

Not Just about the Boys!

Male Gender Bias in Autism



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AUsome Consulting

Christine A. Jenkins, Thursday, January 29, 2026, 1:30 p.m.
<https://tinyurl.com/cjAUsome>

Overview of this talk

- Who is here: online please let us know
- Why we should all care about Male Gender Bias
- Women's health in general
- Some autism research history
- Gender bias in autism today—those RRBs
- The future of research: Call to action



Why we should care

- Underrepresentation in studies: not enough analysis compared to males
- Doubt that so many women/AFAB are autistic
- Women denied a referral for diagnosis if they are good at masking (camouflage); this leads to poorer mental and physical health, stigma, burnout
- Voices missing in the conversation, meaning they don't get supports and services they deserve



Is this who you think of? If not, why not?

Time to shatter the
autism stereotypes.

Credit: PANDA— Promoting Autism
Neuro Diversity Awareness, UK
Intersections are not examined



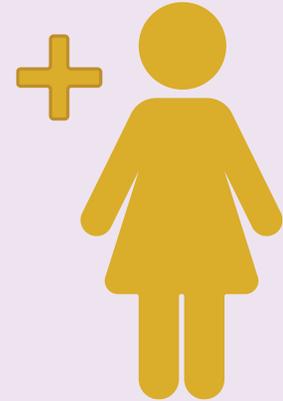
Women's health in general

- Understudied and underfunded
- Misdiagnosed or undiagnosed conditions, which may present differently or carry stigma
- Studies designed by men for men
- Intersecting identities not considered (race, ethnicity, class, disability, age)



Women's health in general

- Lack of sex-disaggregated data (study data collected and analyzed separately based on gender difference)
- Symptoms that look different in women (heart attacks for example) and conditions that are female-predominant
- Examples are estrogen cream vs. Viagra studies. Low risk of cancer caused by cream, 'black box' warning just removed in U.S. not Canada.
- Fibroids in 80% of women, yet get 0.03% of health research funding
- Crash test dummies only recently redesigned to suit female makeup: not small men



Women's health in general

- Medications not required to be tested on women
- Canada did not mandate women be included as research subjects before 1997. The UK just did!
- Senator Danièle Henkel's new bill S-243 National Framework for Women's Health, thewhc.ca
- Dr. Gillian Einstein in Toronto doing cognition studies at einsteinlab.ca



Women's health—Call to action

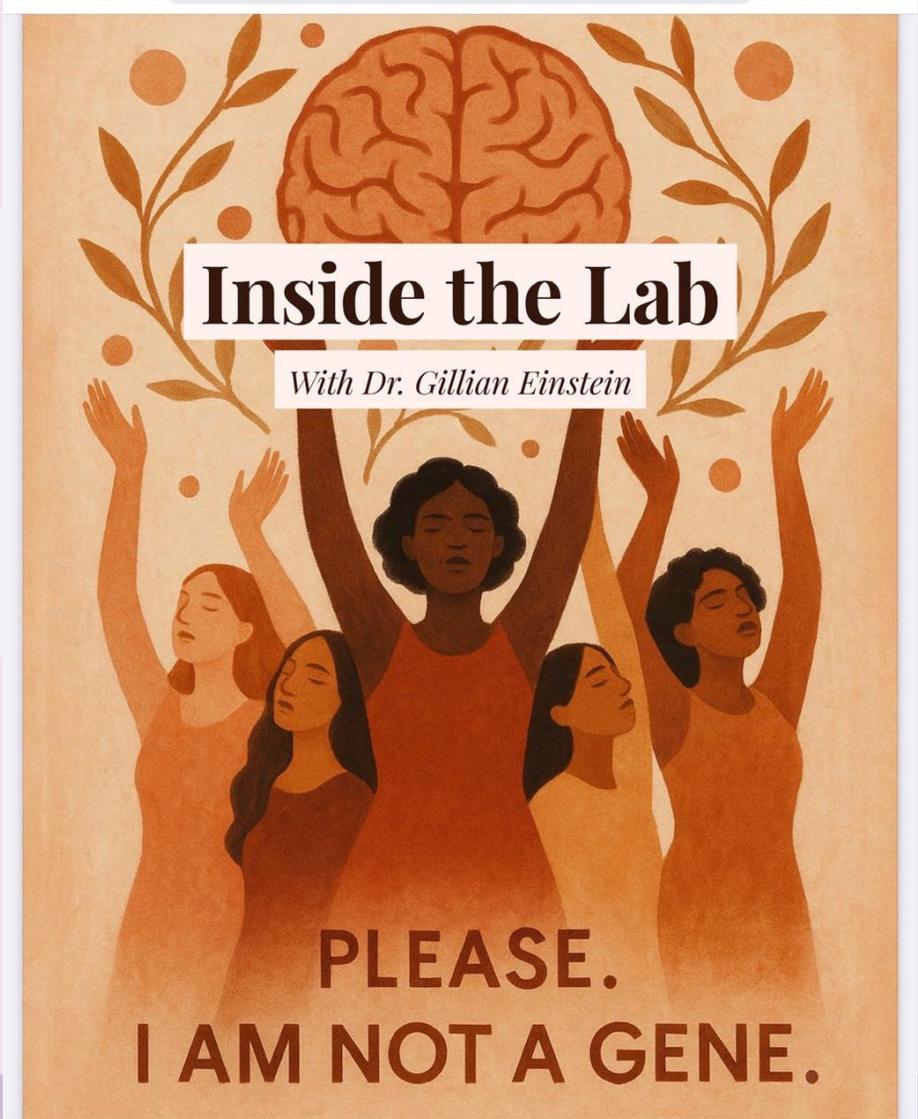


Bill S-243 also recognizes that preventative care for women across the lifespan should be prioritized.

Why this matters:

Over 15 years of funded projects by the Canadian Institute of Health Research (CIHR), only **<5% focused on the top 11 global health burdens affecting women**¹.

This bill opens the door for more attention to these health burdens **across the lifespan**, including cardiovascular disease, depression and anxiety, dementia, musculoskeletal disorders, and cancer.



Some autism research history



- Early 1900s tied to mental illness, schizoid disorder or childhood schizophrenia. Eugen Bleuler's term 'Autismus'
- Kanner focussed on males, so did Asperger. Anni Weiss and her future husband Georg Frankl came from Asperger's clinic in Vienna to work with Kanner, who only published on 4 boys in 1943. The Frankls were among 200 refugee physicians and academics Kanner helped get out of Nazi-occupied territories.



Some autism research history

- Lorna Wing discussed sex ratios in 1981 and was first to propose a ‘camouflage hypothesis’ wherein girls copied and performed social behaviors to blend in.*
- Adults could only be assessed starting in the DSM-III-R in 1987 after the change from ‘infantile autism’ (1979) to the all-ages ‘autistic disorder’. The categories were broadened again in 1994 with DSM-IV. I was assessed using DSM-IV-TR.



*Wing’s paper cited here—she also proposed what we now know as the autism spectrum with Judith Gould in 1979. *Autism and Masking* by Sedgewick, Hull and Ellis, JKP, 2022.



Some autism research history

- The first researcher was ignored—for various reasons! Grunya Efimovna Sukhareva studied boys and girls.
- This is the 100th anniversary of her first paper, translated from Russian into German and published in a journal read by leading psychiatrists in 1926. The 2021 article below still omits her. It is co-written with the creator of the ADOS, Dr. Catherine Lord.



<https://pmc.ncbi.nlm.nih.gov/articles/PMC8531066/> Nicole E. Rosen et al *The Diagnosis of Autism*



Enter Grunya Sukhareva.

1925.

A Ukrainian Jewish psychiatrist publishes a clinical description of autistic traits so accurate it still outshines Kanner.

Two decades before him she mapped everything we now call autism with

- more nuance
- more precision
- more humanity.

And the world shrugged.

Paula Jones
MSc on
Linkedin



Some autism research history (cont.)



A century later, is it not more accurate to call Autism instead Sukhareva Syndrome?

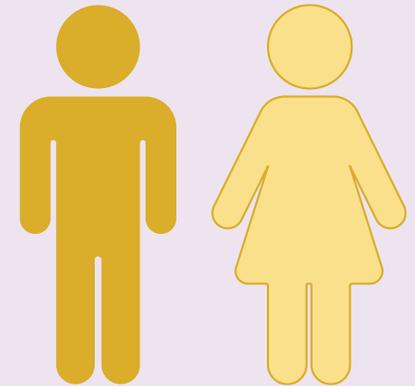
Груня Сухарева is transliterated in French Grounia Soukhareva, in German Grunja Ssucharewa, and in English Grunya Sukhareva. 1928 photo. She and Kanner both died in 1981 but she was only well known in Russia.



Gender bias in autism today

Why does getting this right matter?

- Women and AFAB are ignored, invalidated, underrecognized, dismissed, misdiagnosed and/or underdiagnosed (overshadowing)
- Because of the predominant male autism stereotype, some don't recognize themselves in the criteria, especially section B of the DSM-5



Restricted and Repetitive Behaviors and Interests (abbreviated RRB, alternately RRIB, RRBI)

- Criterion B of the diagnostic assessment process is harder to achieve in AFAB.
- The criteria are still slanted towards male or externalizing presentation and the 'unusual' use of objects.
- The addition of C at the bottom has helped, as it allows for excess social demands and failure of masking
- A skilled assessor is needed to identify someone who collects ideas instead of objects, has imaginary friends, etc. We need to train these.
- Consult *Is This Autism?* a recent text on the internalizing presentation



Restricted and Repetitive Behaviors (RRBs) are often the reason AFAB don't meet the cutoff

See particularly **B3**:

Highly restricted, fixated interests... attachment to or preoccupation with unusual objects as reported by caregivers

Circumscribed interests are shortened to CIs, fixed interests to FIs

DSM-5 autism criterion B

#	Description	Required
B	Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):	2/4
1	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).	2+
2	Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).	2+
3	Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).	2+
4	Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).	2+

DSM-5 autism criteria C–E

#	Description	Required
C	Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).	1/1



RRB Chart based on 2007 list

Table 1 Operational definitions of restrictive and repetitive behaviors (RRBs)

From: [Restricted and Repetitive Behaviors in Autism Spectrum Disorders and Typical Development: Cross-Sectional and Longitudinal Comparisons](#)

Item description	Original source(s)	Modifications made to conceptualization	Examples
Arranges objects in rows/patterns/stacks	RBQ-2, <u>RBS-R</u>	Stacking of toys added. To score this item must occur across 2 + objects or for a significant amount of time	<u>Arranges toys cars in a line</u>
Fiddles with objects/uses objects in repetitive and non-functional manner (e.g. spins, bangs, flicks)	RBQ-2, <u>RBS-R</u> , DORBA	N/A	Flicks dolls eyes repeatedly Pushes one button on a pop-up toy repeatedly
Spins/rocks/paces/jumps (whole body movements)	RBQ-2, <u>RBS-R</u> , DORBA	Groups together three behaviors of spinning, rocking and pacing	Rocks back and forth Spins around in circles
Unusual hand/finger mannerisms	RBQ-2, <u>RBS-R</u>	Bouts/bursts of behaviors coded if these behaviors occur in close succession. e.g. individual "flaps" are not scored whereas "bouts" of flapping are	Flapping Flicks fingers
Unusual interest in smell/touch/sounds	RBQ-2, DISCO, <u>RBS-R</u>	Groups together smell, feel and sounds	<u>Rubs toys against face for tactual sensation</u>
Sensitive to sounds or touch	DISCO	Touch added in addition to sounds	Covers ears in response to sounds Child "reacts" to parent rolling toy car on their leg
Touches part of body repetitively	RBQ-R	N/A	Repeatedly touches back of hand to side of face
Looks at objects at certain angles/visually inspects/brings objects close to eyes	DISCO, <u>RBS-R</u>	Brings objects close to eyes added in addition to angles	<u>Child brings toys to eyes, inspecting certain aspects of toys (e.g. car wheels)</u>
Bangs/taps/shakes/throws objects	Watt et al. (2008), Barber et al. (2012)	Shaking and throwing added in addition to bangs and taps	Taps toys with finger repeatedly Bangs toys together
Mouths objects repeatedly	Watt et al. (2008), Barber et al. (2012)	Modified from 'licks objects or surfaces'	Indiscriminately mouths toys
Repetitive/scripted language and/or intonation atypicalities	DORBA		Says phrase/word repeatedly

New DARB or Dimensional Assessment of RRBs refines this (2022)

<https://www.thetransmitter.org/spectrum/new-tool-aims-to-capture-full-breadth-of-repetitive-behaviors/>

RBS-R = Repetitive Behavior Scale-Revised
RBQ-2 = Repetitive Behaviors Questionnaire 2

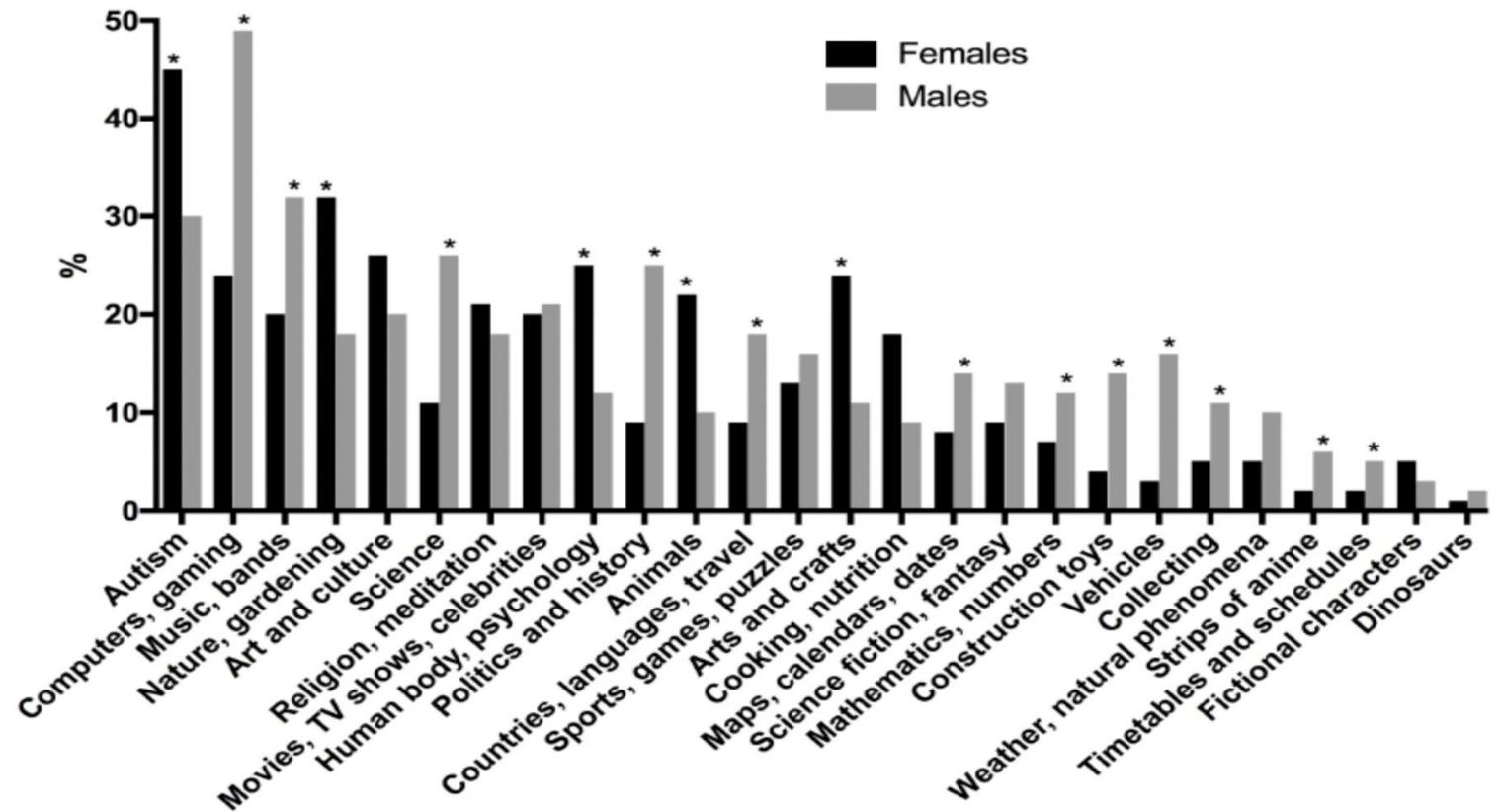


Restricted and Repetitive Behaviors and Interests (abbrev. RRB, alternately RRIB, RRBI)

Important paper by Rachel Grove and team in 2018 on Special Interests showed the disparity between men and women. Autism, computers, gaming and music were most common among both, but **women** were more likely than men to favour autism, nature & gardening, psychology, animals, and arts & culture.

<https://pubmed.ncbi.nlm.nih.gov/29427546/>

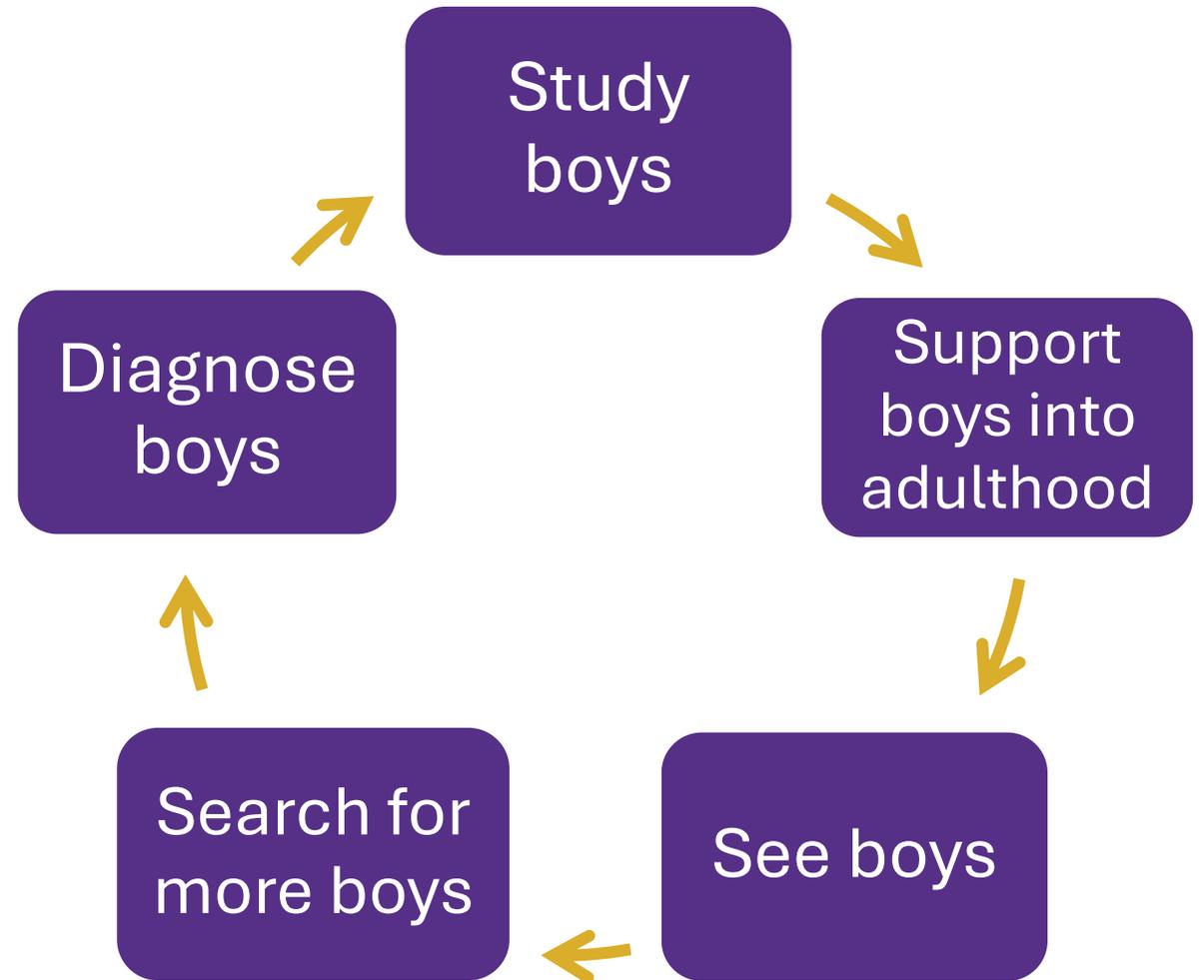
Figure 1. Special interest topics by sex (n = 443)



Note. * Special interest topics in which men and women differ significantly in their likelihood of endorsement ($p < 0.05$)



Gender bias in autism today



Gender ratio and UK stats from wearemorehuman Last Canadian study I saw claimed 3.9 : 1 MFR

A Global Waitlist Crisis

COVID was the catalyst for burnout, mental health crises and a sudden surge in demand for adult autism and ADHD diagnosis. The majority of those waiting are women.

3-10:1

Three times as many boys and men [↗](#) are diagnosed with autism or ADHD, because of harmful sex stereotypes. This rises to 10:1 [↗](#) for autistic girls without a learning disability. Gifted girls are overlooked.

80%

Recent estimates suggest that 80% of autistic girls and women [↗](#) have not been diagnosed before they turn 18. ADHD girls who don't fit the naughty schoolboy persona are equally missed.

30-year gap

The average age of diagnosis for boys is 7 for ADHD [↗](#) and 4 for autism [↗](#). For women? According to our data, 38 and 39. This is thirty years too late.



Gender ratios in Canada—what are they really

- In Canada we really don't know, all based on official diagnoses
- The latest stat I could find was 3.9 : 1 MFR based on age 1-17
Source: Public Health Agency of Canada as of 2019: 1 in 32 boys and 1 in 125 girls This averages to about 2% of the youth population but note this data is nearly 7 years old
- 48% of children and youth had co-existing learning disability compared to 4.8% of the general population aged 1-17
- We are not counting adults. In 2022 StatsCan calculated disabled persons 15+ with developmental disability, which *could* include autism, at 1.5%, an increase from 2017 of 0.4%

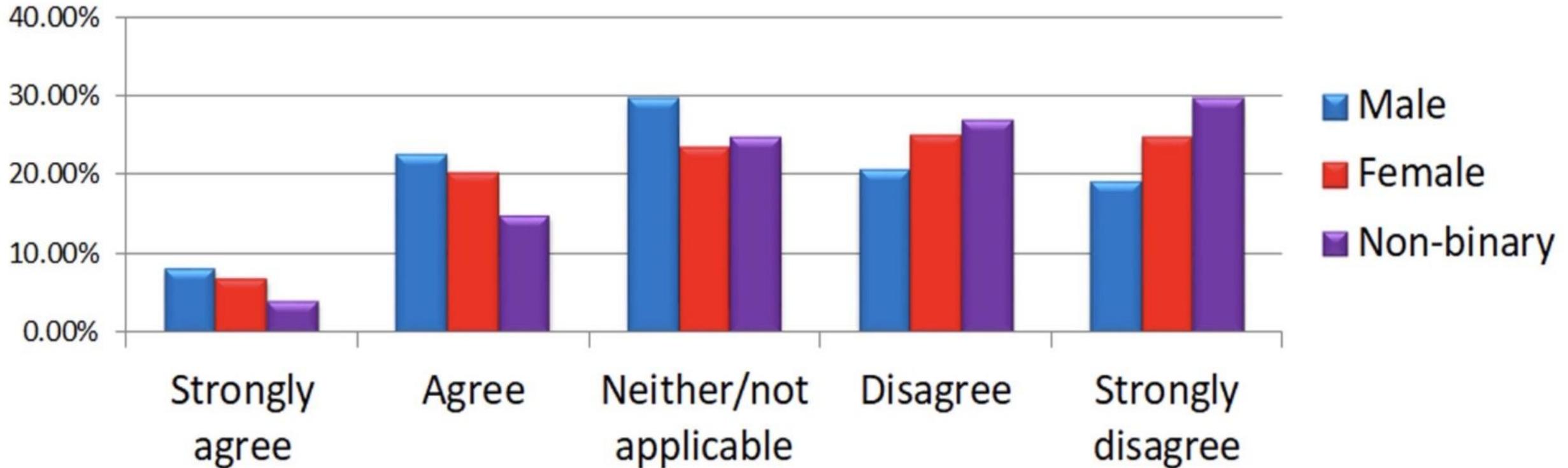


AutisticNotWeird 2022 survey

7491 autistic respondents, NA may include self-Dx

autisticnotweird.com

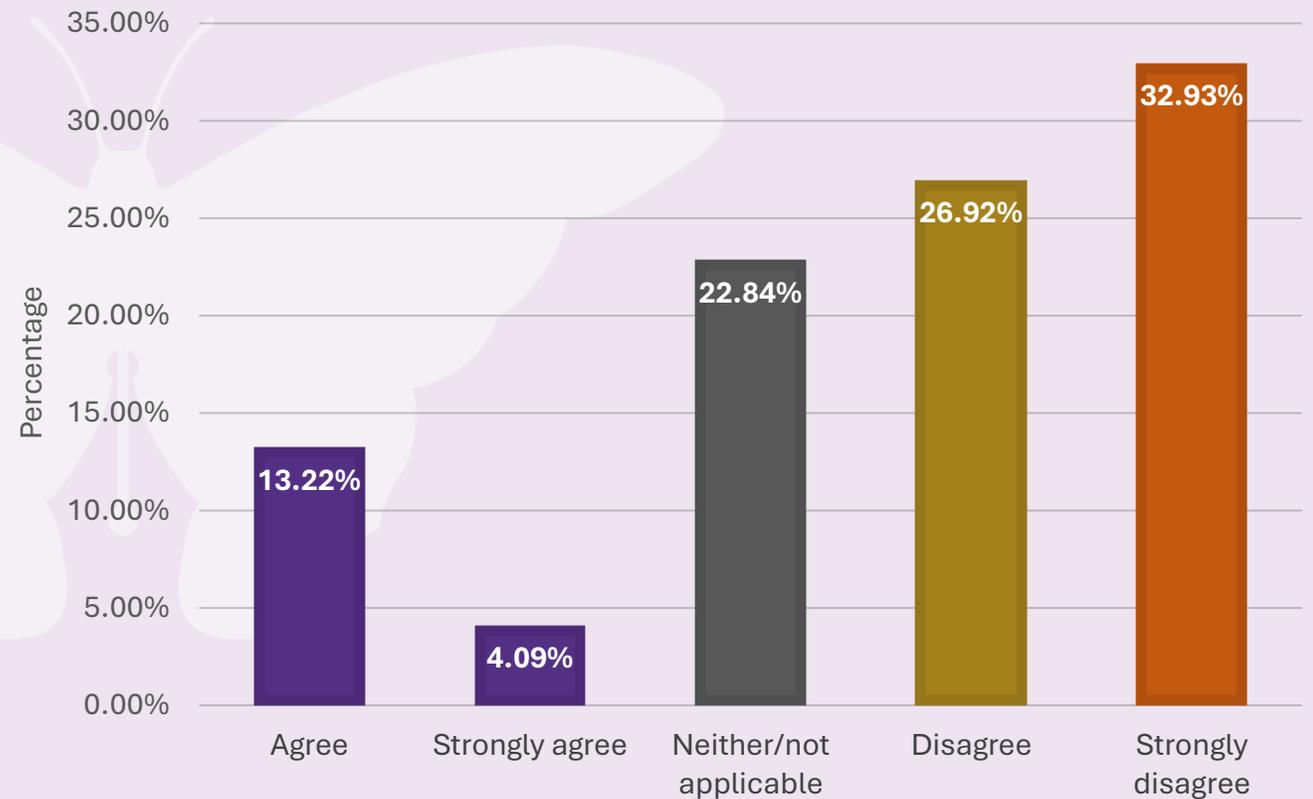
“I found the diagnostic pathway accessible.” [Autistic respondents by gender]



Canadian Autistics in 2022 ANW survey, same question N=378

**Limitations: we don't know
where they got diagnosed
(U.S.?) or how long ago
The 50+ group was too small
to draw a conclusion
SD + D = 60%
Only 17% agreed or strongly
agreed path was accessible**

I found the diagnostic pathway accessible (Canadian, all ages)

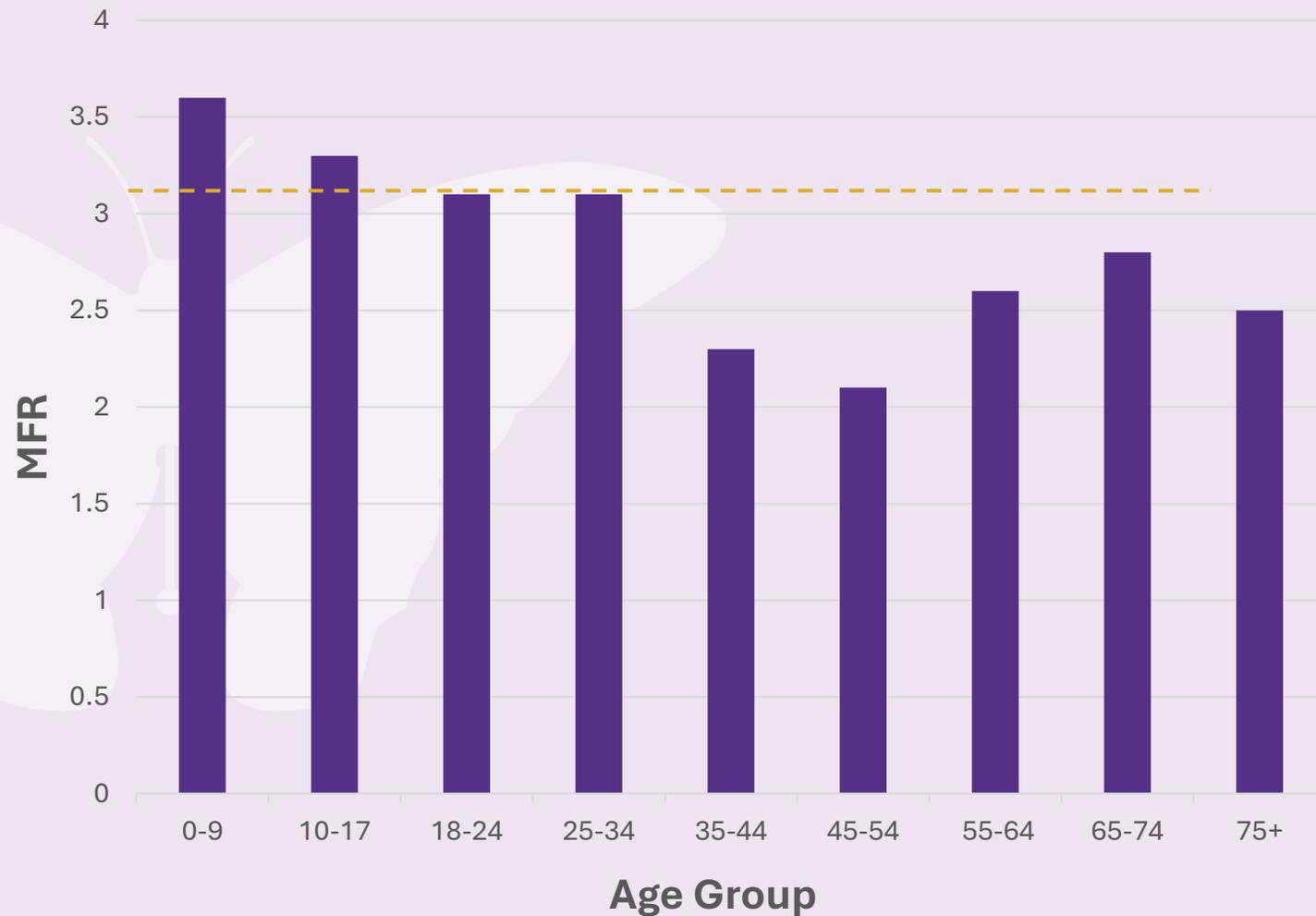


Number of people with autism known to GPs, NHS 2022

All ages average
3 : 1



Male to Female Ratio (MFR) in diagnosed patients recorded by GPs



Number of people with autism known to GPs, NHS 2022

Total recorded 75.9% M 24.1% F
or 3 : 1 MFR

Only 3.2% of females diagnosed past 54

Limitations:

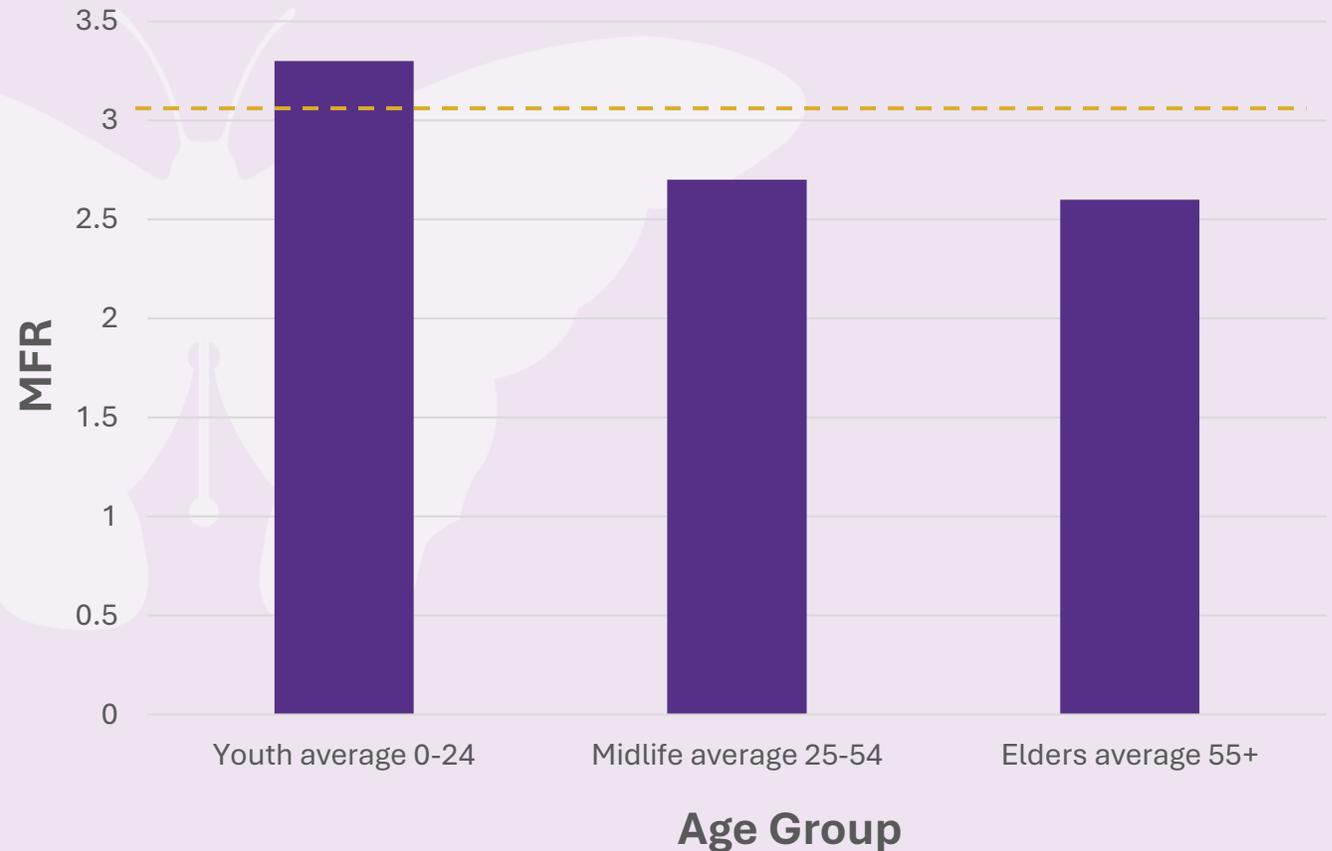
We don't know when each person was originally diagnosed, only that they were recorded by the time they reached that age group

Age 55+ MFR

2.7 : 1



Male to Female Ratio (MFR) in diagnosed patients recorded by GPs



What about the new UK claim of overdiagnosis?

Oh my god. ~~Everyone~~
~~has ADHD/autism now.~~
How did we let so many
people down?

Ellie Middleton, UK author and recent Autistic Barbie spokesperson



Consequences of incorrect/late identification of AFAB

- No true picture of Autistic adults and needs
- Many are suffering and some are suicidal
- Services not provided or not tailored to need
- Underrepresentation of AFAB in autism research
Some of even the most recent studies discount self-assessment, unfortunate when official diagnosis is hard or impossible to obtain. Adult wait lists are long and the diagnosis cost is high.



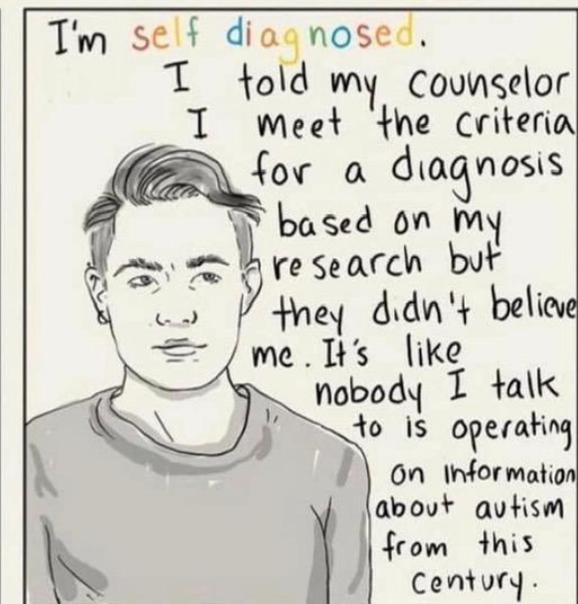
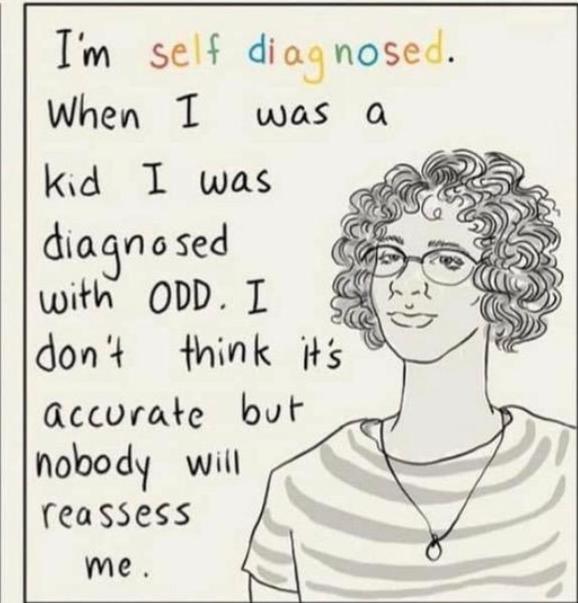
The hard truth about self diagnosis/identification

Happy Hands, Saskatchewan, Canada

- Diagnosis not affordable or even inaccessible \$3000+ in Canada
- Overshadowed by another label which may not be removable
- Fear of discrimination at work or as a parent
- Not believed at assessment because too social, made eye contact, gestured, researched presentations on internet



DELA MARIA '20



Gender bias in autism today

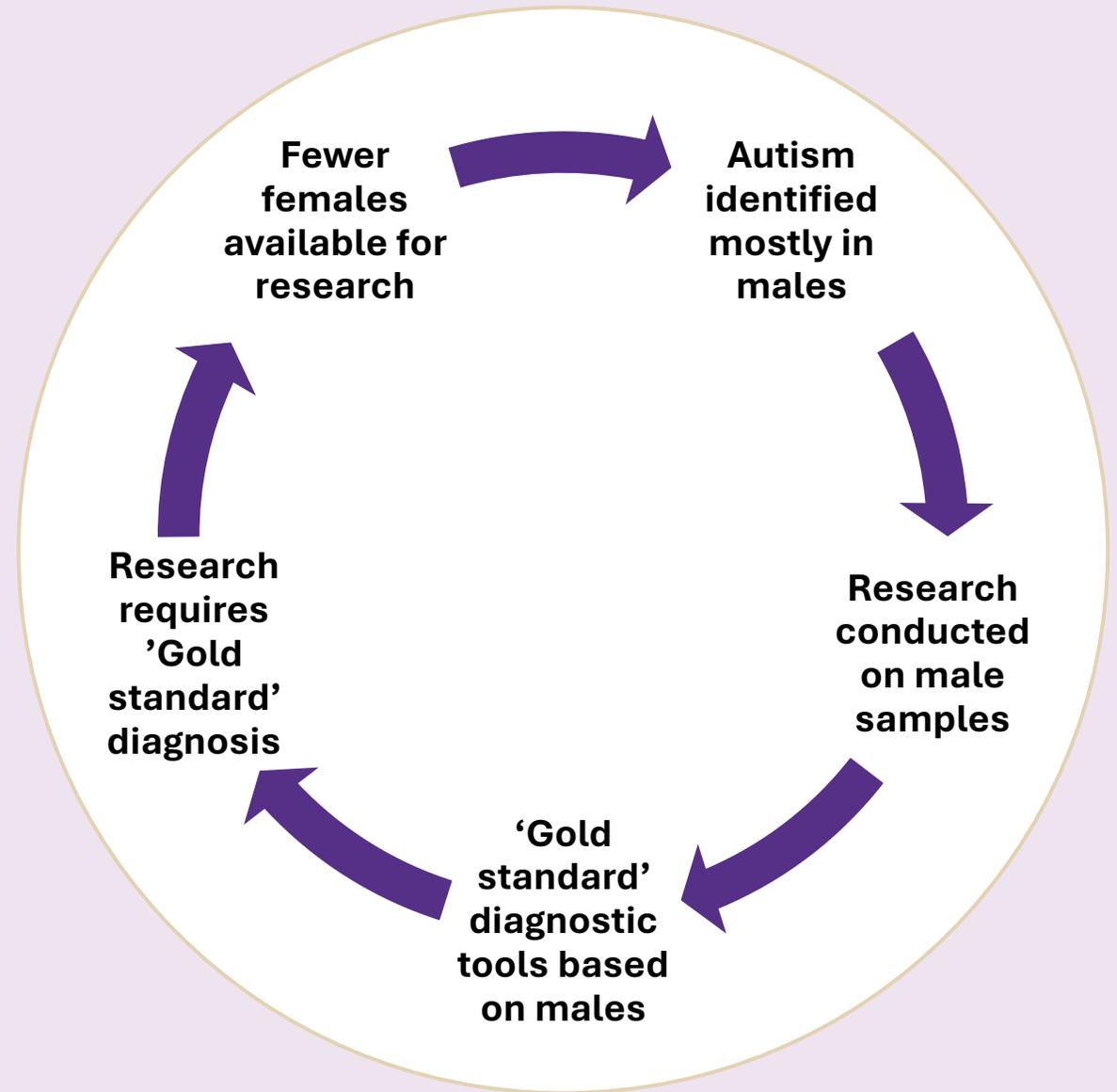
**People are not
faking Autism—
They've been faking the
rest of their lives!**

Christine A. Jenkins



INSAR Conference presentation by Allison Ratto,

Children's National Health
System, Washington DC, 2019



The future of research: Call to action



- Always include the intense interests of girls/non-binary in RRB lists. They may ‘seem’ more typical.
- Educate clinicians on the internalizing presentation so they don’t miss girls and non-binary people.
- Don’t assume that all are assessed by age 18. 80% of AFAB are not. Look at overlaps with disordered eating and/or ADHD (diagnostic overshadowing). Be curious.
- Insist on inclusion of non-males in studies, their analysis and dissemination of results.



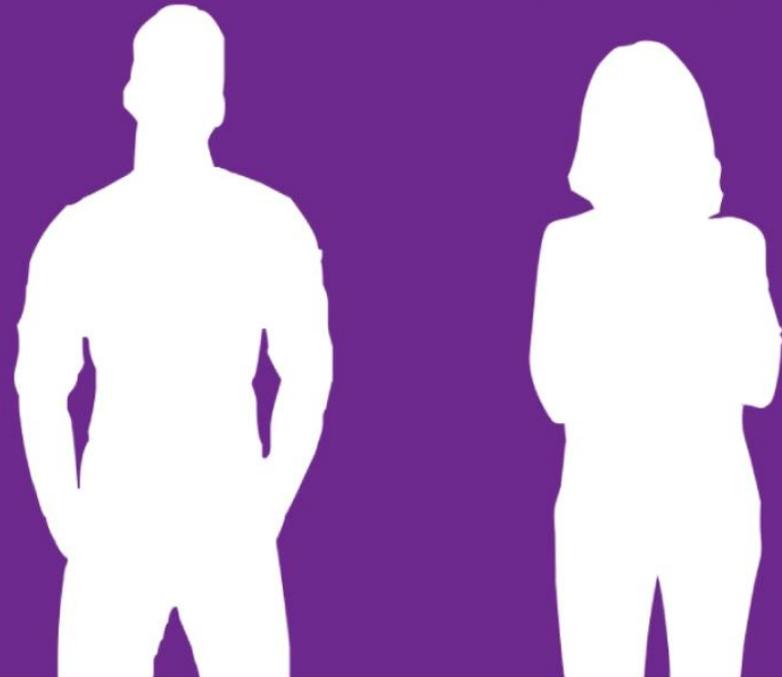
Join womenmind at CAMH

Guidelines for including women in clinical mental health research were only published in 1997. The Centre for Addiction and Mental Health calls us all to demand research that includes all women and AFAB, with no one left behind.

<https://www.camh.ca/en/get-involved/join-the-cause/womenmind>

Women were routinely excluded from clinical trials until 1997 in Canada.

Treatments were based on men, tested on men, then prescribed to women.



Demand women be included
SIGN UP NOW

camh
FOUNDATION



Christine Jenkins tinyurl.com/cjAUsome

Recruitment poster for Bridging the Silos co-production

A commission from an Autistic artist

Colourful illustration by
artist **Mae Greyfrost** of a
diverse group of autistic
people, encircled by flowers,
with a gold infinity symbol for
Neurodiversity below.

www.AutisticMenopause.com
Bridging the Silos



Representation looks like this: A hopeful future

Neurodivergent actor Taylor Dearden on HBO Max's medical drama *The Pitt* plays autistic coded character Dr. Mel King. Reviews by Autistic author Sarah Kurchak in *TIME*: "...it's encouraging to know that some people out there can see us as human." Season 2 just launched.



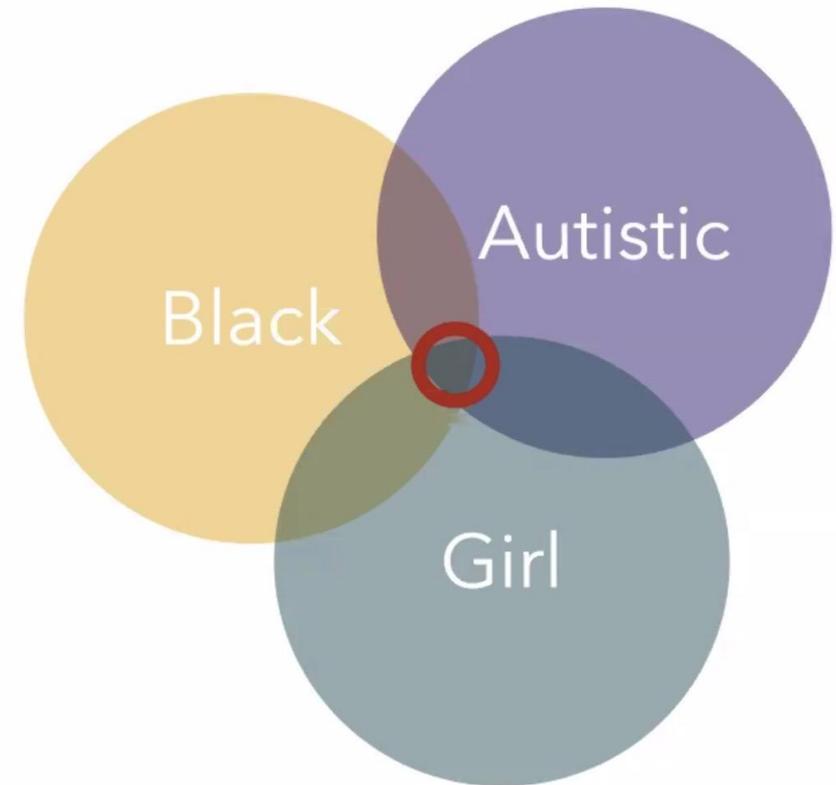
Dr. Melissa King, a.k.a. Mel, on *The Pitt* Courtesy of Max



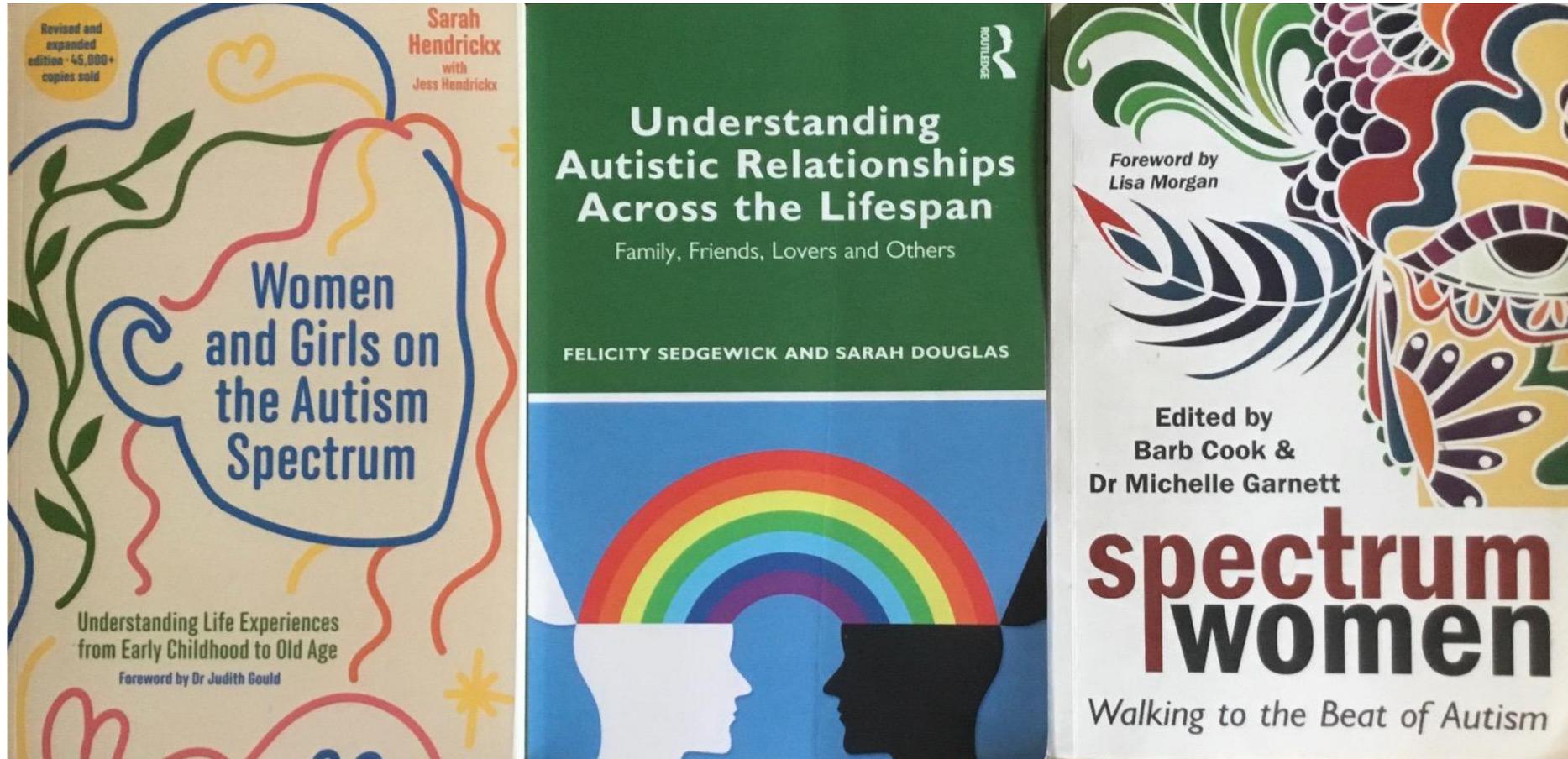
Representation looks like this: A hopeful future

Intersecting identities can make autism recognition harder. Graphic by Marcelle Ciampi aka Sam Craft, one of my co-writers in the book *Spectrum Women* (2018). Multiple marginalization is a topic for another talk...age, class, Global Majority folk.

Allows for the analysis of how these systems of oppression - represented by racism, sexism or gender-based oppression, and ableism - work in concert in ways that each system on its own cannot be quantified.



Good textbooks to refer to by Autistic folk



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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