

What is Autism and does it matter?

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Bleuler 1911



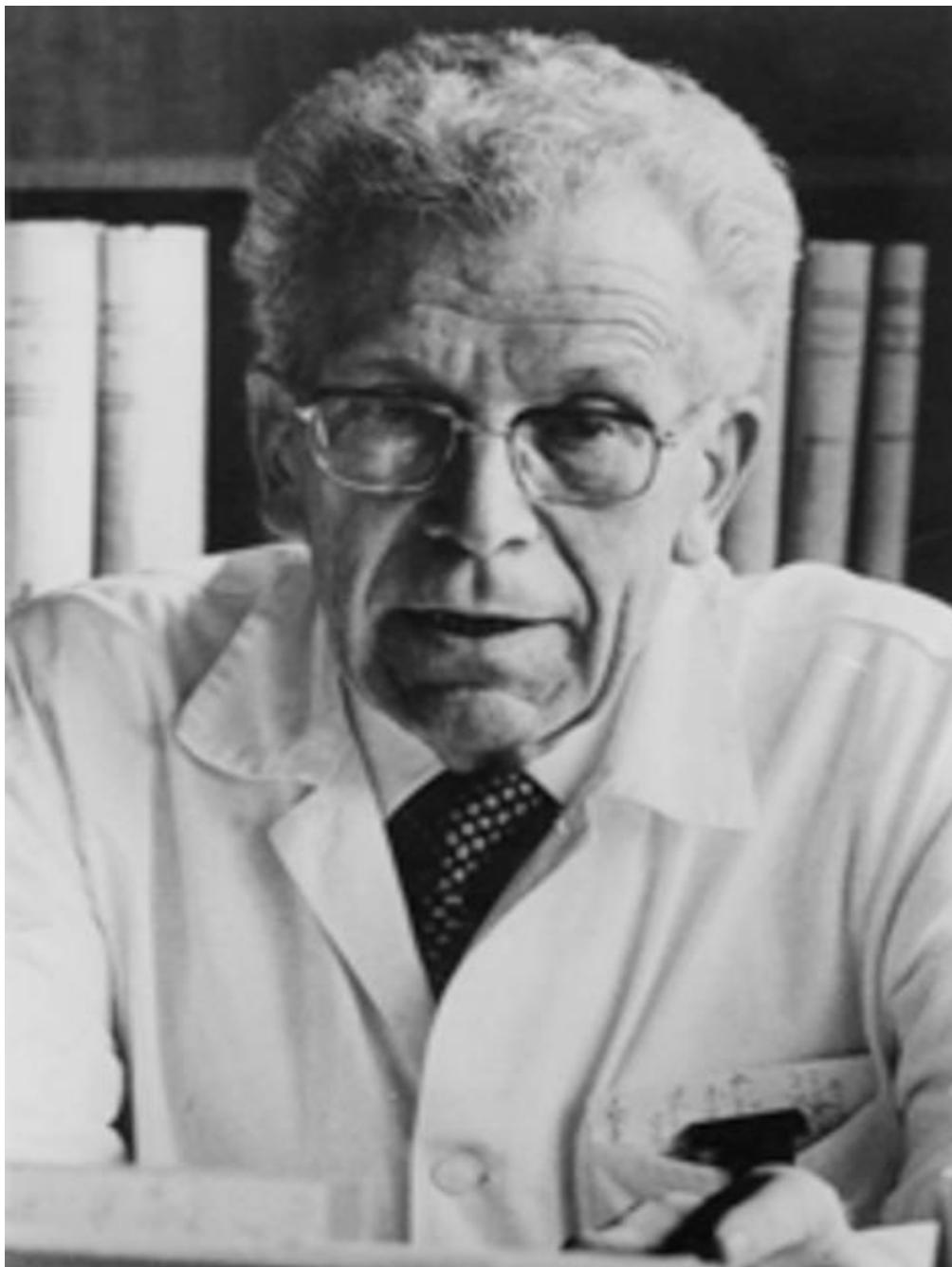
In 1911, the psychiatrist Eugene Bleuler first used the term 'autistic' to denote the state of mind of psychotic individuals who showed extreme withdrawal from the fabric of social life.

Kanner 1943

Describes a group of 11 children of middle class parents who were emotionally and intellectually impaired and showing an extreme ‘aloneness’ from early life.



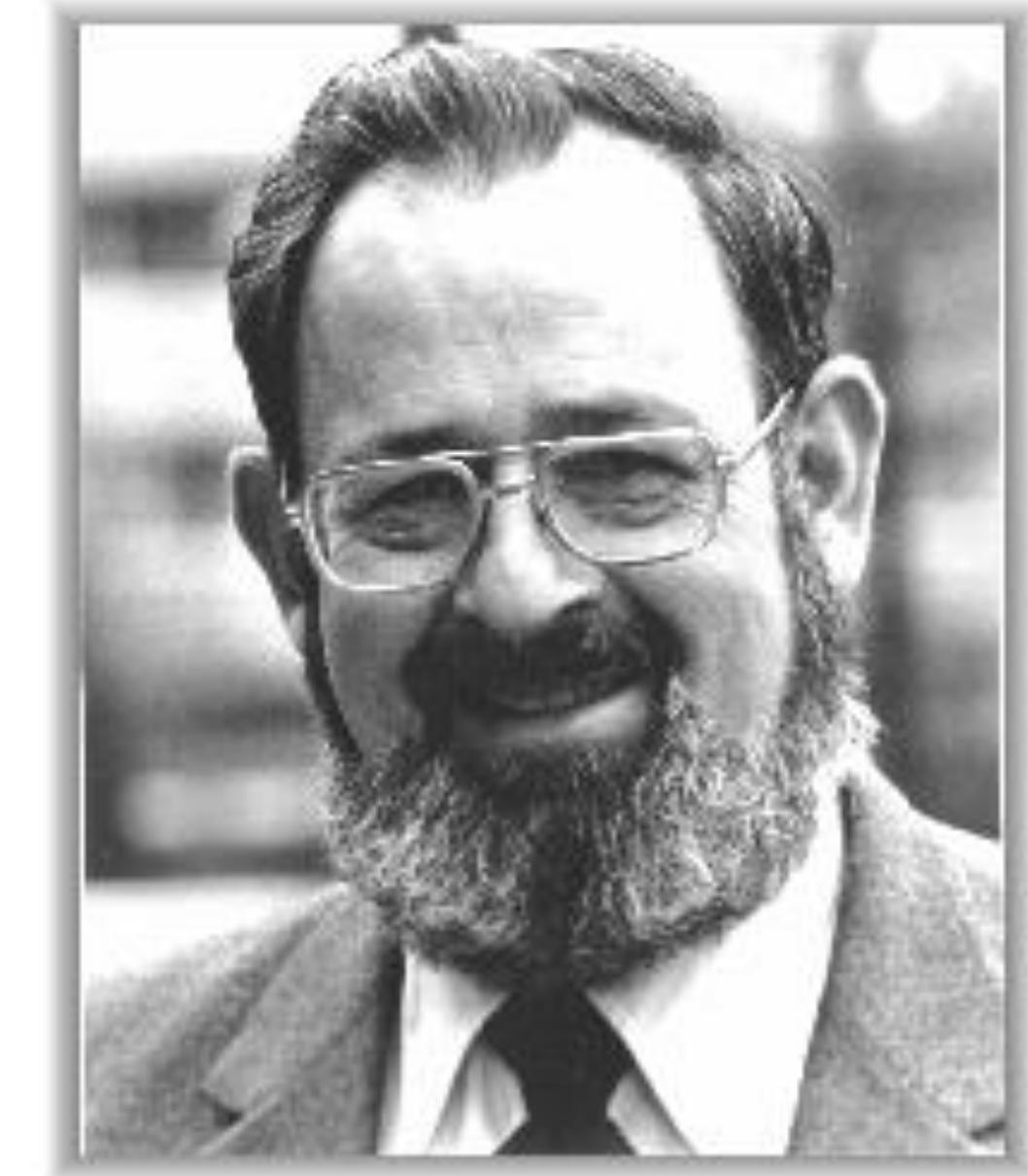
Asperger 1944



Works in Vienna and publishes a paper, largely ignored at the time, in which he described 4 children with no easily recognisable intellectual impairment, but with social communication problems described as ‘manipulative’, ‘vindictive’ and ‘analytical’.

Bernard Rimland 1964

- Psychologist who had son diagnosed with autism.
- Disagreed with ‘refrigerator parent’ theory.
- Book ‘Infantile autism’ 1964, has ‘tick-list’ of symptoms to look for.



Creating the spectrum 1980s



Lorna Wing: in 1981, describes 6 cases with little in common with Asperger's classic four cases beyond sharing a lack of social reciprocity.



Michael Rutter Defined the 'triad' and argued that autism and its spectrum is beyond doubt genetic in origin

Disintegrating concept



Happe (2006): suggests that it is time to give up on the search for a monolithic cause or explanation for the three core aspects of autism, at the genetic, neural and cognitive levels

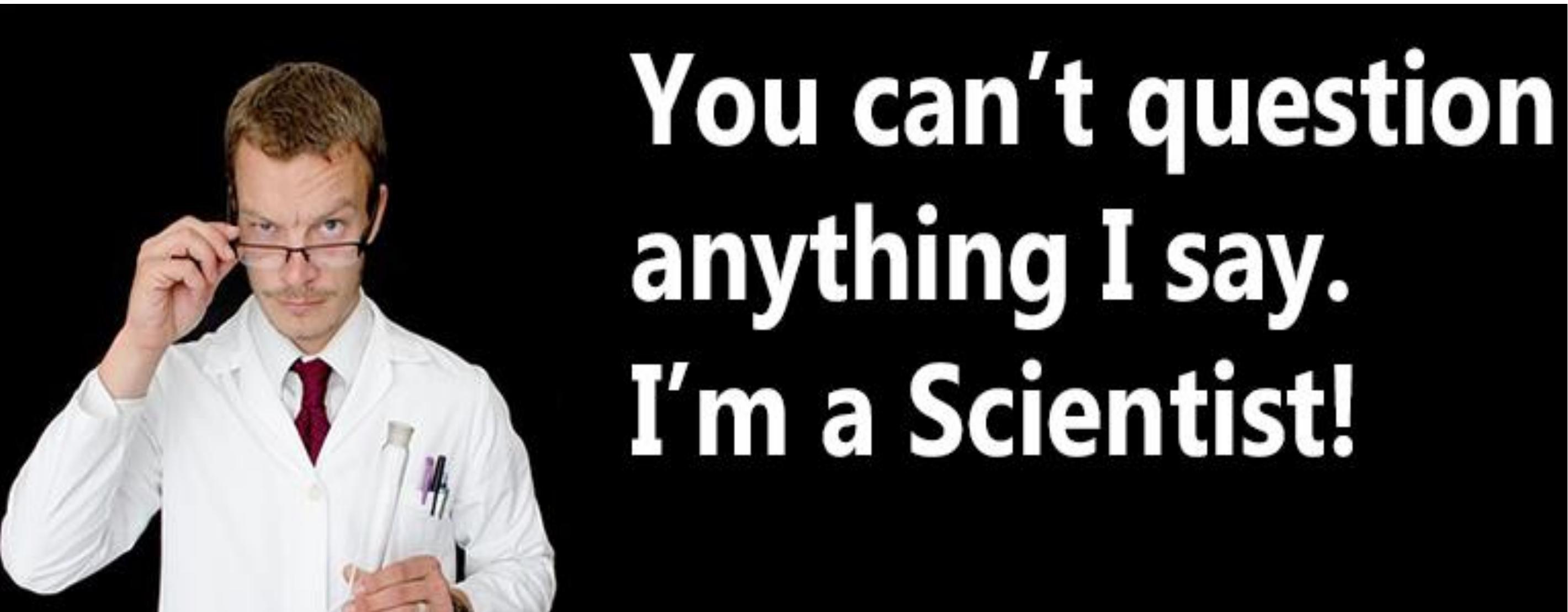


Baron- Cohen: (1997): develops the empathising-systematising theory: Autism is extreme of systematising ‘drive’.

ASD: a disintegrated concept

- **Waterhouse, London, Gillberg (2016)**: “ASD should be disbanded in research because it lacks validity”.
- **Muller and Amaral (2017)** "Replication rates in ASD neuroimaging research have been unacceptably low ... the field has been outstandingly productive in generating thousands and thousands of findings reaching statistical significance in one or the other cohort, but disappointingly incapable of creating a coherent picture of neurobiological features underlying ASD".
- **Al-jawahiri and Milne (2017)** “This heterogeneity is potentially a major factor impacting on the rate of replication of ASD studies, and is leading some researchers to give up on a single explanation for autism and others to propose the possibility that ASD should not be considered as a single disorder .. Instead, they suggest that within ASD, there could be groups of distinct disorders with many aetiologies”.

The spread of ‘Scientism’

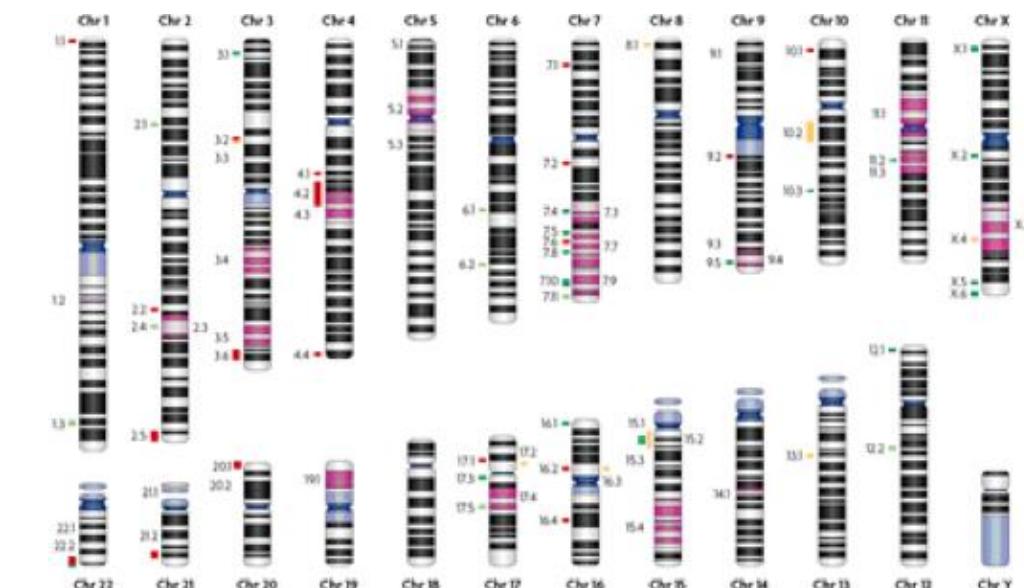


In psychiatry there are no diagnoses

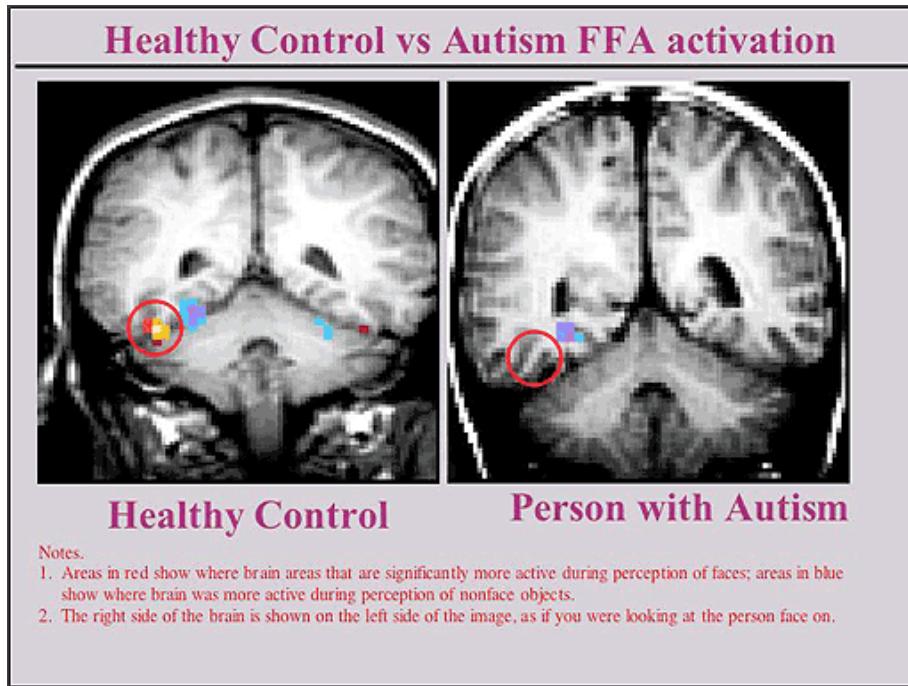
- Diagnoses in psychiatry cannot explain (except dementias).
- Consider the question ‘What is ADHD?’ and compare with the question ‘What is diabetes?’
- Consider what happens when we argue that ‘ADHD causes poor hyperactivity and inattention’.
- In psychiatry we have **classification** (that is descriptive) not diagnosis.
- Ecosystems use multiple classifications – more appropriate for context-rich and dynamic open systems.

Genetics and autism

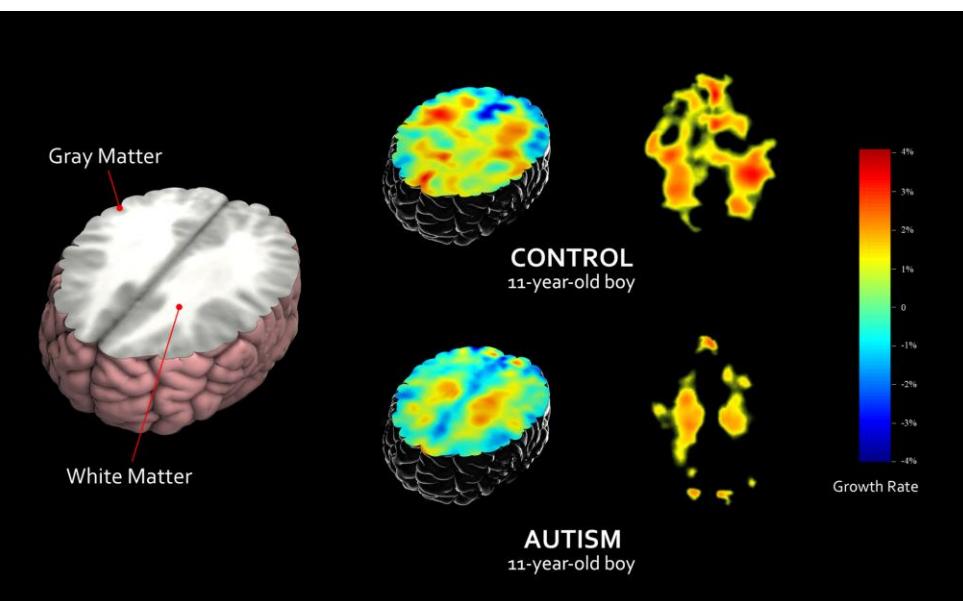
- Assumed high heritability based on twin studies.
- “Many research teams have searched for genes that may be involved. They haven’t turned up any prime candidates yet, only dozens, maybe hundreds of bit players” (Hughes, 2012)
- “First Genome Wide Association Studies (GWAS) on autism implicated two regions with mild effects.. subsequent GWAS failed to turn up any parts of the genome with statistical significance” (Williams, 2012)
- “With the advent of next generation sequencing techniques, the number of genes found that are associated with ASD is increasing to over 800 genes; consequently, it is becoming even more challenging to find unified explanations and functional associations between the genes involved.” (Al-jawahiri and Milne, 2017)



Neuroimaging in autism



- Lack of consistently replicated findings. e.g. studies documented an increase in cerebellar volume, smaller than average, and no significant differences. sample heterogeneity (such differences reflecting IQ differences) regular problem.
- Technical challenges: Brain connectivity theory replicated by head movement.
- “Until its biological basis is found, any attempts to use brain imaging to diagnose autism will be futile” Lange (2012)
- “A Bug in fMRI Software Could Invalidate 15 Years of Brain Research” (2016).



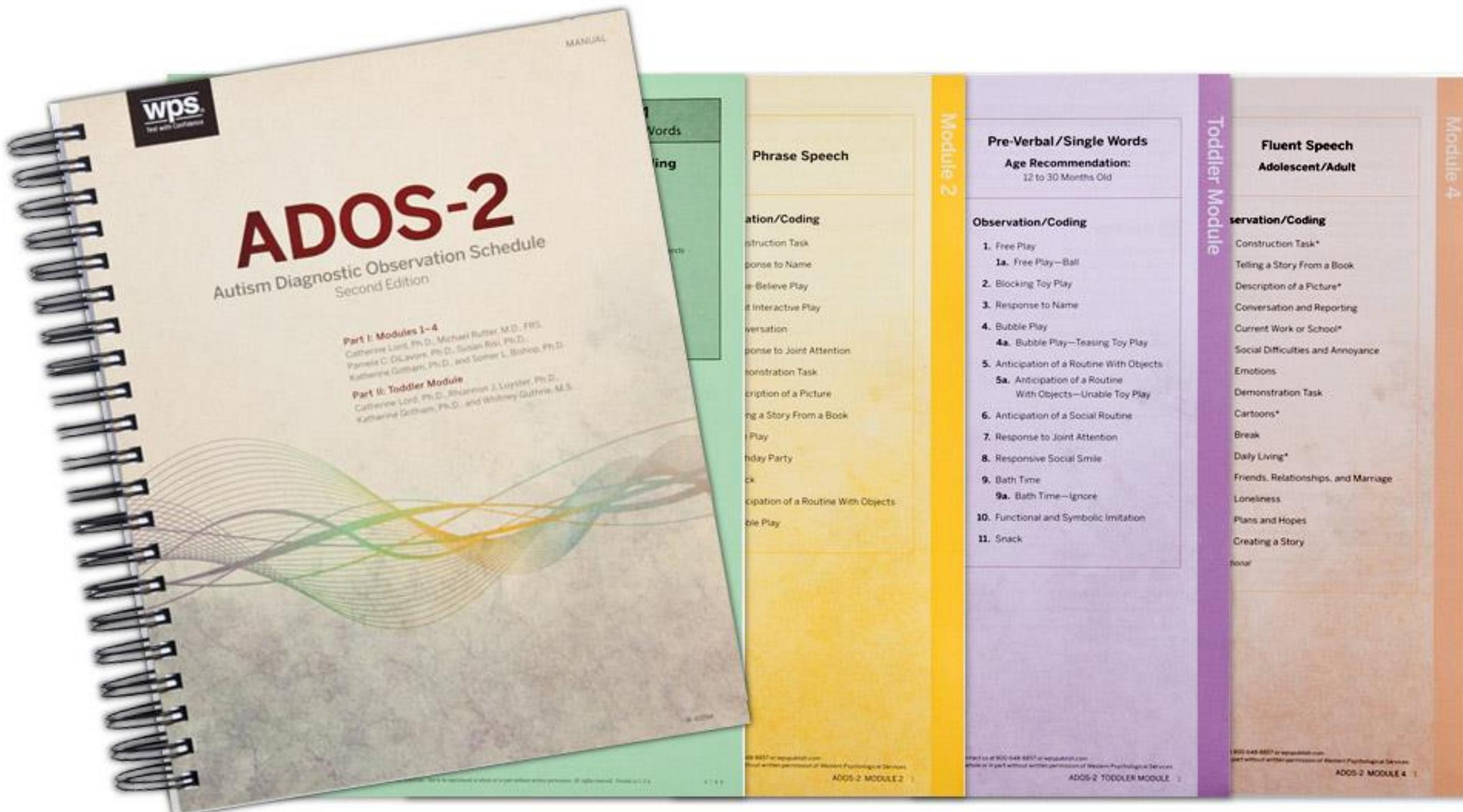
Debate with colleague in March 2017

- Person debating with me put forward 3 papers, summarising the evidence on the ‘biological basis’ for ASD.
- Chen et al (2015) Limbic and Cerebellum.
- Ecker et al (2015) Frontal, Temporal lobes and Cerebral Cortex.
- Fakhoury (2015) Balance of excitatory and inhibitory synapses.
- No attempt in the papers to control for or even mention of ID as a confound.

Heterogeneity in Autism

- **Poor social reading:** Language disorders, ADHD, anxiety, depression, personality disorder, attachment disorders, bipolar affective disorder, psychosis, learning difficulties, a sense of alienation, cultural difference, normal variation, deliberate provocation, boredom, a strong desire for attention, love etc.
- **Restricted interests:** OCD, obsessional personality disorder, schizoid personality disorder, ADHD (such as with computer games), depression (morbid preoccupation with negative aspects), eating disorders (fixation with food and/or weight), most men (e.g. with football), sportsmen and women, and humanity: If someone had not fixated long enough on the tendency of logs to roll down slopes, the wheel may never have been invented!
- “Each person with autism has a different combination of symptoms, and the combination may change over that person’s lifetime” Hughes (2012)

Autism ‘tests’



So what is autism?

Supplement in Nature 2012

The Psychologist 2014

“we still don’t really know what autism is, despite decades of autism research”



nature OUTLOOK



support from:
arks Family Foundation,
ndation, Roche, Autism Speaks,
Science Foundation

Illuminating a
diverse disorder

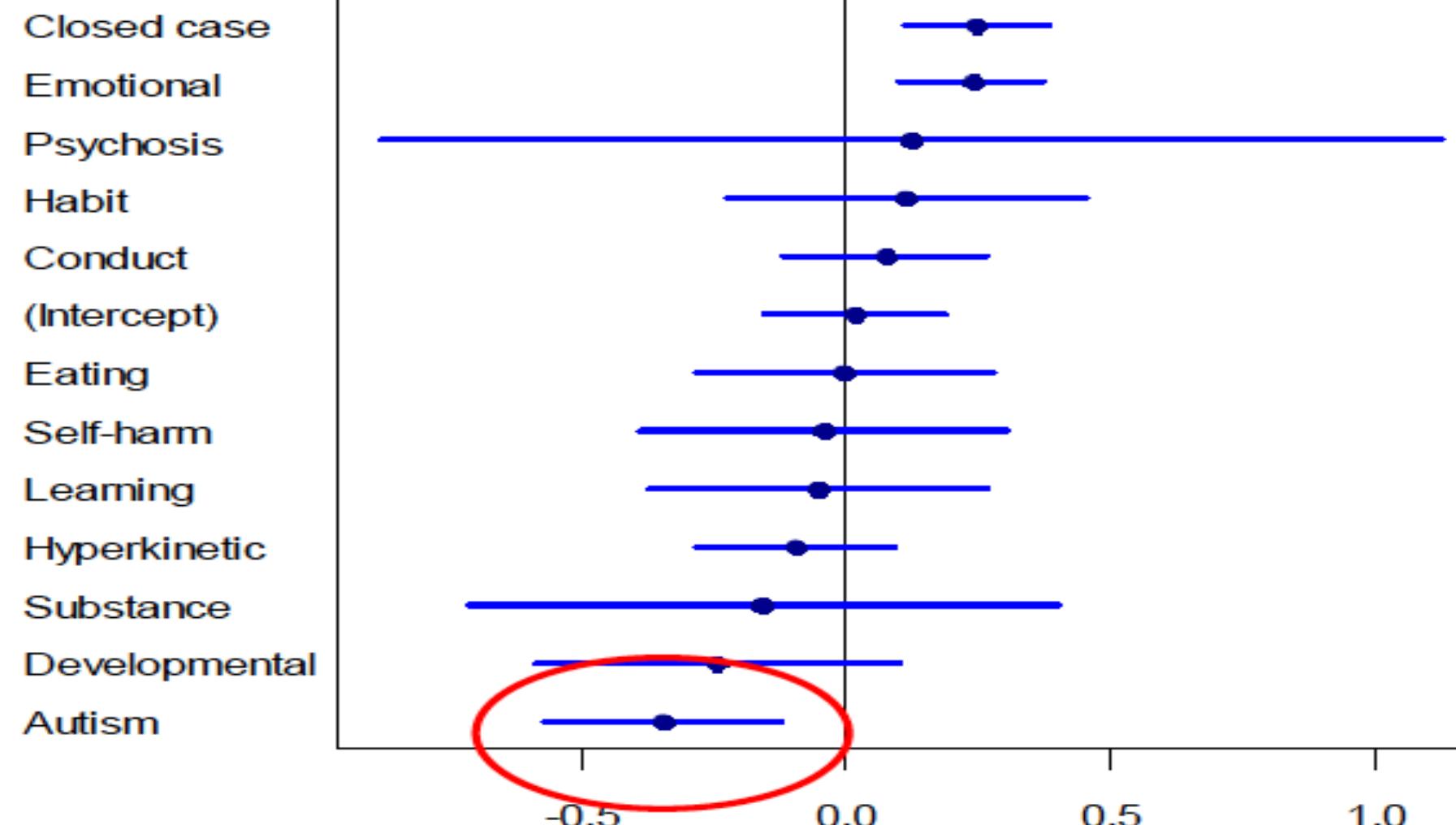
Autism is a fact of culture not
a fact of nature



Does diagnosis improve outcomes?

Outcome on SDQ
after 6 months or
discharge:
Added Value Scores
(AVS)

Moderators of the AVS



What does this indicate?

Outcomes for autism

- The same behaviourally defined syndrome (ASD) is applied to residents of institutions with little hope of living independently and has been suggested for men who have achieved greatness (such as Mozart, Van Gogh, Edison, Darwin, Einstein).
- “Recent prospective studies - a substantial proportion of subjects (24%) having a ‘very good’ outcome.” Szatmari (2011)
- “The results substantiate the possibility of optimal outcome from autism spectrum disorders and demonstrate an overall level of functioning within normal limits for this group” (Fein et al, 2013)

Treatments in autism

- “There is very little evidence that any treatment alters the core symptomatology of ASD ... For these reasons no definite recommendations can be made about individual therapies. There is also emerging evidence that some therapies previously advocated by professionals and parents, such as auditory integration therapy are no more effective than placebo whilst others (such as Facilitated Communication) are now discouraged because of adverse side effects or other risks to the child” (National Autistic Society, 2003)
- The example of Risperidone.

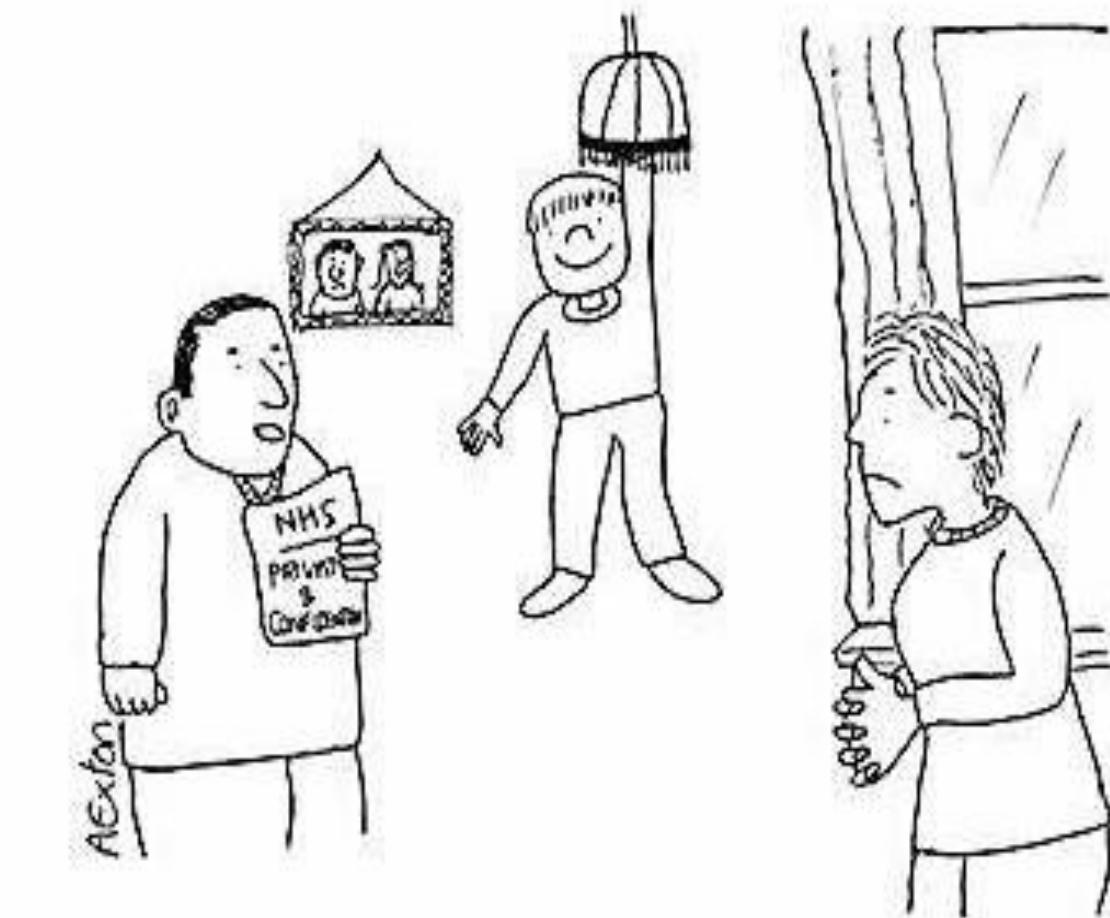


Questionable clinical utility

- **NICE guideline 142:** 25 papers that reached acceptable levels: 15 were on people with Intellectual Disability, 3 were on people with ID and Autistic Spectrum Disorder, leaving 7 without ID. Approaches recommended do not significantly differ from approaches that would be used for anyone with an ID.
- TEACCH and PECS etc. consist of broad behavioural, cognitive and communication principles – nothing that could be thought of as ‘autism specific’.
- Dangers: Stratified services (autism privilege), reified services (autism as barrier – needs an expert).

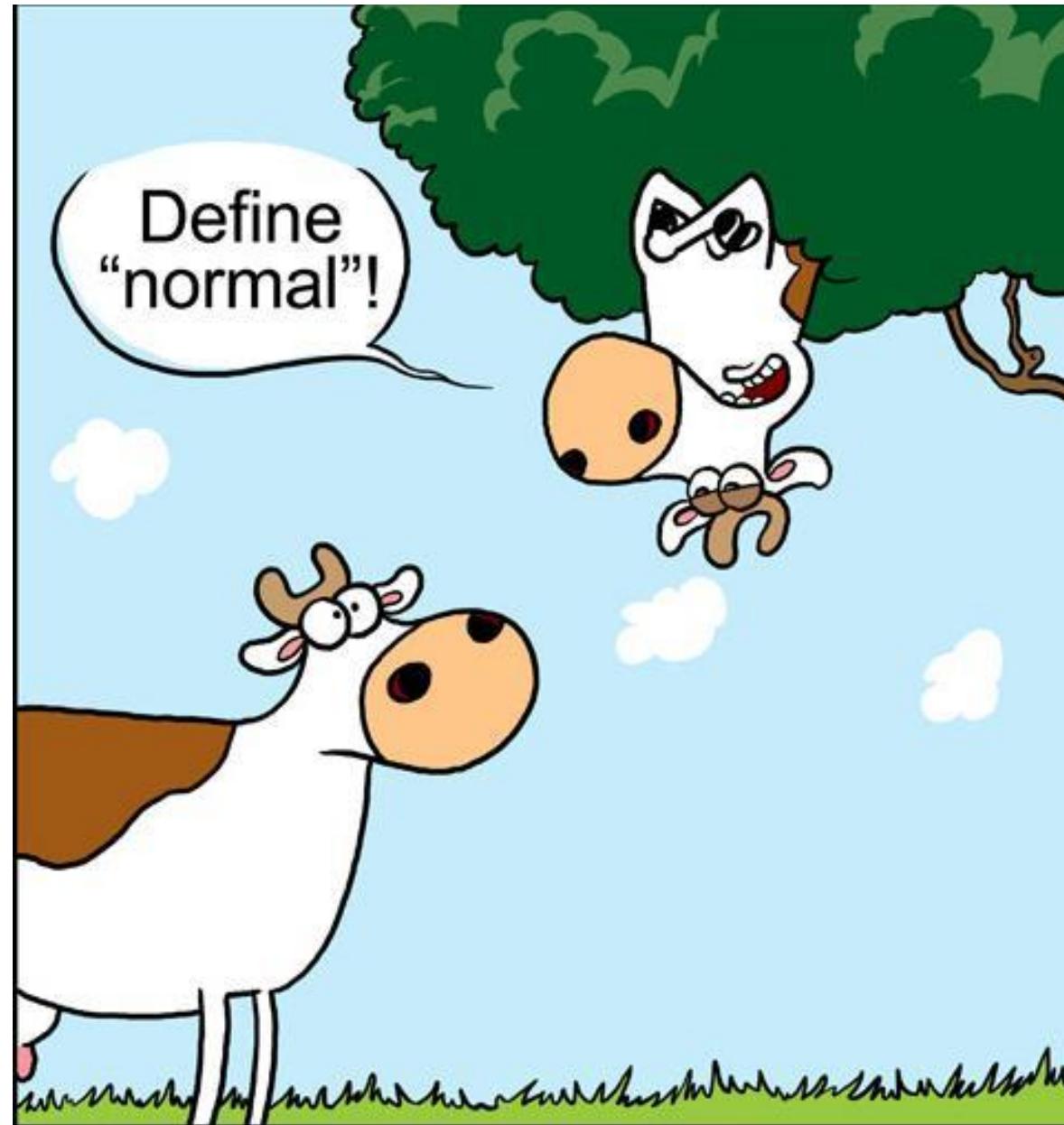
Surveillance and discipline

- Systems for 'discipline' and regulating behaviour.
- Move from external to internal, surface, visual, 'adultified'.
- Increasing levels of surveillance, 'performance' anxiety, focus on consumerism spurring sense of inadequacy, 'self monitoring': growth of 'identity' politics.
- Boys emotional well-being becomes obscured.



"The blood tests confirm what we thought: he has ALBD - Annoying Little Bastard Disorder."

Whose normal?

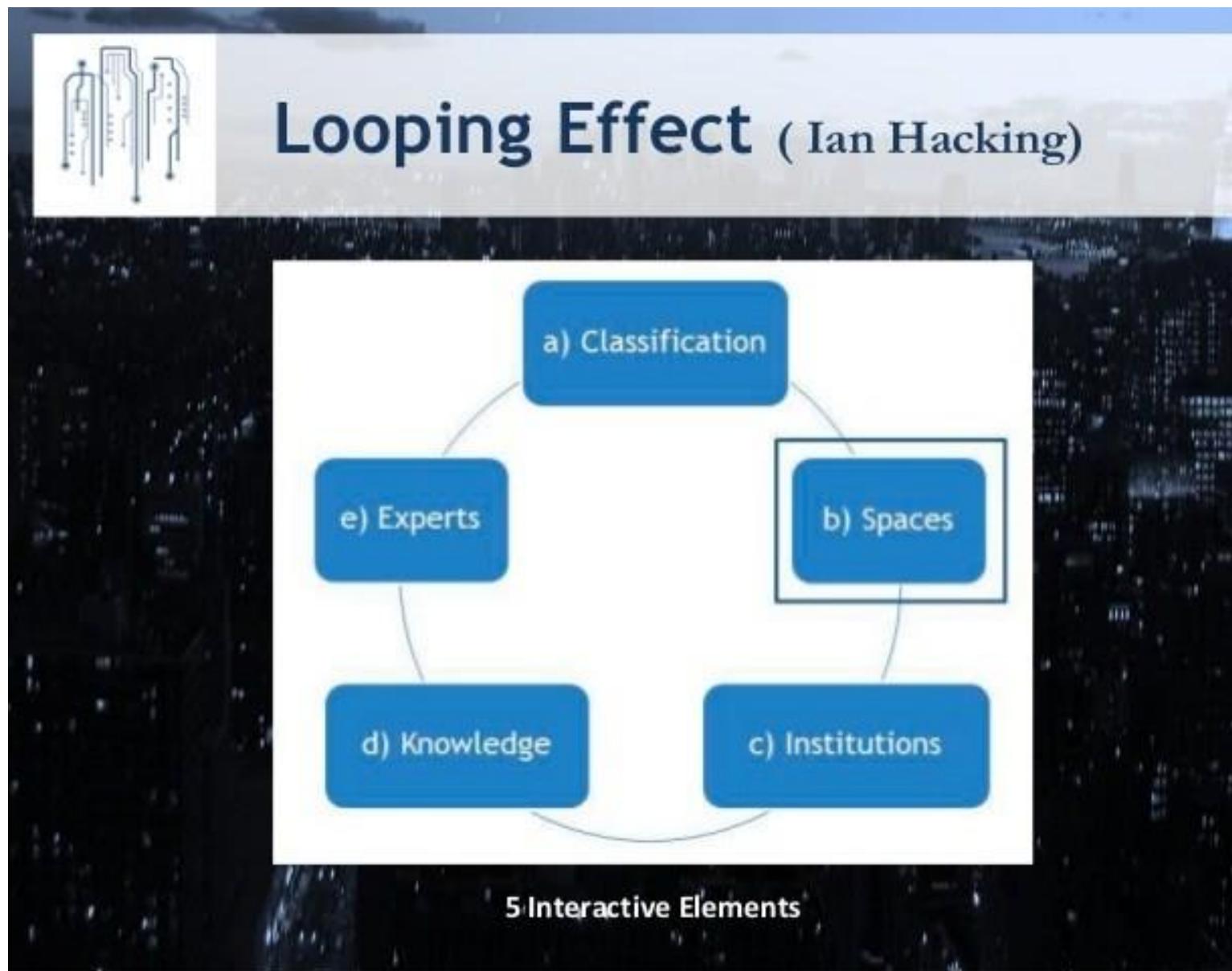


- What is childhood? When does it begin? When does it end? When are the transitions? How do relationships and context construct childhood?
- What is 'normal' child development? Physical, emotional, behavioural, social, spiritual?
- What is 'normal' child rearing? What level of independence, involvement, discipline, attention, education at what ages?
- What is 'normal' attention or normal levels of activity?
- The problem with boys
- Who should set the standards?

Epidemics of Mental illness in the young?

- Individualisation serves neo-liberal capitalism.
- Performance based culture leads to winners and losers.
- Supports idea of ‘expert’ knowledge, and individual deviation needing remedies, rather than systemic interventions.
- Intolerance of suffering – task of professionals.
- Construct as ‘vulnerable’ to soothe the systemic guilt.
- Epidemics of mental health problems: social construct, lets the neoliberal capitalists off the hook!

Social loops create markets



- Hacking: classifications of people to create ‘kinds’ of people
- affect the people classified (identify)
- Creates institutions, knowledge, social discourse.
- In turn effects the classifications and increases interest etc.

Colonialism: The global export of Autism



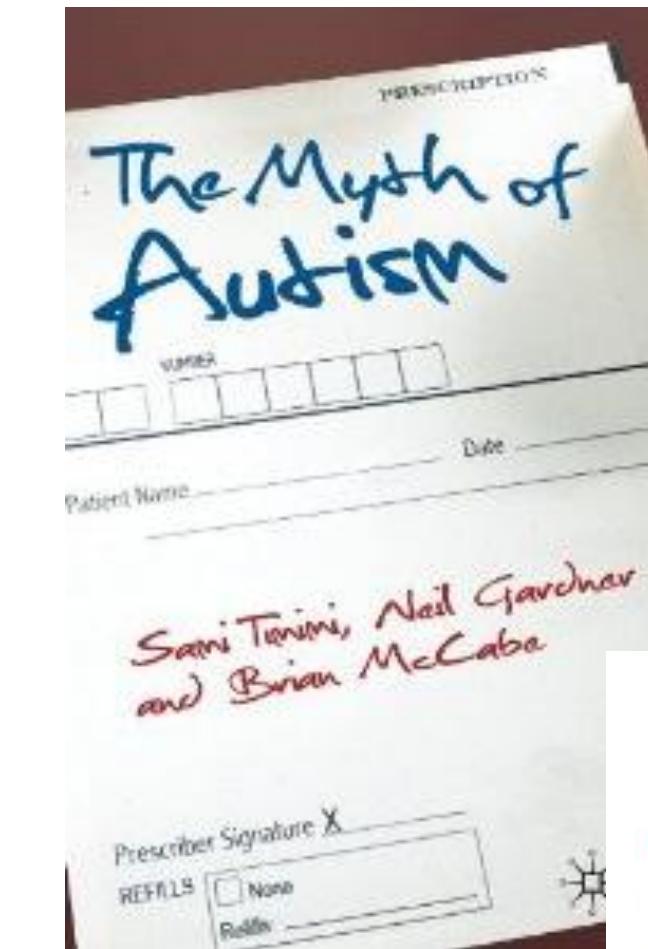
- Autism universal, similar rates globally (claimed).
- Epidemiology: from 0.04% to 1.5%
- High rates in immigrants.
- Study of 55,000 kids in South Korea - 2.6%, most attending mainstream school and not receiving services.
- Cultural variation in symptom meaning, e.g. eye contact, finger pointing avoided in many cultures, rote/photographic learning highly valued in many cultures and religious groups.

Conclusion

- Autism as a construct hinders rather than helps advance scientific knowledge.
- Autism as a construct has little evidence that it helps advance clinical practice.
- Autism has been socially constructed by socio-political drivers – medics, psychologists, parents, neo-liberal individualisation etc..
- The concept is well past its ‘use-by’ date.

Good Practice

- Deconstruct diagnosis.
- Focus on specific issues.
- Use a skills building philosophy.
- Un-diagnose if desired.
- Normalise differences.
- Inspire hope, acceptance and expanded possibilities.



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**Re-Thinking
Autism**
Diagnosis, Identity
and Equality

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