Autistic in Academia

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Faculty of Science, Carleton University

"Positionality", or who am I to give this talk

I've given many physics talks, but this is only my second talk about my experiences as a late-identified autistic person

- PhD 1999 University of California Santa Cruz, postdocs at Fermilab and U. Wisconsin, faculty position at Carleton University (Canada) 2005 (theoretical particle physics)

- Done all the usual academic stuff: teaching, research, grad-student supervision, administrative roles (including Department Chair), conference organizing, grant review committees, etc.

- Formally diagnosed as autistic in 2022 at age 47. Realization was completely unanticipated, though obvious in retrospect: knowledge gap. Sought out info for my own survival; dissemination & advocacy to help others in a similar position.

Outline

Definitions and introduction

The guessing game

Practical challenges

Otherness and belonging

Ways forward

Definitions and introduction

- Neurodiversity – the natural biodiversity of neurological variations within the human species. Reframes autism, ADHD, dyslexia, etc. as natural human variations to be accommodated and appreciated rather than as disorders to be eliminated. Highlights the value of diversity-of-thought to the survival and progress of human societies.

- Social model of disability – the idea that people are disabl**ed** (as a transitive verb) by inaccessible environments and discriminatory behaviours of others ("attitudinal barriers").

- "Nothing about us without us" – research and policy-making around disabilities must be led by people who have the disability in question (lived experience).

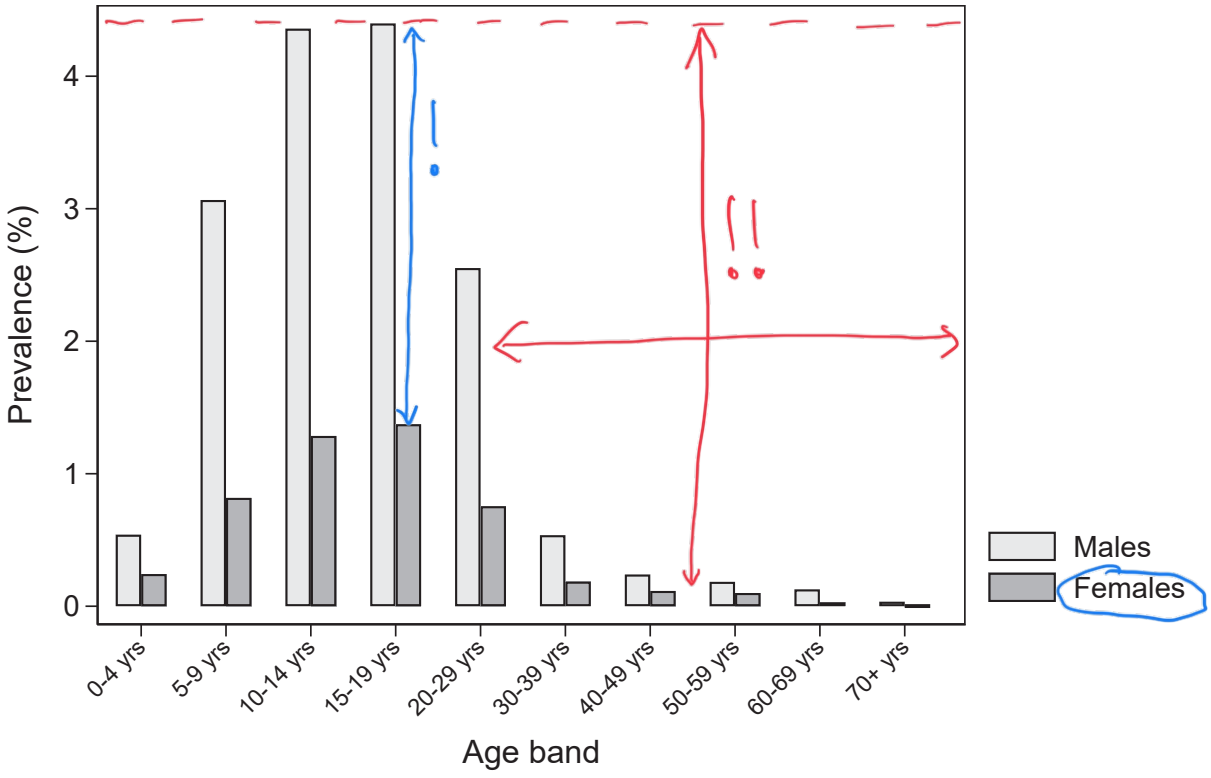
→ I will talk only about autism, because I do not have lived experience of other forms of neurodivergence.

Definitions and introduction

The biggest issue for autistic people (as I see it) is:
Nobody* knows what we're like or what we need!

*To first approximation

- Most autistic adults are unidentified (even worse for females!)



(England 2018)

E. O'Nions et al., The Lancet Regional Health Europe 29, 100626 (2023)

Definitions and introduction

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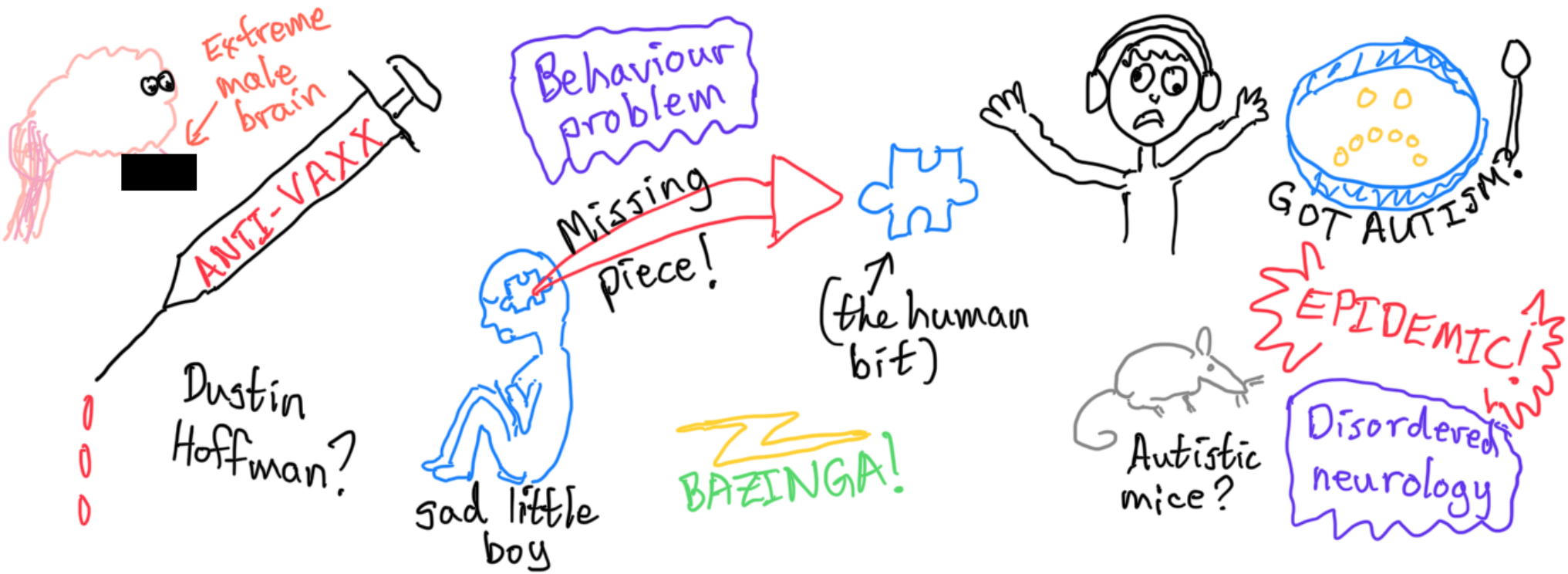
- Most of what the general public knows about autistic people is based on stereotypes and fearmongering



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Two goals:

- Dispel some misconceptions by providing one "data point" of an actual autistic person (me) who is not entirely unlike you

- Emphasize universal design approaches that benefit autistic people (identified or not!) as well as members of other equity-deserving groups

Secret third goal: maybe you are autistic and don't know it yet?
(this was me for ~ 45 years)

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The guessing game

Normal autistic communication is clear, direct, and explicit. We:

- ask questions when we don't understand something

- share our real thoughts and opinions

- tell the truth and expect to be believed

- give a more detailed explanation when a person seems not to understand what we are communicating

In my experience, all of these things are highly valued in academia!
Fantastic environment for an autistic person... once we get here!

The guessing game

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- ask questions when we don't understand something
  → punishment

- share our real thoughts and opinions
  → punishment

- tell the truth and expect to be believed
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- give a more detailed explanation when a person seems not to understand what we are communicating
  → punishment

... across many contexts (mostly outside of my immediate family) and from a very early age!

The guessing game

Long before entering university, I internalized the beliefs that:

- I was only allowed to ask questions in very specific circumstances, and never more than once. → lack of needed info

- I should always follow the other person's lead when deciding what and how much to share, and never say anything that might be controversial. → shallow relationships, isolation

- My words could and would be twisted into unintended meanings, and I would suffer the consequences (so it was safer to just keep my mouth shut). → unmet needs, exploitation, abuse

- Attempts to correct misunderstandings would be met with anger or contempt. → self-blame, shame, situational mutism

The guessing game

None of this was my fault! "Double empathy problem"

Persistent deficits in social communication (DSM-5 2013)

Two-way mismatch in communication styles (Milton 2012)

The guessing game - what can academics do?

Academia is international: most of us already have experience communicating with people from other cultures; making this style the norm benefits "outsiders" of all kinds.

- Be clear and explicit. Don't rely on hints or unspoken messages (even if *you* think they should be obvious).

- Share critical information in writing, and make sure it's up-to-date (program webpages, lab handbooks, shared notes, ...).

- Give context and explain the bigger picture.

- Encourage questions and answer them in good faith (especially those that seem "obvious" to you).

- Be kind! $\rightarrow$ this is Science Kindness Week!

Most autistic people (especially unidentified, and especially those additionally marginalized) already carry communication trauma.

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Practical challenges

Two (intertwined) areas:

- Sensory: processing differences and sensitivities

- Cognitive: information processing and decision making

These vary dramatically from one autistic person to the next, but there are a few general themes.

Illustrate by giving a few personal examples.

Practical challenges

1. Shopping.

Challenging for me because:
- sensory overstimulation (noise; intense visual clutter)
- need lots of time and energy to make each little decision

My strategies:
- small neighbourhood grocery stores
- clothing mostly from hiking shops (less sensory risk)

Disadvantages:
- more expensive, limited selection
- never developed a sense of fashion (ok in physics :)
- difficulty figuring out where/how to acquire uncommon items

Practical challenges

2. Travel.

Challenging for me because:
- navigating unfamiliar environments requires huge amount of processing and decision-making: hard for me to do in real time
- brain doesn't automatically screen out irrelevant details: overwhelming amount of novel information to sort through

My strategies:
- carefully plan routes, itineraries, & meals in advance
- get familiar with new locations using online info/Street View

Disadvantages:
- time-consuming
- incomplete/out-of-date information sources
- unable to do things spontaneously
- very stressful when things don't go according to plan

Practical challenges

3. Driving.

Challenging for me because:
- continuous multi-channel sensory attention, real-time 4-D predictive modelling, and high-precision motor control

My strategies:
- live close enough to walk to campus
- take the bus as much as possible

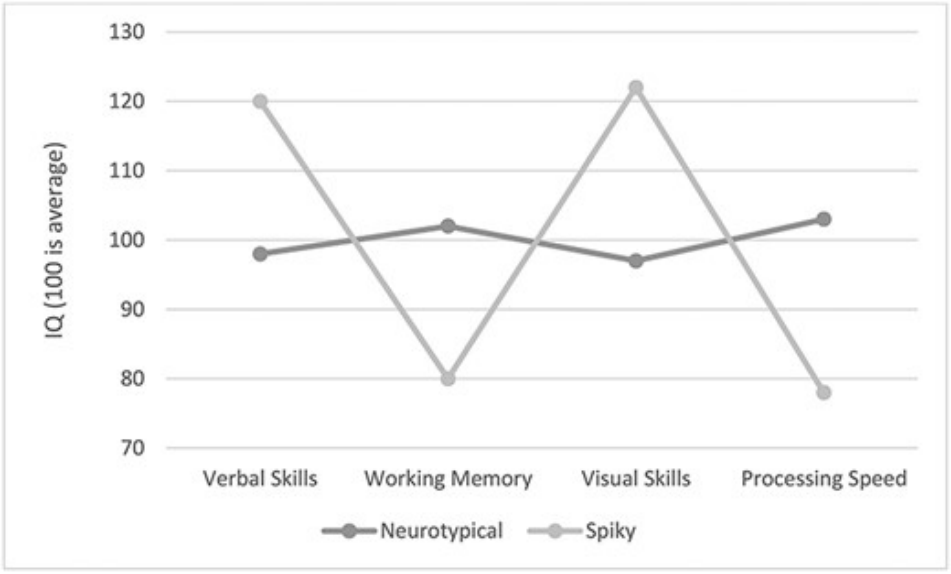
Disadvantages:
- bus unreliable, time-consuming, some destinations inaccessible
- can't transport large/heavy objects
- loss of independence & flexibility
- feel guilty mooching rides off people because I can't reciprocate

Practical challenges

These examples illustrate a so-called "Spiky Profile":

- In most of the population, skill in one area (like academics) can be assumed to indicate general competence in others.

- But autistic people often have a much larger variance between their strengths and their weaknesses: the "spiky profile".



[Stimpunks Foundation]

Very difficult to understand when you don't know you're autistic!

Practical challenges - what can academics do?

- Strive to maintain a peaceful and predictable working/learning environment: reduce stress and preserve our capacity for necessary "difficult" things. (Advance notice of changes helps!)

- Allow for flexibility when designing program requirements and be explicit about what options are available (can everyone tolerate the noisy poster session? can they travel to the offsite event? what unseen costs are you imposing?)

- Be aware of the possibility of "spiky profiles": assume general competence, but don't make normative assumptions about the details of people's abilities, and don't over-focus on "improving" weaknesses to the detriment of overall progress.

- Groups are stronger than individuals: combine complementary skillsets to support each others' weaknesses.

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Otherness and belonging

Autistic people are on a different neurodevelopmental trajectory than most of their peers.

This leads to a persistent feeling of being different.

- Undiagnosed: "what's wrong with me?"
  $\rightarrow$ tries to hide true self to fit in
- Diagnosed: "this is what's wrong with you!"
  $\rightarrow$ trained like a dog to hide true self to fit in

Problems:
- "Masking" burns tons of energy, leads to poor mental health
- Other kids (and adults!) can still tell $\rightarrow$ bullying, exclusion

Otherness and belonging

At age 6 I was already consciously hiding aspects of my self to avoid being bullied by other kids.

By age 10 I thought my unpopularity was due to enjoying math & science.

Around age 12 I made the only childhood friend (outside my family) whom I retain memories of playing with.

Pulled out of school at age 13 due to intense bullying; started undergraduate degree the following autumn (otherness now explainable by age difference... which I kept mostly secret).

Graduated university with a BSc in physics at age 18, moved away for graduate school, PhD at age 24 (otherness explainable by skipping high school? ... which I also kept secret).

Around age 40 I considered (and discarded) the possibility that I might be a changeling (what am I still hiding???).

Otherness and belonging

University was wonderful: I was surrounded by *actual adults* who treated me with basic human decency!

Entering my research subfield was even better: the first time in my life that I felt like I *fit in* with a community!!

$\rightarrow$ Pressure never to do anything to jeopardize this position (ironic)

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↑ THESE THINGS! ↑

- Presume competence and treat other people with respect.
- Practice *active* inclusion; invite others into friend group.

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Why this subfield in particular? My guesses:
- Small, tight-knit, and highly-international community.
- Awareness of history of subfield (founder-effects on culture).
- Nature of research problems favours hierarchy-free cooperation.

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I've talked about:

- Communication differences and the Double Empathy Problem

- Practical challenges and the "spiky profile"

- Otherness and the importance of genuine inclusivity

Ways forward

In many ways, academia can be the ideal autistic habitat.

- Flexibility in where, when, and how most of our work gets done

- Intense interests and resulting deep expertise are prized

- "Weirdness" and idiosyncracies among faculty tend to be well-tolerated by others (at least historically)

- Campus community usually contains open-minded peers seeking new relationships with people from diverse backgrounds

- Heterogeneity in teaching & research methods partially protected by academic freedom – provides some ability to adapt to sensory & cognitive needs (under threat from corporatisation)

Ways forward

Academia also presents many challenges for autistic people.

- Hidden curriculum; lack of support when key information is inaccessible (one snide comment about "spoon-feeding" can cost a student an entire year) – also applies to junior faculty!

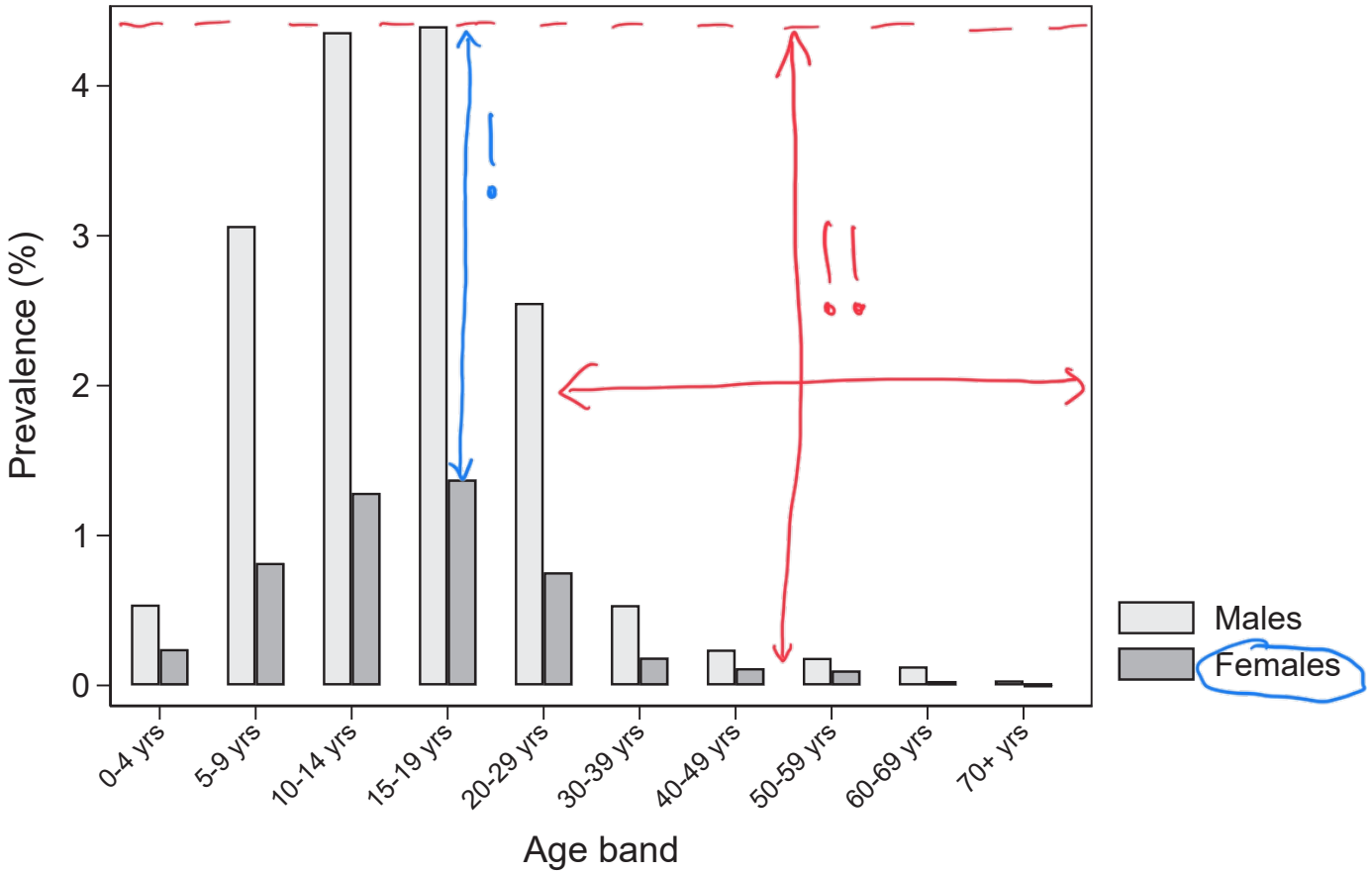
- Hiring/promotion processes rest heavily on "likeability" – documented bias against autistic body language & speech patterns

- Constant pressure to "strive for excellence" in everything + autistic idealism + empathy for students → burnout, especially when upper-admin messaging is taken literally

- Pervasive ableist bias in academia – disabled people dramatically under-represented among faculty; no visible institutional efforts to encourage disclosure/accommodation *for faculty*. Where are the role models for our disabled students?

Ways forward - what can academics do?

Universities cannot rely on formal diagnosis to accommodate!
Universal design approach is the *only* equitable option. e.g. notes



E. O'Nions et al., The Lancet Regional Health Europe 29, 100626 (2023)

Ways forward - what can academics do?

Educate yourself about autistic needs from autistic sources, and talk to others about what you learn

Avoid making assumptions about others' intentions, emotional states, or competence based on their tone and body language

Check your "thin-slice judgements": quick and strong negative first impressions of autistic people based solely on "vibes"

Model inclusive behaviours – especially if you are in a position of (relative) power – and call out bullying when you see it

Actively challenge narratives that frame autistic traits as undesirable (yes, this includes most autism research and therapies!)

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Thank You and Good Luck!

Advertisement:

How to make your research group more inclusive for autistic trainees – an open-access guide (by me)

- 6 pages, $\lesssim$ 15-minute read

- concrete, actionable steps and up-to-date information

- lots of references

- includes a poster

arXiv.org/abs/2410.17929 $\rightarrow$

[end]

Estimating the true number of female autistics – only 1 study!

R. McCrossin, Children (2022) 9, 272 ($N = 1711$ autistic children under 18, diagnoses from single clinic in South East Queensland, Australia, Oct 2014–Apr 2020)

- Key observation by families that second-diagnosed autistic child was easier to recognize than the first

- Assumption that any given child's siblings (if any) are randomly gender-distributed (at rates matching population as a whole)

- Compared gender ratios of single-child or first-in-family diagnoses to gender ratios of second-and-subsequent-in-family (with small adjustment for age-at-diagnosis)

- Quantitative analysis $\rightarrow$ male-to-female odds ratio of 3:4 (girls $\sim$30% more likely to be autistic than boys)

- Most of the gender bias from initial referrals: relies on non-expert spotting autistic traits; heavily influenced by stereotypes

****TITLE & ABSTRACT****

Autistic in Academia

Neurodivergent people are already here: in your courses, labs, research groups, and faculty meetings. Most of us grew up—and many of us remain—unidentified, unaware that the daily barriers we struggle to overcome are not faced by the majority of the population, and those of us who are aware frequently have our needs dismissed or pathologized. In this talk I will reflect on my own experiences as a (formerly) undiagnosed autistic person in academia and use them to introduce some of the simple adjustments that university faculty and staff can make to improve the environment for their autistic students and colleagues.

****BIOGRAPHY****

Heather Logan is a Professor in the Carleton University Physics Department. She has published over 60 journal articles on Higgs physics, collider physics, and physics beyond the Standard Model and served as a theory convener for the Higgs Working Group at the Large Hadron Collider. After experiencing burnout following a term as Chair of her department, she was formally diagnosed as autistic at the age of 47. Since then, she has begun advocating for neurodiversity and disability rights in academia, and recently released a guide on making research groups more inclusive for autistic people.

Direct link to pdf of guide: https://arxiv.org/pdf/2410.17929