

# Time trends in diagnosis rates of autism: Explanations and evidence

ACAMH National Conference Royal College of Physicians, London

Ginny Russell
Senior Research Fellow, University of Exeter Medical School.







### This talk

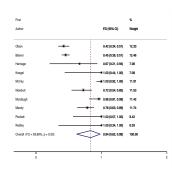
### **Evidence**



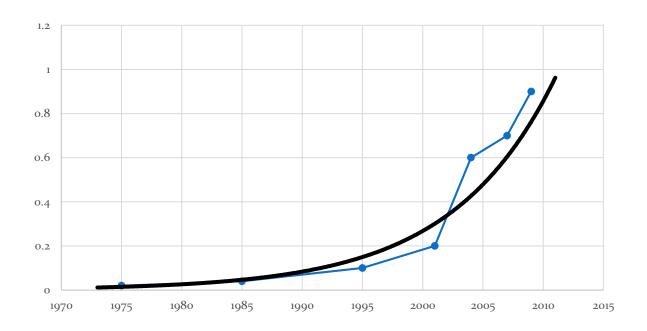
## **Explanations**



### Our work



### Increasing identification of autism



1.00 % is one in every 100.

### **US** data

- Children aged 8, Center for Disease Control
- Trained raters survey and monitor in 11 US sites
- 325,000+ children
- Abstracted information is reviewed systematically by experienced clinicians to determine ASD case status

Est	US ASD Prevalence % (age 8)	95% CI
2012	1.46	0.8-2.7
2014	1.68	1.3 - 2.9

1.68 % is one in every 59 children

### Latest US data

- Children aged 3-17
- 30,000+ children and adolescents
- US NHIS Data in 2018 telephone interviews- 'has a doctor or health professional ever told you that {sample child} has autism, Asperger's disorder, Pervasive developmental disorder or autism spectrum disorder?'

Est. l	JS ASD Prevalence % (age 3-17)	95% CI
2014	2.24	1.9 - 2.6
2015	2.41	1.9 - 2.8
2016	2.58	2.1 - 3.0

• 2.58 % is one in every 39 children

Xu G, Strathearn L, Liu B, Bao W. Prevalence of autism spectrum disorder among US children and adolescents, 2014-2016. JAMA. 2018;319(1):81-82.

### Interpreted as evidence of stability





BEHAVIOR & SOCIETY

### The Prevalence of Autism U.S. Appears Steady

New data suggest the rate hovers between two and three per





News > Medscape Medical News > Psychiatry News

#### Autism Prevalence in US Stable in **Recent Years**

Megan Brooks lanuary 04, 2018

The prevalence of autism spectrum disorder (ASD) in US children and adolescents seems to have stabilized, a new analysis suggests.

On the basis of data from the large population-based National Health nterview Survey (NHIS), the estimated prevalence of ASD ranged from 2.24% to 2.58% among US children and adolescents aged 3 to 17 years from 2014 to 2016, with no statistically significant increase during the 3 years.

By DENNIS THOMPSON | HEALTHDAY | January 2, 2018, 2:48 PM

### U.S. autism rates appear be stabilizing, new study suggests

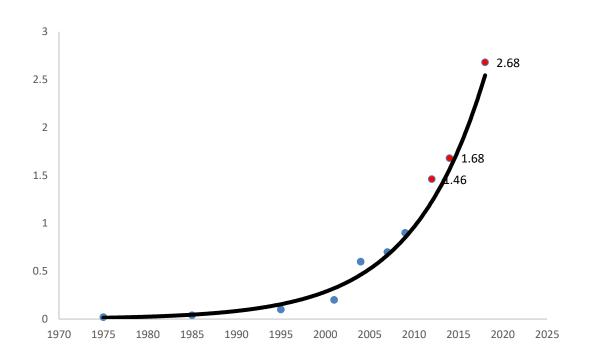
### Data from UK

- Millennium cohort study.
- 19,000+ children. Data collected at age 3, 5, 7, 11, 14 years old.
- 'Has a doctor or health professional ever told you that (sample child) had Autism, Asperger's syndrome or autistic spectrum disorder?'

	SD Prevalence % (age 8)	%	95% CI	
2008	Age 7 years	1.7	1.4-2.0	
2015	Age 14 years	3.1	2.7-3.6	

• 3.1% is one in every 32 children

## Rising use of autism diagnosis?



### Explanation (social and cultural)

- Artefact of changing diagnostic practice
- Consensus amongst epidemiologists and most researchers, clinicians
- Shifts in diagnostic criteria- more diagnosis of those without ID
- Diagnostic substitution- resources targeted to ASD diagnosis
- Younger children diagnosed
- and adults diagnosed (infrastructure)
- Increasing awareness/'better recognition'
- Charities/Neurodiversity movement
- Commercialisation

Fombonne, E. (2001). Is There an Epidemic of Autism? *Pediatrics*, 107(2), 411–412.

Shattuck, P. T. (2006). The contribution of diagnostic substitution to the growing administrative prevalence of autism in US special education. *Pediatrics*, *117*(4), 1028–1037.

### Explanation (biological mechanism)

- Real increase in numbers of children with symptoms of autism
- Parents, and some clinicians, researchers
- Lay theories as to what causes the rise: environmental risk factors
- Pollution
- Medical technology
- Diet /Metals
- Computers/phones
- Older parents
- Vaccine activists

Russell, G, Kelly, S., & Golding, J. (2010). A qualitative analysis of lay beliefs about the aetiology and prevalence of autistic spectrum disorders. *Child: Care, Health and Development*. 36(3):431-6.

Weisskopf, M. G., Kioumourtzoglou, M.-A., & Roberts, A. L. (2015). Air Pollution and Autism Spectrum Disorders: Causal or Confounded? *Current Environmental Health Reports*, 2(4), 430–439.

Thompson, W., Russell, G., Baragwanath, G., Matthews, J., Vaidya, B., & Thompson-Coon, J. (2018). Maternal thyroid hormone insufficiency during pregnancy and risk of neurodevelopmental disorders in offspring: A systematic review and meta-analysis. *Clinical Endocrinology*, 88(4), 575–584



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## Medwatcher Japan "Joint Statement 2018 for the Victims of HPV Vaccines"



Joint Statement 2018 for the Victims of HPV Vaccines

On behalf of the victims of HPV vaccine damage in the UK, Spain, Ireland, Colombia and Japan, an international symposium; "The Current Status of Worldwide Injuries from the HPV Vaccine" was held in Tokyo on the 24th March, 2018.



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Is this connected to interpretation of evidence?

### In public arena -interpretation of stability

News > Medscape Medical News > Psychiatry News

## Autism Prevalence in US Stable in Recent Years

Megan Brooks lanuary 04, 2018

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On the basis of data from the large population-based National Health nterview Survey (NHIS), the estimated prevalence of ASD ranged from 2.24% to 2.58% among US children and adolescents aged 3 to 17 years from 2014 to 2016, with no statistically significant increase during the 3 years.



#### Recommenda



# Is rise in number of children diagnosed with ASD entirely artefactual?

Fombonne: There is no epidemic of autism

 That rates are higher than thirty years ago reflects adoption of much broader conception of autism, its recognition amongst normally intelligent children, improved identification, changes in diagnostic criteria and earlier identification.

Parents, clinicians: A real increase in number of children with ASD

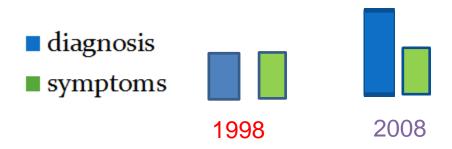
 'I have been amazed at the increased incidence of autism and pondered about the causes.. it can't all be down to better recognition. Since I left [practice] in 1995 something has triggered an explosion.'

### DSM-5

 'it remains unclear whether higher rates reflect an expansion of the diagnostic criteria of DSM-IV to include sub-threshold cases, increased awareness, differences in study methodology or a true increase in the frequency of autism spectrum disorder'

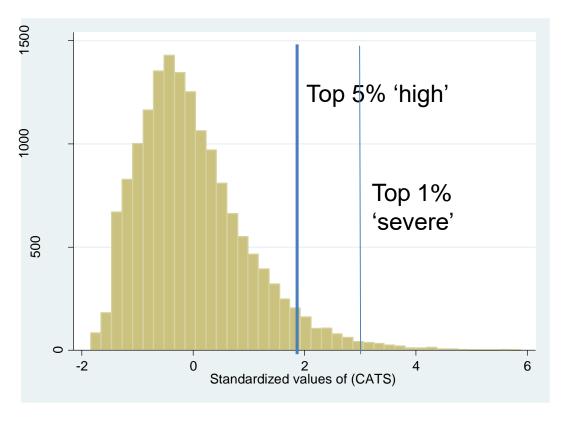
### Our work (2015)

- Comparison of symptom levels and diagnosis over time
- Comparison of two birth cohorts ten years apart at a fixed developmental stage. Secondary data analysis of 2 time points (1998-2008)
- ALSPAC & MCS (cohorts)
- Hypothesis: that a larger proportion of children would be diagnosed in the later cohort, but there would be no parallel increase in the proportion with autismtype symptoms.



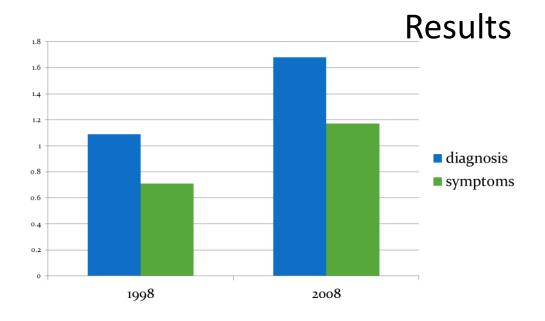
Russell, G., Collishaw, S., Golding, J., Kelly, S. E., & Ford, T. (2015). Changes in diagnosis rates and behavioural traits of autism spectrum disorders over time. British Journal of Psychiatry – Open

### Composite autism-type symptom score (CATS-score)



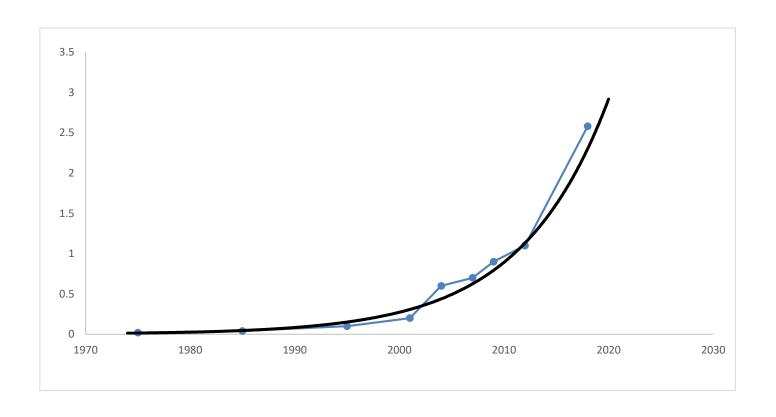
Measures: communication peer relationships fear of new situations lack of cognitive empathy

n=15740



	1998 % (95% CI)	2008 % (95% CI)	Odds Ratio (95% CI)	p
ASD diagnosis	1.09 (0.86 1.37)	1.68 (1.42, 1.99)	1.56 (1.17, 2.08)	0.003
Severe CATS Top 1%	0.87	1.10	1.27 (0.83, 1.92)	0.27
High CATS Top 5%	3.65	5.65	1.58 (1.29, 1.93)	<.001

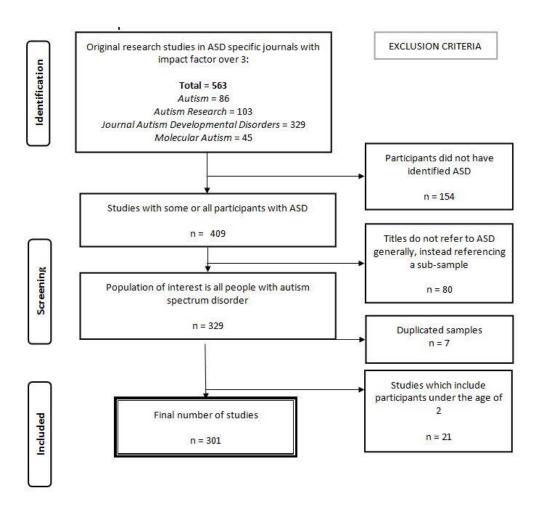
### Rising use of autism diagnosis





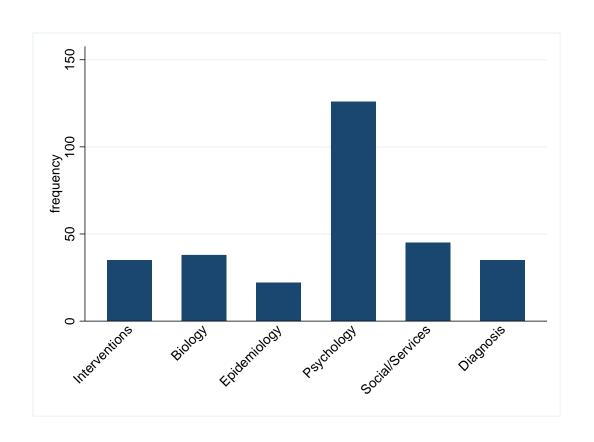
Profile of who is considered to have autism has changed

### Our work (structured review, 2018)

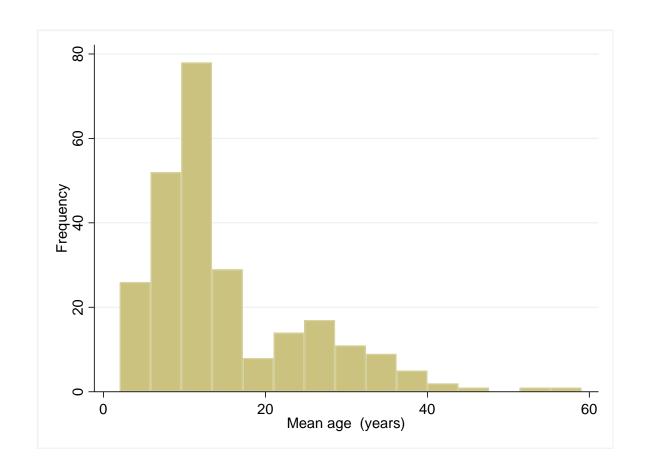


100,245 participants identified with ASD

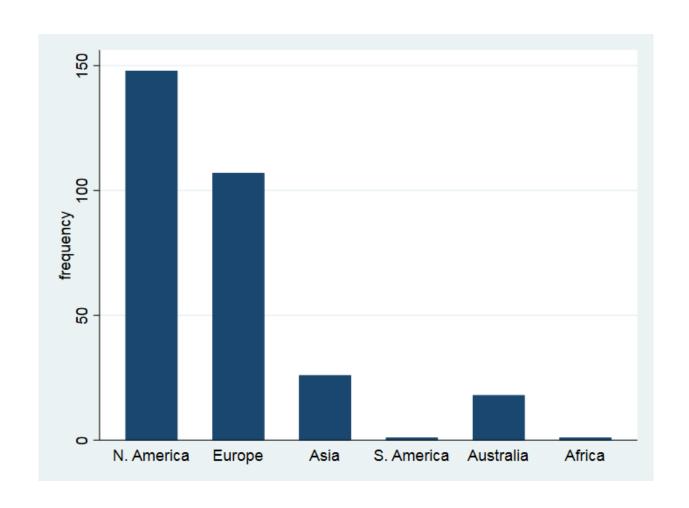
### Breakdown by field



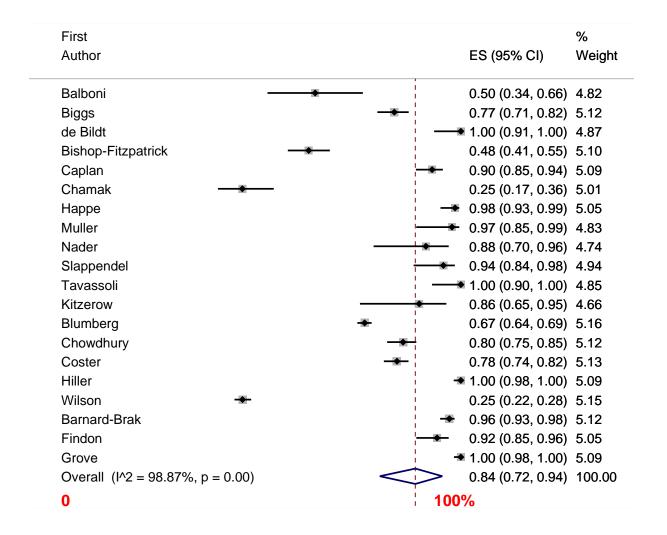
## Age distribution



## Distribution by continent

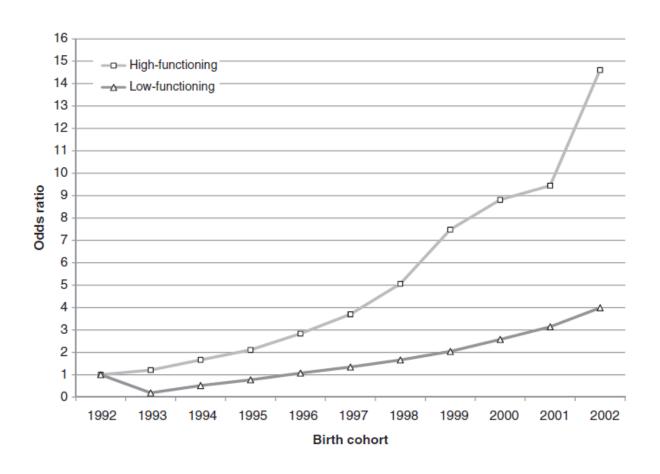


### Meta-analysis



Overall 94% of all ASD participants did not have ID (95% CI 91-97).

### Rising odds of autism diagnosis -US



Keyes, K. M., Susser, E., Cheslack-Postava, K., Fountain, C., Liu, K., & Bearman, P. S. (2012). Cohort effects explain the increase in autism diagnosis among children born from 1992 to 2003 in California. International Journal of Epidemiology, 41(2), 495–503.

### Hacking

The contested production of expert and especially lay knowledge...how there is an interplay of social movements, health institutions and scientific experts that creates and shapes how we view autistic people & ultimately what we understand autism to be.



### Does the rising use of ASD diagnosis matter?

Squeeze on services for children with ASD & ID?

Rise of neurodiversity movement

Change in how we conceive autismmore as an identity Less as a medical condition?



# Autism and Neurodiversity Exploring Diagnosis





- · 1993 -Don't mourn for us
- 1996 -InLv
- 1996 -Autreat /ANI
- · 2002 -Institute for the Study of the Neurologically Typical
- · 2004- Aspies for freedom / Declaration
- · 2005- Autistic Genocide Clock
- 2012 -ASAN & DSM-5 revisions
- · 2016- ND manifesto

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