The past, present and future of autism

Prof Will Mandy

Plan of session

Past

- The changing idea of autism

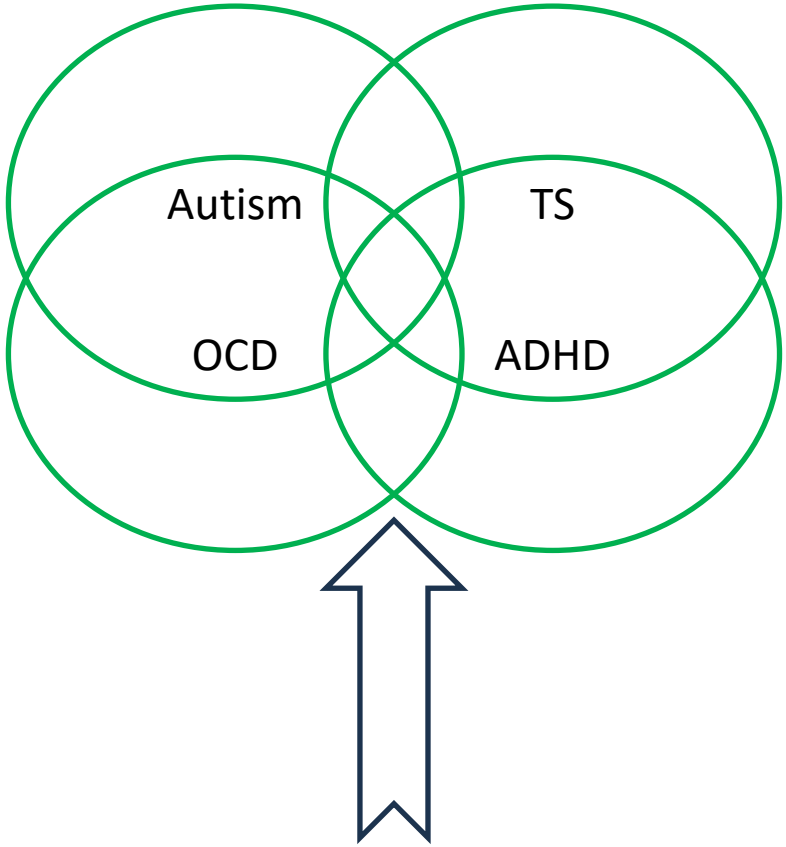
Present

- The autism mental health crisis
- Camouflaging

Future

- The neurodiversity movement
- What next?

Autism and Tourette Syndrome (TS)



Shared risk factors, especially genetic (e.g., Lichtenstein et al., 2010)

They co-occur at rates higher than would be expected by chance:

- TS prevalence in autism estimated at 11% (with tic disorders at 22%) (Canitano & Vivanti, 2007) and 9% (Gulisano et al., 2020)
- Autism in TS estimated by Eapen et al, (2016) at 15%

And this co-occurrence is not just a result of measurement error ('phenocopies'), e.g., Huisman-van Dijk et al., 2016

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The birth of autism

Leo Kanner
(1894-1981)

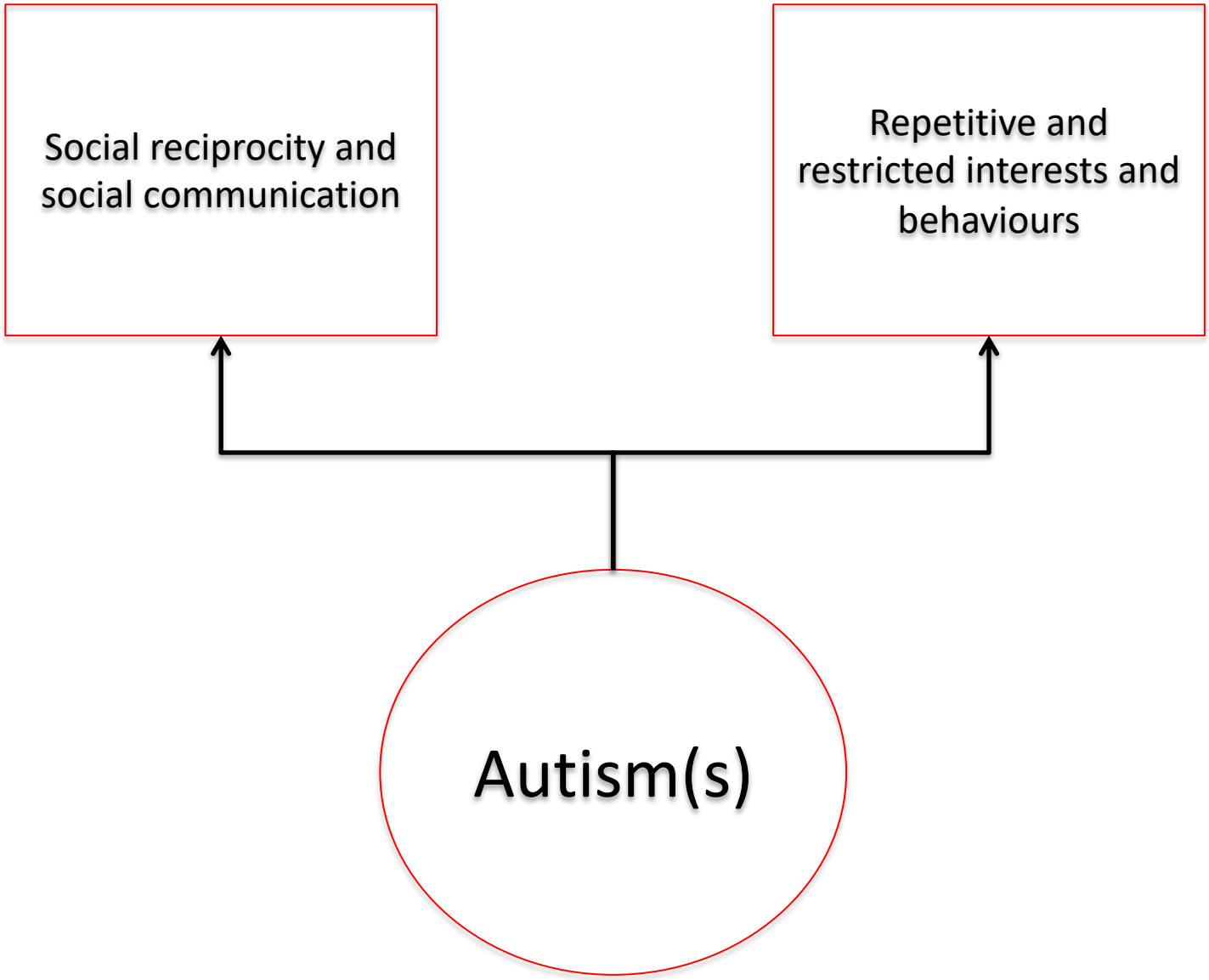
Donald

"happiest when left alone, almost never cried to go with his mother...wandered about smiling, making stereotyped movements with his fingers…spun with great pleasure anything he could seize upon to spin....Words to him had a specifically literal, inflexible meaning....When taken into a room, he completely disregarded the people and instantly went for objects"

Kanner (1943)

"Since 1938, there have come to our attention a number of children whose condition differs so markedly…from anything reported so far, that each case merits…a detailed consideration of its fascinating peculiarities."

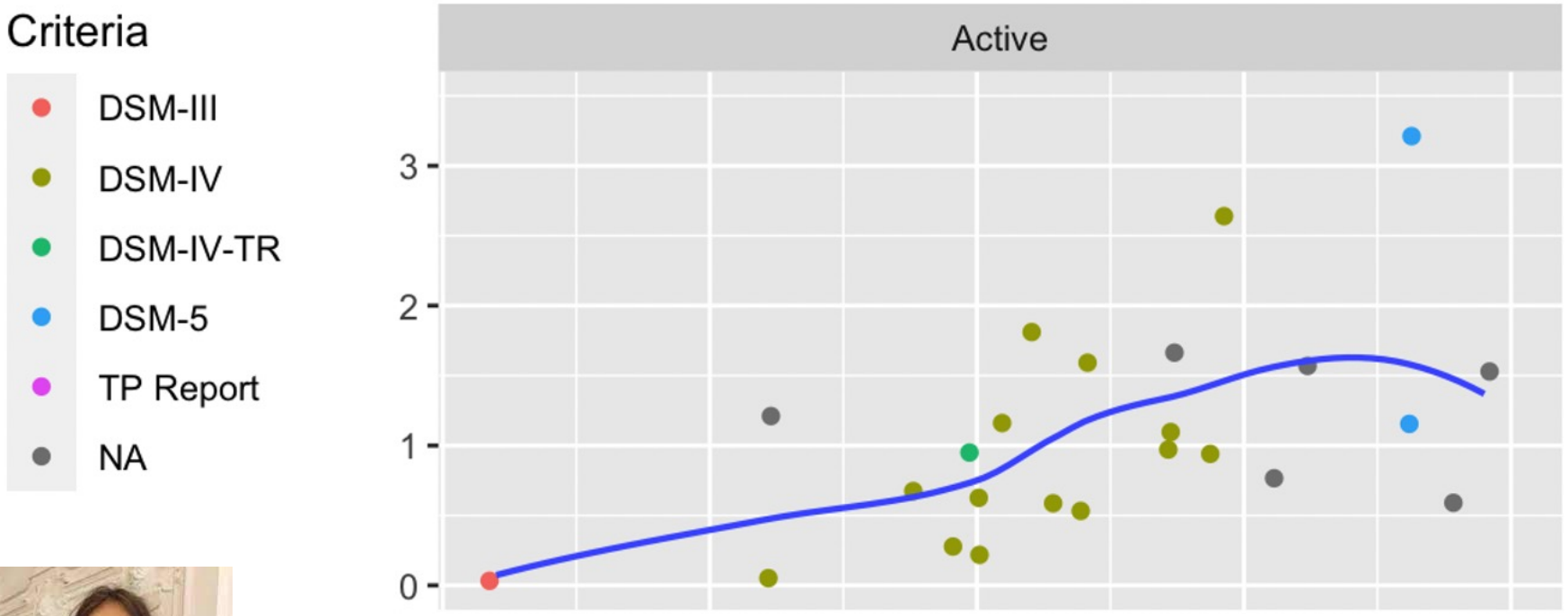
1. "Inborn autistic disturbances of affective contact'
2. "Powerful desire for…sameness"


Social reciprocity and social communication
Repetitive and restricted interests and behaviours
Autism(s)

Autism: the 20th century view

A rare and severe neurodevelopmental disorder that mainly affects males, usually associated with intellectual disability and delayed language development, and categorically distinct from normal development and from other disorders.

Myth 1: autism is rare



Emma Reames

Prevalence estimates of ASD from epidemiological studies involving screening and assessment in community samples (k=37, since 1960s)

Myth 2
"Most people with an autism have a learning disability"

50-70% of people diagnosed with autism have an IQ>70

Centers for Disease Control, 2014; Loomes et al., 2017

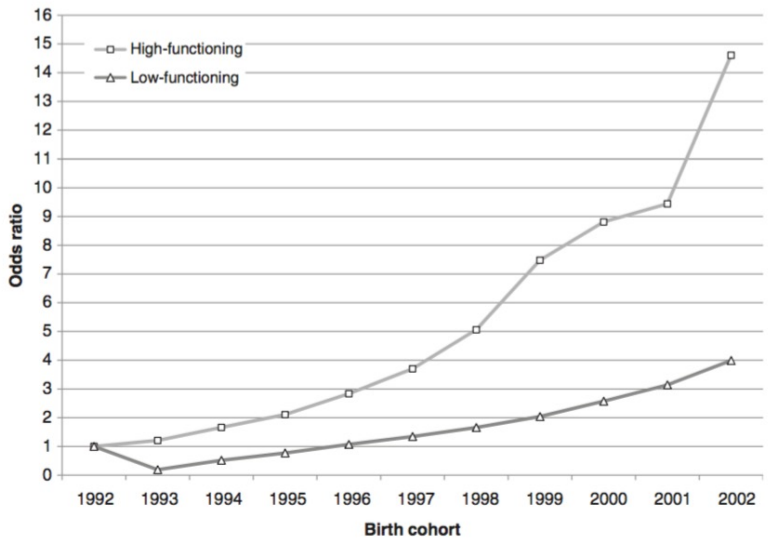
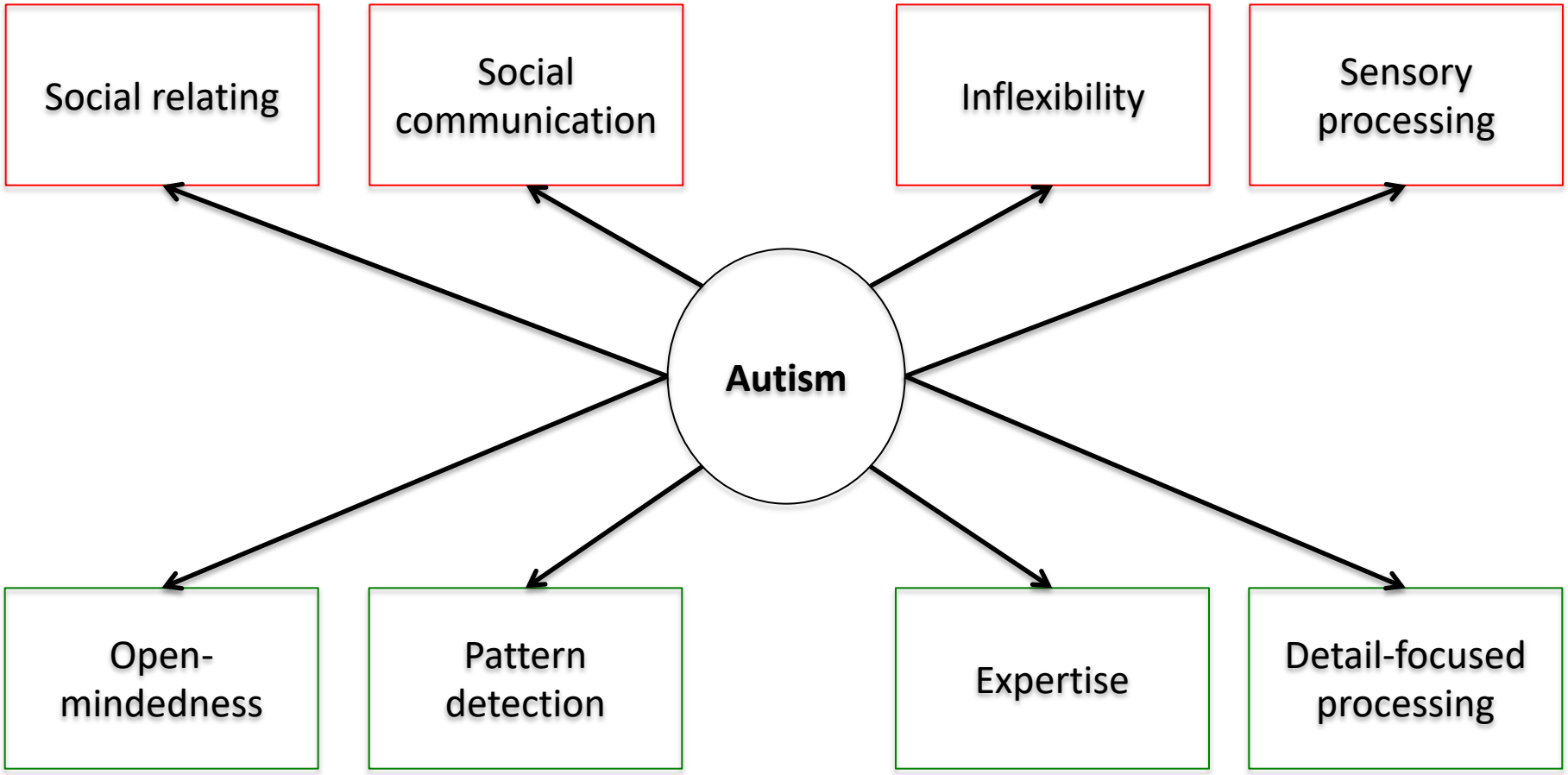


Figure 4 Cohort effects in autism diagnosis in California from 1994 to 2005 by child's functioning (functioning defined by a global index on two dimensions relevant to autism: social interaction, and communication and language, both recorded on the CDER diagnostic and evaluation instrument at the time of intake. Those above the 80th percentile were considered high-functioning children with autism, those in the 20th to 79th percentile were considered mid-functioning, and those below the 20th percentile were considered low-functioning children with autism) at the time of diagnosis

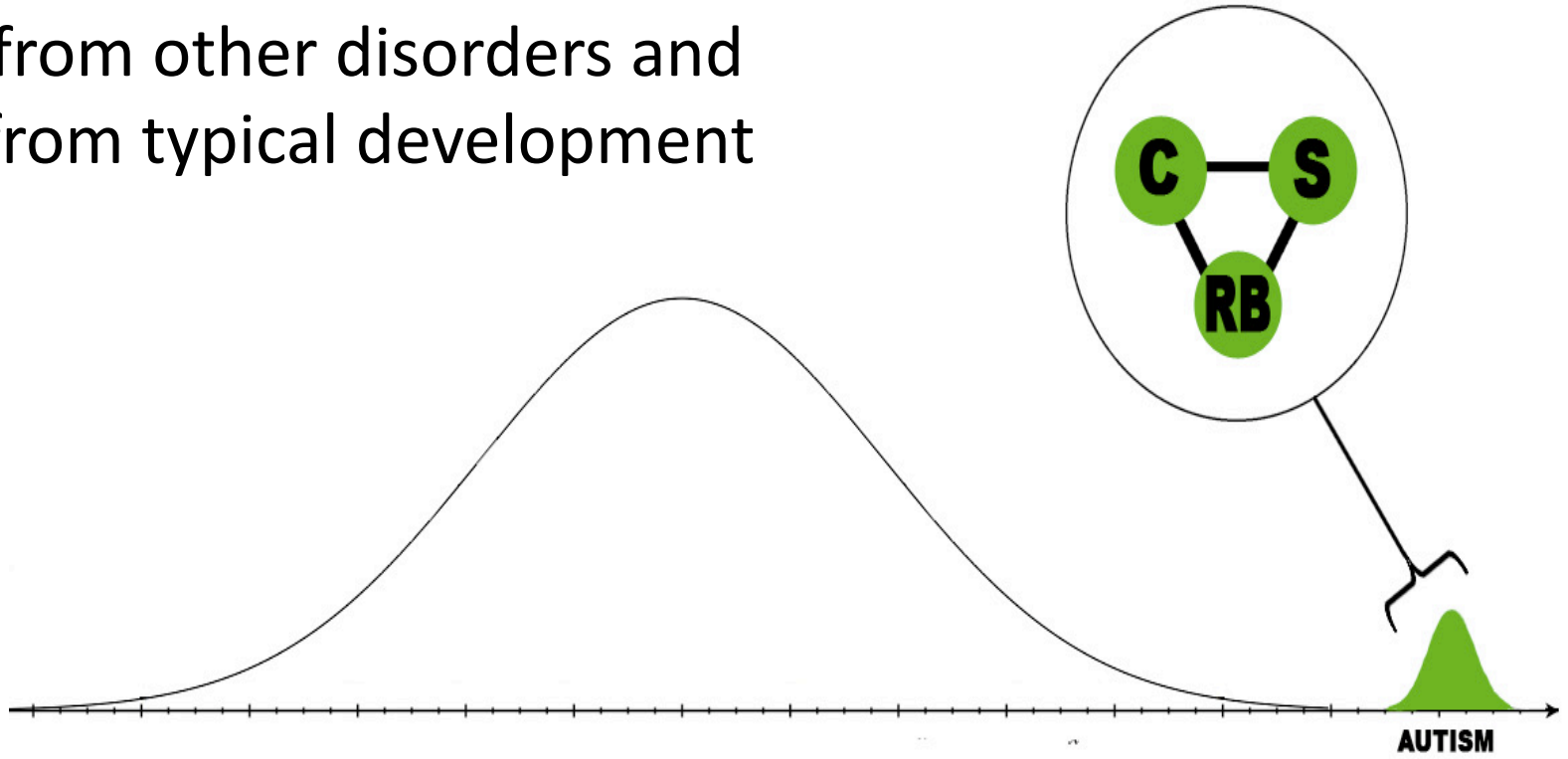
Keyes et al. (2012)
California 1992 - 2003

Myth 3 – autism is just about having difficulties

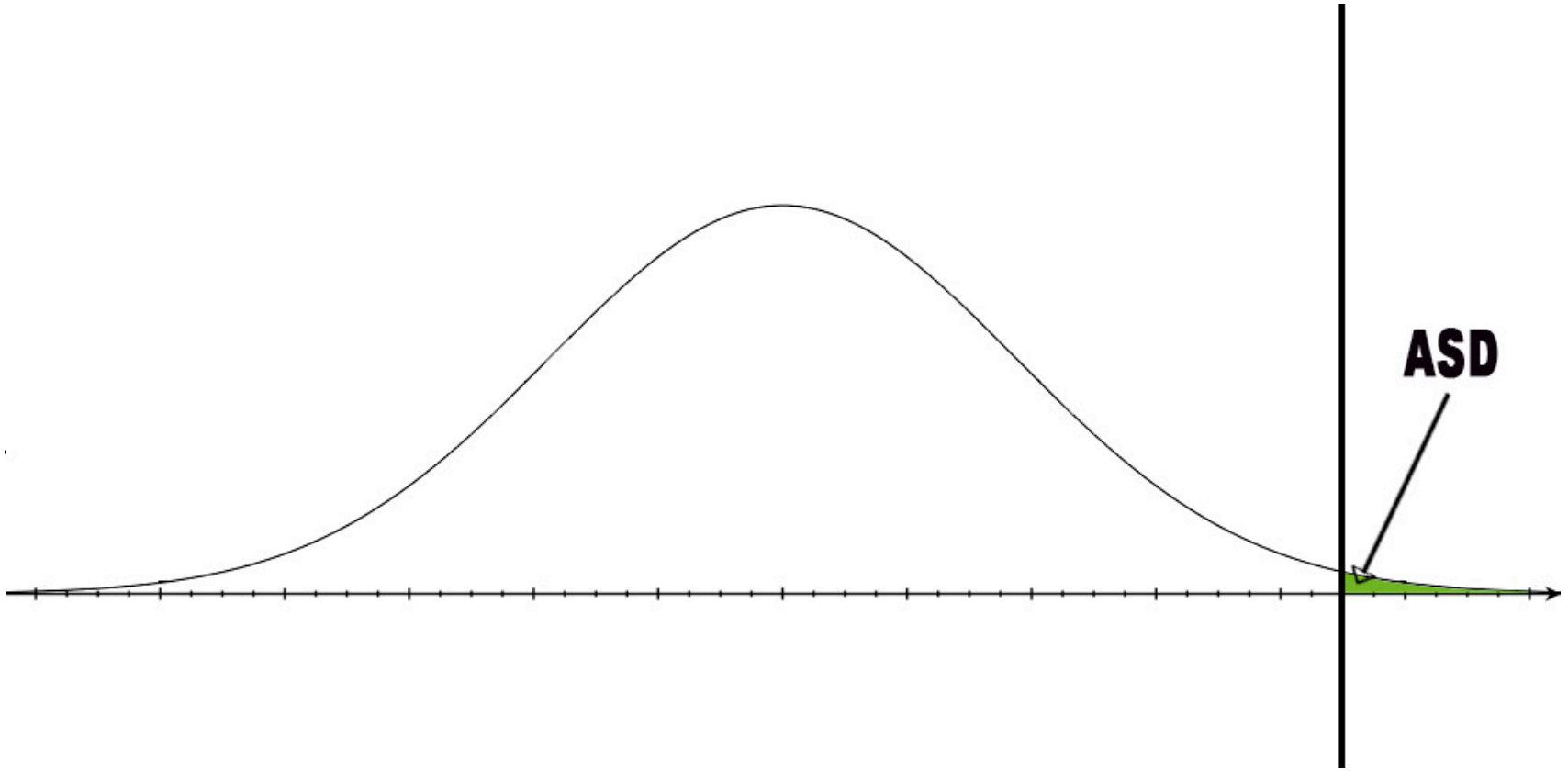


Myth 4:
Autism is a categorical disorder

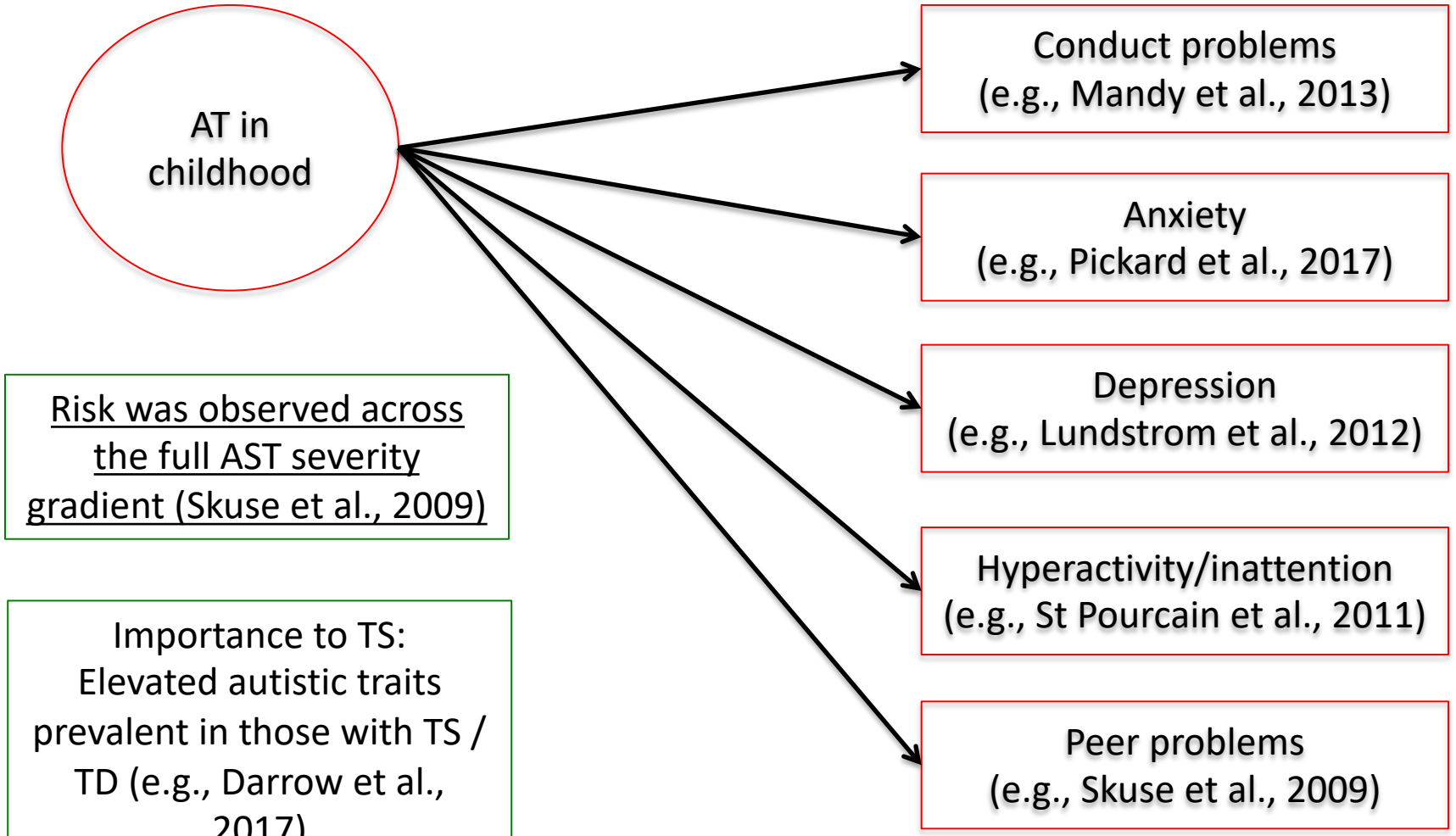
Autism as a category distinct from other disorders and from typical development



The dimensional syndrome model



Autistic traits: a key risk factor in developmental psychopathology



Risk was observed across the full AST severity gradient (Skuse et al., 2009)

Importance to TS: Elevated autistic traits prevalent in those with TS / TD (e.g., Darrow et al., 2017)

Myth 5:
Autism is a male condition

Autistic girls and women are more likely to be:

- ✧Overlooked (Loomes et al., 2017)
- ✧Misunderstood (e.g., Wikramanayake et al., 2017)
- ✧Diagnosed late (e.g., Mandell et al., 2005)

We have tended to underestimate the number of autistic girls and women, compared to males.

DSM-5 states the male-to-female ratio is 4-to-1

Really it is 3-to-1 or lower (Loomes et al., 2017)

Why is there a diagnostic bias against autistic females?

- Sex/gender influences how autism presents…
- …and current diagnostic conventions are more sensitive to autistic presentations in boys and men.
  - Social motivation
  - Focused interests
  - Co-occurring mental health difficulties
- Stereotypes and preconceptions (‘autism is a boy condition’) also appear to be at play (Whitlock et al., 2020)

Autism: the new consensus

A relatively common, neurodevelopmental condition with a gender-specific presentation, usually associated with normal-range IQ, that brings both strengths and difficulties, representing a form of natural human variation.

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Mental Health of Autistic People

- Autism is not a mental health problem…
- …but autistic people are at very high risk of having mental health problems

Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample

EMILY SIMONOFF, M.D., F.R.C.PSYCH., ANDREW PICKLES, PH.D., TONY CHARMAN, PH.D., SUSIE CHANDLER, PH.D.,TOM LOUCAS, PH.D., AND GILLIAN BAIRD, F.R.C.P.C.H.

ABSTRACT

Objective: Autism spectrum disorders are now recognized to occur in up to 1% of the population and to be a major public health concern because of their early onset, lifelong persistence, and high levels of associated impairment. Little is known about the associated psychiatric disorders that may contribute to impairment. We identify the rates and type of psychiatric comorbidity associated with ASDs and explore the associations with variables identified as risk factors for child psychiatric disorders. **Method:** A subgroup of 112 ten- to 14-year old children from a population-derived cohort was assessed for other child psychiatric disorders (3 months' prevalence) through parent interview using the Child and Adolescent Psychiatric Assessment. *DSM-IV* diagnoses for childhood anxiety disorders, depressive disorders, oppositional defiant and conduct disorders, attention-deficit/hyperactivity disorder, tic disorders, trichotillomania, enuresis, and encopresis were identified. **Results:** Seventy percent of participants had at least one comorbid disorder and 41% had two or more. The most common diagnoses were social anxiety disorder (29.2%, 95% confidence interval [CI)] 13.2–45.1), attention-deficit/hyperactivity disorder (28.2%, 95% CI 13.3–43.0), and oppositional defiant disorder (28.1%, 95% CI 13.9–42.2). Of those with attention-deficit/hyperactivity disorder, 84% received a second comorbid diagnosis. There were few associations between putative risk factors and psychiatric disorder. **Conclusions:** Psychiatric disorders are common and frequently multiple in children with autism spectrum disorders. They may provide targets for intervention and should be routinely evaluated in the clinical assessment of this group. *J. Am. Acad. Child Adolesc. Psychiatry*, 2008;47(8):921–929. **Key Words:** autism, child psychiatric disorders, prevalence, Special Needs and Autism Project.

Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis

Meng-Chuan Lai, Caroline Kassee*, Richard Besney, Sarah Bonato, Laura Hull, William Mandy, Peter Szatmari, Stephanie H Ameis*

	Number of datapoints in meta-analysis*	Autism population sample size (n)	Autism population		General population prevalence (95% CI or SE)	Subgroup moderator analysis			
			Pooled prevalence (95% CI; 95% PI)	I^2 (95% CI; p value†)		Prevalence in population or registry-based studies (95% CI; 95% PI)	Prevalence in clinical sample-based studies (95% CI; 95% PI)	R^2 (QE p value)	I^2 (95% CI)	QM p value
Attention-deficit hyperactivity disorder	89	210 249	28% (25–32; 4–63)	99·65% (99·55–99·85; <0·0001)	7·2% (6·7–7·8; point prevalence, aged ≤18 years)[46]	22% (17–26; 1–55)	34% (29–39; 7–69)	2·05% (<0·0001)	99·64% (99·60–99·84)	0·0004
Anxiety disorders	68	169 829	20% (17–23; 2–48)	99·53% (99·42–99·87; <0·0001)	7·3% (4·8–10·9; current prevalence, across ages)[47]	15% (11–19; 0·5–42)	26% (22–31; 1–56)	0% (<0·0001)	99·54% (99·20–99·85)	0·0002
Depressive disorders	65	162 671	11% (9–13; 0–33)	99·41% (99·39–99·81; <0·0001)	4·7% (4·4–5·0; point prevalence of MDD, across ages)[48]	8% (5–11; 0·01–28)	14% (11–18; 1–38)	0·23% (<0·0001)	99·40% (99·37–99·80)	0·0003
Bipolar and related disorders	38	153 192	5% (3–6; 0–19)	99·50% (99·40–99·82; <0·0001)	0·71% (0·56–0·86) for bipolar I; and 0·50% (0·35–0·64) for bipolar II (1-year prevalence, across ages)[49]	3% (2–5; 0–16)	7% (4–10; 0–24)	0·35% (<0·0001)	99·50% (99·48–99·81)	0·018
Schizophrenia spectrum and psychotic disorders	42	166 627	4% (3–5; 0–14)	99·18% (99·00–99·87; <0·0001)	0·46% (0·41–0·50; 1-year prevalence, across ages)[50]	2% (1–4; 0–11)	7% (4–9; 0–19)	0% (<0·0001)	99·18% (99·01–99·84)	0·0004
Obsessive-compulsive and related disorders	47	53 243	9% (7–10; 1–21)	96·85% (96·75–99·87; <0·0001)	0·7% (0·4–1·1; 1-year prevalence, aged ≥18 years)[51]	4% (2–6; 0–13)	12% (10–15; 3–26)	12·51% (<0·0001)	96·20% (96·17–99·37)	<0·0001
Disruptive, impulse-control, and conduct disorders	50	140 946	12% (10–15; 0–36)	99·52% (99·47–99·90; <0·0001)	8·9% (SE 0·5; 1-year prevalence, aged ≥18 years)[52]	7% (4–10; 0–28)	22% (17–27; 3–50)	0% (<0·0001)	99·53% (99·42–99·88)	<0·0001
Sleep-wake disorders	26	190 963	13% (9–17; 0–43)	99·87% (99·78–99·93; <0·0001)	3·7% (NA; 1-year prevalence, aged ≤18 years)[53]	11% (7–17; 0–39)	16% (8–25; 0–47)	8·52% (<0·0001)	99·85% (99·77–99·91)	0·356

General population prevalence estimates were selected from latest meta-analyses or large-scale population-based studies, as cited. R^2 is the proportion of true heterogeneity that can be explained by the moderator, the QE statistic and its p value show the significance of residual heterogeneity that is unaccounted for by the moderator, and the QM statistic and its p value show whether the moderator is statistically significant in explaining heterogeneity. PI=prediction interval. MDD=major depressive disorder. NA=not available. *Number of datapoints extracted from studies reporting the co-occurring condition. †Cochran's Q test p value.

Table 1: **Pooled estimates of prevalence of co-occurring mental health and psychiatric conditions in autism and general population and moderator analysis by study design**

Mental health problems of autistic people:

- Are usually established before the transition to adulthood (Simonoff et al., 2013)
- Reduce quality of life (e.g., Helles et al., 2017) and functioning (Chiang & Gow, 2016)
- Act as a risk factor for further mental health problems (e,g., ADHD -> Depression; Mayes et al., 2014)
- Make a major contribution to the high mortality of autistic people (Schendel et al., 2016)

And yet, mental health services for autistic people are currently not fit for purpose

ORIGINAL RESEARCH

Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership

Christina Nicolaidis, MD, MPH[1], Dora Raymaker, MS[1,2], Katherine McDonald, PhD[3], Sebastian Dern[4], W. Cody Boisclair, PhD[4], Elesia Ashkenazy[2], and Amanda Baggs[4]

- 34% reported unmet mental health needs – twice as high as rates in non-autistic comparison group

ORIGINAL PAPER

Experiences of Receiving a Diagnosis of Autism Spectrum Disorder: A Survey of Adults in the United Kingdom

Lydia Jones · Lorna Goddard · Elisabeth L. Hill · Lucy A. Henry · Laura Crane

- Co-occurring mental health problems were a common reason why people sought autism assessment – yet after assessment most had no idea how to seek help for these
- 45% of participants wanted counselling after assessment, and only 22% were offered it

- Low satisfaction with services received
- High rates of psychopharmacotherapy and polypharmacy for autistic people
- High rates of crisis care - mental health inpatient admissions for autistic people acknowledged to be too high

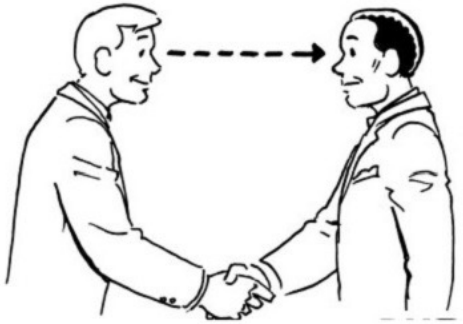
What is camouflaging?

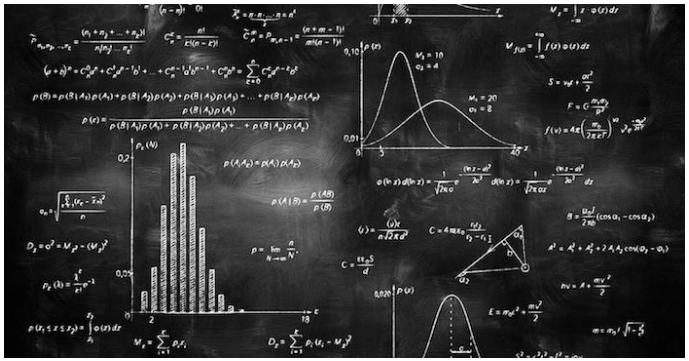
"Putting on my best normal"
Hull et al., 2017

"The dynamic process by which autistic individuals modify their innate autistic social behavior in order to adapt, cope within, and/or influence the predominantly neurotypical environment"

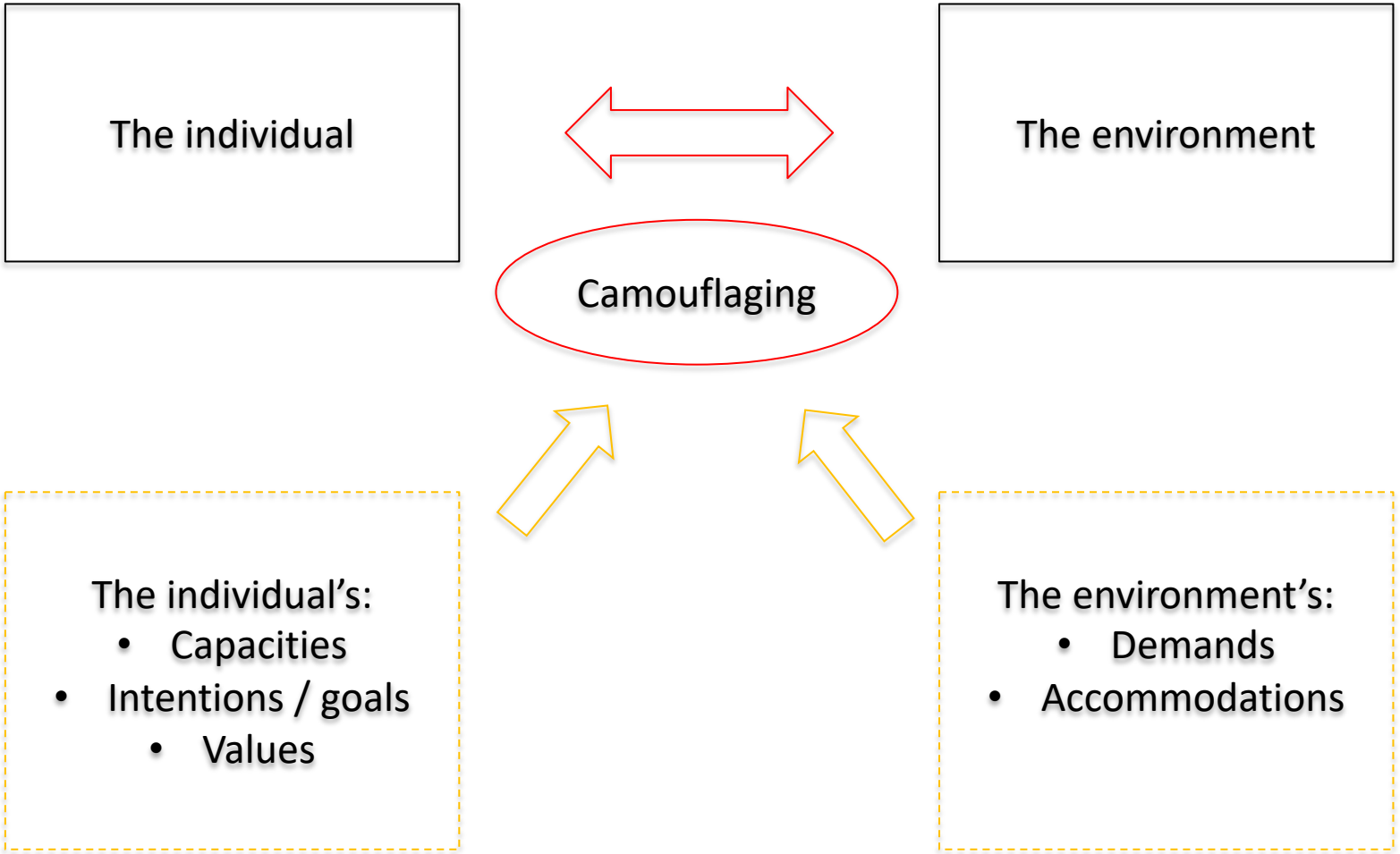
Cook et al., 2020

Camouflage





The dynamic, transactional nature of camouflaging



Three things you should know about camouflaging

- It is commonly a response to environments that are unaccommodating – or outright hostile – to autistic people (e.g., Bargiela et al., 2016)
- It is reported to be exhausting (e.g., Hull et al., 2017)
- It is consistently associated with anxiety and depression (Cook et al., 2022)

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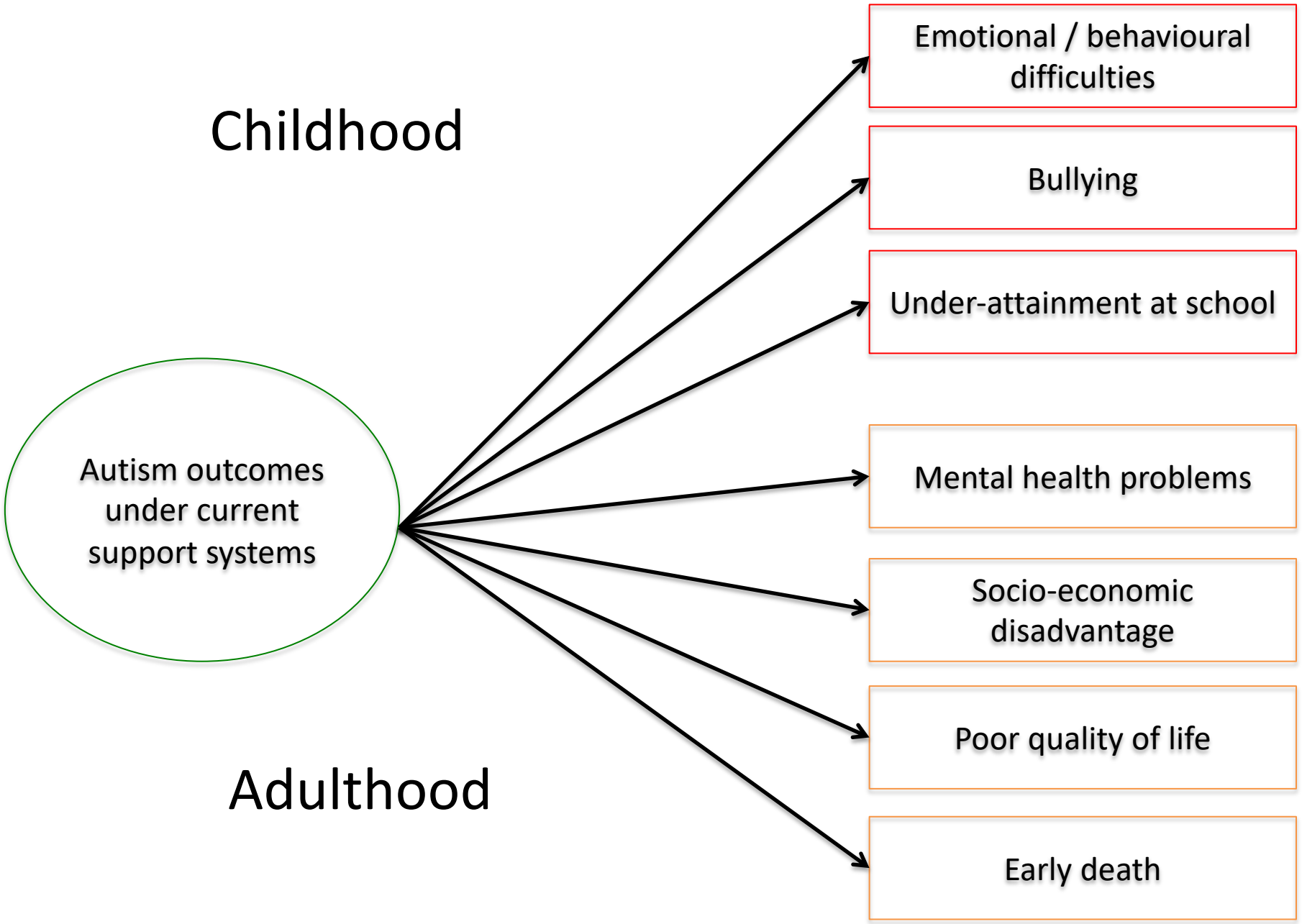
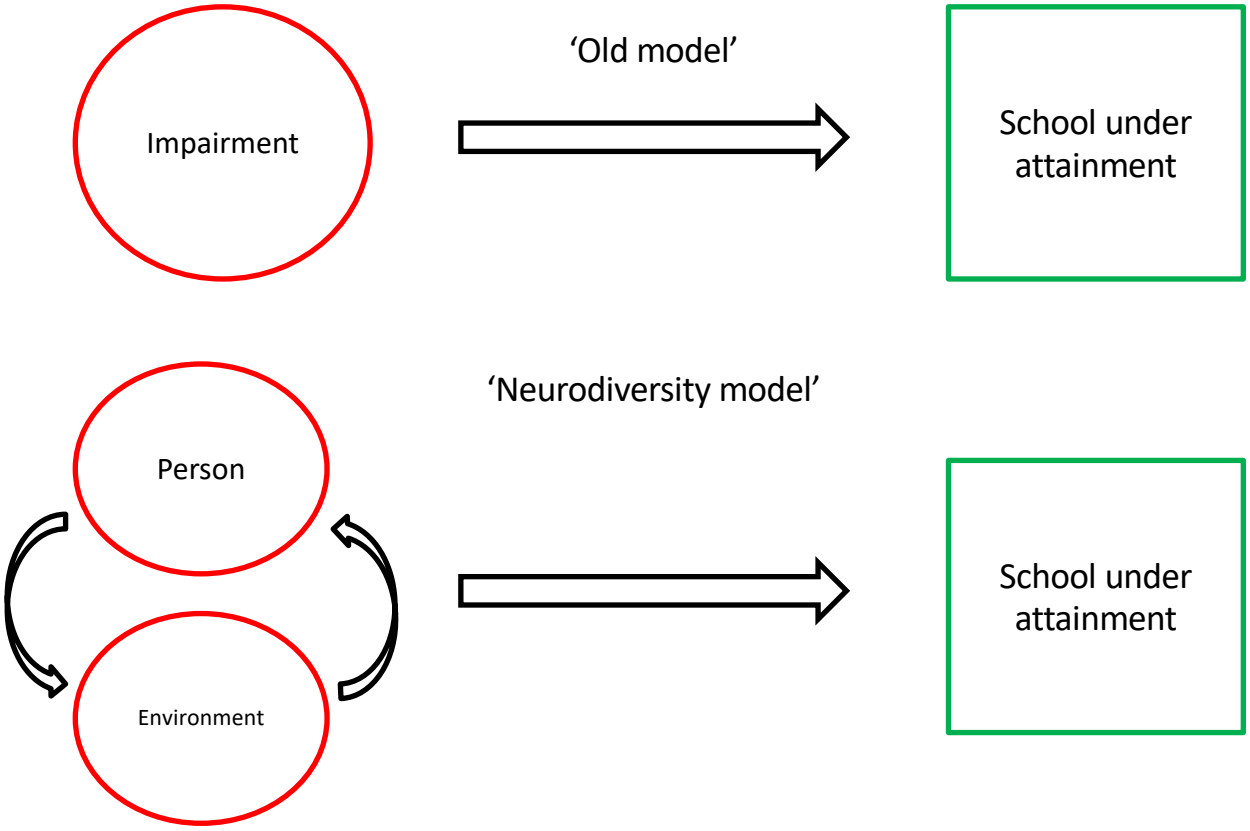

Childhood
Autism outcomes under current support systems
Emotional / behavioural difficulties
Bullying
Under-attainment at school
Mental health problems
Socio-economic disadvantage
Poor quality of life
Early death
Adulthood

Outcomes for autistic people – the old and new approaches



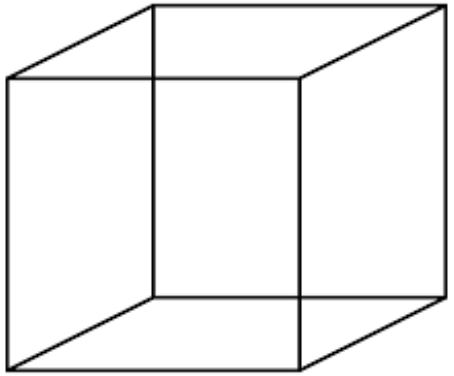
The Journal of Child Psychology and Psychiatry

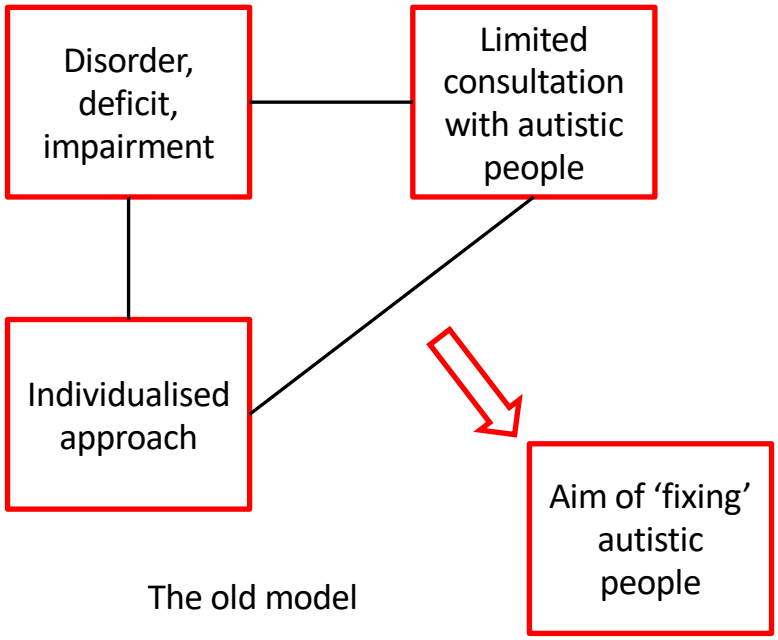
Journal of Child Psychology and Psychiatry **:* (2021), pp **–** doi:10.1111/jcpp.13534

Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science

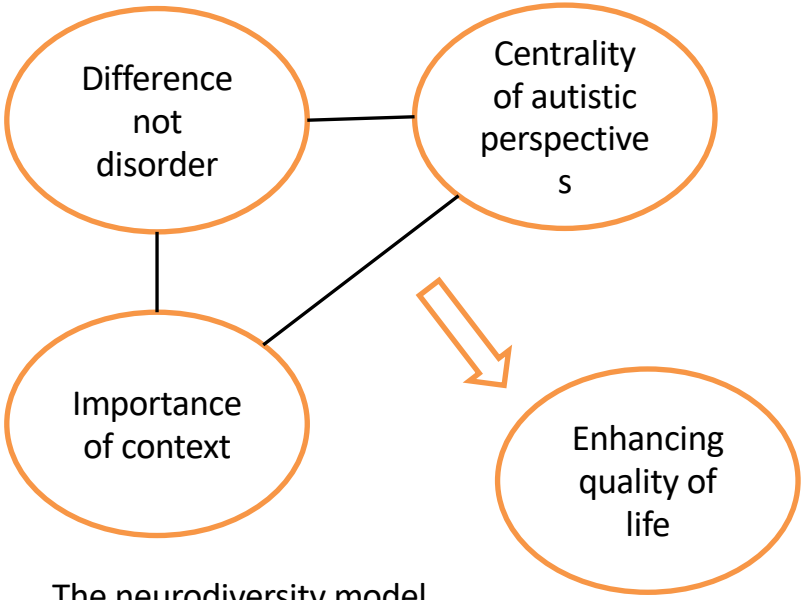
Elizabeth Pellicano,[1,2] and Jacquiline den Houting[1,2]

[1]Macquarie School of Education, Macquarie University, Sydney, NSW, Australia; [2]Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Qld, Australia





The old model



The neurodiversity model

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Priorities for future research and practice developments

A priority setting exercise was recently completed by the James Lind Alliance and the charity Autistica, that consulted >1,000 members of the autism community:

Autism Top 10

1. Which interventions improve mental health or reduce mental health problems in autistic people? How should mental health interventions be adapted for the needs of autistic people?
2. Which interventions are effective in the development of communication/language skills in autism?
3. What are the most effective ways to support/provide social care for autistic adults?
4. Which interventions reduce anxiety in autistic people?
5. Which environments/supports are most appropriate in terms of achieving the best education/ life/ social skills outcomes in autistic people?
6. How can parents and family members be supported/educated to care for and better understand an autistic relative?
7. How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?
8. How can we encourage employers to apply person-centred interventions & support to help autistic people maximise their potential and performance in the workplace?
9. How can sensory processing in autism be better understood?
10. How should service delivery for autistic people be improved and adapted in order to meet their needs?

Summary

- Autism has evolved over the last 20 years, and continues to evolve…
- Key shifts include:
  - Higher prevalence
  - Disorder -> Difference
  - Understanding of sex/gender differences
  - Move to more influence by autistic people
- There is an urgent need to improve outcomes
- This is likely to be achieved by improving person-environment fit