowledge and enough time to support the resident. Activities in nursing homes need to be adjusted

for people with special interests, for example, as someone ages, or moves to a nursing home that may impact their special interest, that's enormously hard. As you get older your needs may increase, and if you can't communicate your needs - then it's hard. Some older people communicate by self-harm or by suicide attempts. It's a way of communicating needs. And I think about selective eating. If an autistic older person is living in the nursing home, they can't choose the food, and they may need to eat the food that they don't like. The transition to a nursing home is hard and the nursing home staff may not know how you are as person and how they can help you.

**Dr Marion Hersh:** While having strangers (medical and rehabilitation professionals etc) enter the home is less disruptive than moving to a care home, it can still cause distress.

**Dr Aimee Grant:** Going into residential care or having carers in your home and not being able to use your coping strategies anymore, being forced into masking when you may already have low energy – it's all very challenging.

**Dr Cecilia Ingard:** And even if you are older and you develop strategies during the lifespan, when you get that you need support from nursing homes, then you can't use your stimming. And then the staff need to know that you have some needs that they must adjust how they treat you.

**Cos Michael:** Resilience and tolerance reduce as you get older – autistic or not. However, for autistic people, changes and reduced resilience can trigger overwhelm. I think that that can be overshadowed - doctors looking for dementia but not looking for autism, which is another reason why older people really need to be diagnosed if possible.

**Prof Mary Stewart:** Yes, we found in our work that people reported that, for instance, sensory sensitivities and challenges in accessing health and social, increased with age due to a life course of inequality and trauma, while others reported that they became more self-aware and related to their own identities more.<sup>27</sup> We also found that everyone wants to have agency regarding their choice of home and what supports them in that space.<sup>28</sup>

### **Diagnosis in Later Life**

**Prof Mary Stewart:** These are really important points about care homes and care at home – the lack of adjustments for neurodivergent people, the need for staff knowledge and time, the loss of autonomy and coping strategies. Cecilia emphasized that staff need to understand residents' needs and how to support them, which connects to a fundamental issue – many older autistic people remain undiagnosed. Cos mentioned that reduced resilience can trigger overwhelm and that diagnosis becomes particularly important. Let's explore diagnosis in later life. What considerations are important here? We know that many older people will not be formally identified. We know that there are disparities in diagnosis across for instance age, gender, ethnicity and whether somebody's LGBTQI+.

**Dr Aimee Grant:** In the menopause and Autism literature, knowing that you're autistic and having more of an understanding about autistic experience is associated with lower symptom severity.<sup>12</sup>

**Prof Hanna Bertilsdotter Rosqvist:** I think that it might be difficult to even reach people in their seventies and older because they don't identify with the label of autism because they think more of themselves as something else. When I come with

my older relative to the hospital, I can support her knowing that she is autistic, even though she does not identify as such. I can communicate with her in autistic way, and I can also assist the healthcare personnel in their communication with my older relative without explicitly mentioning that I am supporting cross-neurotype communication.

**Dr Aimee Grant:** I think that's a really good point – your understanding, Hanna, is leading to accommodations being put in place. In many families where they don't have that understanding, the person might just be seen as being difficult.

**Cos Michael:** Elizabeta Mukaetova-Ladinska, professor in Old Age Psychiatry, University of Leicester reported that older people were sent to her in crisis to be diagnosed with dementia. Quite often she realized that they were autistic, they had been having meltdowns and had got to a stage of crisis.<sup>29, 30</sup>

**Dr Mary Doherty:** Thinking of a couple of illustrative cases - one person was in residential care and one was approaching the end of his life feeling that he had been a failure. Just recognizing that he was autistic at the end of his life – had an impact on how they felt about themselves. It's absolutely transformative for people. It's never too late to recognize that someone is autistic and it's never too late to reframe how people view autism and therefore view themselves. And what I noticed was that the geriatricians and physicians are really recognizing this.

**Dr Cecilia Ingard:** Being formally identified as autistic can be essential for older autistic adults, primarily for their understanding of their needs, but also for relatives and staff's understanding, to support in line with person-centred care. However, being formally identified as autistic in later life can be challenging for older individuals.<sup>10</sup>

## **Successful Autistic Ageing**

**Prof Mary Stewart:** Thank you. The importance of diagnosis and recognition in later life is clear – whether for self-understanding, accessing appropriate support, preventing crisis and misdiagnosis, or transforming how people view themselves. Throughout this discussion, we've explored many challenges older autistic people face. This leads us to think more broadly about successful autistic ageing. What does ageing well look like for autistic people, and what's needed to support this?

**Dr Marion Hersh:** Existing models of ageing have generally focused on reducing disease and disability, maintaining cognitive and physical functioning and engaging in social activity. While not saying this is undesirable, this is a very medicalised approach and cannot always be achieved. I would suggest that the focus should be on autonomy and being in a position to make decisions about both the lifestyle one wants and day to day issues while having the support required to implement them.

**Prof Hanna Bertilsdotter Rosqvist:** I'm thinking about the growing work on resilience (including autistic flourishing),<sup>31</sup> exploring what could a good autistic adult outcome look like from autistic adults' perspectives, and therefore how would a 'successful autistic ageing' look like from an autistic perspective?

**Dr Aimee Grant:** I'm not sure about the term resilience, I think it's often used to imply a moral superiority in those who cope well with things, when often it's because they have more resources than the people who aren't 'resilient'. A salutogenic approach (an approach that focuses on the factors that promote health and well-being rather than the causes of disease) aims to look at what is helping in situations and I think it fits with your point without the stigmatising lens of 'not being resilient'.<sup>32</sup>

**Dr Marion Hersh:** A more positive aspect of ageing is the development of strategies, workarounds and ways of coping as well as learning to recognise which strategies and workarounds are unsuitable for you and should be rejected. Self-image and self-confidence are also important. What you feel about yourself is important in ensuring good quality of life and also helps improve resilience and the ability to respond to challenges.

### **Life course inequalities and intersectionality**

**Prof Mary Stewart:** These are important insights about successful ageing – the need for autonomy and support, understanding flourishing from autistic perspectives, and taking a salutogenic approach that focuses on what helps rather than judging resilience. Marion mentioned the development of strategies and coping mechanisms over time, which reminds us that older age is shaped by a lifetime of experiences. Our research found that some people reported increased challenges with age due to a life course of inequality and trauma. We know that autistic people are more likely to experience anxiety or depression throughout their life course and that stigma has cumulative impacts. We need to understand more about life course inequalities and intersectionality – for instance the intersection of being from a marginalized ethnic group, being autistic, and being female. What are these stressors and how can they be addressed?

**Prof Hanna Bertilsdotter Rosqvist:** I don't know of any study within the autism literature, but we can consider studies that assess the impact of lifelong stress and racism on ethnic and racial minorities, for instance, biological ageing is impacted by racism and structural racism throughout the whole life. <sup>33</sup>

**Dr Cecilia Ingard:** I think it is also important to think about how the person has been treated by staff when for instance they may have experienced mental health issues such as depression and anxiety during their lifespan. They may have that in mind as they get older.

**Prof Hanna Bertilsdotter Rosqvist:** But also think about mistreatment through medications which are wrong for you if you have been wrongly diagnosed throughout a long time of your life and you got different kinds of psychiatric medication, what does that mean for your body ageing and your mental cognitive ageing?

**Dr Marion Hersh:** Unfortunately, many older autistic people have had a lot of very negative experiences. These experiences include disrespectful treatment, deficit models, stigma and not being taken seriously, including when they say they are autistic. This can sap energy and make people question their own competence, again factors which reduce resilience.

**Dr Aimee Grant:** Thinking about trauma, those in a general population who have had difficult births or needed unexpected interventions during birth can end up with PTSD. We don't have direct research on this yet for autistic people, but many things that are associated with birth trauma are reported by autistic people, like lack of control and not being listened to during birth.<sup>34</sup> It may well be that there is more medical PTSD for older autistic people who have used maternity services.

## **Autistic identity and stigma**

**Prof Mary Stewart:** These are powerful insights about accumulated stressors.

**All of this shapes how people understand themselves and their place in the world. This brings us to autistic identity and stigma. What do we need to understand about these in relation to older autistic people?**

**Dr Mary Doherty:** I'm also thinking about identity and how that impacts ageing. In comparison with adolescence where they're in the identity formation stage, once you get to the latter part of life, identity tends to be a bit more solid. But the thing is, if that has been established through this sense of being at our core, defective, deficient, broken, and we talk so much about stigma in the autistic community and in the autistic literature, but we don't talk about how that stigma is embodied - it is embodied through shame.<sup>35</sup> And older autistic people may have embodied that sense of chronic shame and that is their identity - as either a diagnosed or more likely undiagnosed autistic person. Shame has been called an effective determinant of health, even outside of the autistic community. The impact of shame for patients in accessing healthcare, it is huge. But it's never too late to challenge that and making that possible for people can really transform the end of their lives.

**Dr Aimee Grant:** I agree, in a Goffman sense,<sup>36</sup> the shame doesn't belong to autistic people, it's created and reinforced by stigma in society. So, it shouldn't be ours to carry.

**Prof Hanna Bertilsdotter Rosqvist:** It's also sometimes hard because I think part of my coping is to be silent. You have the shame in your stomach and then you try to manage your shame and try to look like you are managing or something. The shame

is part of you. So sometimes you want to have positive coping strategies and you don't know if they're positive or not, if they're basically coming from shame.

**Dr Mary Doherty:** I totally agree. A lot of it comes from when we were young being told that our reactions, particularly to the sensory environment, we're just wrong, we're oversensitive. No, it's not that loud. Why are you crying? We learned to suppress our own needs. And that translates in to care seeking in adulthood and later adulthood. I think it absolutely impacts accessing healthcare, for sure.

**Dr Marion Hersh:** There are also issues around intersectional identity, where the primary identity may or may not be autistic, as well as a greater likelihood of stigma. Even when those with intersectional identities value their differences, they may prefer not to be open about all identities to avoid not being taken seriously or experiencing other forms of discrimination.

### **Intersectionality and representation**

**Prof Mary Stewart:** These are powerful reflections on how stigma becomes embodied as shame and shapes identity across the lifespan, affecting everything from coping strategies to healthcare seeking. This brings us to intersectionality and representation more broadly. How do multiple marginalised identities intersect in older autistic people's lives, and whose experiences are being represented?

**Dr Mary Doherty:** I'll start by just saying I'm quite uncomfortable discussing ethnicity when we're not fully representative. In Autistic Doctors International, we have a majority of white members, but we do have quite a range of ethnicities amongst our members and it's really tricky because we can clearly see that those international

medical graduates, for example, have such additional challenges working in the NHS just as one example.

**Dr Aimee Grant:** I want to echo Mary's point, that we don't want to be talking for people, but I think we have to do our best to bring the issues to light. In my menopause evidence review,<sup>12</sup> I analysed the data with people from a variety of ethnicities and there are differences when you start to build in that there are different cultural norms around menopause, which can mean some people get less knowledge about what to expect as they age as "women's issues" are taboo, or they get less support. We also know that Black women get incorrectly perceived as aggressive due to systemic racism,<sup>37</sup> and that's got to be having an impact when Black autistic people get to the menopause.

We've also found that a lot of making life easier comes from having financial stability – being able to afford going part time at work, being able to pay privately for healthcare or services. That isn't going to be available to everyone and would be likely to disproportionately favour those who are highly educated and white. The research on autistic menopause so far hasn't included autistic people with learning disabilities and doesn't appear to include those who are non-speaking or semi-speaking, so we don't know how those people are impacted.

**Dr Marion Hersh:** This raises crucial questions for both researchers and policymakers about removing barriers to publicly funded health care for all autistic people (and others), particularly since autistic people are more likely to be unemployed or under-employed.

**Prof Hanna Bertilsdotter Rosqvist:** Adding another intersectional lens, talking from a non-English native perspective, it's also about cultures, ethnicity and languages,

the possibility of naming your experiences with your own or other's language. In the current Swedish autistic self-advocacy movement, we are importing concepts (ways of naming our experiences outside of deficit languages) from for instance the UK-based movement. So, we are using words like 'meltdowns', non-translated, directly importing it into Swedish. And it is a challenge not to have Swedish words or ways of naming our experiences in our own native language. And I think that is even more the case when it comes to the older generation. The younger people get their knowledge about themselves through English-based social media and may find that unproblematic, but the older ones may not really feel comfortable or can't identify with those non-Swedish words.

## **Summary**

The roundtable presented here provided a richly textured discussion bringing together research findings and personal experience in a way that differs from standard scientific research articles. Cos Michael raised why we need research about autism and ageing in 2016.<sup>38</sup> Through these discussions key topics in emerging and future research were identified.

The core gaps and priorities identified by the roundtable are:

- 1. Direct Lived Experience Research:** This is needed to move beyond a focus on mental and physical health to focus on the daily lives, living arrangements, employment activities, and social activities of older autistic people.
- 2. Methodological Advancement:** Prioritizing participatory, truly co-productive (PAR/CBPR) research including considering creative methods and alternate ways to ensure meaningful engagement with a diverse group of older autistic people, including those with high support needs.

3. **Policy and Funding:** Co-creating autism policy that explicitly includes older people as a life stage undergoing distinct transitions (retirement, bereavement, care) will generate necessary funding and strategies for improving support.
4. **Professional Education:** Dramatically increasing autism awareness and understanding among **all** health and social care professionals is crucial to enhance access to services.
5. **Intersectionality:** Researching the impact of intersecting factors (ethnicity, gender, disability, AuDHD) on ageing, health, and access to services, is necessary, including actively working to include marginalized voices in the research.
6. **Addressing Life course Inequalities:** Investigating the impact of lifelong stress, stigma, and trauma (e.g., medical PTSD, chronic shame) on health, wellbeing, and identity in later life is needed.
7. **Employment and income:** Recognising different patterns of employment in later life and associated support needs through employment and retirement will be necessary
8. **Successful Ageing:** There is a need to define successful ageing for older autistic people based on **autonomy, choice, and a salutogenic approach** rather than a purely medical model, including research on how to adapt special interests and coping strategies as physical abilities decline.
9. **Targeted Support:** Researching and developing tailored supports for specific life events, such as:

- **Menopause** and the impact of hormone-mediated changes and increased meltdowns.
- **Care transitions** (in-home care and residential care) to ensure needs for routine, sensory accommodation (e.g., sensory audits), and lack of unwanted social interaction are met.
- **Major loss/bereavement** and the need for support.
- **Diagnosis access** for older people and the "therapeutic" impact of self-knowledge, as well as the need for support for undiagnosed people and their families

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