Time trends in diagnosis rates of autism: Explanations and evidence

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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

<table>
<thead>
<tr>
<th>Est. US ASD Prevalence % (age 8)</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2012</strong></td>
<td>1.46</td>
</tr>
<tr>
<td><strong>2014</strong></td>
<td>1.68</td>
</tr>
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- 1.68 % is one in every 59 children

Centre for Disease Control Identified prevalence Autism Spectrum Disorder
https://www.cdc.gov/ncbddd/autism/data.html
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?’

<table>
<thead>
<tr>
<th>Year</th>
<th>Est. US ASD Prevalence % (age 3-17)</th>
<th>95% CI</th>
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</thead>
<tbody>
<tr>
<td>2014</td>
<td>2.24</td>
<td>1.9 - 2.6</td>
</tr>
<tr>
<td>2015</td>
<td>2.41</td>
<td>1.9 - 2.8</td>
</tr>
<tr>
<td>2016</td>
<td>2.58</td>
<td>2.1 - 3.0</td>
</tr>
</tbody>
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- 2.58 % is one in every 39 children

The Prevalence of Autism U.S. Appears Steady

New data suggest the rate hovers between two and three per...
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?'

<table>
<thead>
<tr>
<th>Est. UK ASD Prevalence % (age 8)</th>
<th>%</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008 Age 7 years</td>
<td>1.7</td>
<td>1.4-2.0</td>
</tr>
<tr>
<td>2015 Age 14 years</td>
<td>3.1</td>
<td>2.7-3.6</td>
</tr>
</tbody>
</table>

- 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


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

Is this connected to interpretation of evidence?
In public arena - interpretation of stability

Autism Prevalence in US Stable in Recent Years

Megan Brooks
January 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 Interview 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.
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 autism-type symptoms.

Composite autism-type symptom score (CATS-score)

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

Top 5% ‘high’
Top 1% ‘severe’

$n=15740$
### Results

<table>
<thead>
<tr>
<th></th>
<th>1998 % (95% CI)</th>
<th>2008 % (95% CI)</th>
<th>Odds Ratio (95% CI)</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD diagnosis</td>
<td>1.09 (0.86 1.37)</td>
<td>1.68 (1.42, 1.99)</td>
<td>1.56 (1.17, 2.08)</td>
<td>0.003</td>
</tr>
<tr>
<td>Severe CATS Top 1%</td>
<td>0.87</td>
<td>1.10</td>
<td>1.27 (0.83, 1.92)</td>
<td>0.27</td>
</tr>
<tr>
<td>High CATS Top 5%</td>
<td>3.65</td>
<td>5.65</td>
<td>1.58 (1.29, 1.93)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
Rising use of autism diagnosis

Profile of who is considered to have autism has changed
Our work (structured review, 2018)

Original research studies in ASD specific journals with impact factor over 3:
- Total = 563
- Autism = 85
- Autism Research = 103
- Journal Autism Developmental Disorders = 329
- Molecular Autism = 45

Studies with some or all participants with ASD
- n = 409

Population of interest is all people with autism spectrum disorder
- n = 329

Exclusion Criteria
- Participants did not have identified ASD
  - n = 154
- Titles do not refer to ASD generally, instead referencing a sub-sample
  - n = 80
- Duplicated samples
  - n = 7
- Studies which include participants under the age of 2
  - n = 21

Final number of studies
- n = 301

100,245 participants identified with ASD
Breakdown by field

- Biology
- Epidemiology
- Psychology
- Social/Services
- Diagnosis

Frequency

Interventions

Biology

Epidemiology

Psychology

Social/Services

Diagnosis
Age distribution

![Age distribution graph]

- Mean age: 0, 20, 40, 60
- Frequency: 0, 20, 40, 60

The graph shows the distribution of ages with a peak at around 20 years.
Distribution by continent

- N. America
- Europe
- Asia
- S. America
- Australia
- Africa
Overall 94% of all ASD participants did not have ID (95% CI 91-97).
Rising odds of autism diagnosis - US

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 autism—more 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

Twitter: ExDx_UoE
www.exeter.ac.uk/exdx