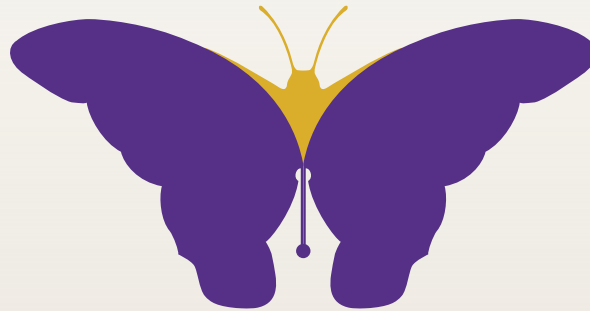


Older not Wiser?

Insights on Autistic Aging and Flourishing



Christine Jenkins
AUsome Consulting

Christine A. Jenkins, Wednesday, January 28, 2026, 3:00 p.m.
<https://tinyurl.com/cjAUsome>

Why do I present on aging well?

- I am late-in-life diagnosed. It is #NeverTooLateToKnow yourself.
- I want older people's lives to make sense. They may suspect autism when a younger family member is being assessed.
- I don't want them to wonder forever why they are wired differently.
- They've been dismissed, gaslit, abandoned, fired, ignored, misdiagnosed, underdiagnosed, plain misunderstood. This has to end.
- Many suffer from imposter syndrome and poor mental health.
- The incorrect labels hurt; knowing you are Autistic can be freeing.
- They may be multiply neurodivergent—ADHD, OCD, and mental health conditions like bipolar may overlap.



Older not Wiser topics

- **Shocking reality:** scant research on older autistics, underdiagnosis and late-in-life identification
- **Challenges:** failure to thrive especially in marginalized populations. Current suicidality stats from recent research, especially since 2019.
- **Web of self worth:** connecting #AutisticElders to enhance overall wellbeing
- **Forging the future:** help for ourselves and the generations to come

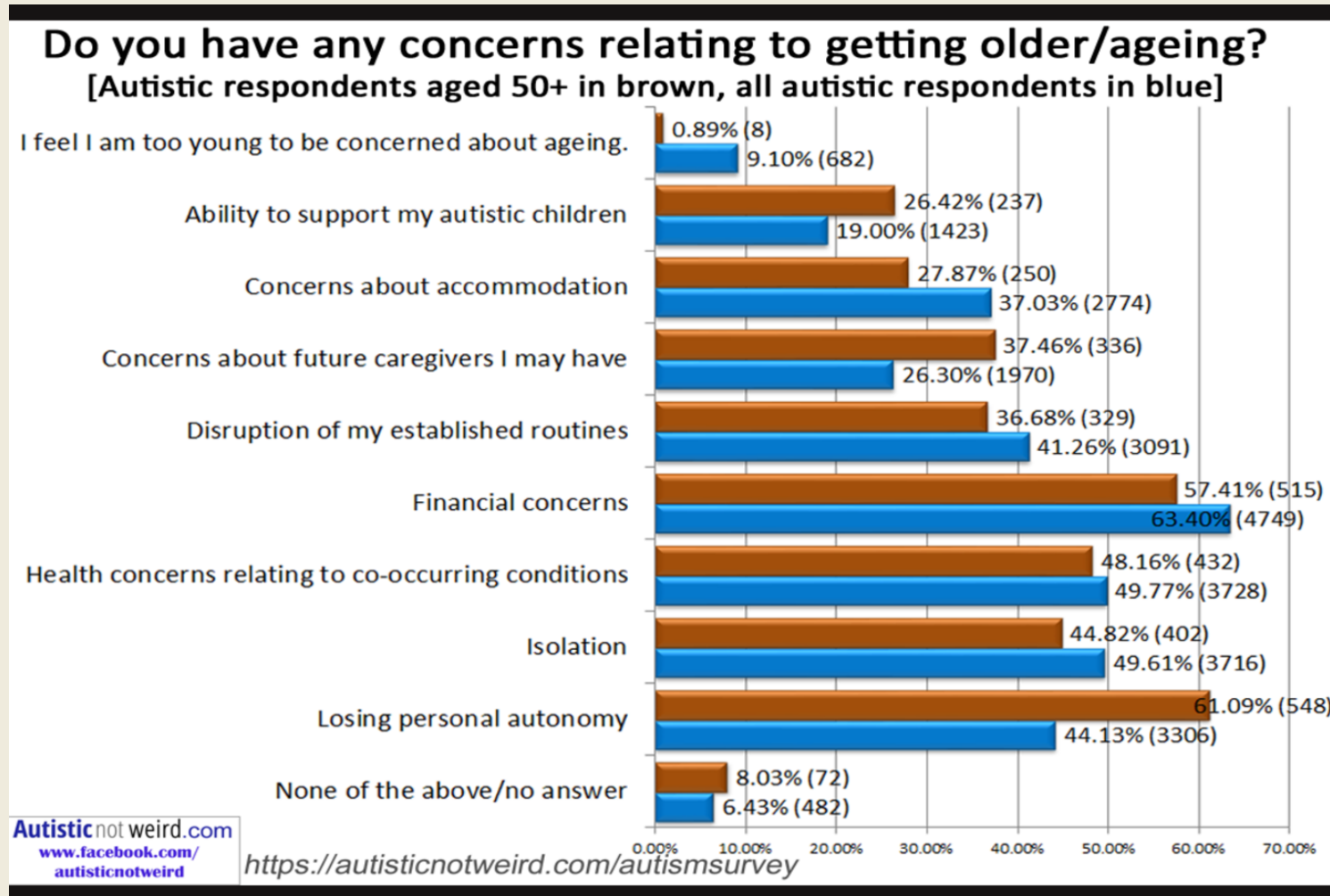


Shocking reality

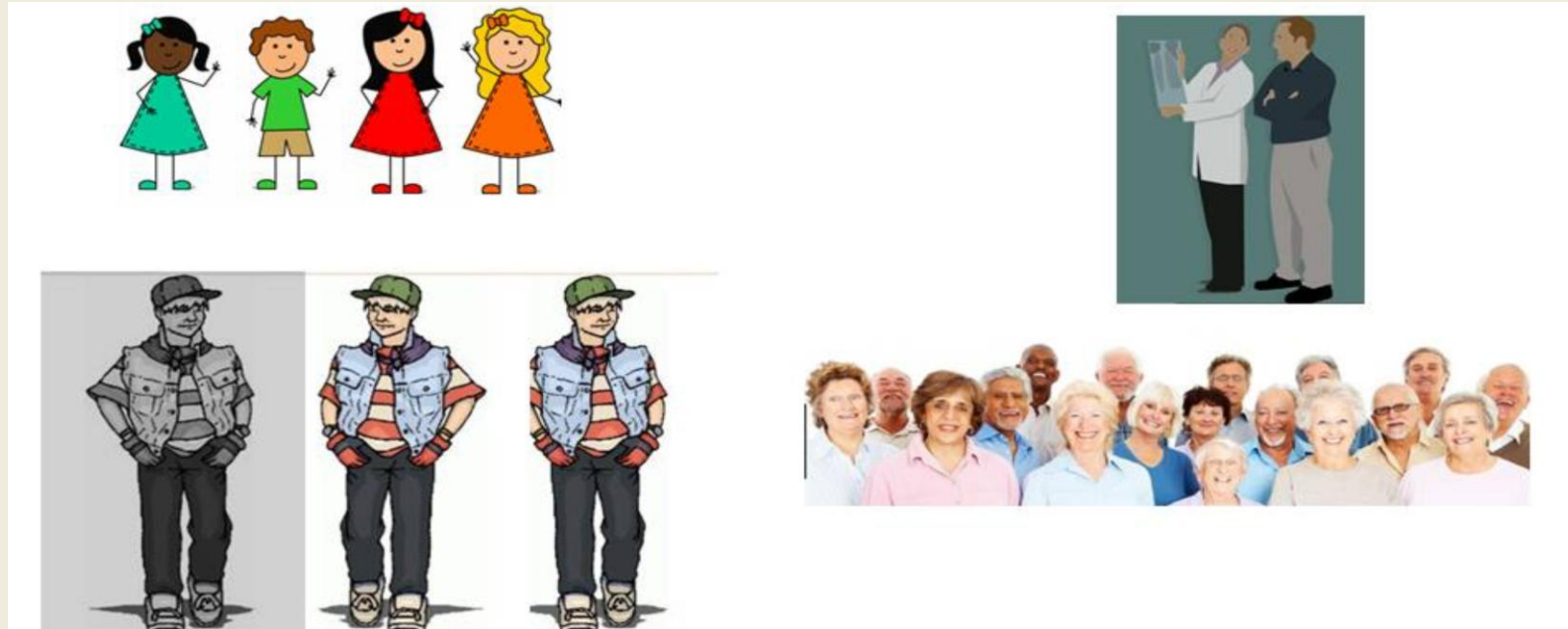
- What are concerns re old age? Results of AutisticNotWeird poll
- Little research on 50+; some on 40+, 0.4% until recently
- Effect of late/missed diagnosis, leading to failure to thrive, early death (Sarah Cassidy, Anne Kirby, Tanya Procyshyn, Meng-Chuan Lai among lead researchers).
- Life expectancy of 54!
- Figuring out what you don't yet know



What we found out in 2022; my aging poll 7,491 Autistic people out of 11,212 total



Challenge: Accurate Research with/not for Autistic People



- Imagining that all of us are children or teenager/students?
- In reality, we're more likely to look like the pictures of older people here....Think carefully...when nearly every person you study is a younger male or a child.

Credit: Ann Memmott

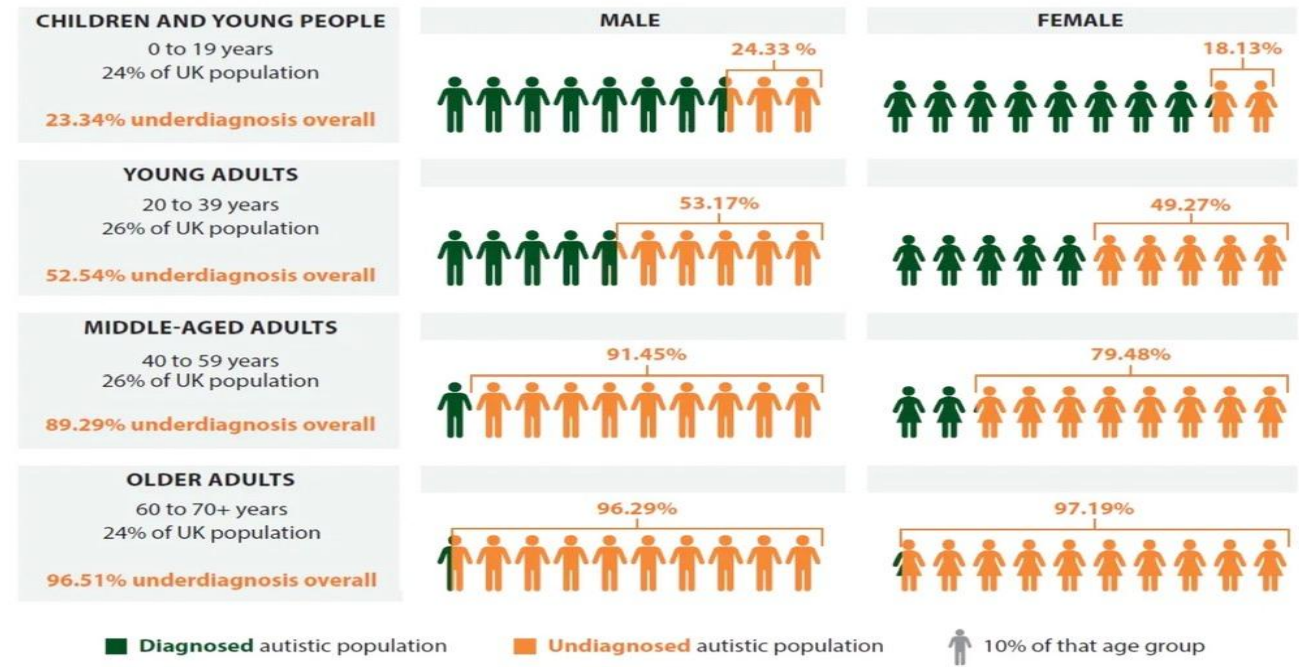


Challenge: Realize that Autistic kids soon become Autistic adults.

New analysis by Happé and Stewart of age 40+ in the UK, published Aug 2025 by King's College London on the missing generations. From *Autism in England*, O'Nions

Over 89 per cent of autistic adults aged 40+ are undiagnosed

Although people do not 'grow out' of autism, there is a large discrepancy in diagnosis rates between younger and older generations. The authors of the review re-analysed previous research on UK [healthcare record data from 2018](#) and found that 89 per cent of people age 40-59 years and 97 per cent of people age 60+ are estimated to be undiagnosed.



Estimates of the percentage of diagnosed and undiagnosed autistic people in the United Kingdom, split into age groups. This figure uses summary data published by O'Nions et al. (2023), which was reanalysed for the purpose of the review article.



Challenge: Poverty and homelessness

Of the **106** homeless people we screened, **13** showed strong signs of autistic traits that would be consistent with an autism diagnosis.

At **12.3%** this is a much higher proportion than the **1%** of people [then estimated] in the general population who are autistic.

“The prevalence of autism traits in a homeless population.” Churchard, Mandy et al. *Autism*, April 2019



Autistic people at greater risk of becoming homeless – new research

June 12, 2018 5:02am EDT



Challenge: suicidality— Life expectancy of 54. We must act

Key implications for clinical practice

- Autistic people require a full psychosocial assessment to identify risk and protective factors to inform a collaborative safety plan, with additional guidance available for safety planning with autistic people.³
- Support needs to be age-, gender- and autism-informed (+ additional intersectional identities which confer risk).

³ Mental Health Autism. *Autism-Adapted Safety Plan*.
<https://sites.google.com/view/mentalhealthinautism/resources/safety-plan>



Challenge: co-occurring health issues

Example of early
research on
adults, pre DSM
5.

U.S. Huge
officially-
diagnosed,
insured sample

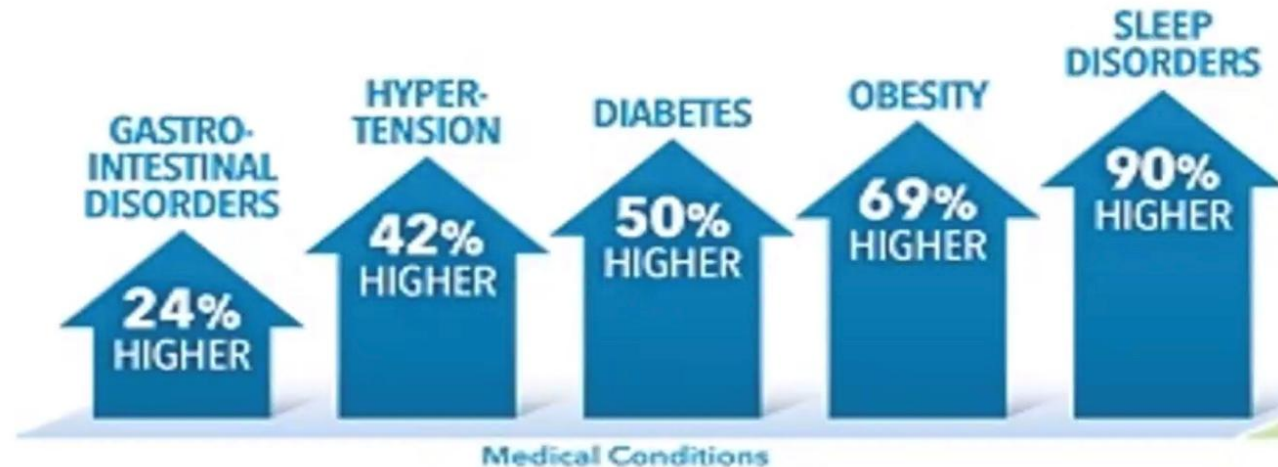


Special Issue Article

The health status of adults on the autism spectrum

Autism
2015, Vol. 19(7) 814–823
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1362361315577517
aut.sagepub.com
SAGE

Lisa A Croen¹, Ousseny Zerbo¹, Yinge Qian¹, Maria L Massolo¹,
Steve Rich², Stephen Sidney¹ and Clarissa Kripke³

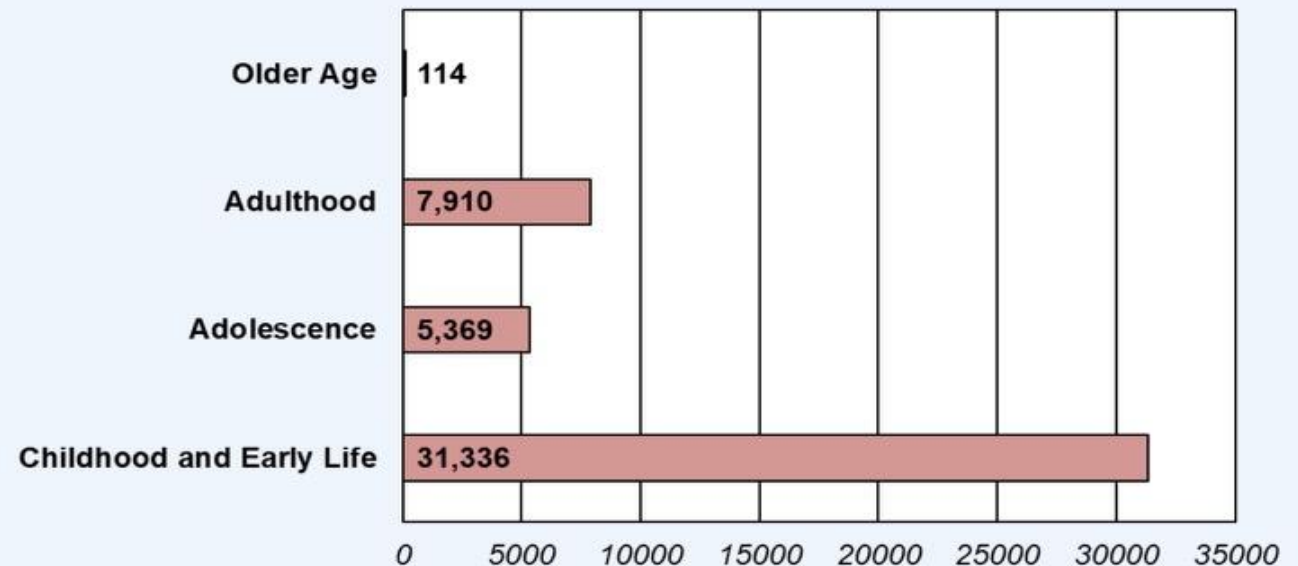


Lack of older adult autism research

- Research has mostly focused on childhood experiences and outcomes.
- Older adults are very difficult to recruit (both autistic and neurotypical).
- Studies tend to be small.
- Not always generalisable.



Total Number of autism publications by age grouping



Stuart-Hamilton, Griffith, & Totsika (2010); Howlin & Taylor (2015). Figure from Mason, Stewart, Capp and Happé (2022).



Autistic kids become Autistic adults. The lost generations are those 40 and over.

29 August 2025

Around 90% of middle-aged and older autistic adults are undiagnosed in the UK, new review finds

89 to 97 per cent of autistic adults aged 40+ years are undiagnosed in the UK, according to the largest review of its kind. The review indicated that middle-aged and older autistic adults are facing higher rates of mental and physical health conditions than non-autistic adults of the same age, alongside challenges with employment, relationships and wellbeing.



New analysis by Happé and Stewart of age 40+ in the UK, published Aug 2025 by King's College London on the missing generations.

Aging study research example

The AgeWellAutism study



- Wave 1 from 2019:
 - 428 participants, 265 autistic (incl. 11 self-identified) and 167 non-autistic.
- Wave 2 from 2023:
 - 652 participants, 469 autistic (incl. 66 self-identified) and 183 non-autistic.
 - Approx. 40% from wave 1 participated again in wave 2, enabling follow-up.
- Both waves broadly matched on demographics:
 - Aged 40 to 93, mean = 60 years
 - 50% gender split
 - 40% have some university education
- 95% diagnosed or self-identified in adulthood (mean age of diagnosis/identity within 10 years of participation).

Co-production with ReSpect lab in the UK, with me as an Autistic expert and co-author. Work with elders has jumped since 2021 #WithNotFor



Autistic kids become Autistic adults. The lost generations are those 40 and over.

“ *These very high underdiagnosis estimates suggest that many autistic adults will have never been recognised as being autistic, and will have not been offered the right support. This could make them more susceptible to age-related problems, for example being socially isolated and having poorer health.*

Dr Gavin Stewart, British Academy Postdoctoral Research Fellow and lead author of the review

Gavin R.
Stewart,
King's
College
London

Dr Stewart added: “The high rates of underdiagnosis also mean that much of our research has systematically overlooked a large proportion of the autistic population, potentially skewing our understanding of how autistic people age, and leaving critical gaps in policy and services.”



Aging study research example

Study 5: Sensory processing and MH

Autism in Adulthood (2024)

“Utterly Overwhelming” – A Mixed-Methods Exploration of Sensory Processing Differences and Mental Health Experiences in Middle-aged and Older Autistic Adults

Yixin Chen, Christine A. Jenkins, Rebecca A. Charlton, Francesca Happé, William Mandy and Gavin R. Stewart



Yixin Chen

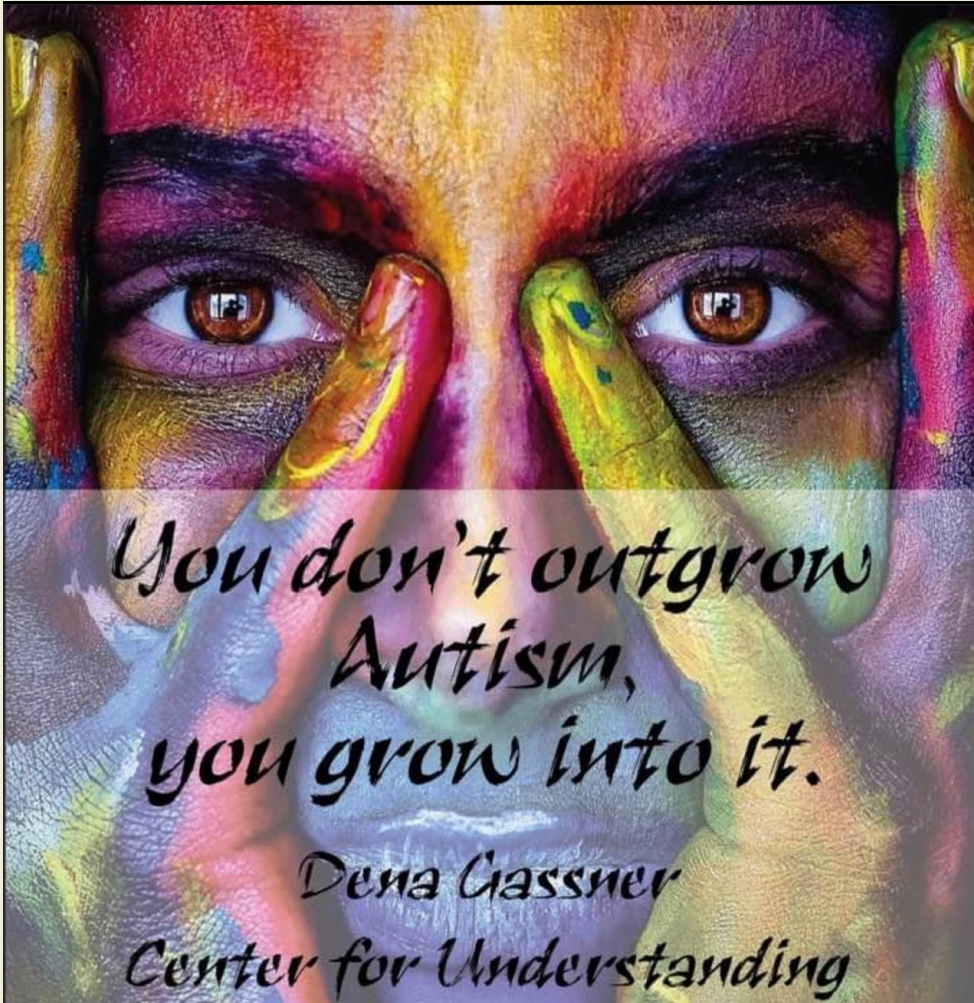


Christine A. Jenkins

Co-production with ReSpect lab in the UK, with me as an Autistic expert and co-author. Work with elders has jumped since 2021 #WithNotFor



It may be hard to believe, but...



#AutisticElders rule. We Have Always Been Here



There is no epidemic; there is missed and mis-diagnosis of adults who grew up before DSM-IV. Some have Autistic children and grandchildren.



Web of self worth: Finding other elders

“(Will) Mandy’s team has found another way to recruit girls and women with autistic traits: online.

Some of the most active bloggers, tweeters and commenters discussing autism online are women...highlighting another intriguing way that autistic women may differ from autistic men: They are driven to connect.”

[This became even truer during and after the pandemic.]

Emily Sohn, *Righting the gender imbalance in autism studies*, Spectrum News (now The Transmitter), 2019



Aging study research priorities

Research priorities:

Participants suggested care homes, menopause, social inclusion, dementia, and healthcare services and staff as priorities for future research.

Autistic Adults' Perspectives on Growing Older,
Birtwell et al,
University of Manchester, 2023
Priorities listed by 121 participants, mean age 45.5 yrs



Web of self worth: Setting research priorities

#AutINSAR
BlueSky chat

Q1: What are
your top 3
priorities for
autism
research?



Christine Jenkins, Canada
[@christineajenkins.bsky.social](https://christineajenkins.bsky.social)

A1: Ageing well, dealing with
trauma caused by society, neuro-
affirming end of life care.

May 3, 2025 at 3:52 PM



Forging the future: Participatory Design and Research Co-Production

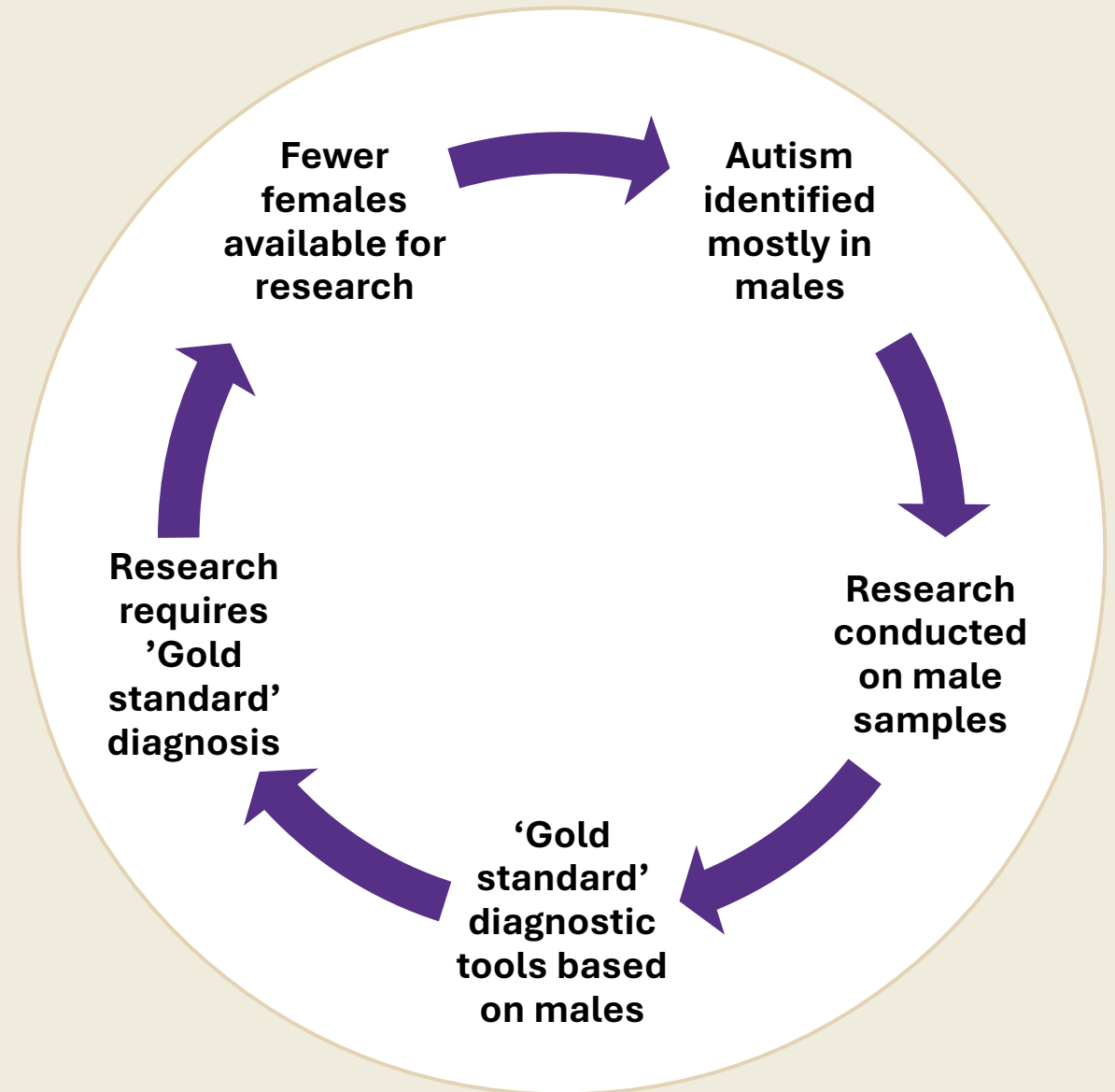
- Respect
- Authenticity
- Assumptions
- Infrastructure
- Empathy

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism journal*. <https://doi.org/10.1177/1362361318786721>



INSAR Conference presentation by Allison Ratto,

Children's National Health System,
Washington DC, 2019



Forging the future: Older AND Wiser

You can assist to:

- Educate others to embrace difference, not use compliance training
- Improve Interoceptive awareness (body sense) and avoid sensory triggers.
- Use beneficial stims and sensory aids, and carefully dosed medication as necessary
- Create Autistic safe spaces to let #AutisticElders unmask safely and help others do likewise. Enhance #AutisticJoy.
#WeHaveAlwaysBeenHere



Forging the future: Older AND Wiser

- We are the experts on our own autism. We aren't the problem: we are part of the solution.
- Ask us! Listen to us!
- We deserve to age *gracefully* and to *thrive*, *not just survive*.

If autistic people know autism the best then why are services that work with autistic people not employing and collaborating with autistic people ?

Autistic Creativity



Why listen to Autistic elders?

Believe that we were once like your child....



Autisticnotweird.com
www.facebook.com/
autisticnotweird

"I don't want to turn an autistic person into a non-autistic person.

I want to turn an autistic person who struggles into an autistic person who doesn't struggle."

-Chris Bonello

When we increase acceptance and value of older Autistics, we all stand to benefit.



Heading in a positive direction— Venessa runs A2ndvoice in the UK

Autism Age and other support groups for 50+

O is for Older Autistic People

Older autistic people, a forgotten generation, especially those from Black, Asian, and dual-heritage communities, remain one of the most overlooked groups in autism support and research. Historically, the focus has been on white boys, leaving older adults misdiagnosed, undiagnosed, or forced to mask for survival. Many carry decades of trauma from being misunderstood.

Quote: “Stigma, myths, and silence in some cultures make it even harder to access a diagnosis or feel safe enough to seek support. My connection to conversations related to older autistic people is Cos Michael, founder of Autism Age, who runs our successful monthly online coffee mornings for 50 plus.

— Dr Venessa Swaby

”



Are we older and wiser?

A pivotal paper by Pellicano & Heyworth on The Foundations of Autistic Flourishing, 2023

- The prioritization of the wellbeing of all Autistics if they are going to thrive, not just physically survive.
- Autistic people as partners in research, not just subjects of study #WithNotFor
- Co-led and co-produced research (more on this tomorrow)

“We have, until recently, assumed that, in order to flourish, Autistic people must need to be *less* Autistic and that their Autistic identity—their Autistic characteristics, traits, and behaviors—could not possibly contribute to their flourishing....”

<https://pmc.ncbi.nlm.nih.gov/articles/PMC10506917/>



A gentle
reminder to
myself and others
to stay brave and
authentic, and
celebrate my right
to thrive

#AutisticRightsAre
HumanRights

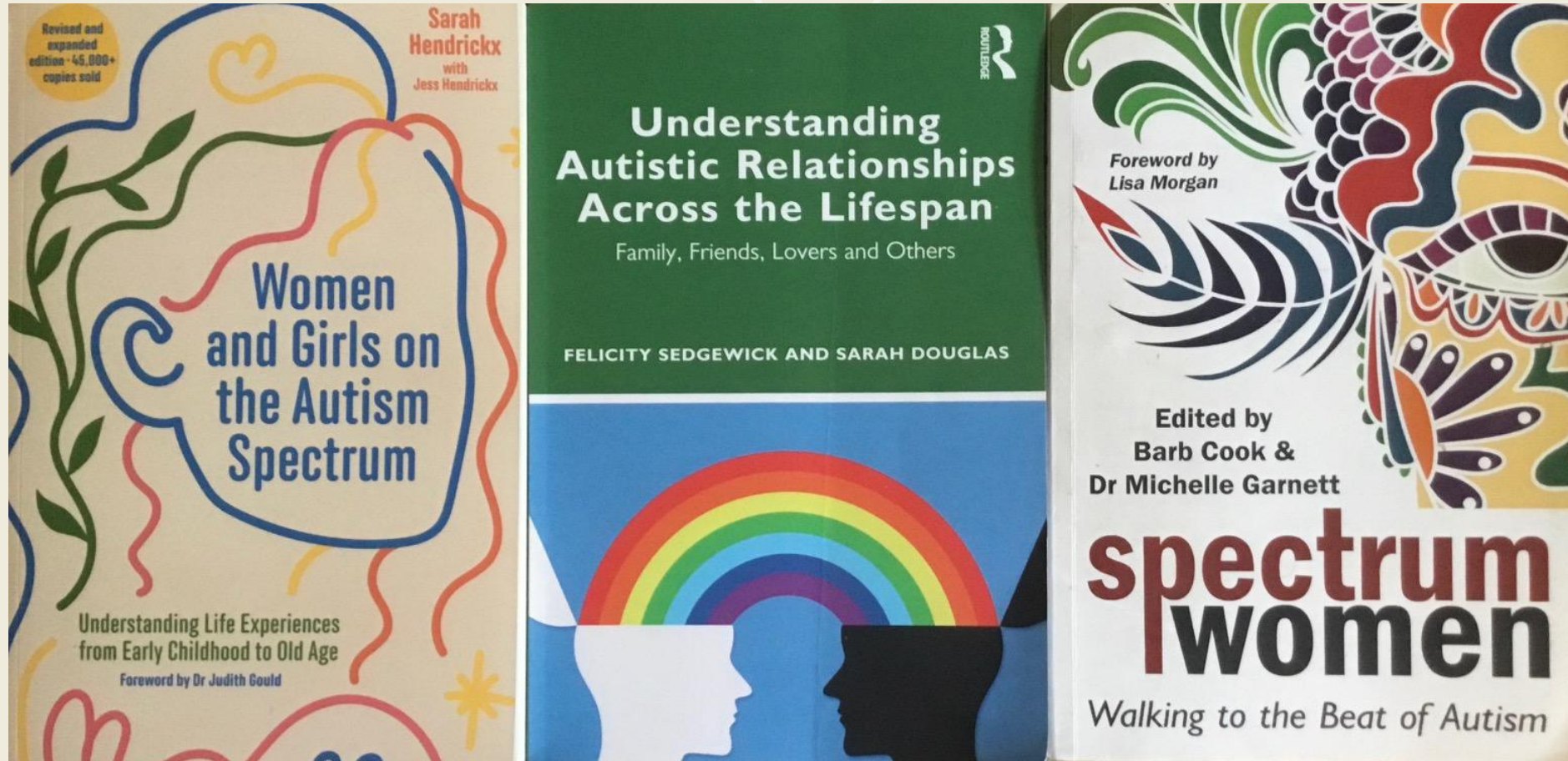


Autistic people, again, can only truly thrive as autistic people, not as imitations of non-autistic people; one does not attain long-term wellbeing by stifling one's True Self

— Nick Walker, autistic advocate and author of Neuroqueer Heresies



Good texts by Autistics especially with internalized presentation; each deals with Aging



A little promo for Day 2 at 1:30 p.m.

Come find out why it's **Not Just about the Boys!**

“Autistic women often don’t see any reason why they shouldn’t do something due to **age**, gender or any other factor. This is enormously liberating and the reason why you’ll find **older** autistic women doing all sorts of crazy stuff!”

[#BetterLateThanNever is my motto]. From the book on the left.

Sarah Hendrickx in *Women and Girls on the Autism Spectrum: Understanding Life Experiences from Early Childhood to Old Age*. JKP, Second edition, 2024, p. 141.



Thanks for coming!

We will now turn off the recording, take a short break, and return for Q & A in 10 minutes.

This will give the moderator time to go over the questions submitted. I reserve the right not to answer any that are too personal or considered off topic.

Please do not share these slides with non attendees. The Resource list is found as a Google doc here:

<https://linktr.ee/christineajenkins>



How to contact me: Resource list links here

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* linktr.ee/christineajenkins

