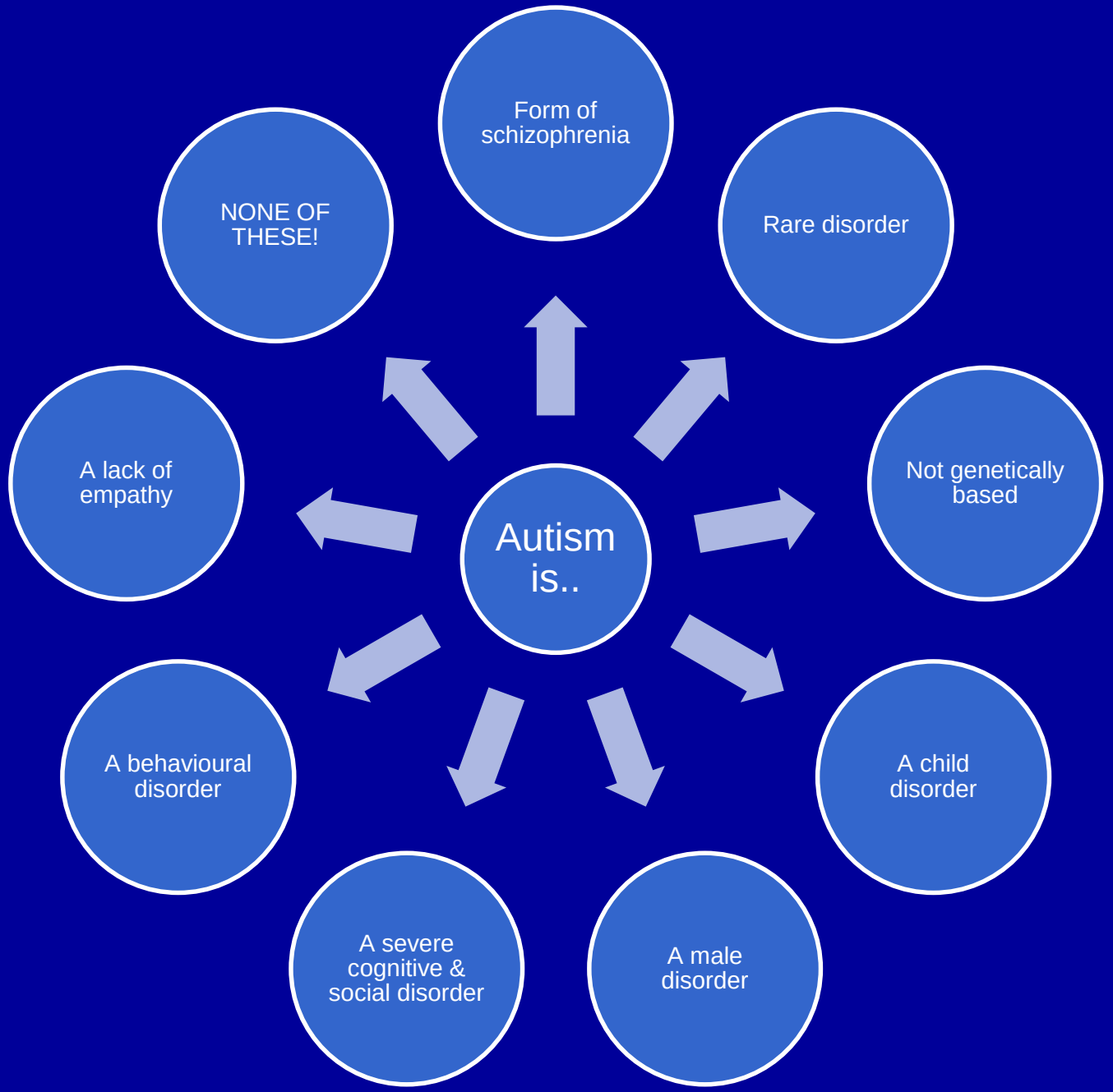
Eight Decades of Autism

Patricia Howlin

Pre- INSAR Meeting, Stockholm

May 2023

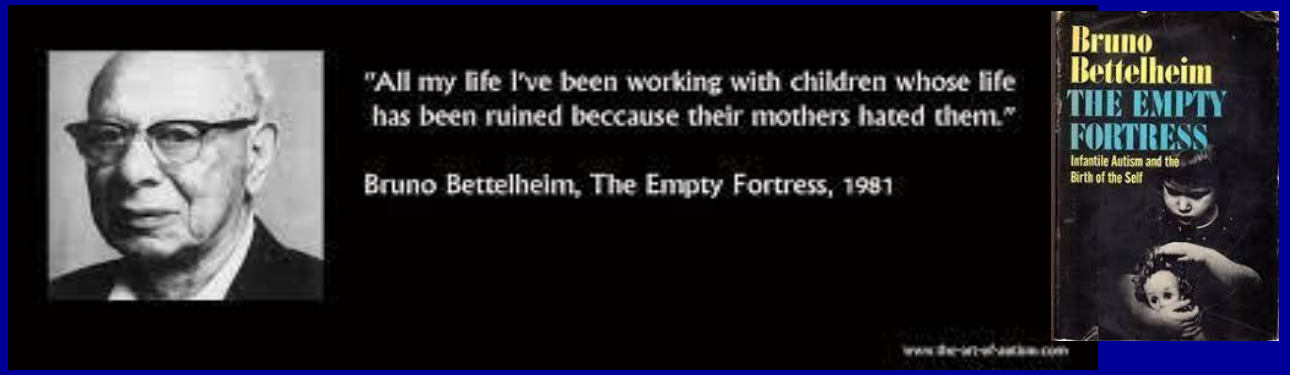

Autism is..
Form of schizophrenia
Rare disorder
Not genetically based
A child disorder
A male disorder
A severe cognitive & social disorder
A behavioural disorder
A lack of empathy
NONE OF THESE!

1.Autism- a form of childhood psychosis/ early schizophrenia

- Kanner (1949)*“ I do not believe that … early infantile autism will at any future time have to be separated from the schizophrenias”*

“Early Childhood Schizophrenia”

“Childhood Psychosis”



1940-50's : Schizophrenia

Parenting style/ emotional coldness

- Psychoanalysis for parents and/or children
- Removal of children to long-stay institutions
- Drug and medical treatments (including ECT) as used for schizophrenia

Changing views

(1965) “*Infantile autism has an identity of its own”*

- Rimland (1964) *“ Infantile autism and childhood schizophrenia are separate and quite unrelated”*

- Rutter (1972) The term *”Childhood schizophrenia” has ceased to have any scientific meaning".... belongs to "the history of psychiatry.”*

2. Autism- a rare disorder

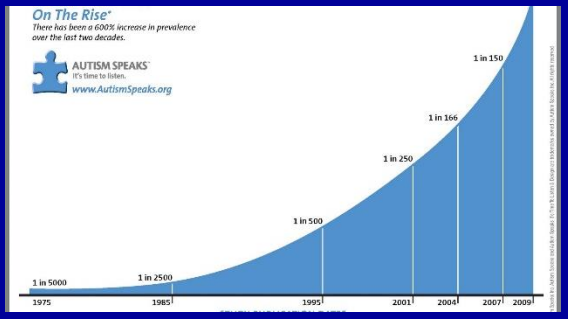
Estimated prevalence

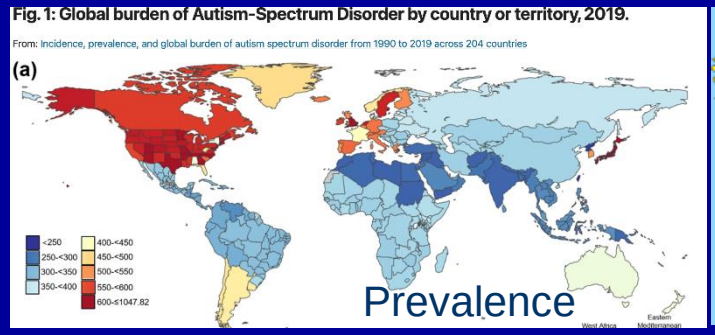
1970's 2-4 per 10,000, ~ **0.02%**

2022 Zeidan et al. **~1%**

But varies across the world –

Lower in <income countries (Solmi et al. 2022)





World discrepancies - major implications for identification & intervention. What are the factors (e.g. gender/early mortality/ services/ etc) that influence prevalence data?
(Solmi et al., 2023)

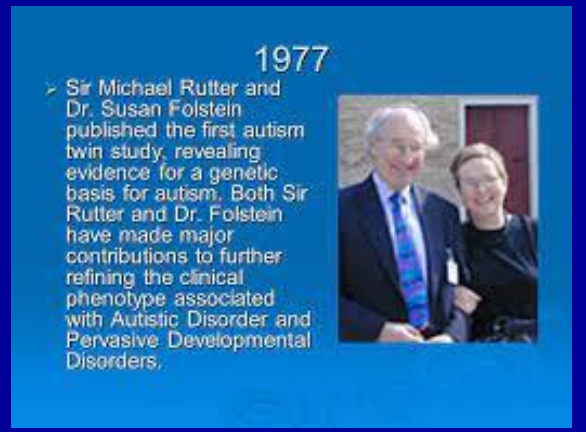
3. Autism- not associated with physical or genetic causes

- Kanner (1951) *No evidence of congenital, cerebral or other physical illnessses. Enquiry into the hereditary element "entirely useless"*

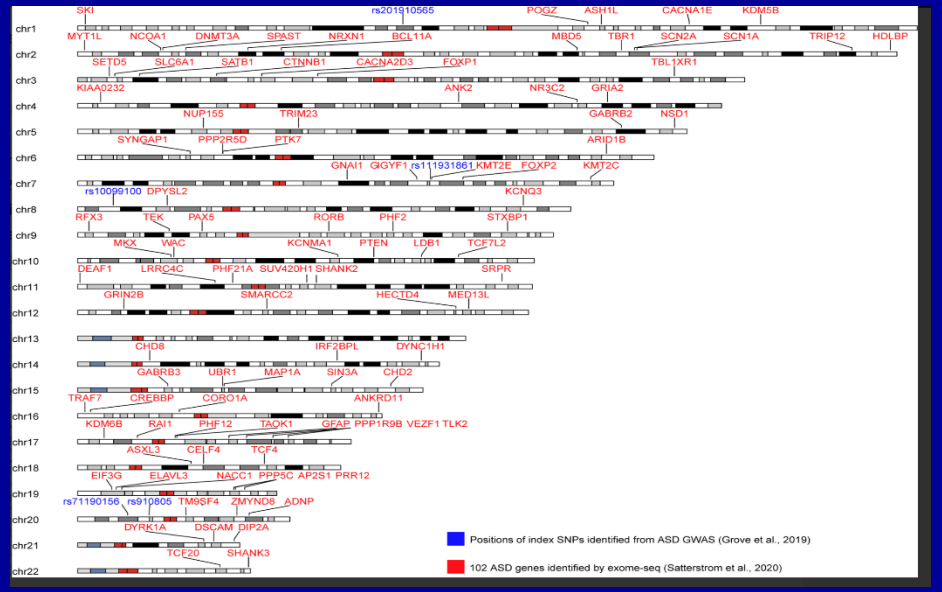
- Rutter (1972): *Notes "potential influence of organic brain dysfunction" but also the "possible adverse influences in the home, the school, and the community"*

- Rutter & Bartak (1971) *"Genetic studies ...disappointingly limited (although may be) a genetically determined type of autism that constitutes a small subgroup of autistic disorders"*

- Folstein & Rutter (1977) first twin studies on "Genetic influences and infantile autism"



- *”Autism one of the most highly heritable disorders with negligible shared environmental contributions. .... rare variants of large effect size & small effect common gene variants all contribute to autism risk. These discoveries challenge traditional diagnostic boundaries and highlight huge heterogeneity in autism*. Thapar & Rutter (2021)



Havdahl et al., 2021 Genetic contributions to autism spectrum disorder

- Rutter (1967) Autism rare in other genetic conditions (e.g. Down syndrome /Cerebral palsy)

- Now: Significantly increased rates of autism in many genetic conditions
  - Cornelia de Lange, Rubinstein Tabi, Prader Willi, Smith Magenis, FraX, Down syndrome & many others (Bozhilova et al., 2023)
- Challenges for identification, diagnosis & intervention

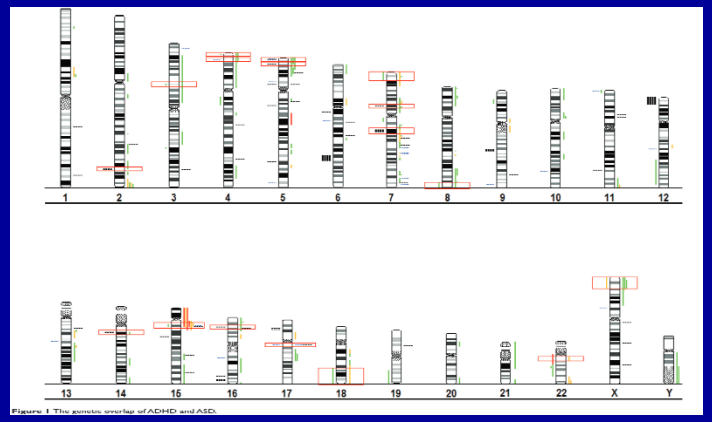





ADHD (exclusion criterion for autism until DSM-5)

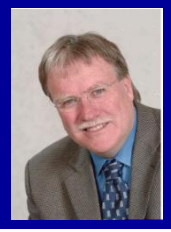
Co-occurrence in 50% to 70%

Significant genetic overlap (Stam et al., 2022)



- Combination may = more disturbance, disruption to education etc .
- Effects of interventions (drug +/- social, behavioural) less predictable
- (Hours et al, 2022)

4. Autism- a childhood disorder



ANI
1992

AANE
Support Groups
2021 - 2022

#AutisticTransPride
ASAN
AUTISTIC SELF ADVOCACY NETWORK
National Center for TRANSGENDER EQUALITY
NATIONAL LGBTQ TASK FORCE

ASAN
AUTISTIC SELF ADVOCACY NETWORK

A4A
AUTISTICS FOR AUTISTICS

Nothing about Autism without Autistics
info@autisticuk.org
UK Autistic
Contact Us

AA CC
AUTISTIC ADVOCACY COALITION OF CANADA

nature
International weekly journal of science

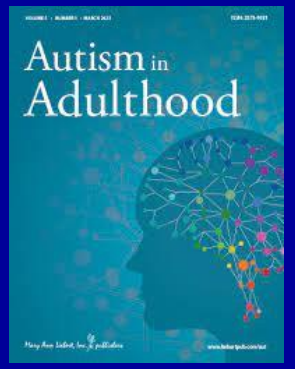
THE LANCET

Autistic scientists, teachers, medics, researchers, innovators, writers, actors, artists, musicians, comedians,influencers, environmentalists, technology, computing, wealthy philanthropists, wealthy non-philanthropists

- ***Changes in specification of diagnostic criteria:***
- DSM-IV

  Evidence of “Delays or abnormal functioning ….prior to 3 years”
- DSM-5
  - “Symptoms may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life”

Adult research increasing- but still very limited (especially for older adults)



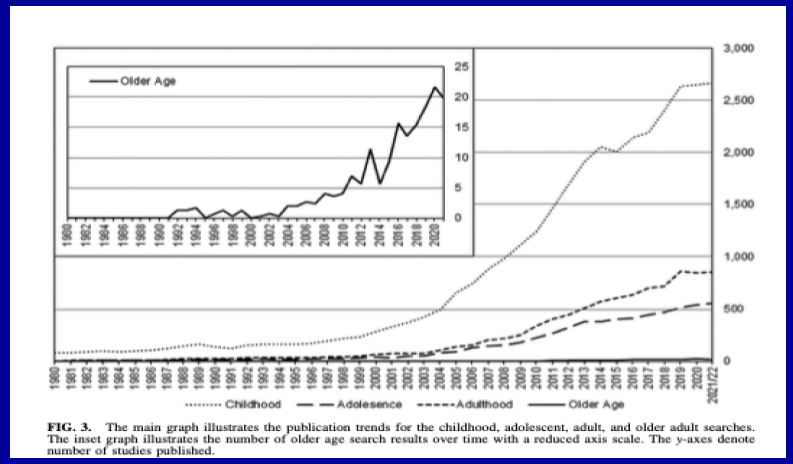
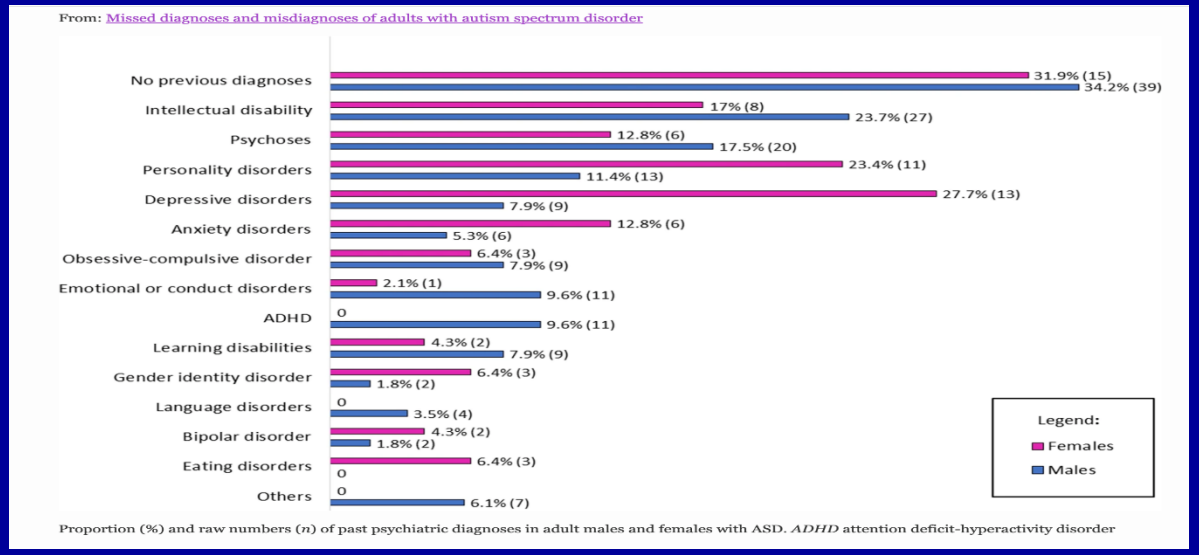


FIG. 3. The main graph illustrates the publication trends for the childhood, adolescent, adult, and older adult searches. The inset graph illustrates the number of older age search results over time with a reduced axis scale. The y-axes denote number of studies published.

”Older adult” papers <1% of all autism research”

(Mason et al., 2022)

- Increasing numbers of late- diagnosed adults (especially wonen)
- Many personal accounts refer to earlier ***mis***diagnoses



N= 161; Median IQ 100 (30-145); Age :Ist diagnosis 13 yrs (range 1-50yrs); autism diagnosis 23 yrs (18-55yrs). Previous diagnoses ID; psychoses, personality disorders

Fusar Poli et al (2022)

Impact of late diagnosis

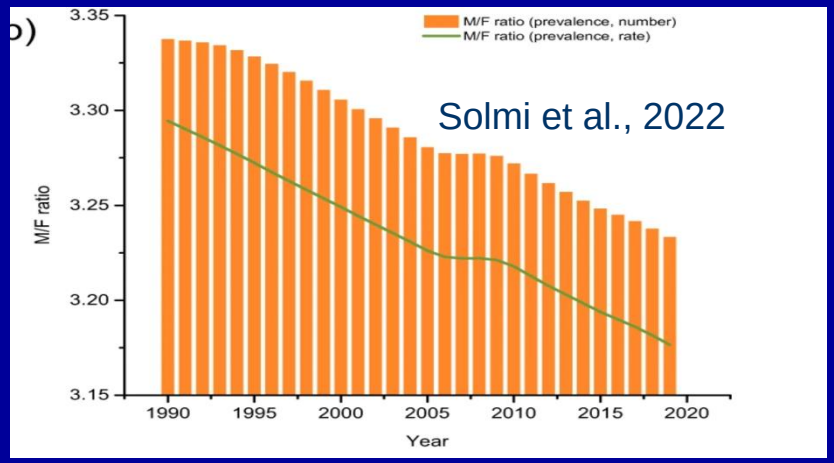
- Childhood- adolescence: > Social exclusion, bullying, isolation, mental health problems

- Adulthood-Response to late diagnosis mostly positive
  - (Huang et al., 2020- sytematic review of 82 studies)
- Relief & >understanding of difficulties for individuals & families/partners
- Increased self esteem/ self-worth/ feeling of belonging/ empowerment
- >Access to
  - support & interventions for mental health problems
  - autism groups/forums
  - social & environmental adaptations (work college, family)

5. Autism- a male disorder

- Initial estimates 4:1 (?10-1 in high IQ groups).
- Now ~ 3:1 and falling

(Burrows et al., 2022 Loomes et al., 2017, Posserud et al., 2022)



Solmi et al., 2022

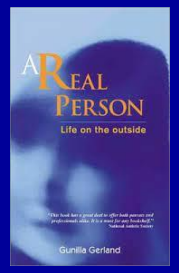
- DSM-5 recognises issues of diagnosis in females

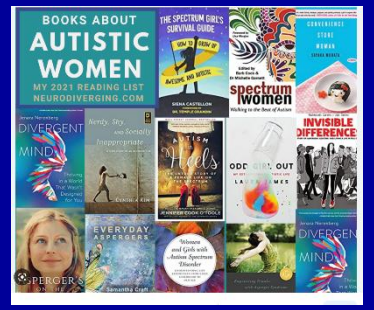
  “Girls without accompanying intellectual disability or language delays may go unrecognized, perhaps because of subtler manifestation of social and communication difficulties”

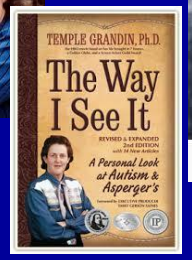
- And patterns of interests(makeup, pop stars, films)

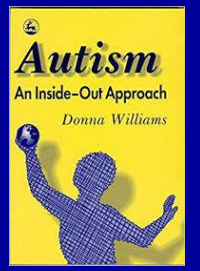
- 1980-90’s influential females regarded as “exceptions” rather than examples of how autistic women feel/ act/ achieve
- Early accounts/ research- few references to females- highlighted more severe intellectual impairments
- Gradual awareness of :
  - male: female differences;
  - inadequacy of standard assessments/ diagnostic instruments (Milner et al., 2023)
  - camouflaging- & impact on mental health/ quality of life

(Cook et al. 2021, Tubio-Fungueiriño et al., 2021)









6. Autism- a severe cognitive & social disorder

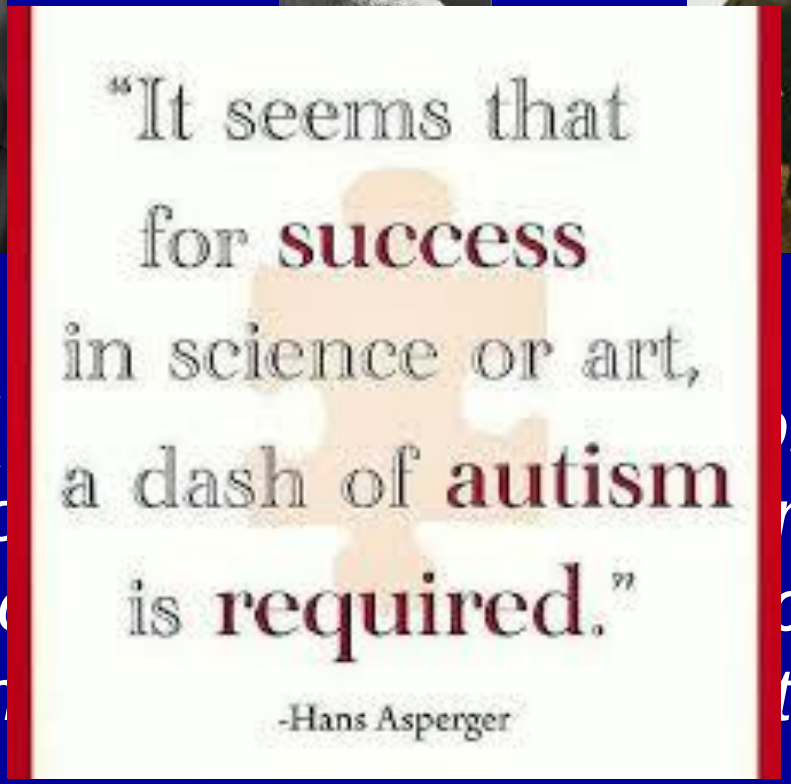
- Kanner (1943/1949) *" Profound withdrawal from contact with people", "extreme emotional isolation", "persisent lack of responsiveness". "Symptom combination in most instances warrents an unequivocal diagnostic formuatiion*".

- DSM-IV- TR *" In most cases ...an associated diagnosis of mental retardation.. Gross deficits in language development"*

- *" A devastating condition" (EU Healthcare and Social Care News, Feb 2020), "Having a child diagnosed with autism can be devastating" (Stem- therapy "cure" advert 2023)*

- **Fact** ~ 60% develop useful speech (Tager Flusberg & Kasari, 2013) 60-70% IQ in average (70+) range (MacKay et al., 2018)

Strengths based approach to intervention/education



- Asperger(*rity of cases work perfo nt, and with this comes soc cular line of work ofter their special abilities..”*

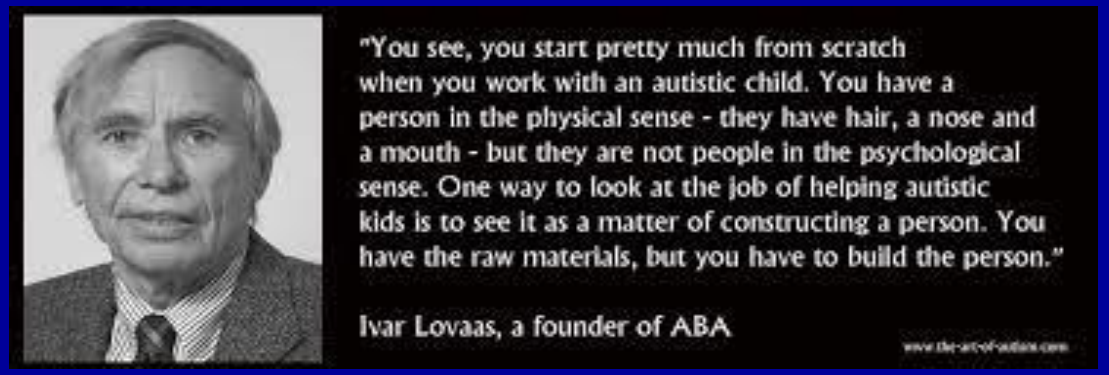
- ~60% of autistic individuals have an exceptional cognitive or other skill (Uddin 2022)
  - Bal et al. (2022) 46% of 1470 children had social talent; + 23 % a personal strength
  - Memory, Visuo-spatial, Numbers/dates, Music, Spelling/reading, Art
- Strengths based focus can improve quality of life, mental health, educational & employment prospects

- Self reported use of personal strengths : > Qol & well being ; < anxiety, depression and stress (Taylor et al. 2023; Urbanowicz et al,2019)

- ? How best to enhance/facilitate this potential for education, work, social integration (Halder et al., 2022)

7. Autism -a behavioural disorder

Implications for intervention…



1960's Focus on "challenging" behaviours

Time out; extinction; withdrawal of rewards; physical punishment, electric shock

Little attention to normal developmental stages/learning processes

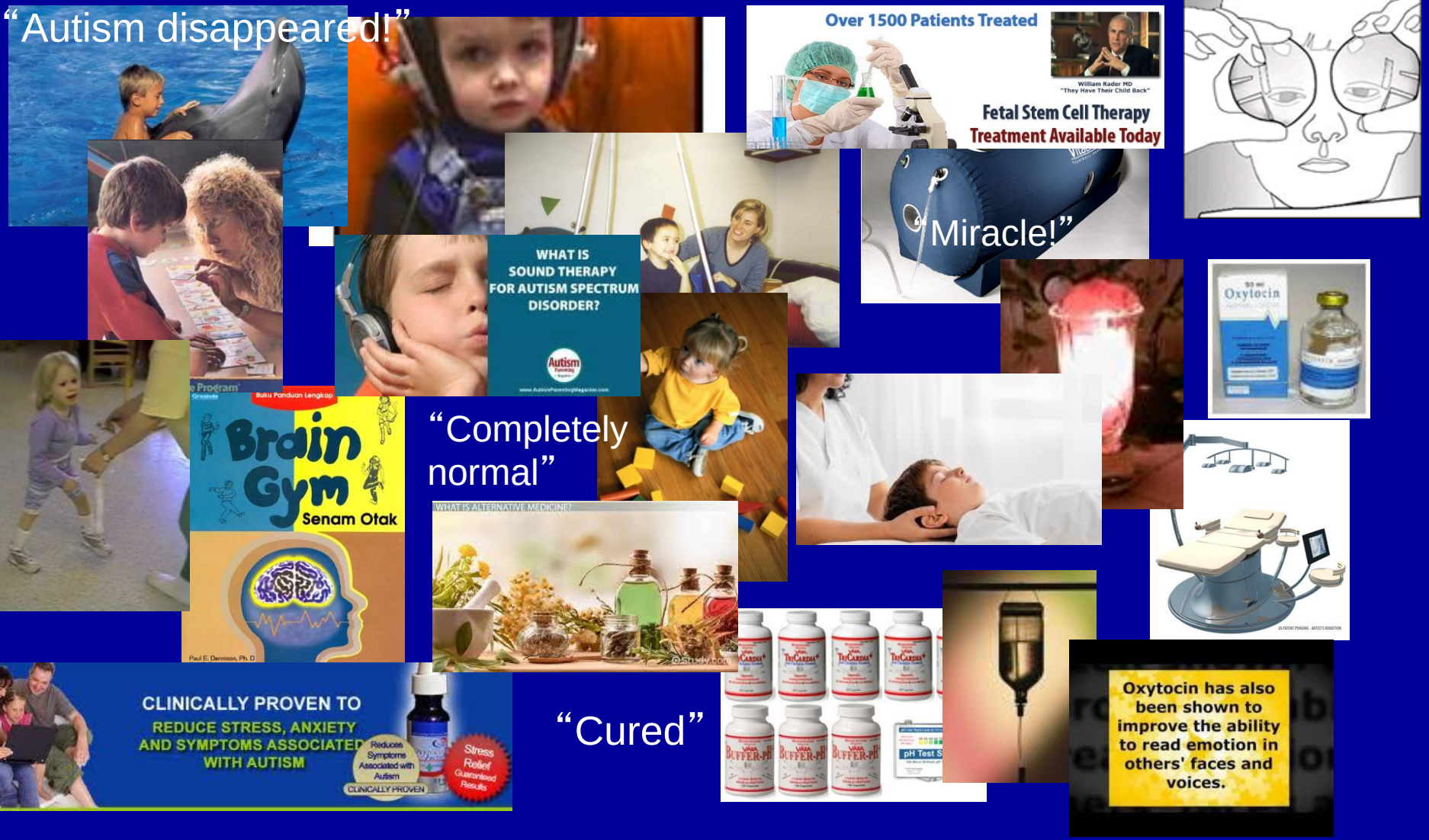
Limited involvement of /high demands on families

Unwarranted claims

"Normal intellectual and educational functioning" in 47% of children receiving this intervention (Lovaas, 1987)

"Early Intensive Behavior Intervention …saves up to $2.500,000 per individual over the lifetime". (*Jacobson et al. 1998)*

Also rise of “alternative” interventions



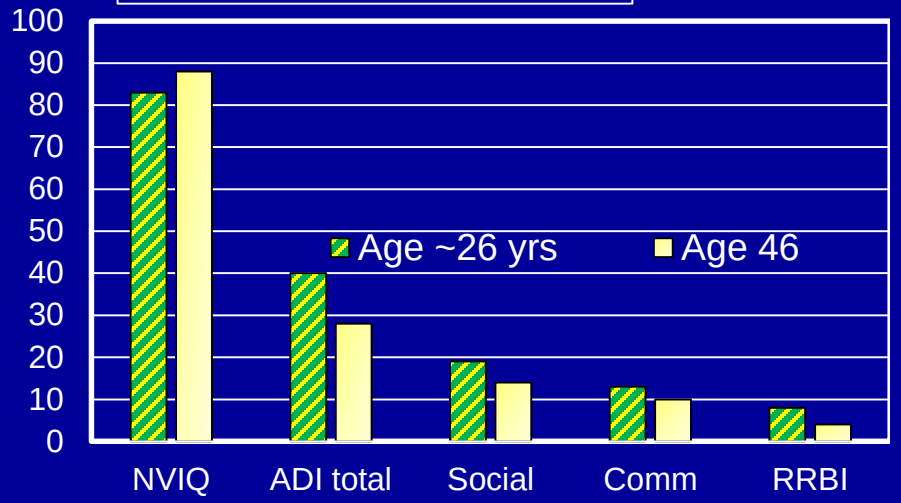
Now.... focus on adult-child synchrony, social-communication interaction, daily life issues

- But limited evidence on :
  - Long term effects- impact on adulthood
  - Optimal age (cf Guthrie et al., 2023)
  - Optimal strategies - which interventions work best for which children/which families

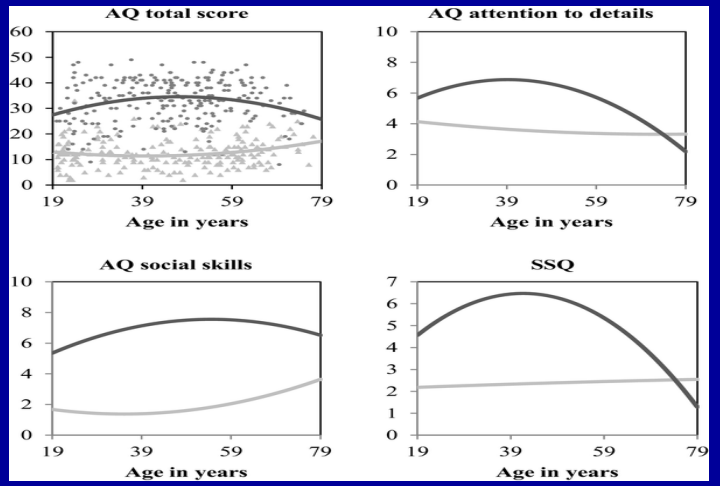
8. Autism -increased problems in adulthood; outcomes poor

Age related changes in IQ,autism traits,QoL

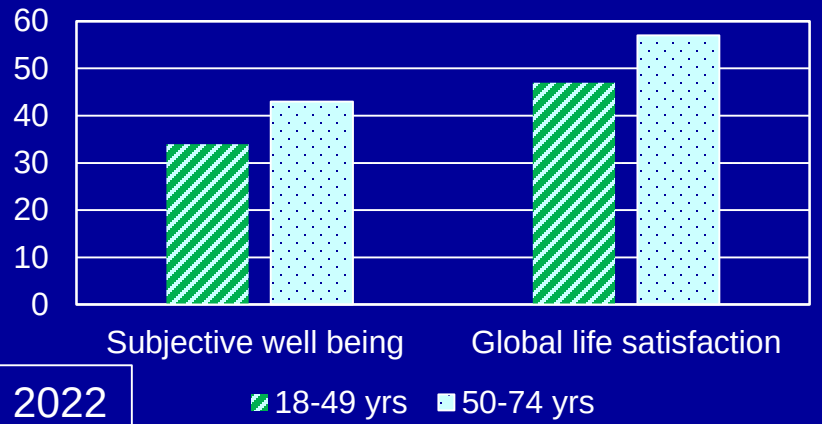
Howlin et al., 2003- 2013



Lever & Guerts, 2018



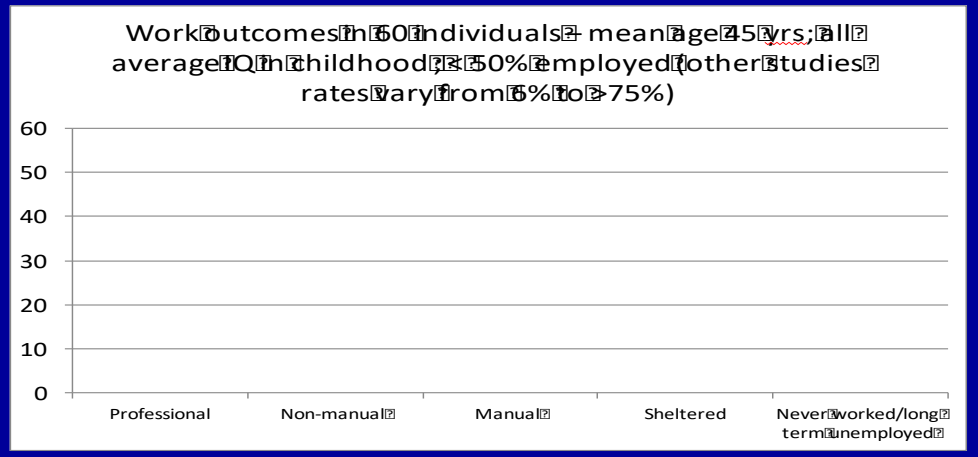
QoL (adults </> 50 yrs)



Yarar, Roestorf et al, 2022

But :

- Higher risk of mental and physical health problems
- **General outcome**, as measured by standard assessments (independent living, jobs, relationships, Quality of Life) generally rated as poor even in comparison with other disadvantaged groups.



What is a good outcome?

- Danger of reliance on "neurotypical" norms
- Higher social/occupational attainments may come at the cost of poorer mental health; lower QoL
- Inconsistent relationships between:
  - objective & subjective measures
  - self & proxy reports

Need measures that "*capture diversity across the spectrum…describe progress on a wide range of domains*"
(Georgiades& Kasari; 2018)

"Person-environment fit" the crucial issue
(Henninger & Lounds Taylor, 2013)

9.Autism - a lack of empathy

Autism-a *double* empathy problem

"A different embodied way of being that can lead to effects on social interactions and understanding"
(Milton [2022] The double empathy problem: 10 years on.)

" Misperceptions by the typical majority "– lead to isolation, & affect health and behaviour of autistic people. (Mitchell et al., 2021)

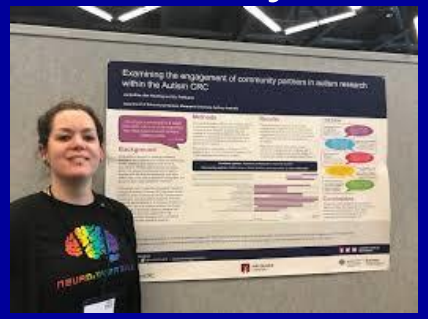
Autism-a *double* empathy problem

Needs – Milton et al.2021

- A more continuous understanding of neurodiversity and ‘recognition’ *not* ‘diagnosis’ of autism
- Identify sources of mutual misunderstanding
- Awareness of how differences in the social lifeworld of autistic and non- autistic unfold at the macro (i.e. lifespan/development) and micro level (e.g.social relationships at work or school).
- Inclusion of both autistic and non- autistic stakeholders in every stage of future research

10. Autism –
NOT A DISORDER!

- “Paradigm shift” in autism research- from “normal science” to “neurodiversity in autism science”

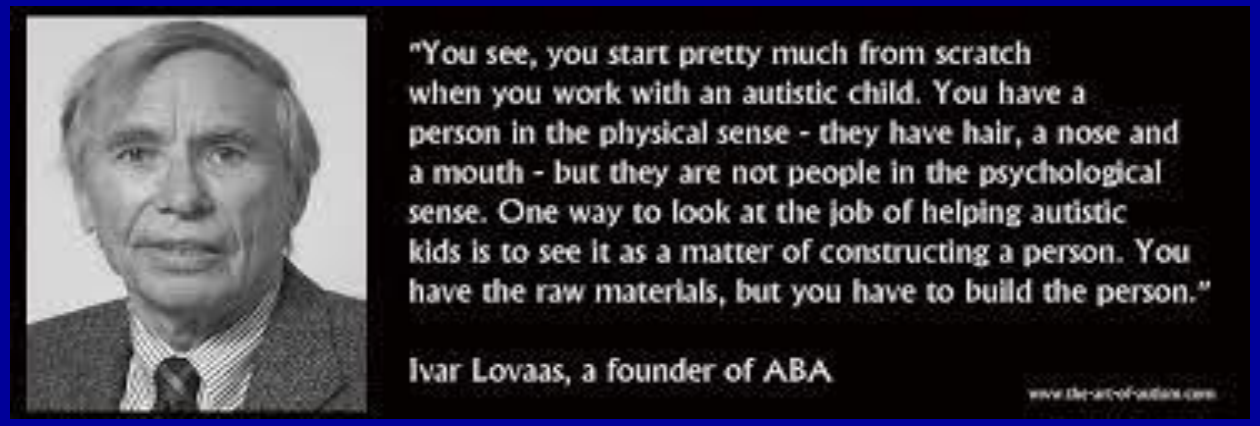


Pellicano, den Houting , 2022

- Focus on Neurodiversity/ Neurodivergence includes...
  - strengths-based approach not focus on areas of difficulty
  - recognising & exploring bias in autism research
  - language that avoids negative value judgements
  - learning and using ideas, theories, and concepts used by autistic people
  - collaborating with community stakeholders using participatory methods. (Dwyer;2022)

- Need
  - social, environmental & attitudinal changes among the neurotypical population to meet the needs/facilitate the development of those who are neurodiverse

  - and undo the long-term damage of early concepts and " treatments" for autism (Anderson, 2023)



Identity (Autism) or Person First Language? (IFL vs PFL)

- US/ UK on-line surveys preference for IFL (Taboas et al.(2022) Autism Survey. N=728. 87% >IFL)

- Netherlands (Buijsman et al. 2022): N=1300; 68% adults; 82% parents >PFl (younger, higher IQ adults more likely to prefer IFL)

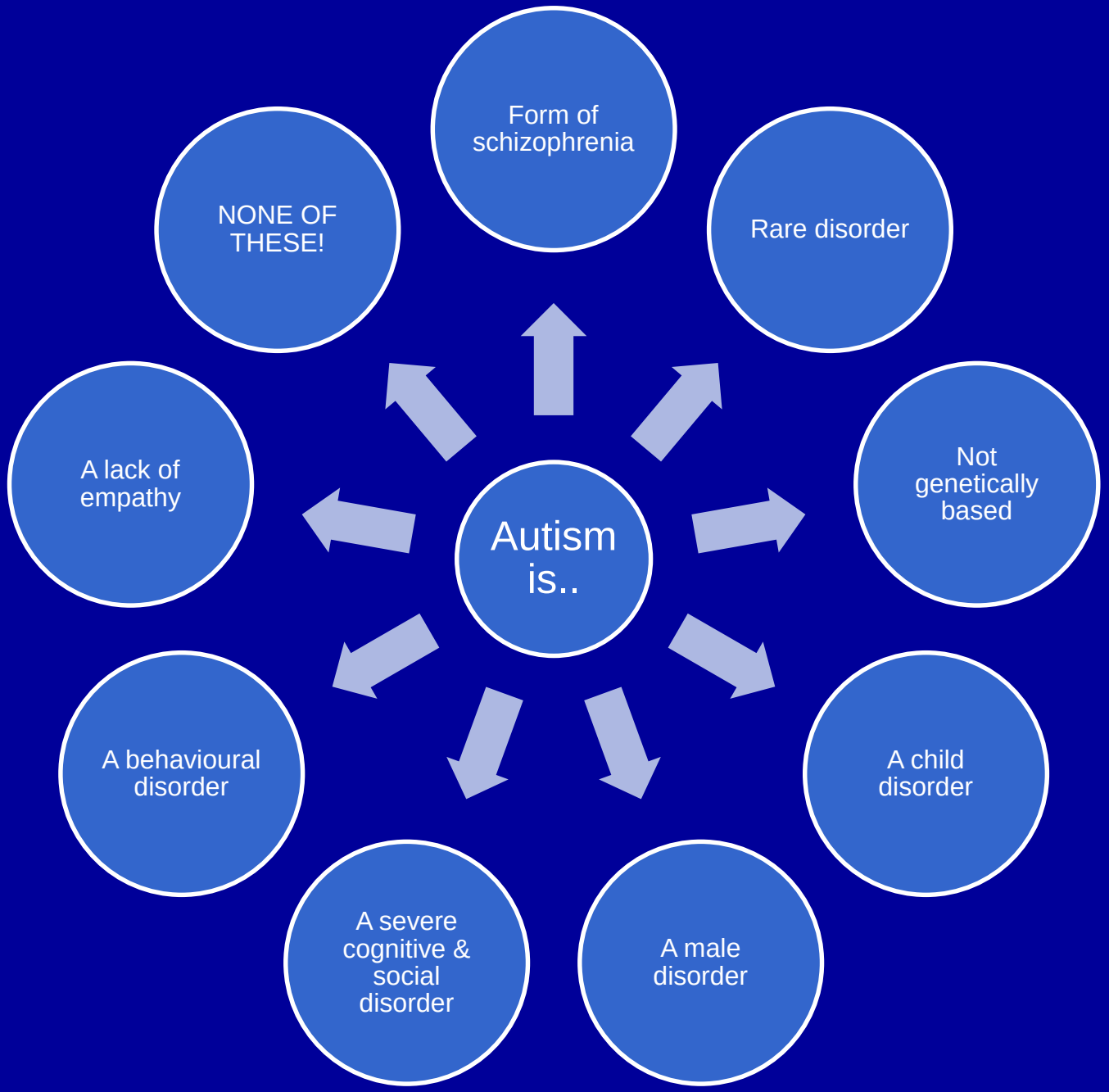
- Age, culture, and personal choice all important- suggest researchers use a mix of language - clinicians be guided by individual's personal choice

IFL reflects more positive self-perception of autism

- *“It defines who I am”*
- *“Autism makes me who I am. …an integral part of who I am. It affects the way I think, communicate and socialise”.*
- *“Identity versus person shouldn’t be a thing because they are one and the same. I am autistic. It’s not an item I carry, can put down, it’s who I am.”*
- *“Autism makes my brain work somewhat different at a fundamental level, and thus it is fundamental to who I am. Identity first all the way for me. Plus it’s much less clunky to say.”*
- (Botha et al 2020; Keating et al., 2022)

Family of 50 yr old, severe intellectual and communication difficulties. Told by social services that their language was “disrespectful”

“He’s NOT an autistic, he’s my son/grandson /brother ...its him that makes him what he is, why we love him..... not his condition”


Autism is..
Form of schizophrenia
Rare disorder
Not genetically based
A child disorder
A male disorder
A severe cognitive & social disorder
A behavioural disorder
A lack of empathy
NONE OF THESE!