



Research on autistic adults' perspective on ageing,
and healthcare research

Presenters: Kelly Birtwell, Laura Brown, Erin Beeston

Co-authors: Rebecca Aitken, Katherine Berry, Donna Bramwell, Emily
Corsellis, Emma Gowen & Christine Rowland

Outline

1. Autism and ageing research (approx. 12 mins)
 - Study 1: interviews
 - Study 2: survey
2. Research on general practice (GP) support for autistic adults (approx. 4 mins)
3. Autism and health inequalities research (approx. 4 mins)
4. Questions and answers (approx. 10 mins)

Aim of today and questions to consider

- We are here to share what we've found, and to tell you about our new research studies that are ongoing.
- Do any of our findings match your experience?
- Is there anything that surprises you?
- Do you have any thoughts or suggestions about our newer research (the GP project, and the health inequalities project)?

****Note: we will share the slides****

A note on our findings

- Our findings are based on information from the particular participants in the studies, who we will describe.
- These findings may or may not ring true for you – you may have different experiences, which we would love to hear about.

1. Autism and ageing research

Background

- Autistic people have an increased rate of some physical and mental health problems (e.g. Huang et al., 2020)
 - At least partly due to inequalities in access to appropriate services.
- There has been very little research about ageing as an autistic person (Wright et al., 2019).
- This lack of knowledge makes it difficult to provide appropriate information, advice, support and services.

We aimed to:

- Explore autistic adults' perspectives on growing older.
- Understand what concerns autistic people about ageing, and what helps them to age well.

Study 1: Interviews

- One-to-one interviews with seventeen autistic people
 - Ten women and seven men
 - Aged 46 -72 years (average age was 56 years)
- Fifteen interviews were done over Zoom video, one over Zoom chat, and one by telephone
- Questions about
 - What it means to age well
 - Support that could/did help them to age well
 - What else could help autistic adults to age well

Findings: Physical Health

- People experienced interactions between autism and physical ageing
- People wanted to know whether being autistic increased their risk of age-related illnesses
- Autism can make it more difficult to engage in preventative health behaviours

*‘Menopause can be particularly destabilising for autistic women compared with neurotypical women. **If I'd known** that I maybe would have been able to ride it out better.’*

*‘I think there's an increased possibility of dementia [...] for people that have got autism. And, okay, that's going to be horrible if it happens. But at least **if I know** there's a possibility it might happen, I can be looking out for the signs [...] not in a negative way, [but] in a practical way. [...] I can start doing the things that might help*

‘Inertia can be a theme for autistic people.’

Findings : Age-Related Changes

- Some aspects of autism became more challenging with age

'I think the [sensory] triggers get worse. What I wouldn't necessarily notice so much as a young person, I'm now immediately screaming in my head.'

- Some people reported changes in their ability to 'mask' autistic characteristics

'You know, we still have the same problems and issues we might be better controlling them or managing them or masking them.'

'As you get older, the question of just the amount of energy you have to be able to do the masking'

- Some people were concerned about changes in caring responsibilities

'My mother's part of my support network [...] And I know it's something that everybody gets to in middle age, to worry about the parents [...] and what they're gonna do about their care. And I think that's magnified to some extent with autism, because I know that I could not go and stay at hers and look after her'.

Findings : Social Support

- People felt they had smaller social support networks throughout life

'I take care of myself. I generally have difficulty dealing with other people'

- They often relied a lot on support from family members

'A lot of autistic people end up staying at home with their parents'

- People felt that being autistic put them at greater risk of social isolation in later life

'Older people tend to progressively lose out on social contact. And if you if you've had a fairly low level of social contact to start with, which autistic people probably do, then it may be more important to retain what little I do have.'

Findings: Knowledge and Attitudes

- People wanted more knowledge about ageing with autism

'Autistic people do need to know what's going to happen as they get older.'

- Many people struggled to find older autistic 'role models'

'There are not very many over 50s who even have diagnoses and very few over 70. So how are we even supposed to know what happens when we get older?'

- People felt that there should be more knowledge and understanding of autism within services

'We can, well, be seen as difficult clients, which might reduce the quality of the support we get.'

Findings: Seeking Formal Support

- Some characteristics of autism made it harder to access support

'Executive functioning and my ability to engage with the world really fluctuates so that when I'm overwhelmed, I lose a bit of speech.'

- Many health and social care services are currently not suitable for autistic people

'[My GP] have the radio and it's just a massive trigger. And then there are kids they're running around and screeching and banging on the toys. [...] We cannot seek the health care that we need because seeking it is worse than any illness.'

'One of my worst nightmares is ending up in an old people's home because I have these sensory processing difficulties. So being in an overheated room that's far too warm with a lot of other people with a TV up turned over full blast [...] is literally one of my worst nightmares.'

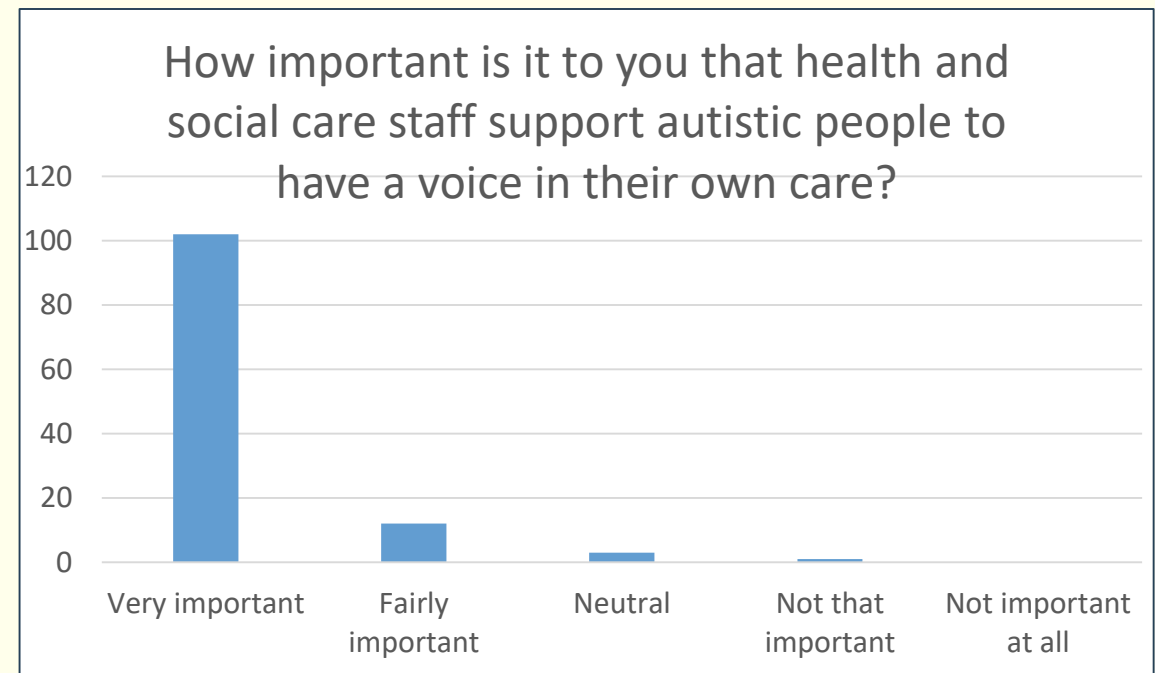
Study 2: survey

- Online survey for autistic adults aged 18+.
- 121 participants: 23 male, 76 female, 16 non-binary.
- Mean age: 45.5 years (18-45: N=71; 46-88: N=50).
- Ethnicity: 112 white.
- 59 people identified as heterosexual, 55 identified as a different sexual orientation.
- Most common health conditions: anxiety (n=71, 58.7%), depression (n=59, 48.8%), and being overweight/obese (n=46, 38.0%).
- Questions about: support to do well in older age, worries about older age.

Results: doing well in older age

- Factors considered important:
 - support for independent and autonomous living;
 - support from people with a good level of knowledge about autism (ideally autistic themselves);
 - social and digital inclusion.

“Anything that reduces uncertainty and increases my control over how I live as I age” (M101, 58, M).



What would support you to do well in older age?

“Access to and [neurodivergent] /autism specific supported living services - or the sort of OT [Occupational Therapist] that would allow someone to retain independence/remain in their own home with familiarity as long as possible. New environments are hard for autistic people to settle into so being moved in and out of home/hospital/residential care would be distressing and leads to worse health outcomes across all factors.” (M042, 40).

“Would like healthcare staff to have a better understanding of autism - starting with the realisation that it doesn't mean I have a learning disability!” (M023, 61).

“Access to socialising based on needs rather than age and diagnoses. Being able to socialise with people with common interests.” (M044, 54).

“Appropriate groups for physical activity / exercise for autistic older adults” (M105, 45).

“Having social groups to access, helping to reduce loneliness”. (M065, 30).

Results: worries about growing older

- Participants worried about:
 - losing their independence and autonomy (and having to move to unsuitable care homes);
 - health and care staff and services not being autism-informed;
 - health conditions like dementia and menopause;
 - isolation and a lack of support.

“What I fear (at any life stage) is having to be dependent on staff. It's complete pot luck, hit or miss. ... Bad care and lack of power to challenge detrimental practice is what I fear most.” (M100, 41, D).



What worries you about growing older?

“My biggest fear is dementia, and forgetting why I transitioned.” (M115, 74).

“I think one of my biggest concerns is not being able to do the things I love doing anymore, whether through physical/cognitive health or care setting etc., because I’m not sure I want to experience life without those things and the joy they bring me” (M021, 28).

“Lack of contact with autistic people of ALL ages, as autistic people may not want age based apartheid. Most societies benefit from inter-generational mixing, in many contexts.” (M018, 64).

“Support for my autistic daughter - after I have died, how will others be able to support her needs” (M040, 41).

Conclusions

- There is an urgent need for more knowledge and education about the age-related needs and experiences of autistic people.
- Health and social care services need to be designed to better meet the needs of autistic people.
- If you design or deliver services (of any kind), try to involve autistic people in the design and delivery of these services.
- Inclusivity and adjustments tend to benefit everyone.

2. Research on general practice (GP) support for autistic adults

Optimising general practice support for autistic adults

Claire Planner¹, Geoff Wong², Emily Corsellis³, Monique Botha⁴, Sophie Longley¹, Ghafaria Khan⁵, Cathy Stratton¹, Tracy Epton¹, Emma Gowen¹, Kelly Birtwell¹
1) University of Manchester; 2) University of Oxford; 3) Independent researcher; 4) University of Durham; 5) UCL.

Background:

- Autistic adults experience health inequalities and barriers to accessing general practice
- Autistic adults are often excluded from research processes

Aim:

To understand how, why, and when general practice best supports (or not) autistic adults, with or without learning disabilities, across the lifespan.

- ❖ Involving autistic adults throughout
- ❖ Neurodiversity affirmative approach



Method and preliminary results

Method:

- “Realist review” (type of systematic review). We are:
 - looking at the research that has already been done
 - bringing it together
 - speaking to stakeholders to make sense of it
- Autistic co-applicant, four autistic assistant reviewers, autistic and non-autistic stakeholders (including NHS staff)
- Involvement in research processes e.g. screening and extraction
- Training, ongoing support, written guidance

Preliminary results:

| | |
|------------------------------|--------|
| Title and abstracts screened | 12,749 |
| Full texts screened | 867 |
| Included in review (so far) | 42 |

- The following lead to delayed help-seeking and worse health outcomes:
 - General practice environment
 - Communication methods
 - Lack of understanding from staff
 - Poor quality care

Preliminary results (continued), and implications

Preliminary results (continued):

- Delayed help-seeking may be judged negatively by general practice staff
- This could increase anxiety and stigma
- This creates a negative cycle where treatment and support are delayed, and outcomes worsened.
- Lack of research on general practice support for autistic adults with learning disabilities.

Implications:

- We are creating guidance for:
 - General practices: potentially helpful changes to services
 - Autistic adults: help people gain the support they need
- This will help to improve health outcomes.
- Our review is centring autistic experience:
 - Helps to prevent epistemic injustice
 - Unique development opportunities for early career researchers

3. Autism and health inequalities research

Background

- Autistic adults experience increased rates of most medical conditions compared to the general population
- They experience significant barriers to equity in health, and their voice is virtually unheard in health services research
- Autism@Manchester researchers have identified barriers that relate to:
 - (a) Characteristics associated with being autistic such as sensory sensitivities, motor coordination difficulties and inertia
 - (b) Services and staff not being autism informed
- Healthcare provision rarely meets their needs, and autistic adults experience lower life expectancy than non-autistic adults

We aim to:

1. Establish an interdisciplinary network of external autism support groups, charities, health networks, local government, and commissioners
2. Improve autistic adults' access to health research
3. Develop a collaborative grant application to fund more in-depth research addressing autistic health inequalities

Marginalisation multiplied: Improving autistic health inequalities with collaborative interdisciplinary research and knowledge transfer through Autism@Manchester

- This project uses expertise within Autism@Manchester to co-design resources, project plans and pathways to impact, to reduce autistic health inequalities.
- Funded by University of Manchester's Interdisciplinary Research Pump-Priming 2023-24, supporting the Research Associate/Co-producer role (Dr Erin Beeston/me!)
- Our three aims are in progress:
- Erin, Elizaveta Nosova and Dr Emma Gowen are working to produce 'Research Involvement toolkit' for launching on the University of Manchester's Open Research website in the summer.
- The network have begun meeting to identify research priorities to development for a larger project funding bid.

Preliminary findings

- The network is in progress. This includes colleagues in Manchester City Council, Healthwatch Manchester, adult social care practitioners, colleagues at the University of Manchester and beyond.
- Feedback on module one of the 'Research Involvement toolkit' has been given by Autism@Manchester's 'Expert by Experience' group.
- We are partnering with colleagues at the University of Manchester Library, Open Research and e-Learning teams to create online modules for the Research Involvement toolkit.
- Academic literature (research papers) suggest that peer support communities – especially for late diagnosed adults - are effective at creating space for people to come to terms with their new identities, foster a collective sense of belonging and provide space for individuals to re-frame traumatic experiences.
- Key research questions are being developed around use of the toolkit to support health equity, supporting the wellbeing of peer supporters, and tailoring the peer support model for individual differences to tackle autistic health inequalities.

Implications

- The Research Involvement toolkit will ensure health research is more accessible, inclusive and representative of the wider autistic population.
- The peer support model uses a strengths-based approach and increases community connectedness, which will improve wellbeing, sense of self and belonging.
- This research will actively support the autistic community to navigate the complexities of the healthcare system, reducing inequalities through enhancing access to services.

4. Questions and answers

For further information

...about the work presented today: Laura.Brown@manchester.ac.uk
Kelly.Birtwell@manchester.ac.uk or Erin.Beeston@manchester.ac.uk

...about other autism-related research at the University of Manchester:

Autism@manchester: aim to create research that has real meaning for autistic people, and have a number of initiatives – events, presentations, expert by experience group etc .

<http://www.autism.manchester.ac.uk/>

Contact Erin.Beeston@manchester.ac.uk for more information or to join the mailing list.



Our questions for you

- Do any of our findings match your experience?
- Is there anything that surprises you?
- Do you have any thoughts or suggestions about our newer research (the GP project, and the health inequalities project)?

Links and resources

- **National Autistic Society** (<https://autism.org.uk/>)
- **Embrace Autism** | The ultimate autism resource (<https://embrace-autism.com/>)
- **Ambitious about Autism** | National charity for autistic children and young people: <https://www.ambitiousaboutautism.org.uk/>
- **Autism Support** | HealthUnlocked: <https://healthunlocked.com/autism-support>
- **Actually Autistic** | Facebook: <https://www.facebook.com/actuallyautistic/>
- **Autistic Doctors International (ADI)**, represents over 800 autistic medical doctors: <https://autisticdoctorsinternational.com>
- **CAPTAP language guide**: How to talk about autistic ways of being: <https://captapnetwork.wordpress.com/2023/09/19/how-to-talk/>
- Gowen, E. et al. (2019). **Guidelines for conducting research studies with the autism community**. *Autism policy & practice*, 2(1), 29–45.

Further references

- Botha, M. (2021) Academic, Activist, or Advocate? Angry, Entangled, and Emerging: A Critical Reflection on Autism Knowledge Production. *Frontiers in Psychology*, 12:727542. <https://doi.org/10.3389/fpsyg.2021.727542>
- Botha, M., Hanlon, J., & Williams, G. L. (2023). Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti. *Journal of autism and developmental disorders*, 53(2), 870–878. <https://doi.org/10.1007/s10803-020-04858-w>
- Hand, B. N., Angell, A. M., Harris, L., & Carpenter, L. A. (2020). Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults. *Autism: the international journal of research and practice*, 24(3), 755–764. <https://doi.org/10.1177/1362361319890793>
- Kenny, L. et al. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442–462.
- Lagos, R. S. et al (2021). *Older Autistic Adults, In Their Own Words: The Lost Generation*. AAPC Publishing.
- Liu, S., Larsson, H., Kuja-Halkola, R., Lichtenstein, P., Butwicka, A., & Taylor, M. J. (2023). Age-related physical health of older autistic adults in Sweden: a longitudinal, retrospective, population-based cohort study. *The lancet. Healthy longevity*, S2666-7568(23)00067-3. Advance online publication. [https://doi.org/10.1016/S2666-7568\(23\)00067-3](https://doi.org/10.1016/S2666-7568(23)00067-3)
- Moseley, R. L., Druce, T., & Turner-Cobb, J. M. (2020). 'When my autism broke': A qualitative study spotlighting autistic voices on menopause. *Autism: the international journal of research and practice*, 24(6), 1423–1437. <https://doi.org/10.1177/1362361319901184>
- Maddox, B. B., Dickson, K. S., Stadnick, N. A., Mandell, D. S., & Brookman-Frazee, L. (2021). Mental Health Services for Autistic Individuals Across the Lifespan: Recent Advances and Current Gaps. *Current psychiatry reports*, 23(10), 66. <https://doi.org/10.1007/s11920-021-01278-0>
- Mason, D. et al. (2022). Older Age Autism Research: A Rapidly Growing Field, but Still a Long Way to Go. *Autism in Adulthood*, 4(2). www.liebertpub.com/doi/10.1089/aut.2021.0041
- Micallef, Paul / Autism from the Inside (2022). [Autism and Aspergers in Older Autistic Adults \(60+ Years Old\) | Patrons Choice YouTube](https://www.youtube.com/watch?v=...)
- Michael, C. (2016). *Autistic older women: an interview with Cos Michael*. <https://www.autism.org.uk/advice-and-guidance/professional-practice/older-women>
- Pickard, H., Pellicano, E., den Houting, J., & Crane, L. (2022). Participatory autism research: Early career and established researchers' views and experiences. *Autism: the international journal of research and practice*, 26(1), 75–87. <https://doi.org/10.1177/13623613211019594>
- Roestorf, A., Bowler, D. M., Deserno, M. K., Howlin, P., Klinger, L., McConachie, H., Parr, J. R., Powell, P., Van Heijst, B. F. C., & Geurts, H. M. (2019). "Older Adults with ASD: The Consequences of Aging." Insights from a series of special interest group meetings held at the International Society for Autism Research 2016-2017. *Research in autism spectrum disorders*, 63, 3–12. <https://doi.org/10.1016/j.rasd.2018.08.007> [says ageing and autism research should focus on adults aged 50+].
- Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. (2017). GPs' confidence in caring for their patients on the autism spectrum: an online self-report study. *British Journal of General Practice*, 67(659), e445–e452. <https://doi.org/10.3399/bjgp17X690449>.