Exploring Sex And Gender And Their Influence On Recognizing Autistic Characteristics

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Autism ONTARIO
see the potential voir le potentiel

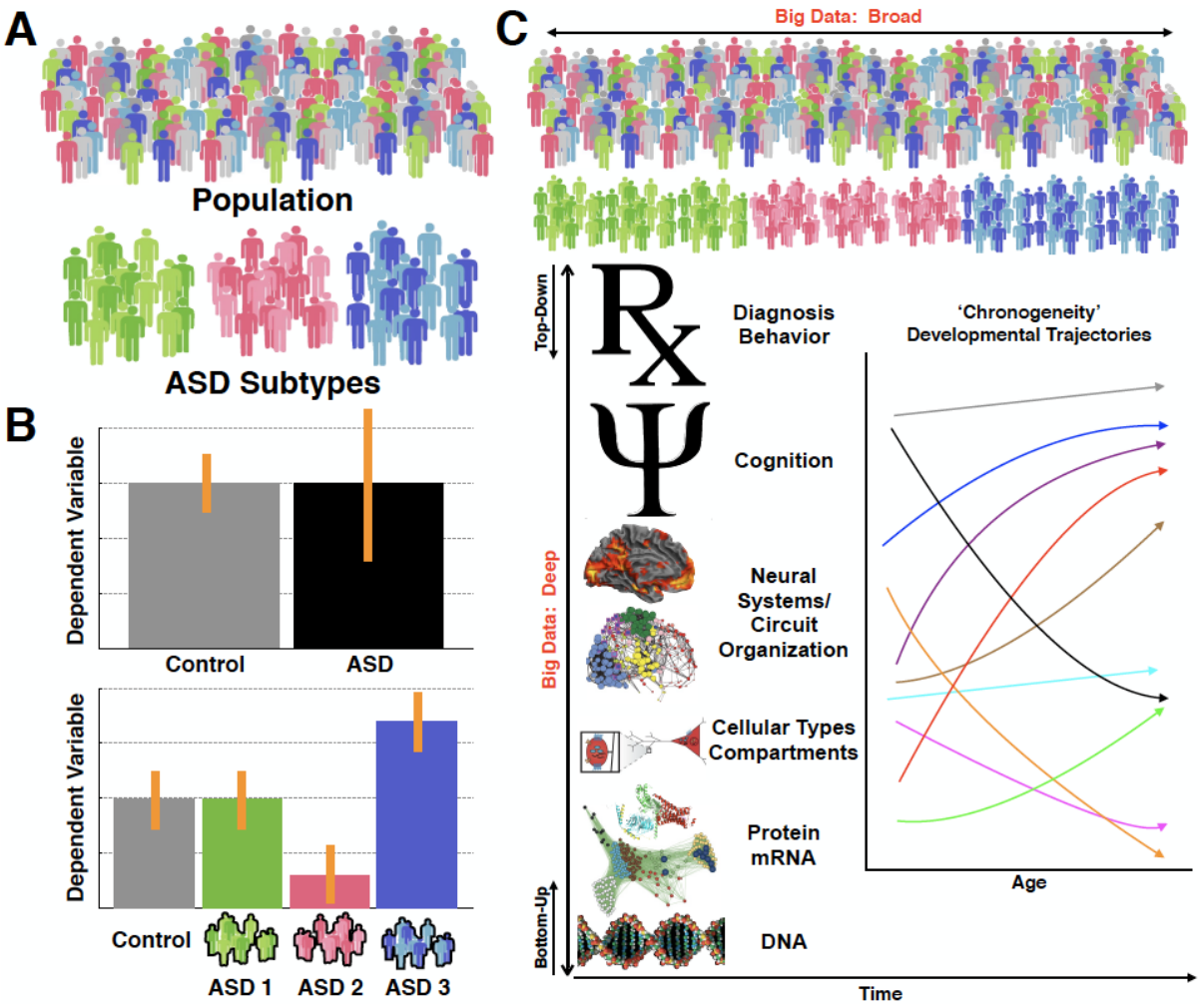
camh
mental health is health

In this webinar

We will discuss:

- how sex and gender may influence the behavioural characteristics of autism
- what we have learned from research and the perspectives of girls and women themselves on their experiences

Autism is heterogeneous



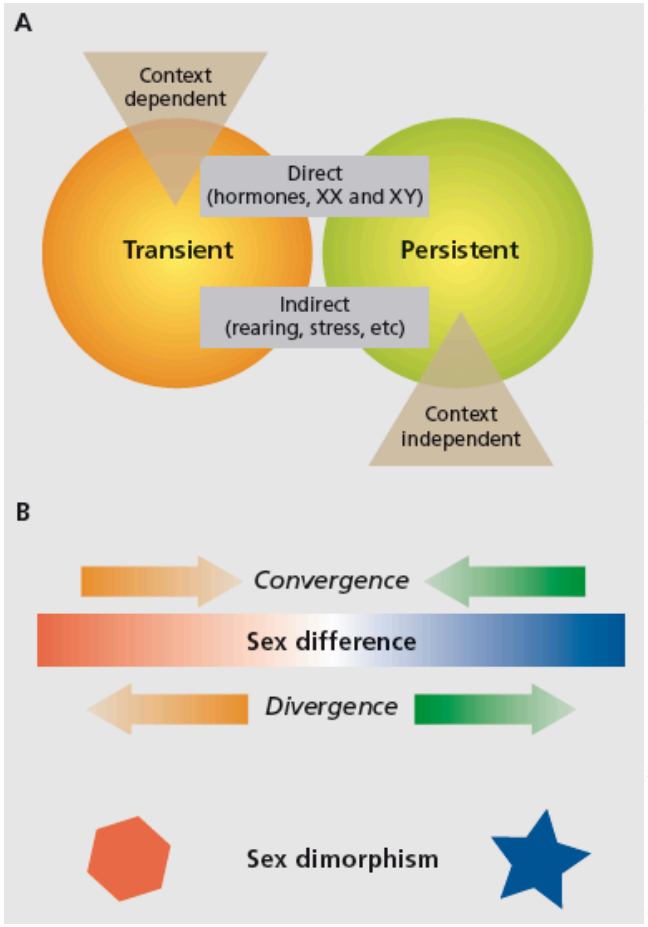
'Autism Spectrum' includes a highly heterogeneous group of people.

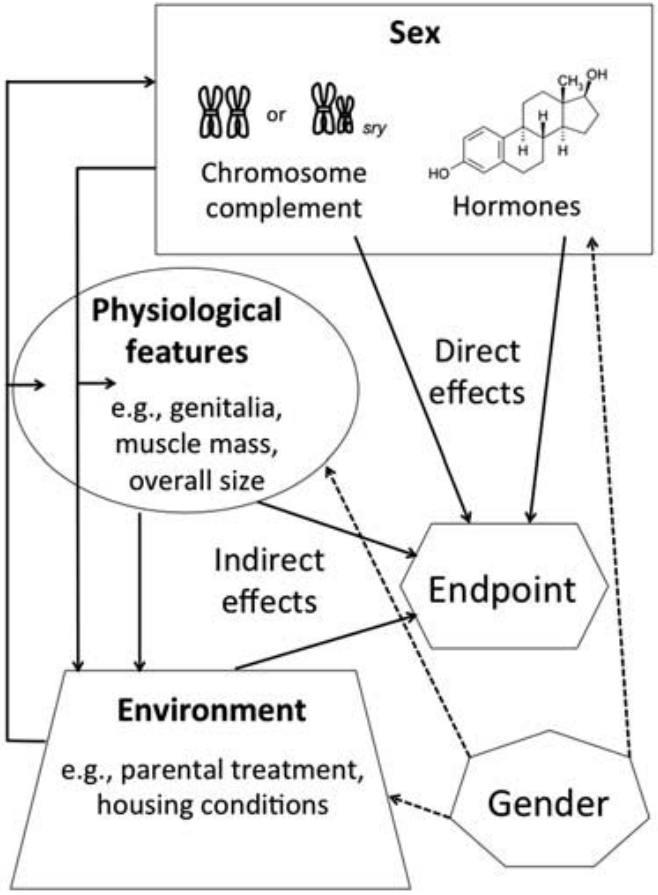
The 'Duality of Autism' – a medical condition entailing disability AND one form of human variation.

Goal of Support – recognizing BOTH identity and disability – alleviating distress and improving adaption and wellbeing.

Lombardo, Lai & Baron-Cohen, 2019, *Molecular Psychiatry*
Lai et al., *in revision*

Sex ≠ Gender





Multi-component constructs

Not always binary

But: current research mostly treat them as a single, binary variable…

Joel & McCarthy, 2016, *Neuropsychopharm*
McCarthy, 2016, *Diaglogues Clin Neurosci*
Cost et al., *in preparation*

Autism is a male-predominant condition – *Is it?*

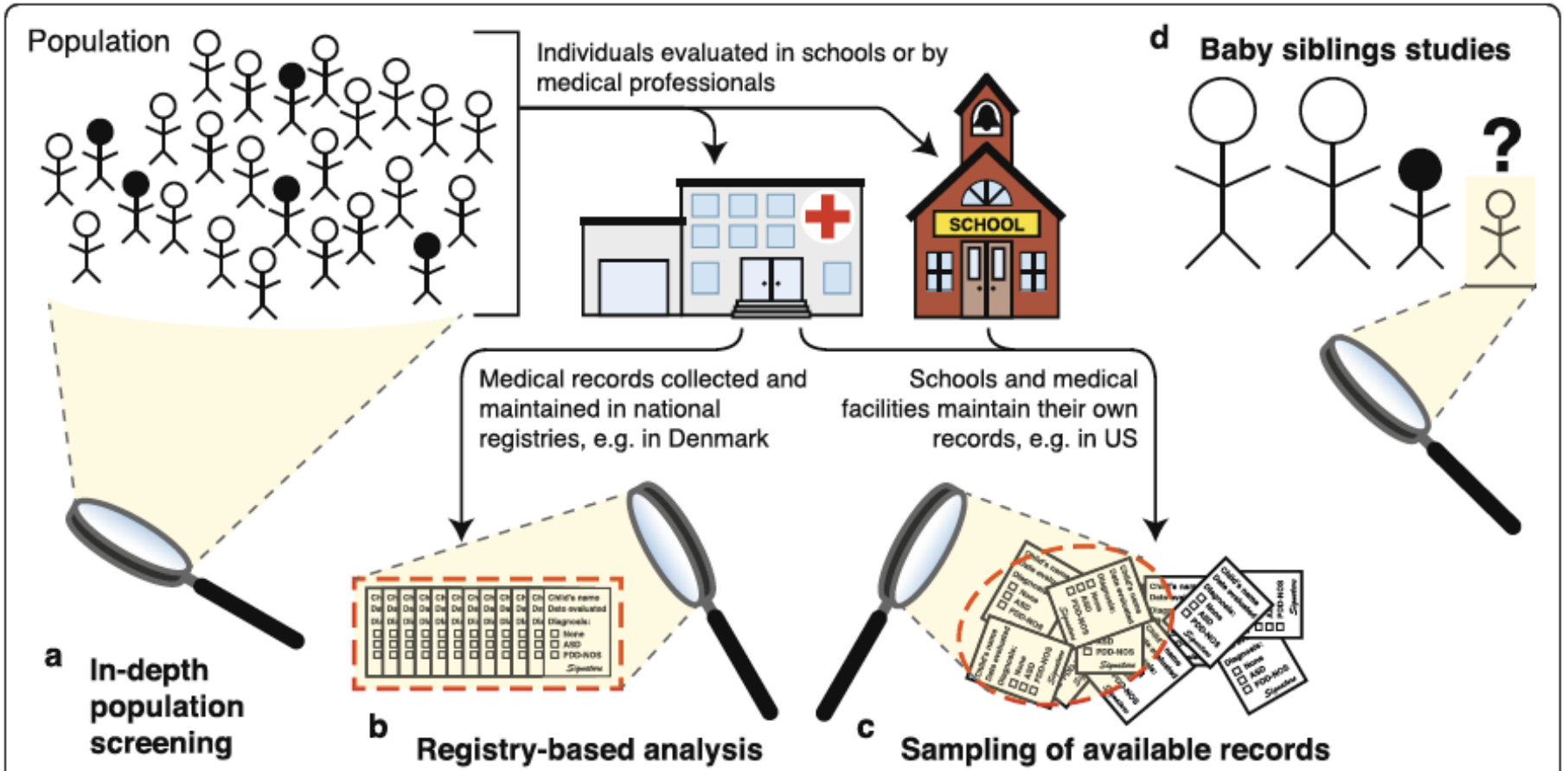
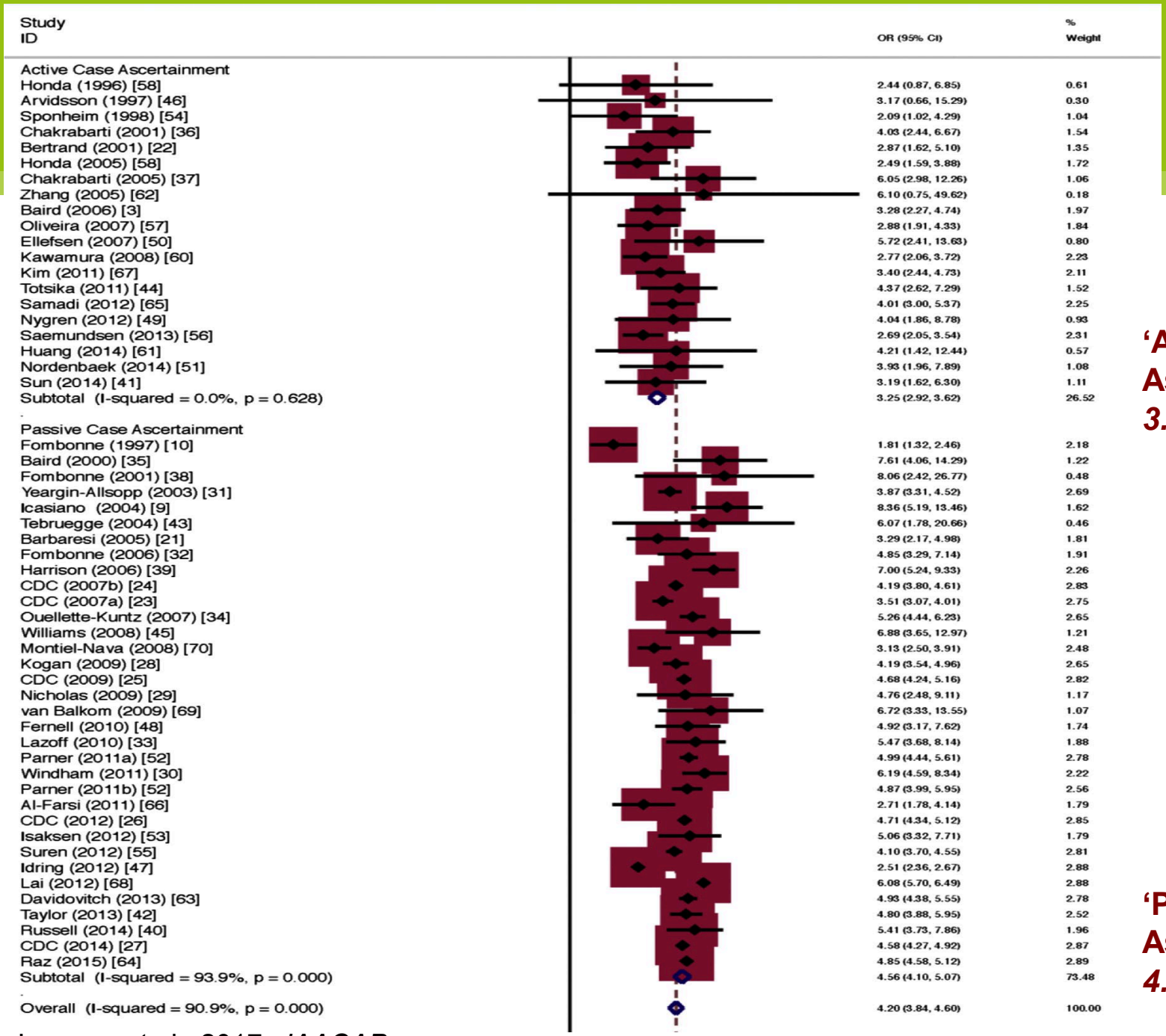


Fig. 1 Approaches used to estimate ASD prevalence and male:female ratio. Different approaches may identify different overall, and sex-specific, prevalence rates. **a** Screening populations in full, irrespective of existing diagnostic status. **b** Analysis of records in existing, standardized registries. **c** Collating and/or sampling and interpreting available records from scholastic or medical records. **d** Baby siblings studies, where researchers prospectively monitor the younger siblings of autistic children for recurrence of ASD and other traits of interest. *Filled figures* represent individuals with ASD

Werling et al., 2016, *Biol Sex Diff*



'Active' Ascertainment ***3.25*** **(2.92 – 3.62)**

'Passive' Ascertainment ***4.56*** **(4.10 – 5.07)**

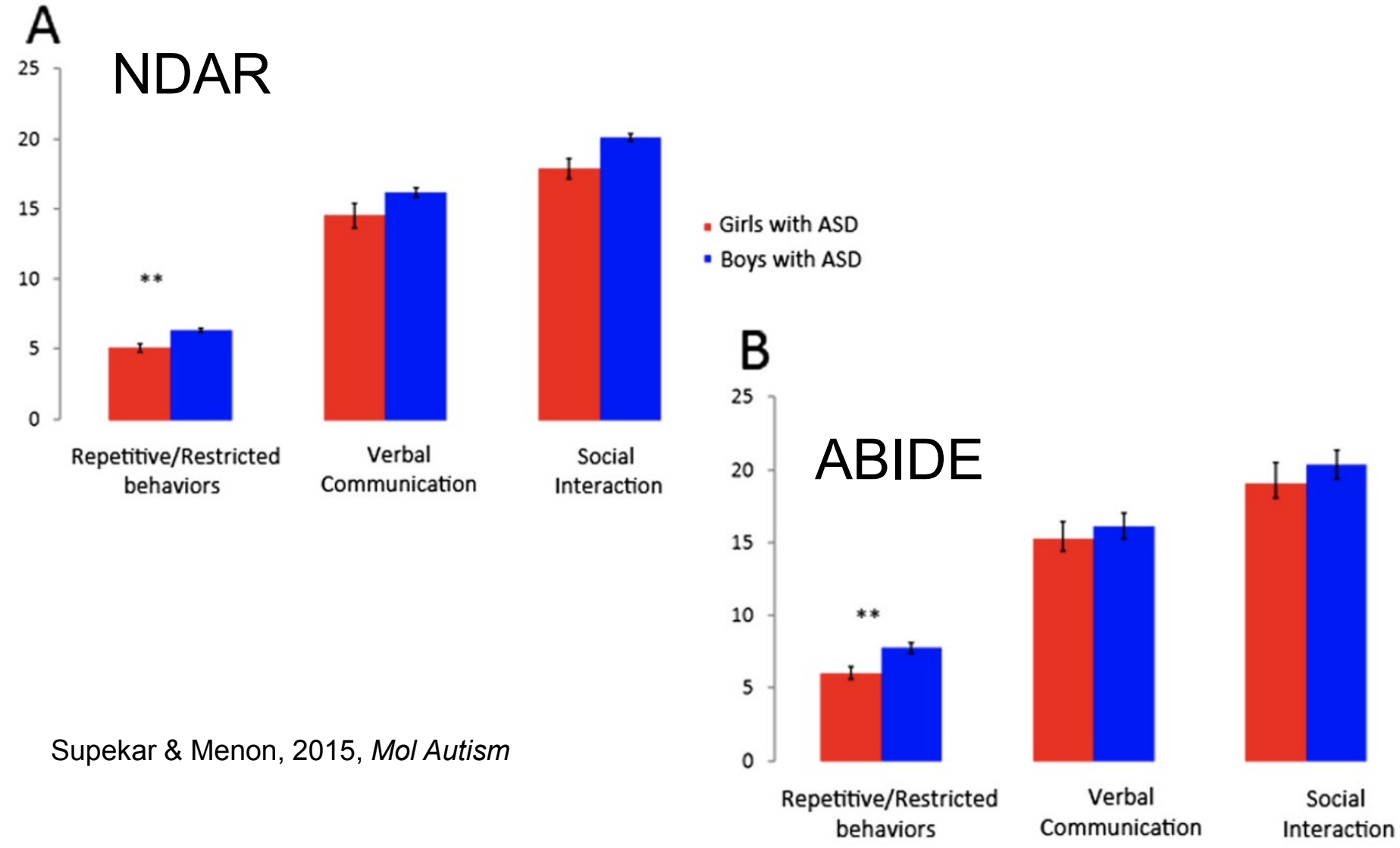
Loomes et al., 2017, *JAACAP*

“Girls/women (& people of other sexes/genders) may present autism partially differently from boys/men.”

“Autism in girls and women are under-recognized.”

IF SO, HOW AND WHY?

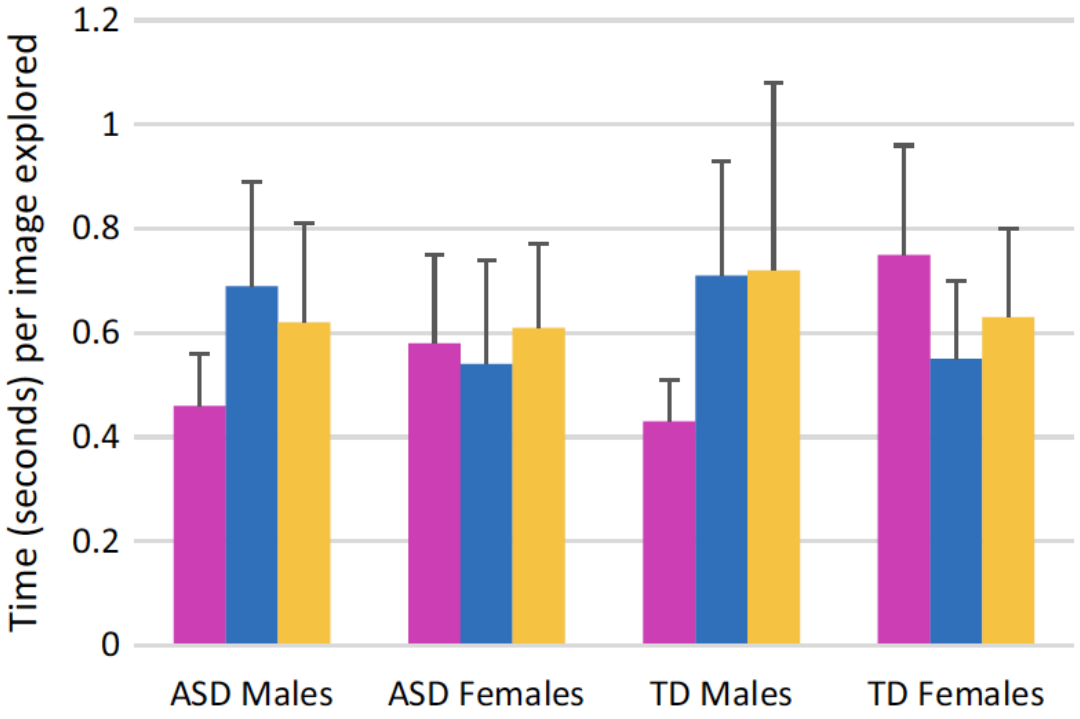
Using "standard" measures



Supekar & Menon, 2015, *Mol Autism*

Sex/Gender can have impact…

- e.g. Autistic girls show more gender-typical visual attention in circumscribed interest (Harrop et al., 2018, *JADD*)





Female: Male (16:8 ratio)

Female Images

Male Images

Neutral Images

Sex/Gender can have impact…

Table 3. Example of POPE variables and observational field notes.

Minute	Engagement state	Description
Solitary		
1	S	Wandering the yard by himself
2	S	Sits next to a paraprofessional, conversation
3	S	Talks to paraprofessional, neutral affect
4	S	Walking around the yard, neutral affect
Joint Engage		
1	JE	Walking and talking with two friends, laughing
2	JE	Sits with two friends, talking and sharing snack
3	JE	Sharing snack, new friends join, happy
4	JE	Sitting and talking to one friend, serious
Game		
1	G	Playing handball with a group of boys
2	G	Got out, sits on bench and watches the game
3	G	Sitting on bench waiting turn
4	G	Has a turn, in the game, serious

S: Solitary; JE: Joint Engagement; G: Game.

Table 4. Descriptive statistics and significant between-group differences on Game, Joint Engage, and Solitary.

	TD boys	TD girls	ASD boys	ASD girls	Significant between-group differences
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	
Games	41.50 (35.91)	13.75 (27.84)	10.87 (18.63)	6.68 (12.63)	TD (boys and girls) > ASD (boys and girls) Boys (TD and ASD) > girls (TD and ASD) TD boys > TD girls, ASD boys, ASD girls
Joint Engage	31.67 (31.44)	52.08 (35.01)	23.55 (27.80)	39.00 (31.46)	Girls (TD and ASD) > boys (TD and ASD)
Solitary	3.81 (6.91)	7.92 (14.46)	43.57 (33.90)	26.69 (28.51)	ASD (boys and girls) > TD (boys and girls) Boys ASD > TD girls, TD boys, ASD girls

TD: typically developing; ASD: autism spectrum disorder; SD: standard deviation.

"*girls with ASD used compensatory behaviors, such as staying in close proximately to peers and weaving in and out of activities, which appeared to mask their social challenges*."

Dean et al., *2017, Autism*

Sex/Gender can have impact…

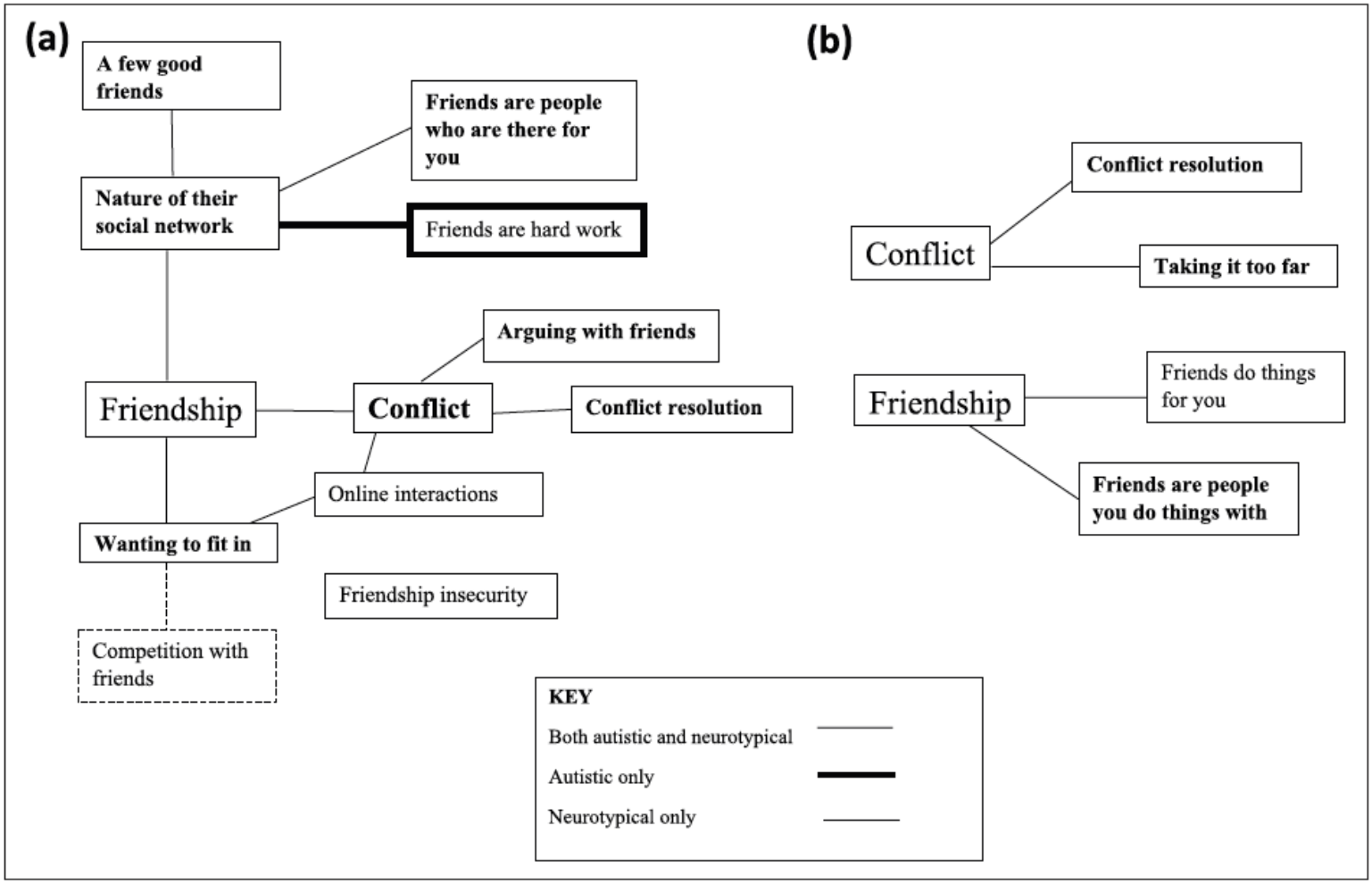
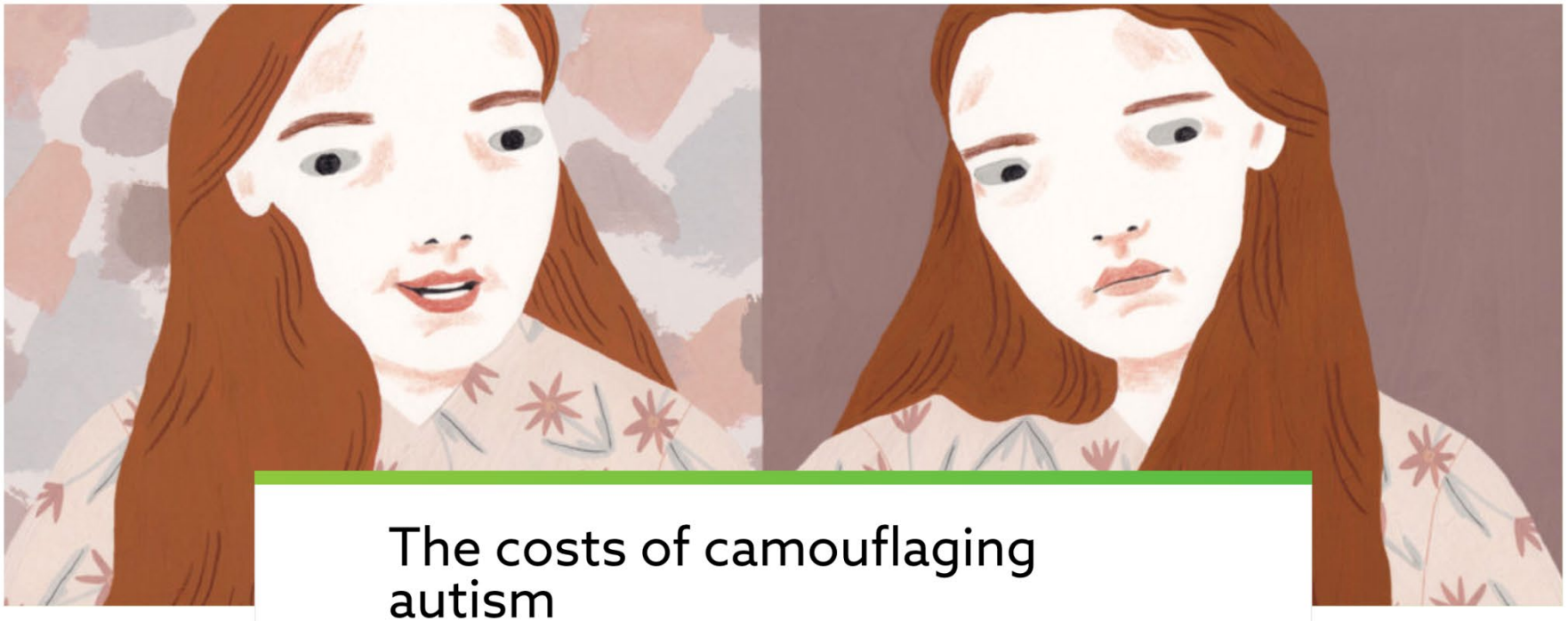


Figure 1. Diagram showing the themes emerging from interviews with adolescent (a) girls and (b) boys.
Bold lines denote themes unique to autistic participants and dashed lines denote themes unique to neurotypical participants. Bold text denotes the most common themes.

Sedgewick et al., 2018, *Autism*

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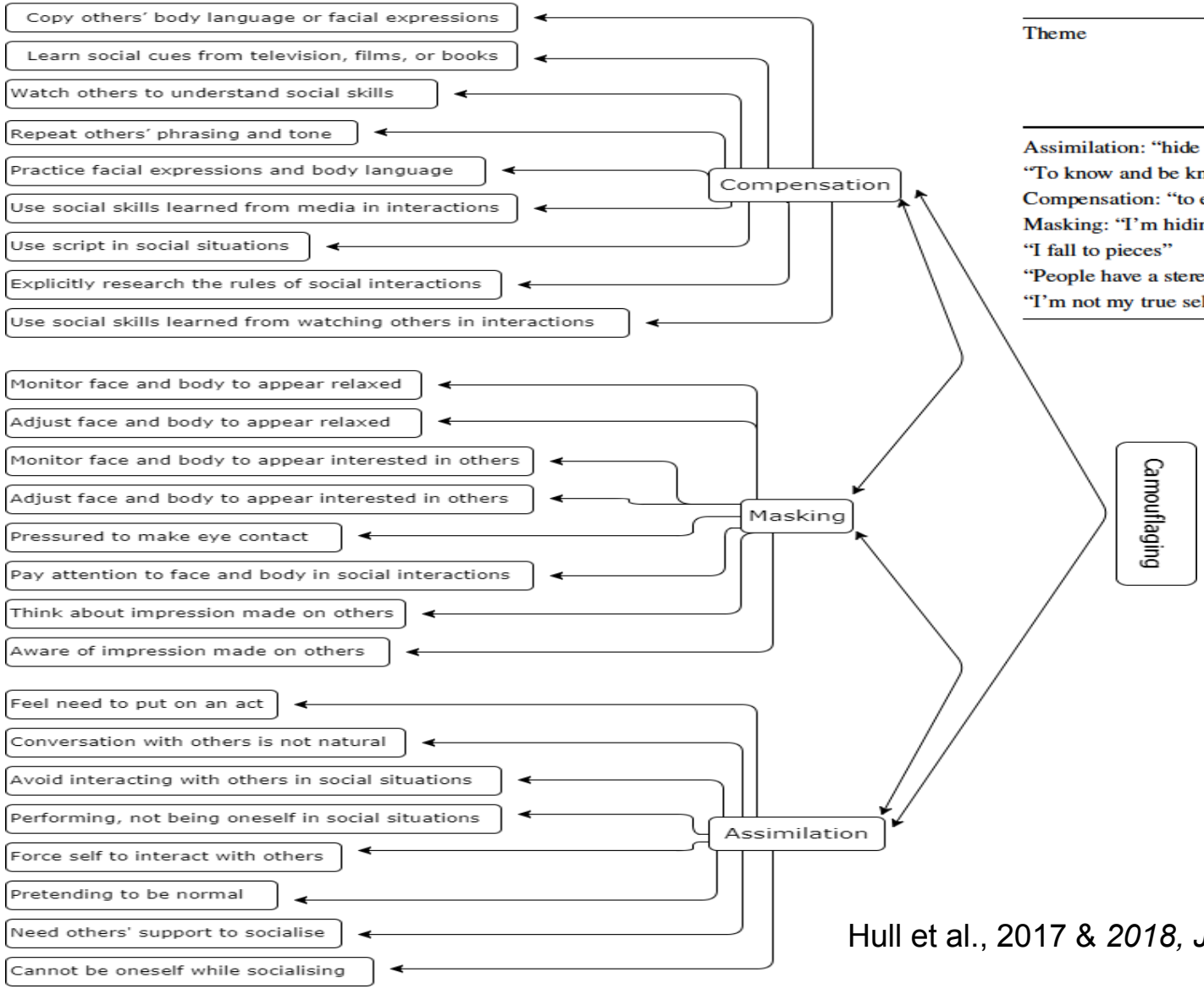
The costs of camouflaging autism

BY **FRANCINE RUSSO**

Many girls hide their autism, sometimes evading diagnosis well into adulthood. These efforts can help women on the spectrum socially and professionally, but they can also do serious harm.

https://spectrumnews.org/features/deep-dive/costs-camouflaging-autism/
https://spectrumnews.org/features/multimedia/podcasts/spectrum-stories-camouflaging-autism-traits/

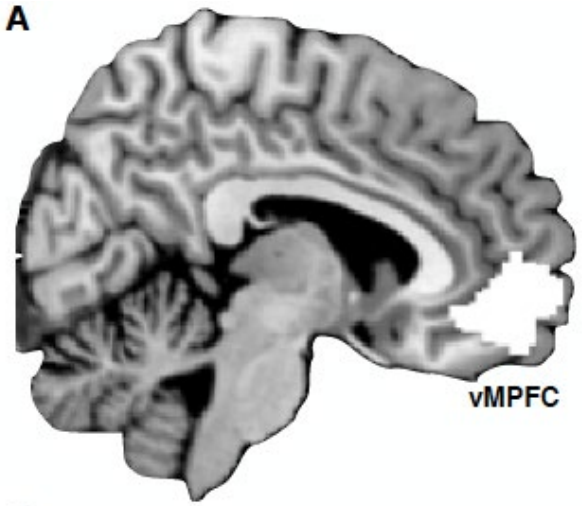
Camouflaging: self-report

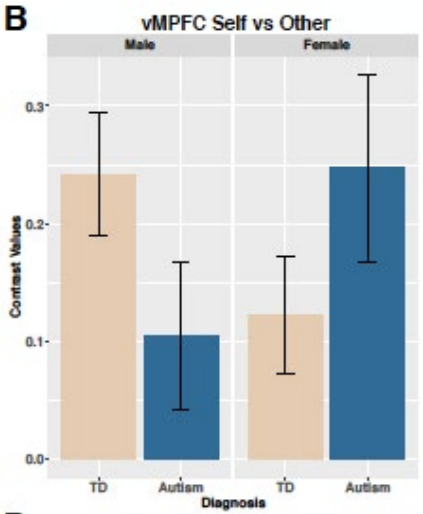


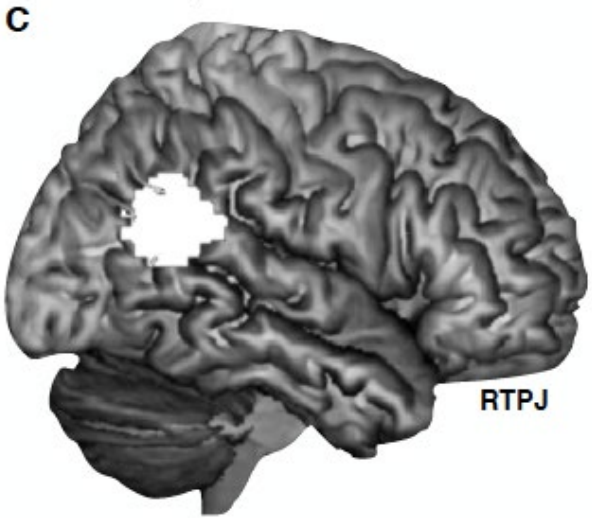
Theme
Assimilation: "hide in plain sight"
"To know and be known"
Compensation: "to exceed what nature has given"
Masking: "I'm hiding behind what I want people to see"
"I fall to pieces"
"People have a stereotyped view"
"I'm not my true self"

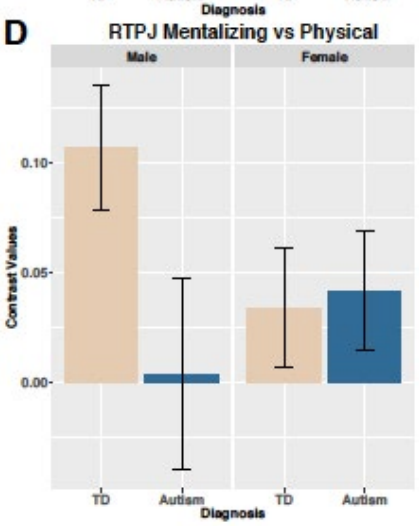
Hull et al., 2017 & *2018, JADD*

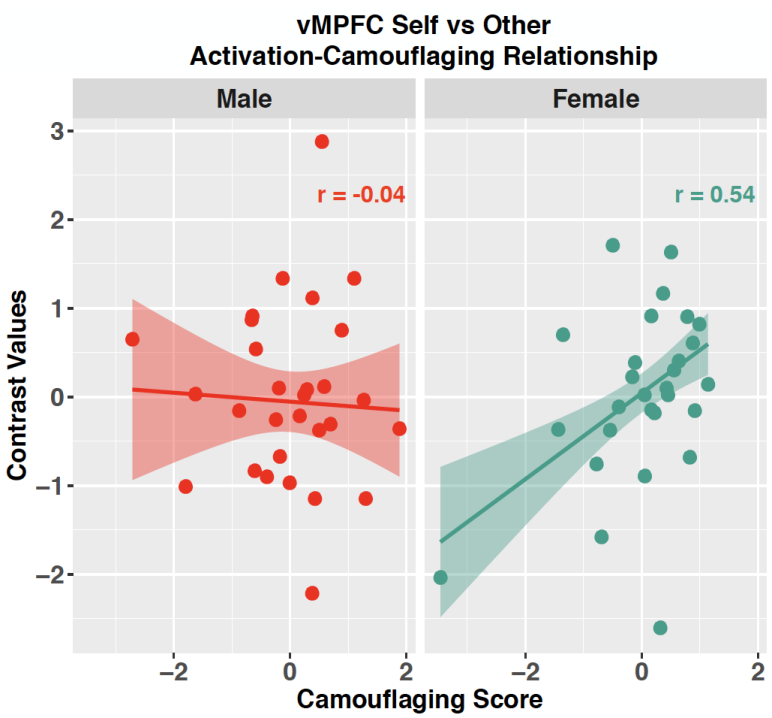
Camouflaging: indirectly measured





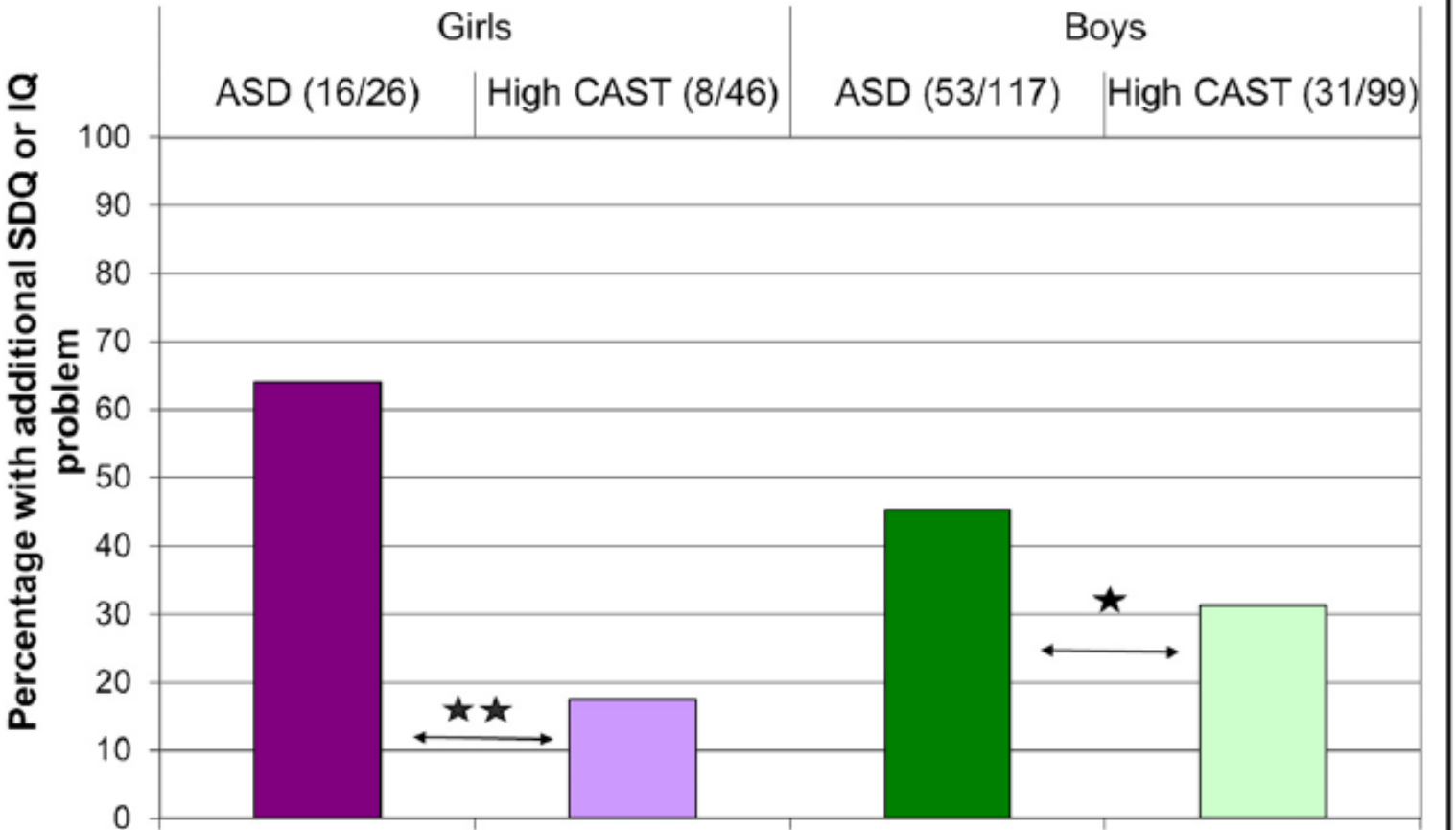






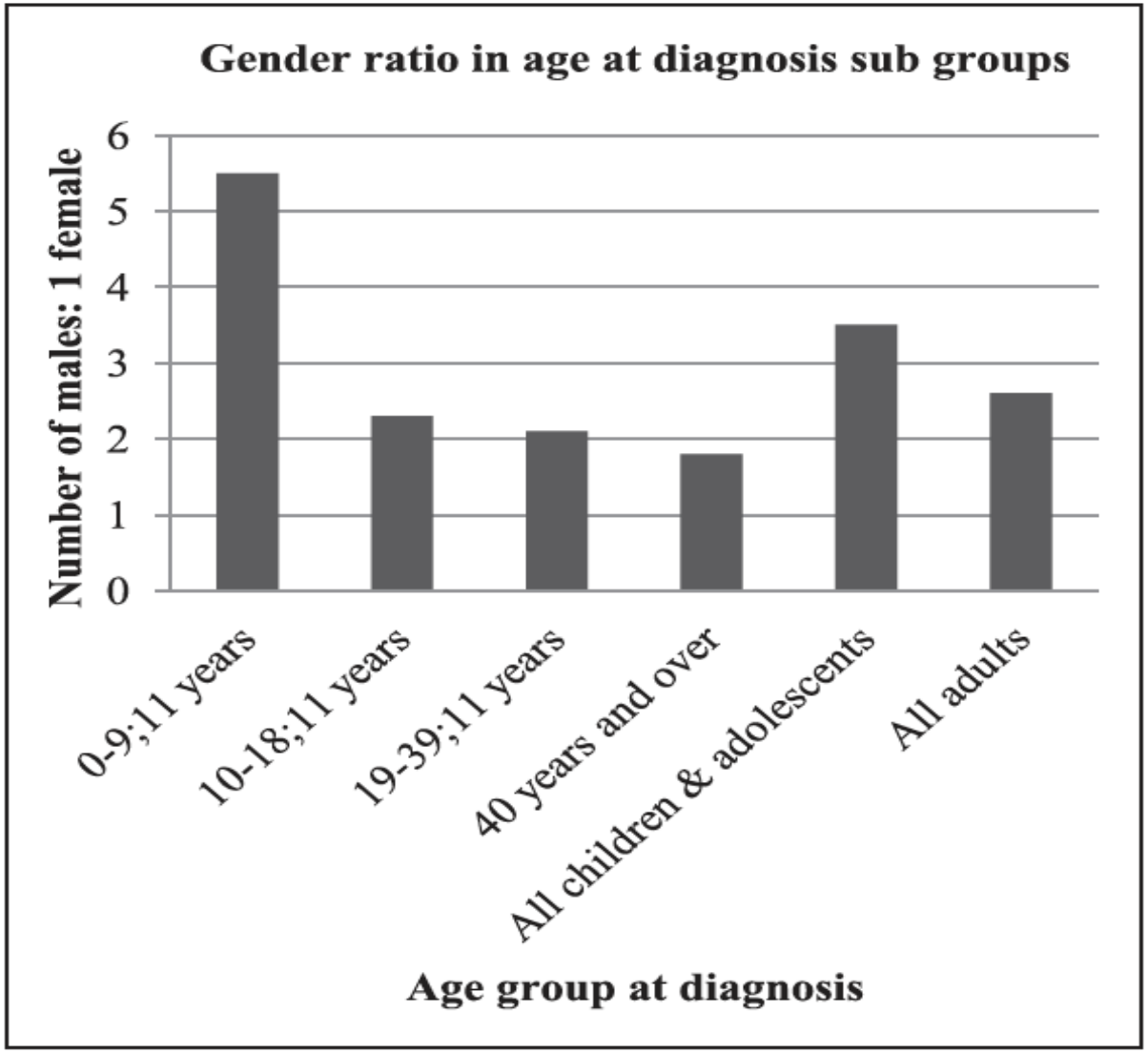
Lai & Lombardo et al., 2018, *Autism*

Biases in recognition of autism?



	Odds ratio Comorbid score either IQ or SDQ (95% CI)
Early IQ or SDQ age 7 / 12 (G) by diagnosed / High CAST	
Girls	8.44 (2.76–25.81)[a]
Boys	1.82 (1.04–3.18)

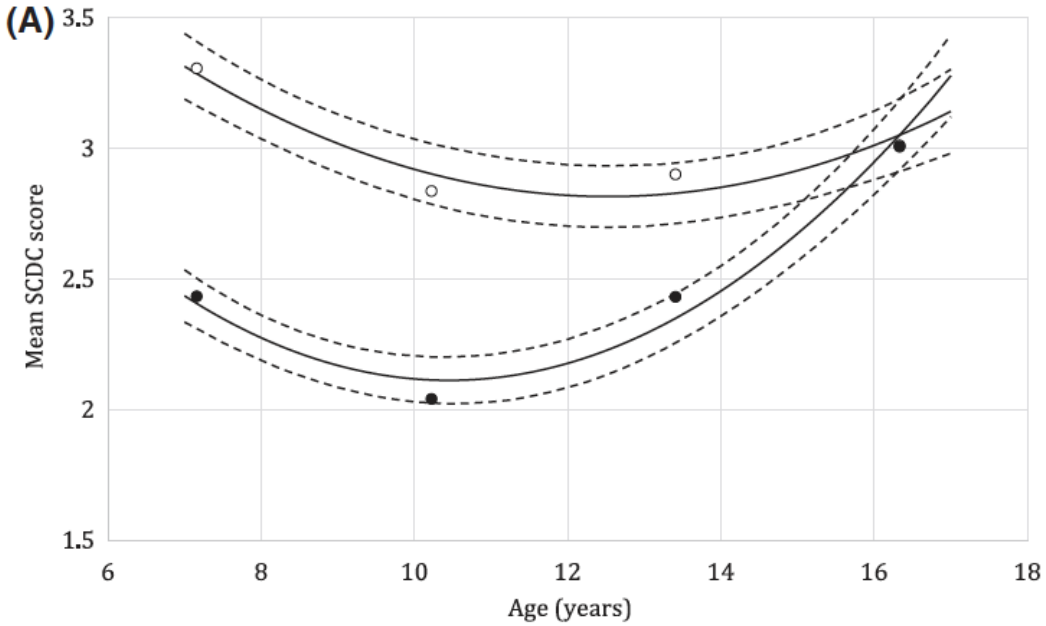
Dworzynski et al., 2012, *JAACAP*



Rutherford et al., 2016, *Autism*

What're the sources of such diagnostic bias?

- Presentation difference?
- Gender-based stereotypes of referral source?
- "Need" of diagnosis emerges later for girls?



Mandy et al., 2018, *JCPP*

Understanding the health and health care experiences of girls and women on the autism spectrum

Yani Hamdani, Yona Lunsky, Caroline Kassee, Frishta Nafeh, Brenda Gladstone, Nicole Bardikoff, Stephanie Ameis, Amanda Sawyer, Pushpal Desarkar, Peter Szatmari & **Meng-Chuan Lai**

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SickKids

Autism ONTARIO
see the potential voir le potentiel

Video



https://www.youtube.com/watch?v=JMio2xG6VCw

Background

Girls and women on the autism spectrum:

- autism-related traits & behaviour may present differently than boys/men
- often go undiagnosed, misdiagnosed or diagnosed later in life
- many experience:
  - mental health, self-identity & gender-related challenges
  - inadequate or insufficient health care & support

Study Objectives

To understand the **gendered** experiences of autistic girls and women, including:

- experiences of autism and intersection with gender (instead of sex)
- experiences of diagnosis & health care

Conceptualizing sex & gender

Sex: The biological and physiological characteristics that distinguish males from females

Gender: The socially constructed roles, expectations, relationships, behaviours, relative power, and other traits that societies ascribe to women, men and people of diverse gender identities

CIHR 2010, Day et al. 2016

Conceptualizing disability

- Concept of 'disability' created in relation to concept of 'normality'[1,2]
- Statistical norms become population/social norms[2]

[1]Williams 2001, [2]Davis 2013

Qualitative Methodology

- Interviews & focus groups
- Three groups:
  1. Autistic girls (12-18 years)
  2. Autistic women (18 years +)
  3. Parents/guardians of a girl/woman on the autism spectrum

Summary of Study Results

Navigating 'normal' ways of being & doing:

- Navigating neurotypical and gender norms
- Developing strategies to 'fit in'
- Promoting positive aspects of autism
- Has both beneficial and (unintentional) harmful effects

Becoming aware of differences

"… **it's a little bit like someone standing behind you all day and randomly jabbing you with a pen**… the pen doesn't actually hurt you at all… it really **drains me…** you don't know when the pen is coming…"

Ellen, 32 y



Becoming aware of differences

"My entire life, I've always assumed that I was like everyone else. I never felt that I fit in but **I assumed nobody felt like they <u>fit in</u>**… I have this blanket of I assume everyone is like me…"

Elsa, 41 y

Becoming aware of differences

"I also had **hyperlexia**. So I learned to read all by myself when I was 4… just snap, I started reading at grade 7 level."

Emma, 26 y

"Haley was reading very obsessively... **it wasn't lining up trains… what you typically hear of with boys**.... she's reading, **she's so intelligent**"

Carol, parent of Haley, 19 y

Comparing to developmental norms

"I realized **she talked at <u>normal time</u>, and no concern with speech…**

now I look back, most of her language were just **echolalia**… ok, **<u>she's kind of different</u>**…."

Helen, daughter is 17 y

Performing to ‘fit in’

“… a **mental image** that’s kind of like a cross between a **<u>rolodex</u> and a TV <u>teleprompter</u>**… or trying to **<u>memorize pop culture</u> references to make more sense** and understand what people are talking about…”

Olivia, 28 y





Performing to ‘fit in’

“I am a **chameleon** - I can literally blend into any environment I'm put in and seem like I fit in… **everything about me is very different.”**

Elsa, 41 y



Developing autism pride

"… now that I understand why I'm so different, but other people also understand what this difference is...**It's a gift**. I think it's a gift and I have like **superpowers**, a little bit."

Debbie, 35 y, self-diagnosed

"I started to feel actually grateful for it [the diagnosis of autism], cause I started to look at the **gifts** and say okay now I can **make these stronger**…"

Donna, 52 y

Navigating gender expectations

"…. **I do feel compassion and empathy and pity but when I look at a person… I can't look at their face and I can't understand what I see there**… which makes it very difficult for them to go to me, **a woman**, and expect the same **emotional labour**, and the same **emotional social cues** that they expect from every other woman…

but I am a woman, I do identify as such"

Alexis, 19 y

Resisting gender binaries

"Basically my gender I identify it's called **gender flux**. I actually **fluctuate between having a gender and having no gender at all...** gender is irrational why do we have this?" *Veronica, 20 y*

"I know that I'm boyish and I'm **a tomboy**…. I get that a lot whenever someone says, "Thank you little boy for holding the door for me"; **I don't bother saying anything because it doesn't bother me**". *Cara, 12 y*

Effects of navigating norms: exhaustion, mental health

"**I'm tired all the time** and I think it's partly physical, but I think for me it's more **mental fatigue**. When I talk to people and I deal with clients at work…

we [autistic women] are **over analyzers and hyper thinkers**… **my brain gets so tired**. So there's that **exhaustion** too…"

Sue, 44 y

Effects of navigating norms: exhaustion, mental health

" …People have always described me as **<u>I'm a duck on the water</u>**… **on the top it looks smooth and everything**… on top you look so graceful and calm and serene and **underneath you're paddling.**" *Elsa, 41 y*



Navigating gender-autism norms

- Shapes how girls/women think about & conduct themselves
- Shapes their gender & autistic identities, which are entwined
- Has effects on their mental health, wellbeing & their behavioural presentations

Conclusions

Presentations of autism in girls & women influenced by:

- Interaction of bodily experiences of autism and social experiences
- Intersection of gender & autism identities
- Strategies for reproducing & resisting 'normal'

Conclusions

We can increase awareness of how social understandings of gender & autism can impact on:

- Clinical judgments
- Recognition of autism in girls & women

Further research

- Refine & evaluate diagnostic/screening practices
- Map diagnostic & service pathways
- Develop methodologies tailored to younger group, ID
- Extend research to other gender groups (e.g. gender diverse people, males)

"Our daughter said something…she blew us away when she said, 'You know what my problem is -

I'm Sheldon but I look like Penny.'

Mitchell, parent, daughter is 12 y



Acknowledgements

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