

27th January 2026

Autism in Midlife and Older Age

What happens to autistic people when they grow old?

KING'S College LONDON

The British Academy

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Talk overview

- Background:
  - What is autism?
  - What is the prevalence of autism?
  - Why is autism in older age important?

- Research overview:
  1) Cognitive profiles, cognitive ageing, and dementia
  2) Health profiles across midlife and old age and life expectancy
  3) Mental health and correlates
  4) Social problems and potential mechanisms
  5) Lived experience insights

- Conclusions

Note: I'll be using 'identity first' language in this talk, as many autistic people prefer this to 'person-first' language.

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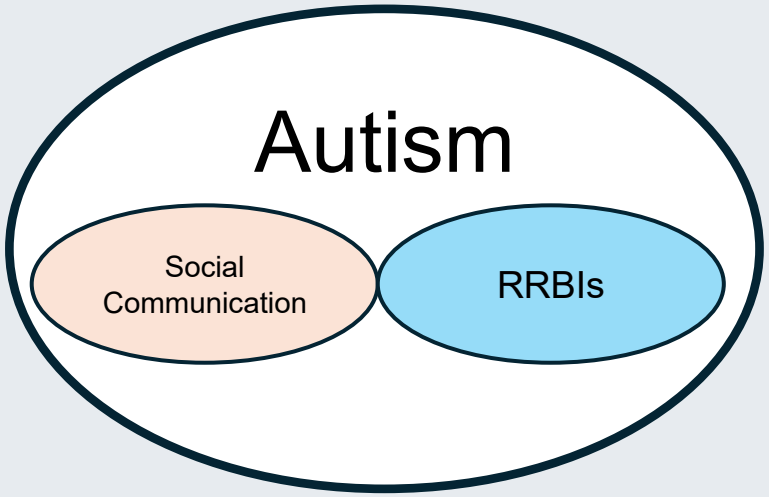
- Conclusions

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What is autism?

- Autism is a set of highly heritable lifelong heterogenous neurodevelopmental conditions.

- Characterised by early onset…
  - social communication and interaction differences,
  - rigid and repetitive behaviours and interests.



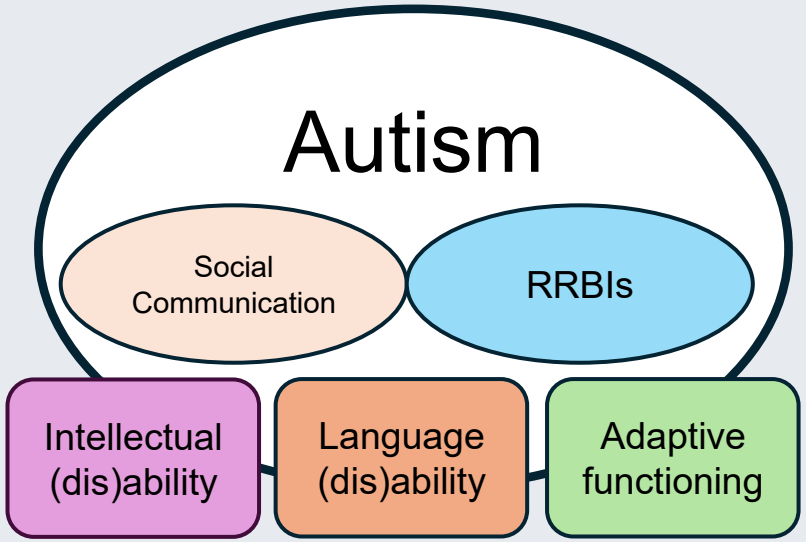
Definitions:

- *Highly heritable = strongly influenced by genetics, often runs in families.*
- *Lifelong = something innate, people will grow from autistic children to adults to older adults.*
- *Heterogenous = lots of variability between people, an individual's needs can change depending on setting.*
- *Neurodevelopmental condition = something that influences thoughts and behaviours.*

What is autism?

- Other features are often associated with autism…
  - adaptive functioning differences,
  - perspective taking differences,
  - sensory processing differences,
  - alexithymia,
  - strong attention to detail.

- Intellectual disability is also common (approx. 1 in 3).

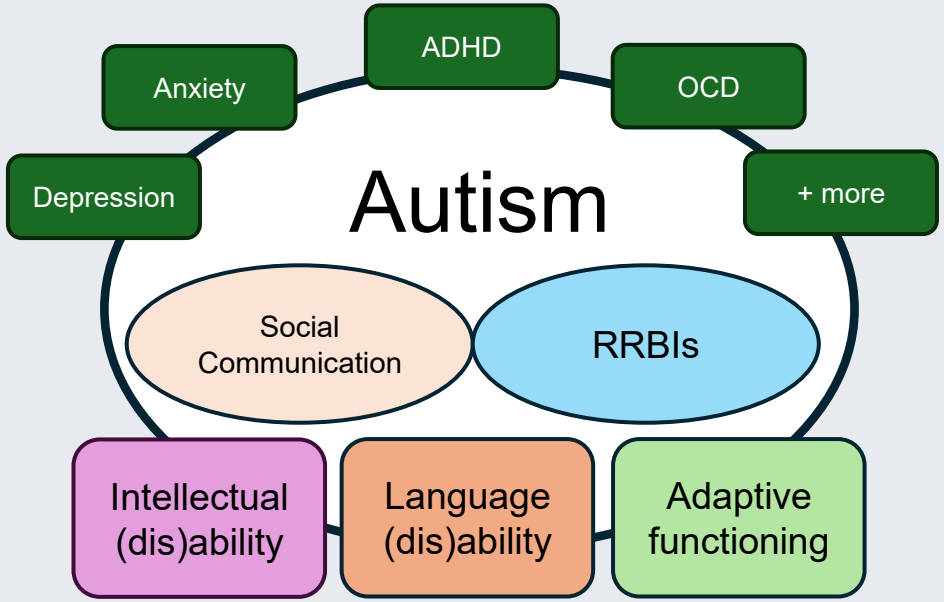


DSM-5, American Psychiatric Association (2013); Thrum et al. (2019)

What is autism?

- Many conditions also co-occur at high rates, but not part of diagnostic criteria.

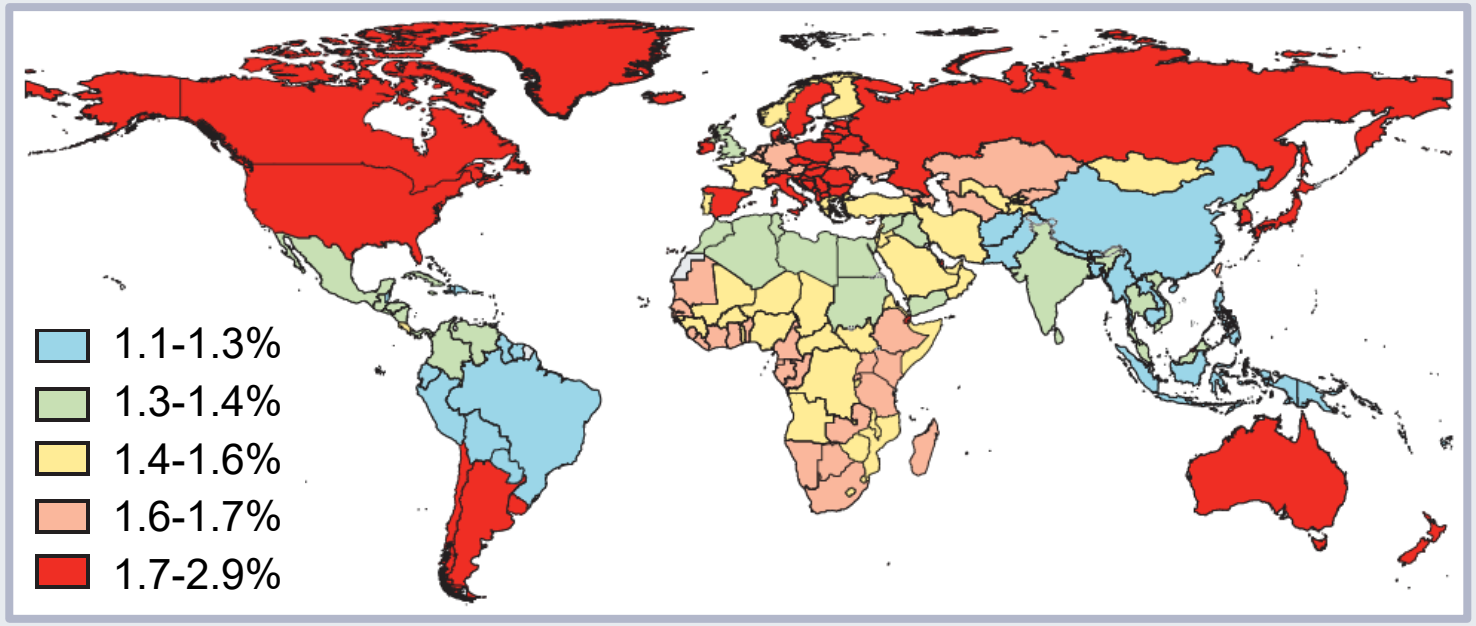
- Autistic people often have:
  - Poor mental health,
  - Higher support needs,
  - Experience have poor normative outcomes,
    - Barriers to education,
    - Barriers to employment,
    - Barriers to relationships and social integration,
  - And more…



DSM-5, American Psychiatric Association (2013); Mason et al. (2022)

What is the prevalence of autism?

- Estimated global prevalence rate of 1%, but up to 3% in some areas.

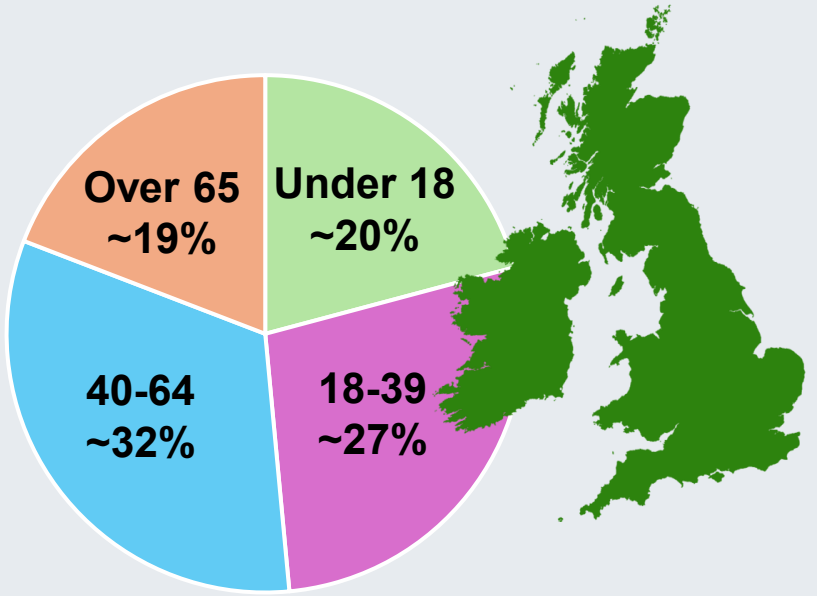


- More commonly diagnosed in men and boys than women and girls (3:1 to 2:1).

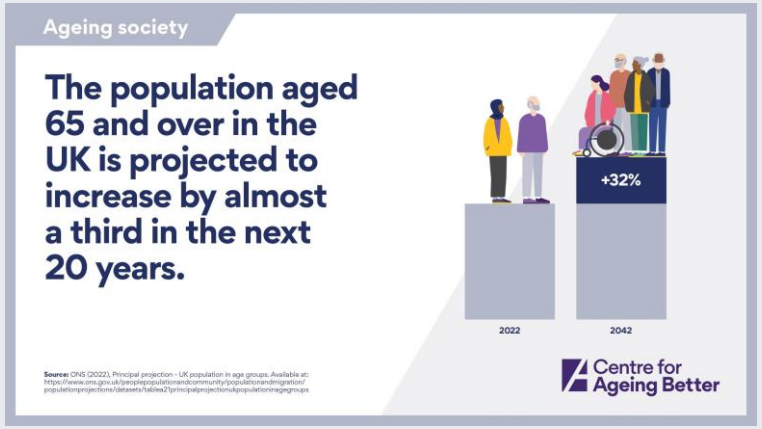
Brugha et al. (2016); Office for National Statistics (2023); Santomauro et al. (2025)

Why autism in midlife and older age?

- UK population (c. 2023): ~68million
  - Approximately 680,000~2,100,000 autistic people.
- The UK has a median age of 40, and (like many Western countries) has an ageing population.
- The number of people over 65 set to increase by a third over the next 20 years.
- While most autistic people are adults, age disparities are evident in health records:
  - 1 in ~400 people aged 40-49 have an autism diagnosis (0.24%)
  - 1 in ~1,400 people aged 50+ have an autism diagnosis (<0.01%).



Similar patterns in Europe, USA, Canada, Brazil, Australia, China, Japan and more

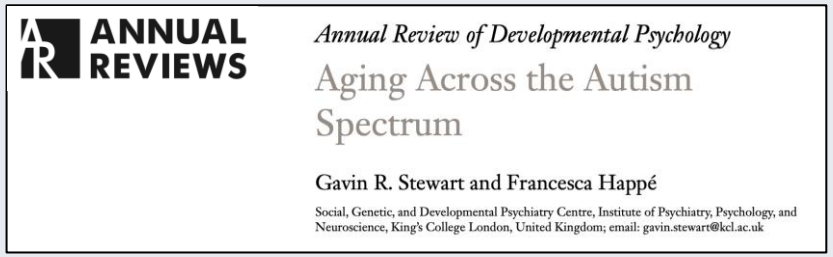


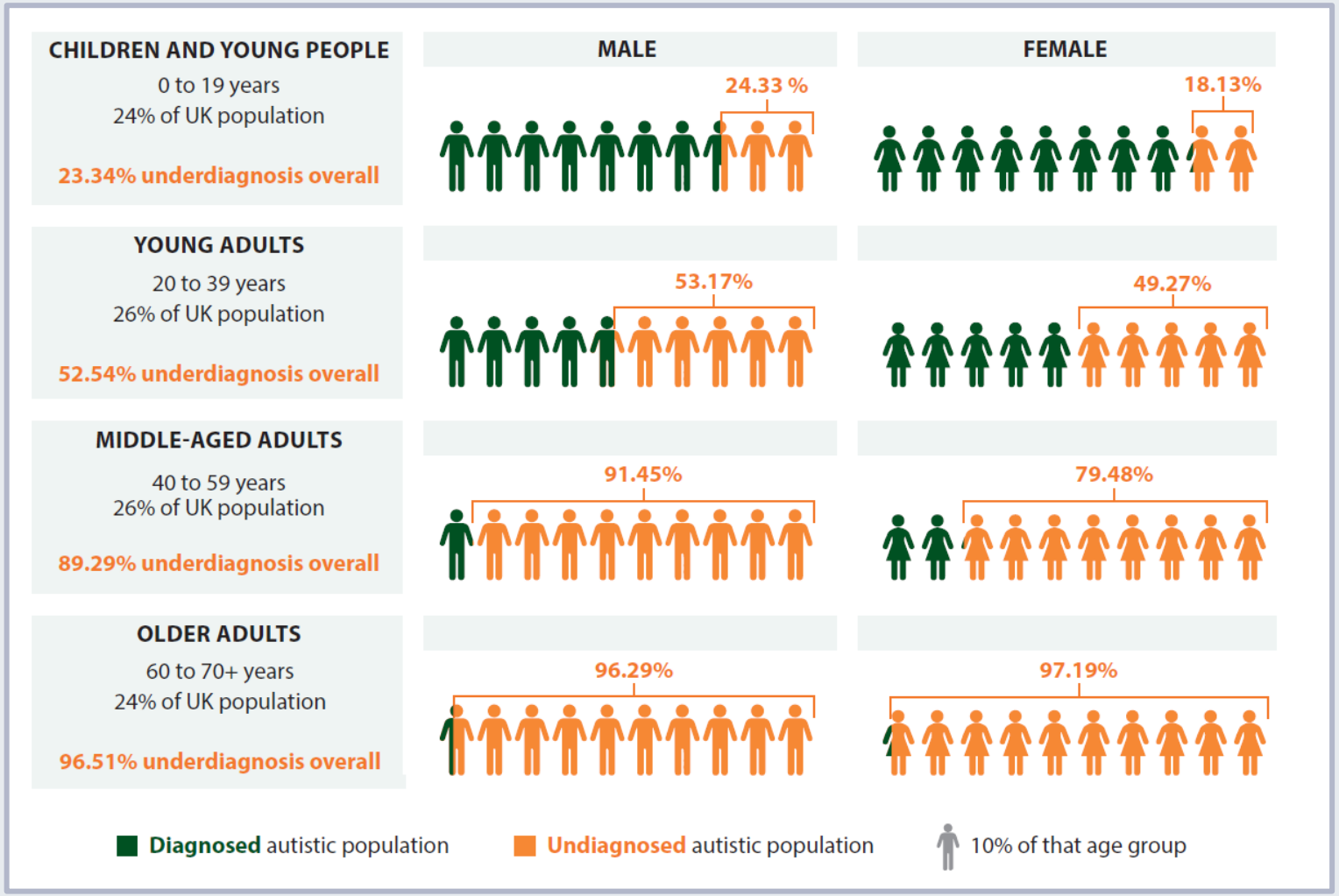
Office for National Statistics (2023); O'Nions et al. (2023); Santomauro et al. (2025)

The underdiagnosis problem

- Most autistic people are adults, and most are undiagnosed.

- UK health records indicate:
  - ~89% of autistic people in midlife are undiagnosed.
  - ~96% of autistic people in old age are undiagnosed.



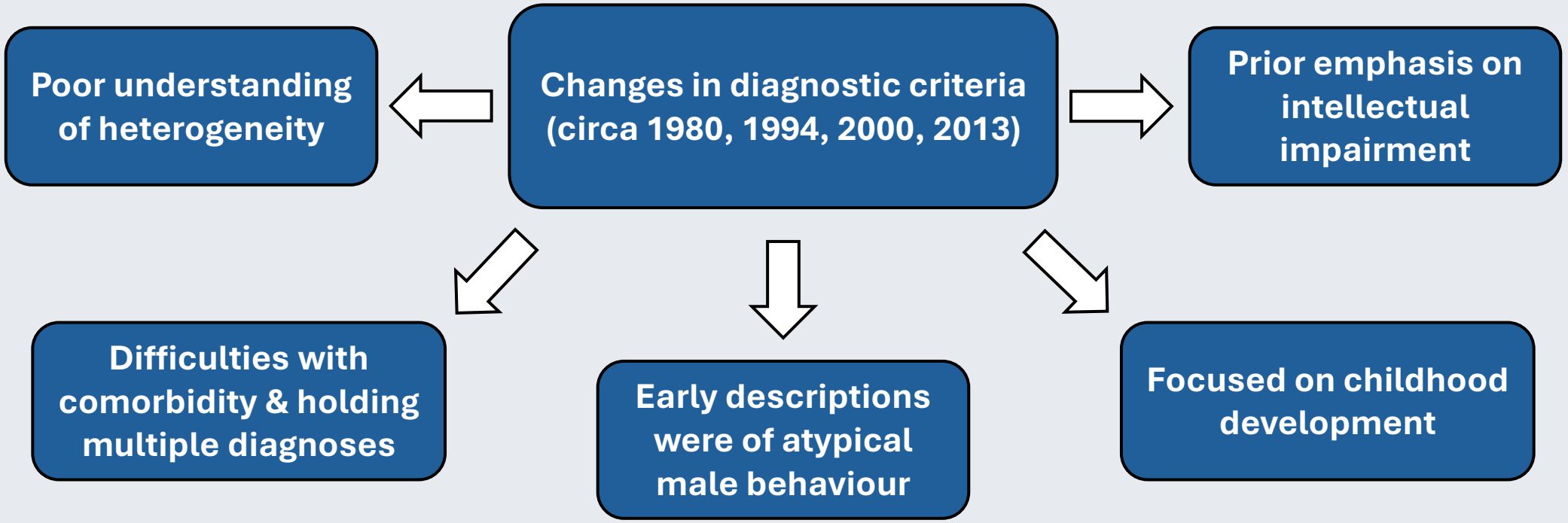


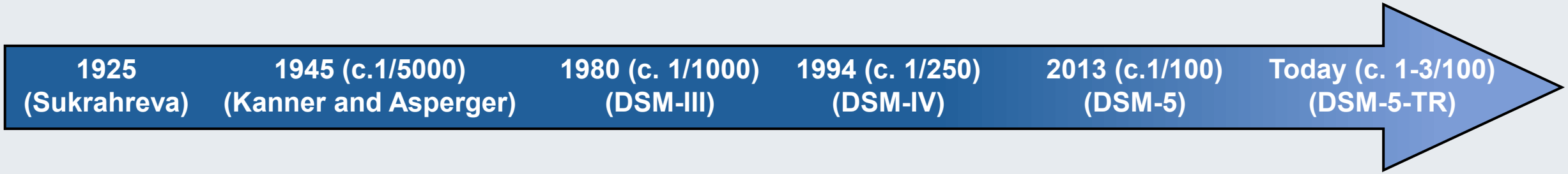
Note: Estimate accounts for male/female ratio.

Lai and Baron-Cohen (2015); O'Nions et al. (2023); Figure from Stewart and Happé (2025)

Reasons for underdiagnosis

- Several barriers to older autistic people receiving a diagnosis.

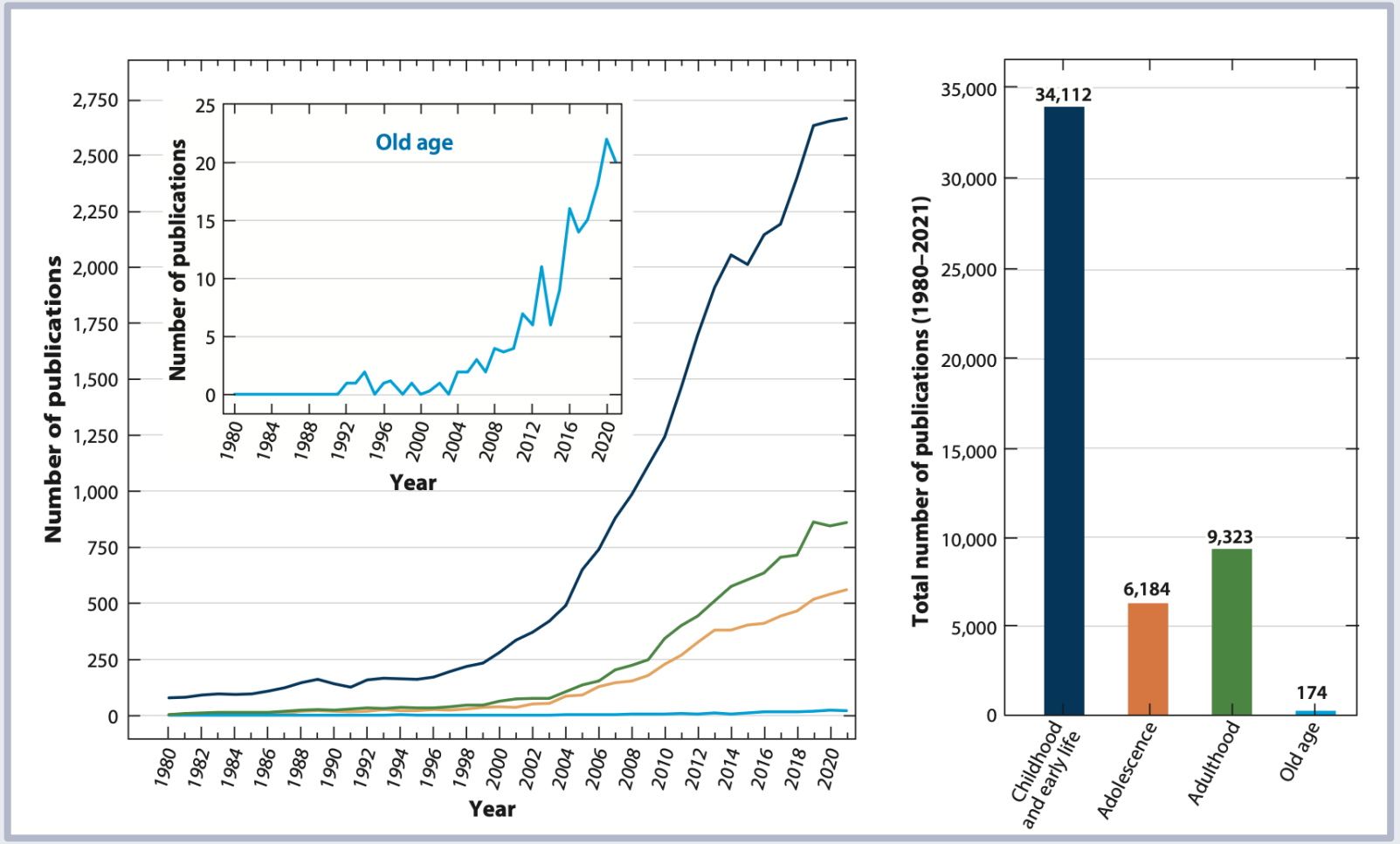




Happé and Frith (2021); Stewart and Happé (2025)

Lack of older adult autism research

- Research has mostly focused on childhood experiences and outcomes.
- Less than 1% of research focuses on older age.



ANNUAL REVIEWS
Annual Review of Developmental Psychology
Aging Across the Autism Spectrum
Gavin R. Stewart and Francesca Happé
Social, Genetic, and Developmental Psychiatry Centre, Institute of Psychiatry, Psychology, and Neuroscience, King's College London, United Kingdom; email: gavin.stewart@kcl.ac.uk

*Here, 'Older Age' means people 50+

Figure from Stewart and Happé (2025); Mason, Stewart, Capp and Happé (2022).

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- Conclusions

Cognitive Profiles

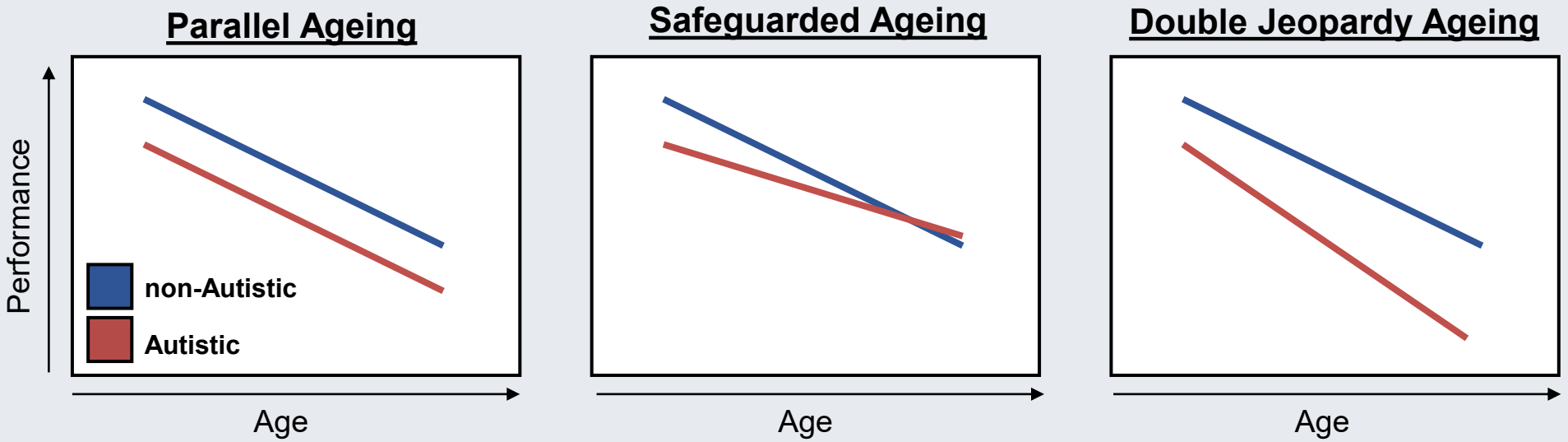
- First study to explore cognition in middle-aged and older autistic people.
- Found subtle cross-sectional differences in cognitive profiles (with autistic people having poorer performance than non-autistic comparisons in several domains).
- Hypothesised three possible trajectories of age-related change in autistic populations.

J Autism Dev Disord (2012) 42:665–675
DOI 10.1007/s10803-011-1291-0

ORIGINAL PAPER

Elderly with Autism: Executive Functions and Memory

Hilde M. Geurts · Marlies E. Vissers





Prof Hilde Geurts (UvA)

Geurts and Vissers (2012); Note: Figures do not represent real data and are for illustrative purposes.

Cognitive Profiles

- Largest longitudinal study of cognitive ageing in autistic people.
- 128 autistic people aged 25-85 years (mean age = 55 years), with matched non-autistic comparisons.
- Tracked over a 3.5-year period.
- Autistic people generally had lower performance scores across 15 cognitive measures.
- BUT – age-related change was similar in both groups.



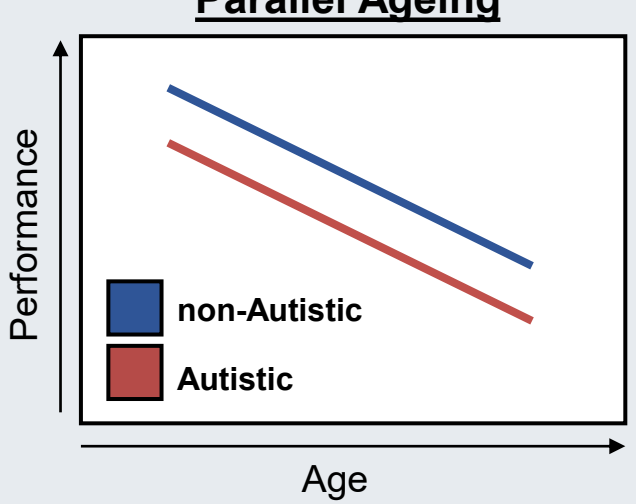
Contents lists available at ScienceDirect

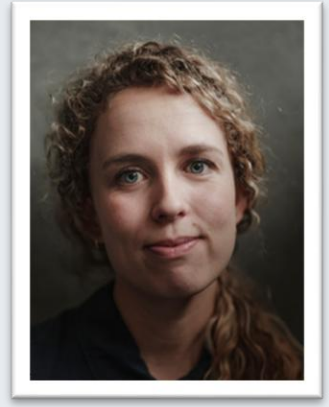
Psychiatry Research

journal homepage: www.elsevier.com/locate/psychres

A longitudinal study on cognitive aging in autism

C. Torenvliet[a,*], A.P. Groenman[a,b], T.A. Radhoe[a], J.A. Agelink van Rentergem[a], W.J. Van der Putten[a,c], H.M. Geurts[a,c]





Dr Carolien Torenvliet (UvA/Radboud)

Torenvliet et al. (2021, 2023); Note: Figures do not represent real data and are for illustrative purposes.

Cognitive Profiles

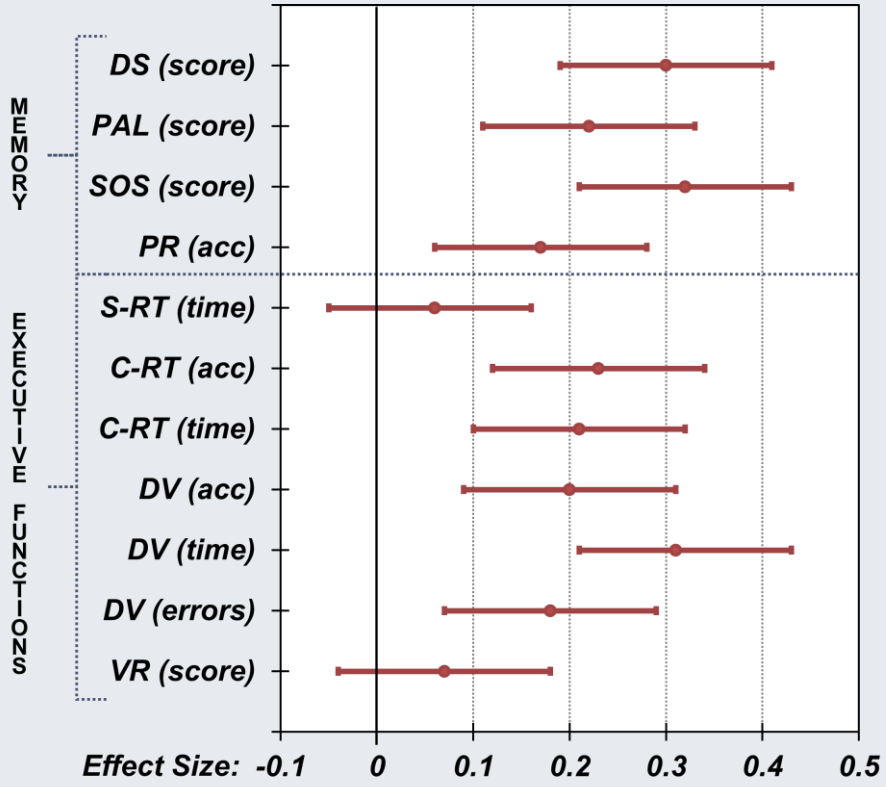
- Also replicated in very large samples using a dimensional approach (i.e., people with high autistic traits who may be autistic but undiagnosed).

- PROTECT Study: 22,000+ people aged 50-80 years (mean age = 61), with c.1% meeting cut-off for ‘high autistic traits.

- Subtle cross-sectional differences in cognitive profiles:
  - Middle-aged and older people with high autistic traits had poorer performance than non-autistic comparisons in several domains.

The cognitive profile of middle-aged and older adults with high vs. low autistic traits

Gavin R. Stewart[1] | Anne Corbett[2] | Clive Ballard[2] | Byron Creese[2] | Dag Aarsland[1] | Adam Hampshire[3] | Helen Brooker[2] | Rebecca A. Charlton[4] | Francesca Happé[1]



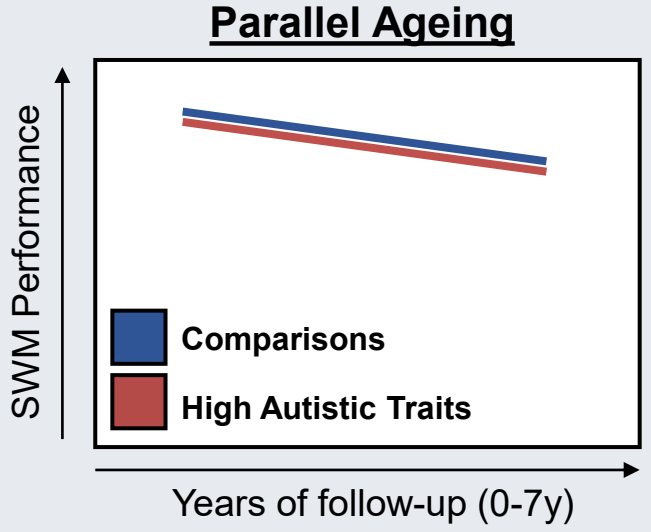
Cognitive Profiles

- What about age-related change?
- PROTECT Study: 12,000+ people aged 50-92 years at baseline (mean age = 61), with approx. 1% meeting cut-off for ‘high autistic traits’.
- Tracked annually over a 7-year period.
- Growth mixture modelling indicated a ‘One Class Model’.
- Age-related change in Spatial Working Memory was similar for whole sample.

The Gerontologist, 2025, **65**, gnaf096
https://doi.org/10.1093/geront/gnaf096
Advance access publication: 12 March 2025
Special Issue: Bridging Aging and Disability Research: Research Article

The Association Between Autism Spectrum Traits and Age-Related Spatial Working Memory Decline: A Large-Scale Longitudinal Study

Saloni Ghai, MSc,[1] Aphrodite Eshetu, MSc,[1] Anne Corbett, PhD,[2] Clive Ballard, MD,[2] Dag Aarsland, MD, PhD,[3] Adam Hampshire, PhD,[4,5] Elizabeth O’Nions, PhD,[1] William Mandy, PhD,[1] Joshua Stott, PhD,[1,*] Gavin R. Stewart, PhD,[1,6,a] and Amber John, PhD[1,a]



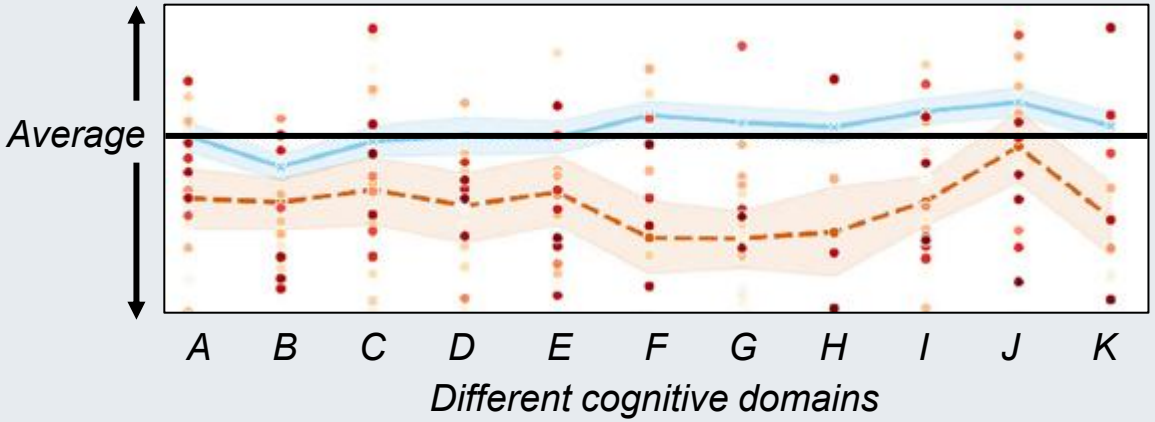


Saloni Ghai (UCL)

Ghai et al. (2025; The Gerontologist). Note: Figure does not represent real data and is for illustrative purposes.

Cognitive Profiles

- However, approx. 20% of autistic people have ‘deviant’ cognitive profiles.



Received: 8 July 2022 | Accepted: 2 December 2022
DOI: 10.1002/aur.2878

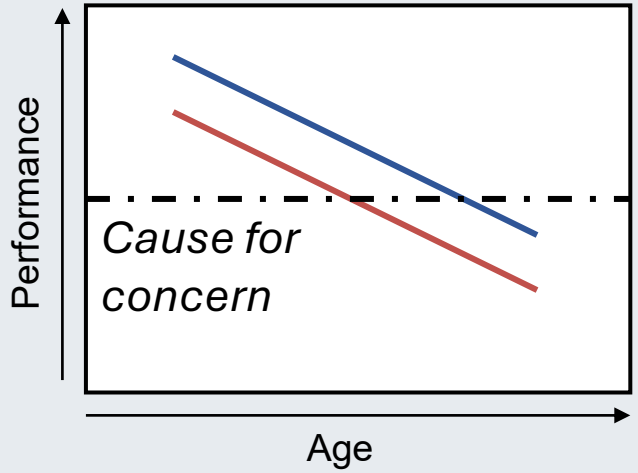
RESEARCH ARTICLE

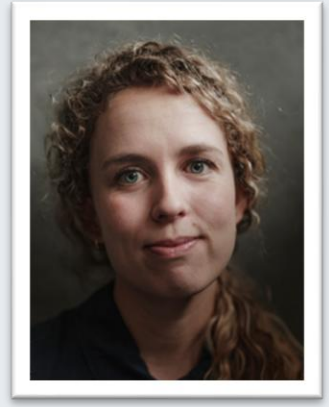
One size does not fit all: An individualized approach to understand heterogeneous cognitive performance in autistic adults

Carolien Torenvliet[1] | Annabeth P. Groenman[1,2] | Tulsi A. Radhoe[1] | Joost A. Agelink van Rentergem[1] | Hilde M. Geurts[1,3]

- Why is this important? May result in an ‘old age’ cognitive profile at a younger age, so red flags for dementia may appear earlier.

- More work needed in this area.





Dr Carolien Torenvliet (UvA/Radboud)

Torenvliet et al. (2022).

Cognitive Profiles

- Middle-aged and older autistic people often self-report cognitive challenges, including perceived cognitive decline.
- 210 autistic people aged 42-81 years (mean age = 55 years).
- 30% scored above cut-off on a dementia screener.
- Age was weakly correlated with decline scores.

Received: 25 August 2022 | Accepted: 4 December 2022
DOI: 10.1002/aur.2877

RESEARCH ARTICLE

Self-reported cognitive decline among middle and older age autistic adults

Claire B. Klein[1] | Goldie A. McQuaid[2] | Rebecca A. Charlton[3] | Laura G. Klinger[1] | Gregory L. Wallace[4]

The cognitive profile of middle-aged and older adults with high vs. low autistic traits

Gavin R. Stewart[1] | Anne Corbett[2] | Clive Ballard[2] | Byron Creese[2] | Dag Aarsland[1] | Adam Hampshire[3] | Helen Brooker[2] | Rebecca A. Charlton[4] | Francesca Happé[1]

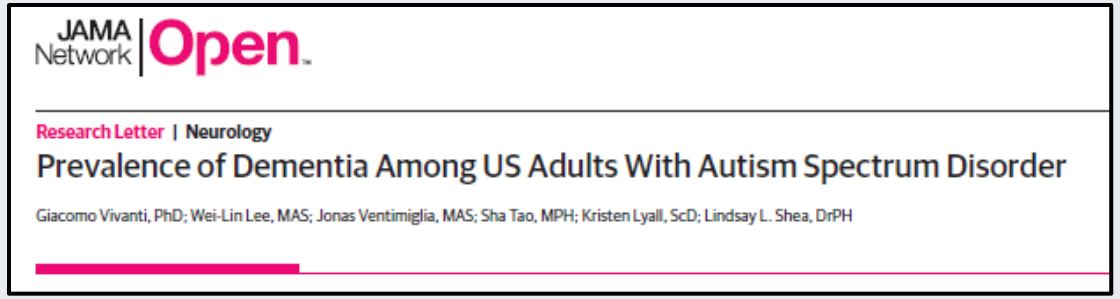


Claire Klein (UNC-CH/UPMC)

Stewart et al. (2023), Klein et al. (2023).

Rates of Dementia

- Middle-aged and older autistic people have been found to have higher rates of dementia (early onset and old age onset) compared to non-autistic people.


JAMA Network | Open

Research Letter | Neurology

Prevalence of Dementia Among US Adults With Autism Spectrum Disorder

Giacomo Vivanti, PhD; Wei-Lin Lee, MAS; Jonas Ventimiglia, MAS; Sha Tao, MPH; Kristen Lyall, ScD; Lindsay L. Shea, DrPH

- Analysis of USA Medicare and Medicaid data (totalling 90million people, 100,000+ with an autism diagnosis).

- Prevalence of early onset dementia in autistic people aged 30-64 was ~4% (compared to <1% in general population).

- Prevalence of dementia in autistic people aged over 65 years was ~30% (compared to ~10% in general population).

- BUT – only 10% of autistic people over 40 have a diagnosis, many older autistic people likely not counted in these studies.



Dr Giacomo Vivanti (Drexel)

Vivanti et al. (2025)

Challenges with assessing dementia

- There have been concerns raised by clinicians that we lack validated tools for assessing dementia in autistic populations.
- May result in inaccurate assessments.
  - Could autism-related differences and experiences like burnout be picked up as dementia symptoms?
- We need more applied clinical research to test and develop the tools being used in practice to ensure they are fit for purpose.
- We also need to improve older adult service clinical awareness of autism.

International Journal of Geriatric Psychiatry

WILEY

International Journal of Geriatric Psychiatry

LETTER TO THE EDITOR

Addressing the Gaps in Assessing Dementia in Older Autistic Adults

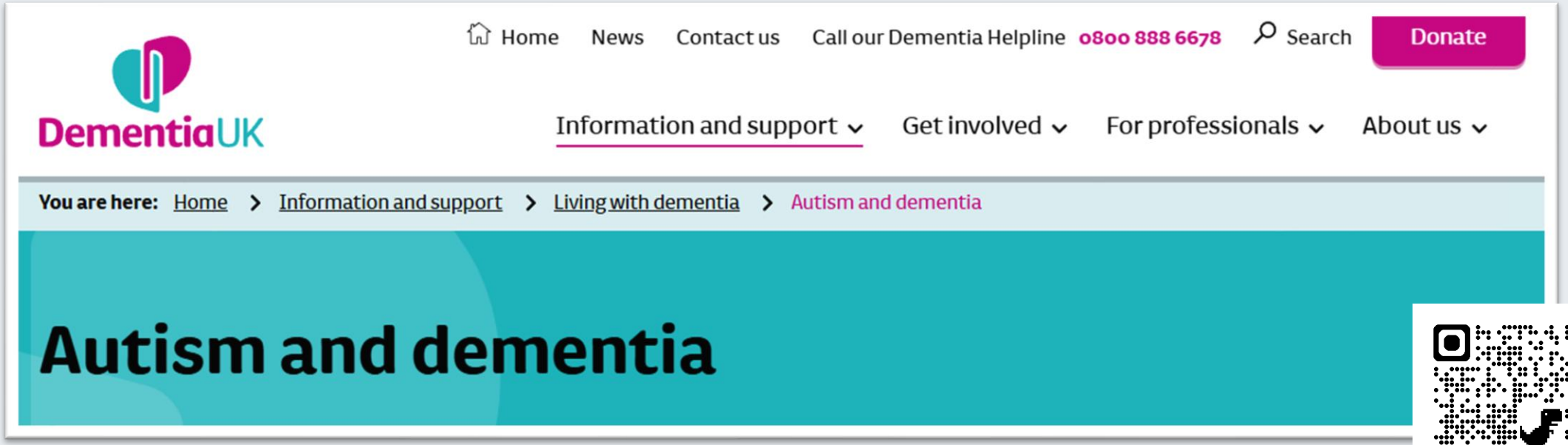
Freddie O'Donald[1,2] | Jamie Ferrie[2] | Clara Calia[1]

[1]School of Health in Social Science, University of Edinburgh, Edinburgh, UK | [2]Department of Clinical Psychology, NHS Tayside, Dundee, UK



Dr Jamie Ferrie (NHS Scotland)

Resources about autism and dementia



autistica

DementiaUK

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- Conclusions

Health Diagnoses

- Middle-aged and older autistic people have been found to have higher rates of most health conditions compared to non-autistic comparison.


Original Article

autism

Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults

Autism
1–10
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DOI: 10.1177/1362361319890793
journals.sagepub.com/home/aut
SAGE

Brittany N Hand[1], Amber M Angell[2], Lauren Harris[1] and Laura Arnstein Carpenter[3]

- USA Medicaid data (4,600+ with an autism diagnosis with 10x matched comparisons).
- Higher rates of common conditions: mood disorders (OR=5.6), gastrointestinal disorders (OR=2.7).
- Higher rates of age-related conditions: Parkinson's disease (OR=6.1), cognitive disorders (OR=8.4), osteoporosis (OR=4.4), arthritis (OR=1.6), and heart disease (OR=2.1).



Dr Brittany Hand (OSU)

Health Diagnoses

- Growing evidence that autistic people have health issues throughout their lives, including in midlife and older age.
- PROTECT Study: 22,000+ people aged 50-80 years (mean age = 61), with c.1% meeting cut-off for ‘high autistic traits’.
- Higher rates of common conditions: depression (OR=4.4), anxiety (OR=3.4).
- Higher rates of age-related conditions: mild cognitive impairments (OR=7.3), arthritic conditions (OR=2.14).
- More likely to have multiple mental health diagnoses.

THE GERONTOLOGICAL SOCIETY OF AMERICA®

Journals of Gerontology: Psychological Sciences
cite as: *J Gerontol B Psychol Sci Soc Sci*, 2020, Vol. XX, No. XX, 1–12
doi:10.1093/geronb/gbaa112
Advance Access publication August 5, 2020

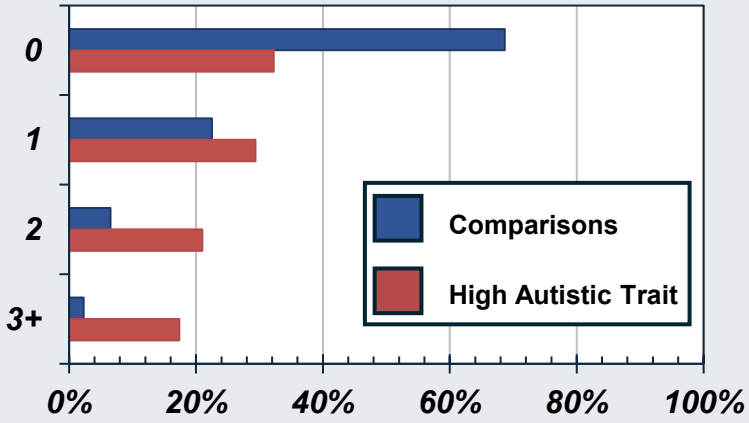
OXFORD

Research Article

The Mental and Physical Health Profiles of Older Adults Who Endorse Elevated Autistic Traits

Gavin R. Stewart, MSc,[1,*] Anne Corbett, PhD,[2] Clive Ballard, MD,[2] Byron Creese, PhD,[2] Dag Aarsland, PhD,[1] Adam Hampshire, PhD,[3] Rebecca A. Charlton, PhD,[4] and Francesca Happé, PhD[1]

Total number of mental health diagnoses



Stewart et al. (2020)

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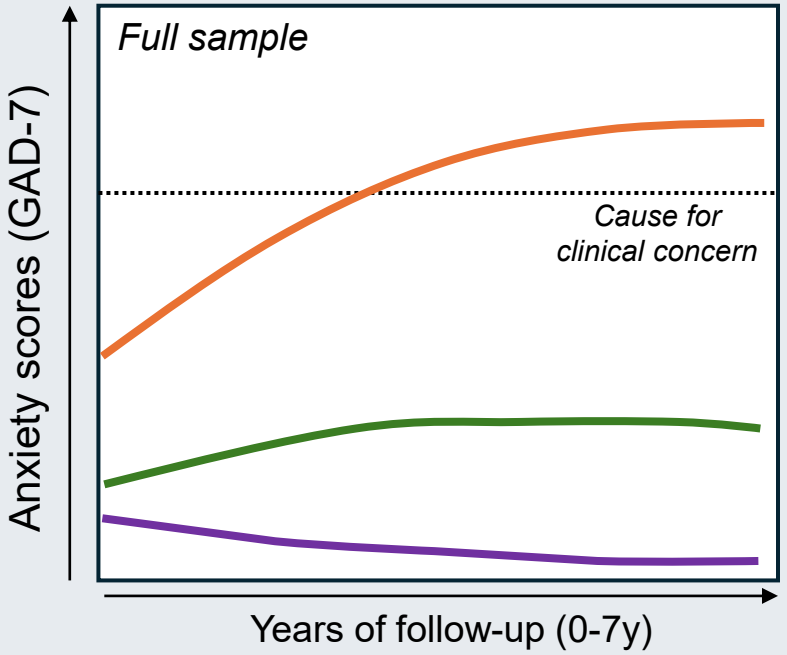
Mental Health Symptoms

- Longitudinal analyses have indicated that people with high autistic traits are more likely to have persistent mental health symptoms.
- PROTECT Study: 22,000+ people aged 50-92 years at baseline (mean age = 61), with approx. 1% meeting cut-off for ‘high autistic traits’.
- Tracked annually over a 7-year period.
- Growth mixture modelling indicated a ‘Three Class Model’.
- For anxiety, people with high autistic traits were 12x more likely to be in the persistent high symptom (orange) class than comparisons.

Under Review

The Association Between Autistic Traits and Trajectories of Anxiety in Middle-Aged and Older Adults: A Growth Mixture Model Analysis

Aphrodite Eshetu, Saloni Ghai, PROTECT team, Joshua Stott, Amber John, and Gavin R. Stewart





Aphrodite (Effie) Eshetu (UCL)

Correlates of poor MH (Sleep)

- Sleep problems are associated with mental health problems.
- AWA Wave 1: 276 autistic adults aged 40-91 (mean age = 60) compared to matched non-autistic comparisons.
- Anxiety has a particularly strong relationship with sleep problems for autistic people.

Under Review

Sleep quality and mental health in middle-aged and older autistic and non-autistic adults.

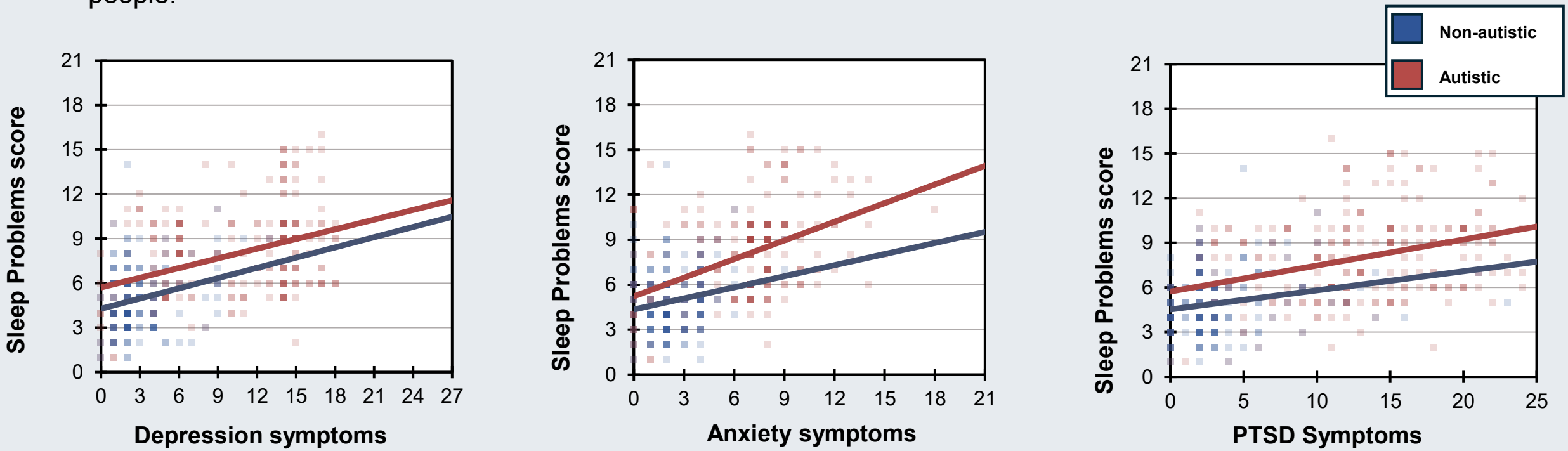
Sophie Roper, Andreea Barbinta, Alice Quinton, Rebecca A. Charlton, Francesca Happé, and Gavin R. Stewart



Sophie Roper (KCL)



Andreea Barbinta (KCL)



Correlates of poor MH (Sensory Problems)

- Middle-aged and older autistic people have been found to have more sensory processing problems compared to non-autistic comparison.
- AWA Wave 1: 276 autistic adults aged 40-91 (mean age = 60) compared to matched non-autistic comparisons.
- Noise and overcrowded areas often source of sensory sensitivities.
- Sensory processing problems are associated with mental health problems.

AUTISM IN ADULTHOOD
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DOI: 10.1089/aut.2024.0031

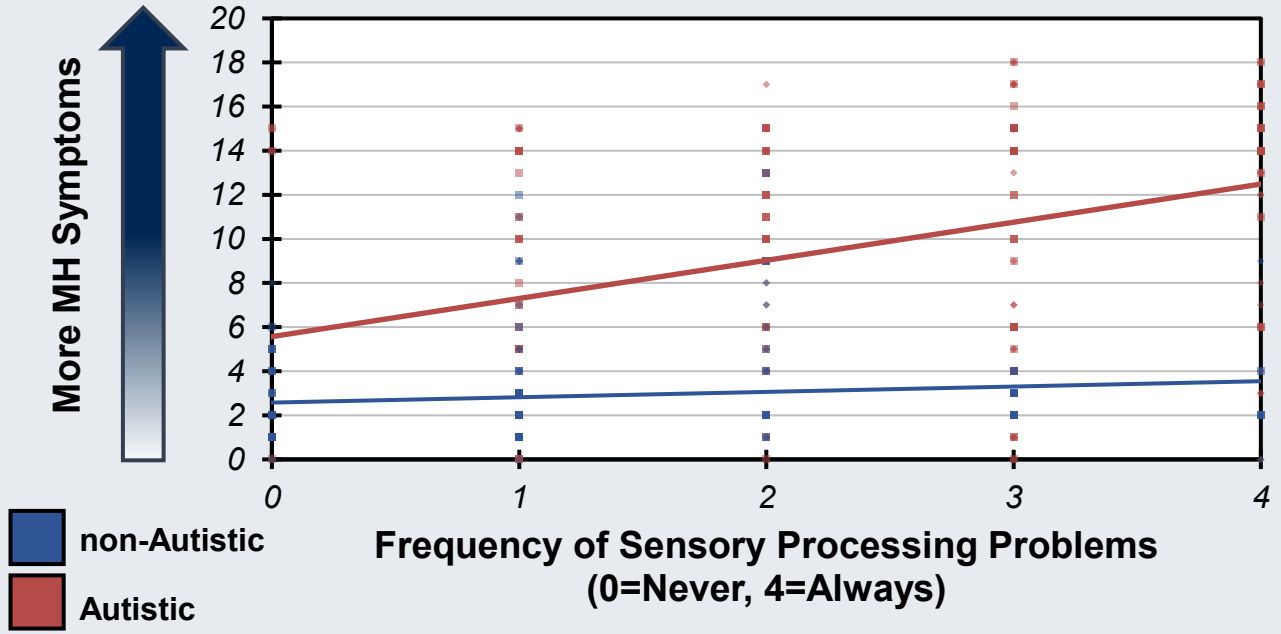
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"Utterly Overwhelming"—A Mixed-Methods Exploration of Sensory Processing Differences and Mental Health Experiences in Middle-Aged and Older Autistic Adults

Yixin Chen, MPhil,[1] Christine A. Jenkins,[2] Rebecca A. Charlton, PhD,[3] Francesca Happé, PhD,[4] William Mandy, PhD, DClin,[1] and Gavin R. Stewart, PhD[4]



Yixin Chen (UCL)



Talk overview

- Background:
  - What is autism?
  - What is the prevalence of autism?
  - Why is autism in older age important?

- **Research overview:**
  1) **Cognitive profiles, cognitive ageing, and dementia**
  2) **Health profiles across midlife and old age and life expectancy**
  3) **Mental health and correlates**
  4) **Social problems and potential mechanisms**
  5) **Lived experience insights**

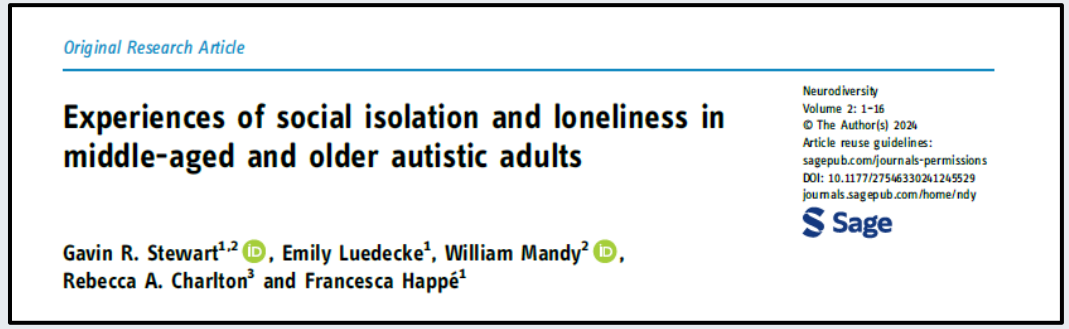
- Conclusions

Social problems

- Middle-aged and older autistic people have been found to have lower social connectedness and higher rates of social isolation compared to non-autistic comparison.

- AWA Wave 1: 276 autistic adults aged 40-93 (mean age = 61) compared to matched non-autistic comparisons.

- Approx. 20% of autistic people had no contact with family of friends each month (compared to approx. 5% of comparisons).



Original Research Article

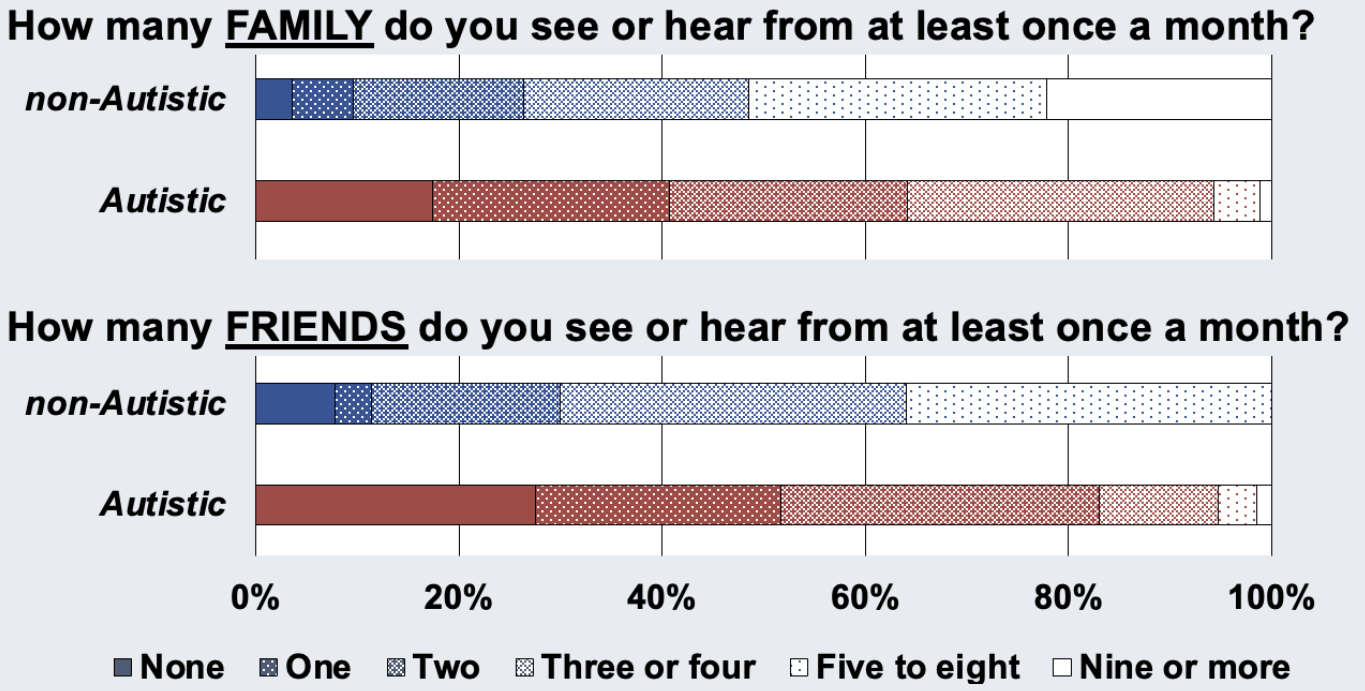
Experiences of social isolation and loneliness in middle-aged and older autistic adults

Neurodiversity
Volume 2: 1–16
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Sage

Gavin R. Stewart[1,2], Emily Luedecke[1], William Mandy[2], Rebecca A. Charlton[3] and Francesca Happé[1]

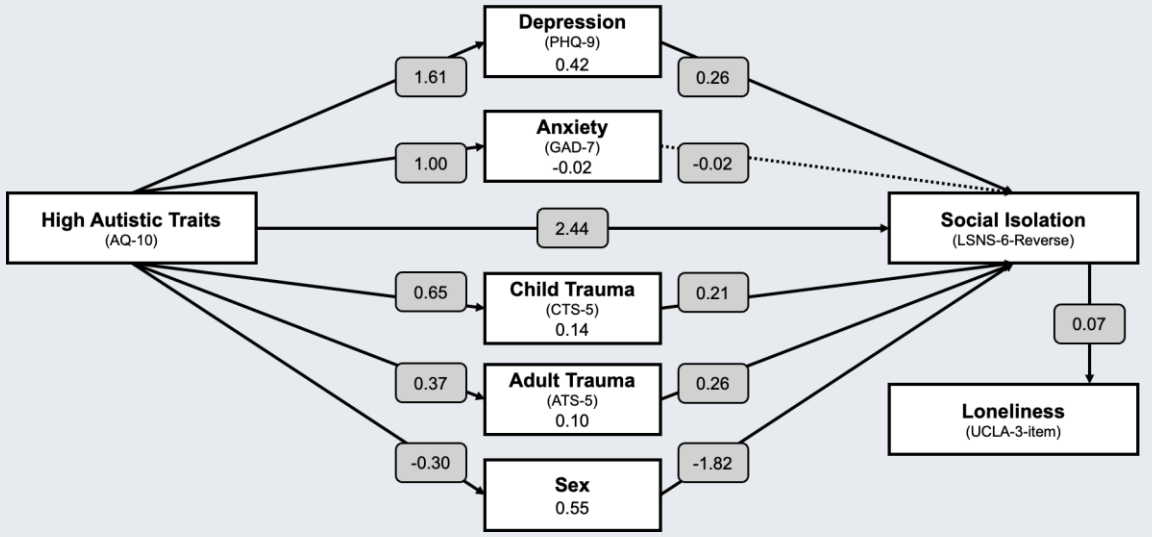


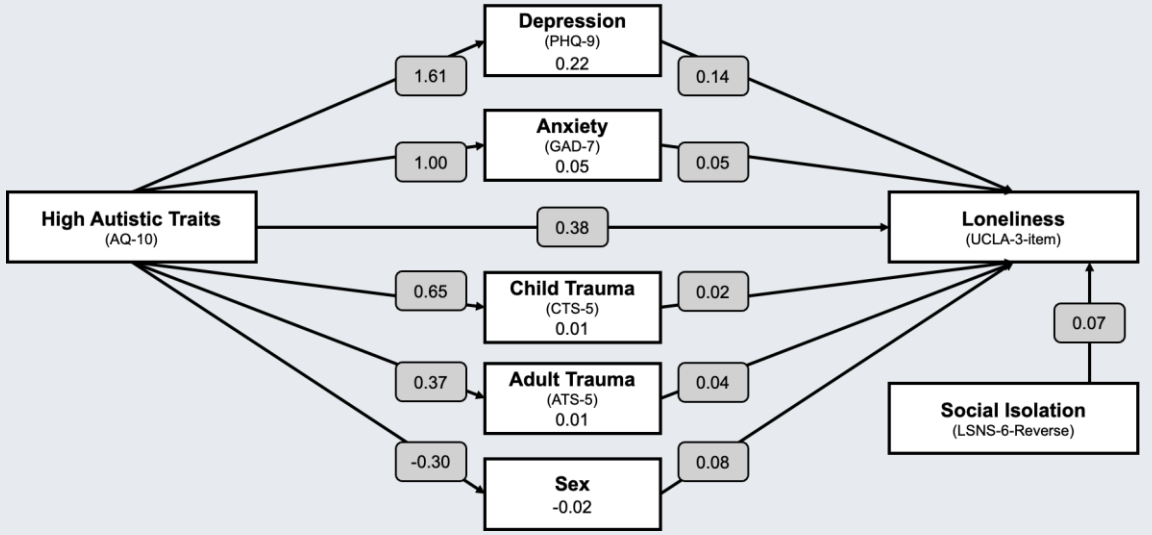
Emily Luedecke (KCL)



Social problems

- PROTECT Study: ~10,000 people aged 50-95 years old (mean age = 68), with approx. 6% meeting cut-off on the AQ-10 for ‘high autistic traits’.
- Direct effects between High Autistic Traits and Social Isolation and Loneliness were partially mediated by mental health and interpersonal trauma.
- Are autistic people are predisposed to these social problems?







Dr Radvile Medeisyte (UCL)

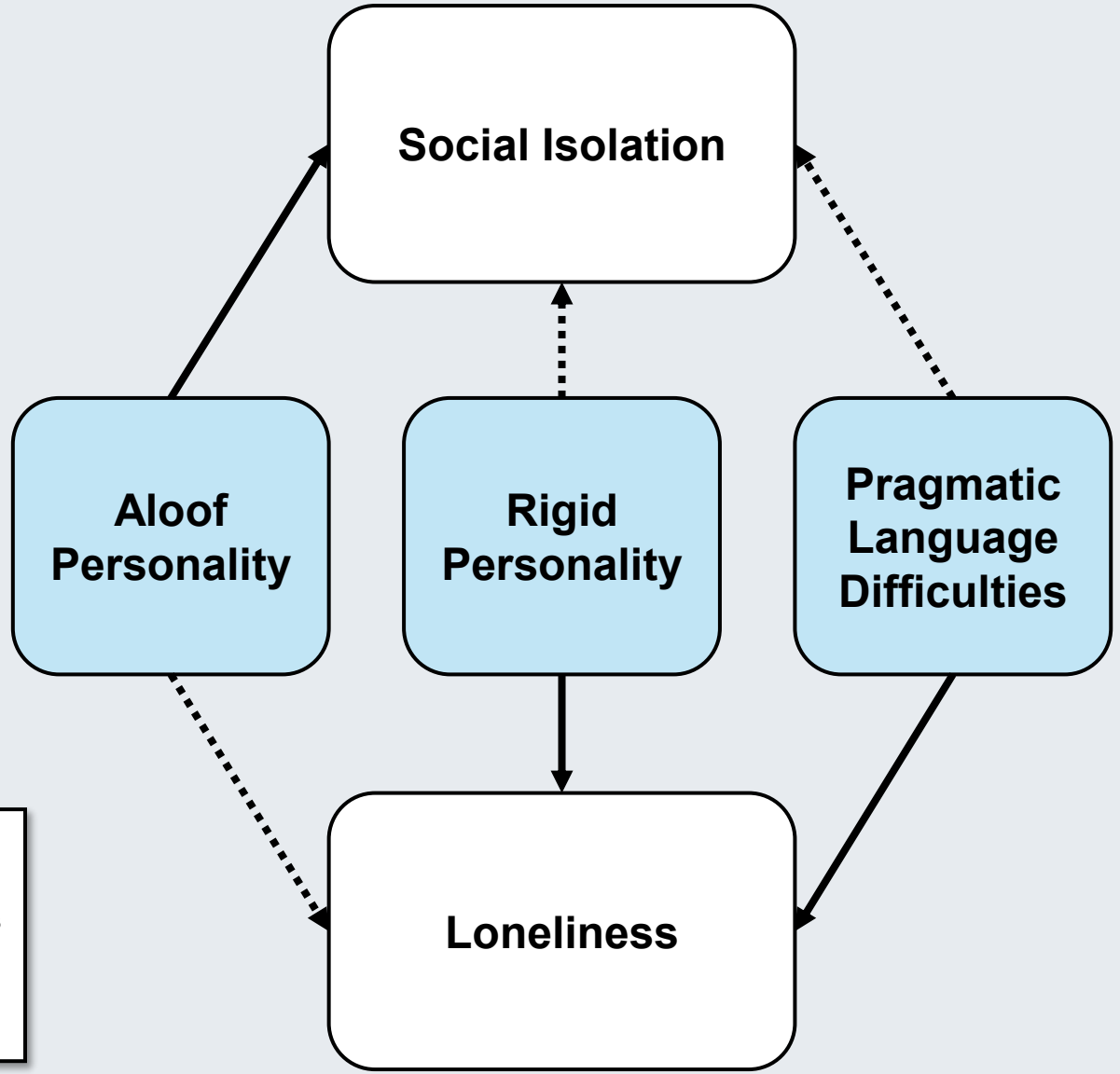
Under review

Social isolation and loneliness in adults over 50 with high autistic traits

Radvile Medeisyte, Eleanor Nuzum, Aphrodite Eshetu, Sarah Hoare, PROTECT, Amber John, Josh Stott, and Gavin R. Stewart

Social problems

- Different autistic traits and characteristics are associated with Social Isolation and Loneliness.
- Aloof personality predicts social isolation.
- Rigid personality and pragmatic language difficulties predict loneliness.
- Helpful for designing and implementing interventions for supporting autistic people.





Dr Radvile Medeisyte (UCL)

Under review

Social isolation and loneliness in adults over 50 with high autistic traits

Radvile Medeisyte, Eleanor Nuzum, Aphrodite Eshetu, Sarah Hoare, PROTECT, Amber John, Josh Stott, and Gavin R. Stewart

Social problems

- Cognitive differences associated with autism may also play a role.
- Theory of Mind was a partial mediator in the relationship between autistic traits and social isolation.
- May provide some support for the ‘double empathy’ theory.
- Helpful for designing and implementing interventions for supporting autistic people.

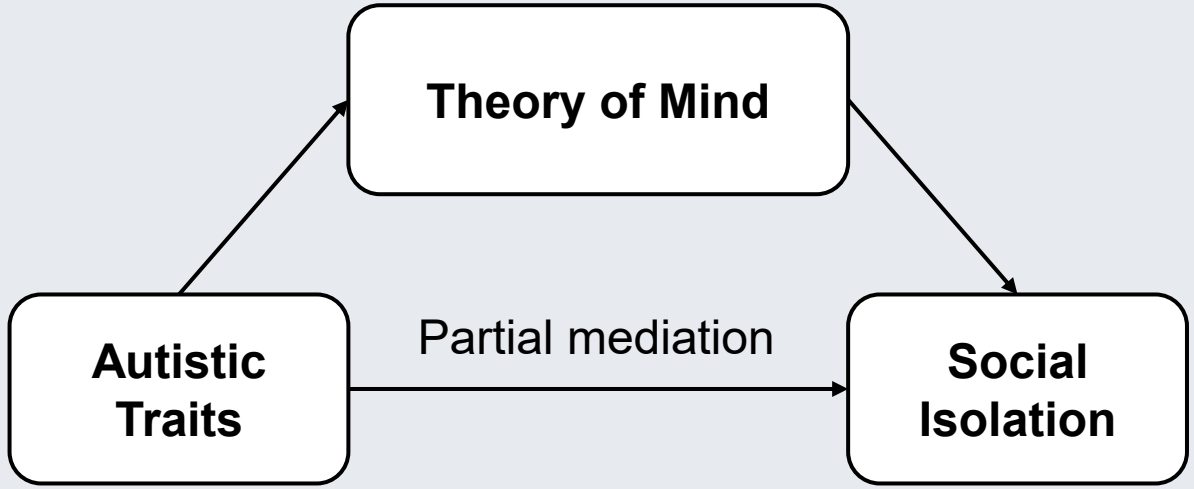
Autism Research (2025)

Theory of Mind Mediates the Association Between Autistic Traits and Social Isolation in Middle-Aged and Older Adults

Gloria Hei Man Lo, Clemie Dale, Francesca Happé, and Gavin R. Stewart



Gloria Lo (KCL)



Social problems

- Social connections are an important predictor of better mental health and quality of life in middle-aged and older autistic adults.

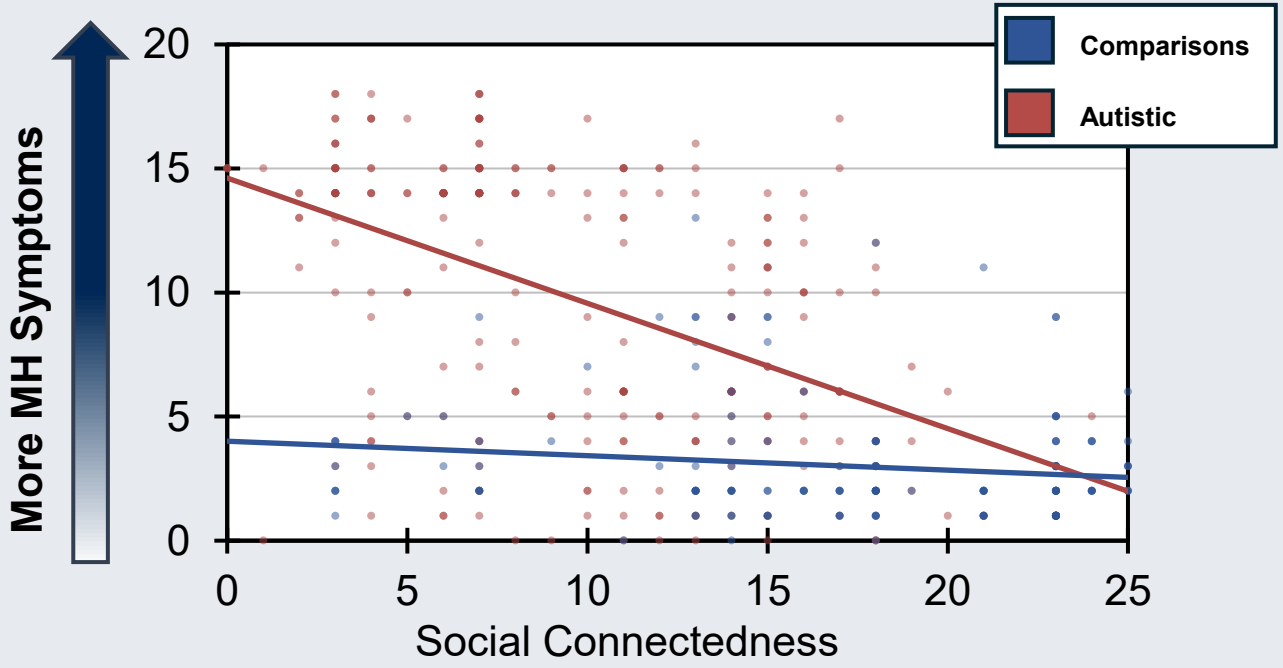
Under Review (preprint coming soon)

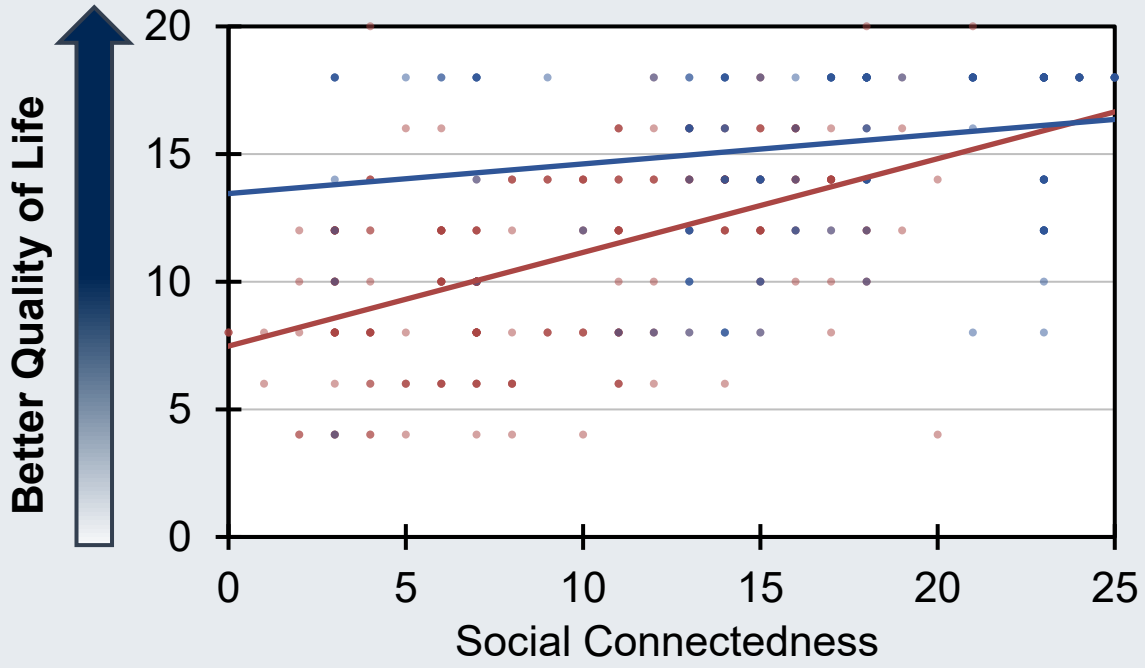
The benefits of being Socially Connected on Mental Health and Quality of Life in middle-aged and older autistic and non-autistic adults.

Hanna Muse, Emily Luedecke, Rebecca A. Charlton, Francesca Happé, and Gavin R. Stewart



Hanna Muse (KCL)





Talk overview

- Background:
  - What is autism?
  - What is the prevalence of autism?
  - Why is autism in older age important?

- **Research overview:**
  1) **Cognitive profiles, cognitive ageing, and dementia**
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  3) **Mental health and correlates**
  4) **Social problems and potential mechanisms**
  5) **Lived experience insights**

- Conclusions

Lived experience insights - diagnosis

- Lived experience can provide important insights into how autistic people experience the world.

- 13 autistic adults aged 51-71 years completed semi-structured interviews about receiving their autism diagnosis later in life.

Original Article

'Suddenly the first fifty years of my life made sense': Experiences of older people with autism

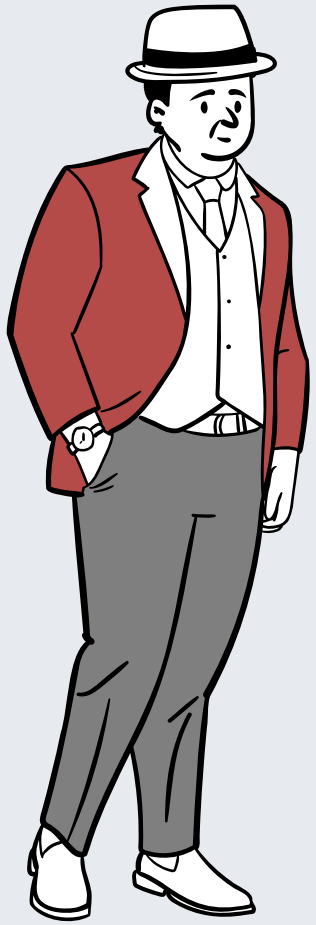
Aoife Hickey[1], Jason Crabtree[2] and Joshua Stott[3]



Prof Josh Stott (UCL)

Lived experience insights - diagnosis

Recognising being different



"The very first time I thought I was different, maybe in that way but I didn't know why, was when I was eight years old in 1966. When they didn't put me up to the secondary school from the primary school. And I thought, 'Oh, why are they doing that? What's wrong with me?"

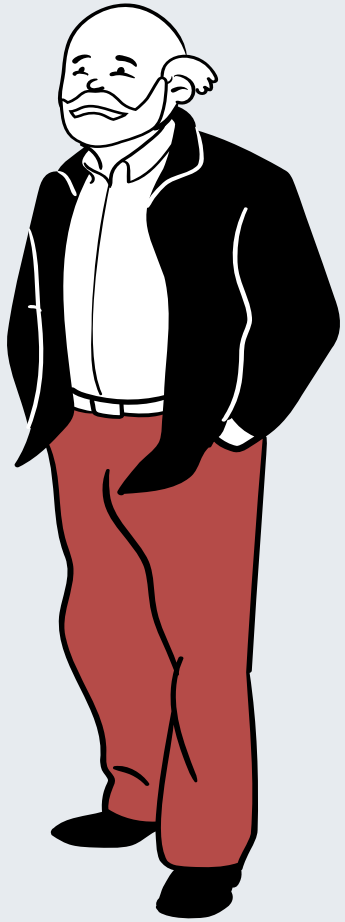
– Autistic man, mid-50s

Lived experience insights - diagnosis

Reflecting on being autistic

"Well, for example, you have an explanation why is it [that] you find it difficult to meet people and relate to them. Once you have a few explanations, you find things smooth themselves out a bit."

– Autistic man, early 70s



Lived experience insights - diagnosis

Self-acceptance of being autistic



"I'm not pressurising myself to be like everyone else. You know, it doesn't matter if I like being on my own, living on my own. That's fine. It's 'cause I – you know, people with Asperger's are like that. So I can feel like I'm not somebody who's failed to have a relationship, failed to have children, failed to hold down a job or get to a higher position in a job."

– Autistic woman, early 50s

Lived experience insights

- Lived experience can provide important insights into how autistic people experience the world.
- 15 autistic adults aged 50-78 years (mean age = 61) completed semi-structured interviews about their life experiences.
- Project was steered by a group of middle-aged and older autistic and non-autistic people.

Contents lists available at ScienceDirect

Research in Autism

journal homepage: www.elsevier.com/locate/rasd

"Bigger lows, but higher highs": A qualitative exploration of the similarities and differences in quality of life of middle-aged and older autistic and non-autistic adults

Dayna Francis [a,1], David Hershman [a,1], Rebecca A. Charlton [b], Francesca Happé [a], Gavin R. Stewart [a,*]

[a] Institute of Psychiatry, Psychology & Neuroscience, King's College London, SE5 8AF, UK
[b] Department of Psychology, Goldsmiths University of London, SE14 6NW, UK



Dr Dayna Francis (KCL)

Lived experience insights

Cognitive changes

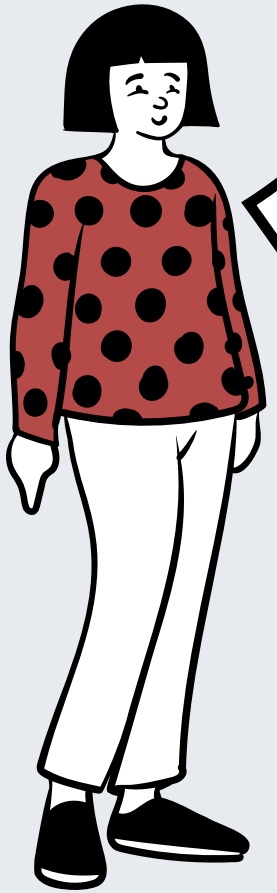


"My memory is getting worse. I forget names more than before, lose my train of thought mid-sentence, take longer to finish what I'm saying and sometimes struggle to find the word I'm looking for."

– Autistic woman, early 50s

Lived experience insights

Health and Sleep

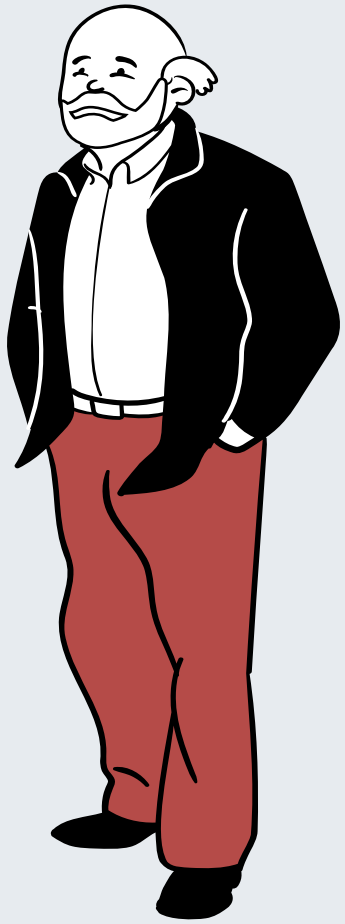


"All the different physical and psychological things combine to close down my life. I do fewer things, stay close to home."

– Autistic woman, late 50s

"[My sleep] has got shorter and [I've] been waking earlier. I can't really pin point when that started changing though. I've always had quite broken up sleep but it's definitely getting worse [as I get older]."

– Autistic man, mid-70s



Lived experience insights

Sensory and Environmental Influences



"I notice a lot of small noises, which become irritating, I tend to avoid the school rush."
– Autistic woman, mid-70s

"All those things [noise, crowding] narrow down what I can do, where I can go, or at least limit how long I can do a particular thing for."
– Autistic woman, late 50s



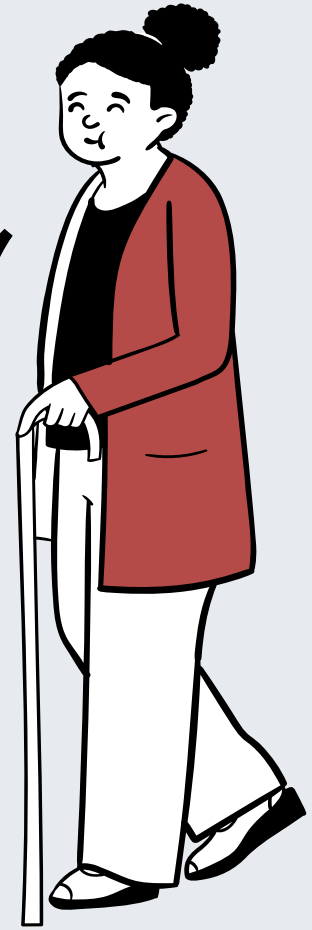
Lived experience insights

Social Connections – Friends and Family



"[My social life] is probably as much as I can cope with, but I still get lonely." – ***Autistic woman, late 50s***

"I am satisfied [with my social life]; I am not a social person, so I'm happy not to have friends." – **Autistic woman, mid-50s**



Talk overview

- Background:
  - What is autism?
  - What is the prevalence of autism?
  - Why is autism in older age important?

- Research overview:
  1) Cognitive profiles and longitudinal change
  2) Health profiles across midlife and old age
  3) Experiences and transition periods
  4) Social problems and potential mechanisms
  5) Lived experience insights

- **Conclusions**

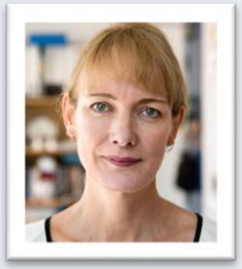
Some important considerations

- Most studies that have focused on ageing use some form of online element (survey, recruitment, etc.), and some may find that a barrier to participation.
- Most studies also have samples tend to be predominately well educated (e.g., AWA: ~40% hold university degree) and almost all were diagnosed in adulthood.
- The underdiagnosis problem is likely to impact broader generalisability of our research.
- Middle-aged and older people who have an autism diagnosis, self-identify as autistic, and who have high autistic traits often have similar experiences and profiles.
- Many targets for supporting autistic people to flourish.

Thank you

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- Thank you to the British Academy and ESRC for funding my work.
- And collaborators at KCL (ReSpect lab), UCL (Mandy lab and ADAPT lab), Goldsmiths (GoldAge lab) and PROTECT.
- And the autistic people who have helped steer my work.

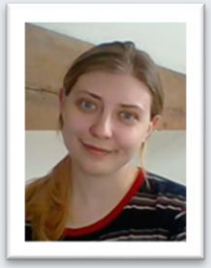

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Prof Rebecca Charlton


Dr Elizabeth O'Nions


Dr David Mason


Prof Josh Stott


Dr Amber John


Prof Will Mandy


Yixin Chen


Christine Jenkins


Dr Alice Quinton


Gloria Lo


Dr Eleanor Nuzum


Dr Radvile Medeisyte


Ellen McAdams


Andreea Barbinta


Hanna Muse


Saloni Ghai


Aphrodite Eshetu


Emily Luedecke


Dr Dayna Francis


Sophie Roper

Thank you

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Scan here for a recent narrative review on ageing and autism

Scan here for my Google Scholar profile (all open access)

Scan here to sign-up to the ReSpect Lab Newsletter

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RESEARCH ACROSS THE AUTISM SPECTRUM AND LIFESPAN
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