Epidemiology of Autism Spectrum Disorders: update on rates, trends and new studies

The Help Group Summit 2012

Oct. 27th, 2012

Pr. Eric Fombonne
Oregon Health & Science University
Outline

• Past and recent prevalence surveys
• Best current estimate for ASDs
• World wide efforts on ASD epidemiology
• Time trends: is there an epidemic?
Prevalence of autism in 34 surveys

Year of Publication

Prevalence of Autistic Disorder (per 10,000)

- Japan
- North America
- Scandinavia
- Western Europe

Newschaffer, 2007
Time trends: AD
(Rate/10,000 and 95% CI)

Year of publication: r=.43 p <.001
Year of publication x Region : n.s.
## Relative rates of AD and PDD NOS

<table>
<thead>
<tr>
<th>Study</th>
<th>Definition for other PDD</th>
<th>AD</th>
<th>PDD NOS</th>
<th>Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lotter (1966)</td>
<td>behaviour similar to autistic children</td>
<td>4.1</td>
<td>3.3</td>
<td>0.8</td>
</tr>
<tr>
<td>Brask (1970)</td>
<td>‘other psychoses’ or ‘borderline psychotic’</td>
<td>4.3</td>
<td>1.9</td>
<td>0.4</td>
</tr>
<tr>
<td>Wing et al (1976)</td>
<td>socially impaired (triad of impairments)</td>
<td>4.9</td>
<td>16.3</td>
<td>3.3</td>
</tr>
<tr>
<td>Hoshino et al (1982)</td>
<td>autistic mental retardation</td>
<td>2.3</td>
<td>2.9</td>
<td>1.3</td>
</tr>
<tr>
<td>Burd et al (1987)</td>
<td>‘autistic-like’</td>
<td>3.3</td>
<td>&gt; 7.8</td>
<td>2.4</td>
</tr>
<tr>
<td>Cialdella &amp; Marmelle (1989)</td>
<td>other forms of ‘infantile psychosis’</td>
<td>4.5</td>
<td>4.7</td>
<td>1.0</td>
</tr>
</tbody>
</table>
# Relative rates of AD and PDD NOS

<table>
<thead>
<tr>
<th>Study</th>
<th>Definition for other PDD</th>
<th>AD</th>
<th>PDD NOS</th>
<th>Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fombonne &amp; Mazaubrun (1992)</td>
<td>other PDDs</td>
<td>4.6</td>
<td>6.6</td>
<td>1.4</td>
</tr>
<tr>
<td>Fombonne et al (1997)</td>
<td>other PDDs</td>
<td>5.3</td>
<td>10.9</td>
<td>2.1</td>
</tr>
<tr>
<td>Powell et al. (2000)</td>
<td>autism-spectrum disorders</td>
<td>7.8</td>
<td>13.0</td>
<td>1.7</td>
</tr>
<tr>
<td>CDC (2000)</td>
<td>PDD NOS</td>
<td>40</td>
<td>27.0</td>
<td>0.7</td>
</tr>
<tr>
<td>Baird et al (2000)</td>
<td><strong>PDD NOS</strong></td>
<td>27.7</td>
<td>27.1</td>
<td>1.0</td>
</tr>
<tr>
<td>Chakrabarti &amp; Fombonne (2001)</td>
<td><strong>PDD NOS</strong></td>
<td>16.8</td>
<td>36.1</td>
<td>2.1</td>
</tr>
</tbody>
</table>
Childhood disintegrative disorder (CDD)

<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>M/F</th>
<th>Prevalence estimate (/10,000)</th>
<th>95% CI (/10,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burd et al., 1987</td>
<td>2</td>
<td>2/0</td>
<td>.111</td>
<td>.013; .399</td>
</tr>
<tr>
<td>Sponheim &amp; Skjeldal, 1998</td>
<td>1</td>
<td>?</td>
<td>.152</td>
<td>.004; .848</td>
</tr>
<tr>
<td>Magn. &amp; Sæm., 2001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1974-93</td>
<td>2</td>
<td>2/0</td>
<td>.234</td>
<td>.028; .844</td>
</tr>
<tr>
<td>1964-73²</td>
<td>4</td>
<td>3/1</td>
<td>.311</td>
<td>.085; .795</td>
</tr>
<tr>
<td>Chakrabarti &amp; Fombonne, 2001</td>
<td>1</td>
<td>1/0</td>
<td>.645</td>
<td>.016; 3.59</td>
</tr>
</tbody>
</table>

1: 95% CI derive from exact binomial calculations
2: data from Magnusson (1977)
Asperger syndrome in recent autism surveys

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sponheim &amp; Skjeldal, 1998</td>
<td>4.9</td>
<td>32</td>
<td>.3</td>
<td>2</td>
<td>16.0</td>
</tr>
<tr>
<td>Taylor et al., 1999</td>
<td>8.7</td>
<td>427</td>
<td>1.4</td>
<td>71</td>
<td>6.0</td>
</tr>
<tr>
<td>Kadesjö et al., 1999</td>
<td>72.6</td>
<td>6</td>
<td>48.4</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td>Powell et al. 2000</td>
<td>-</td>
<td>54</td>
<td>-</td>
<td>16</td>
<td>3.4</td>
</tr>
<tr>
<td>Baird et al. 2000</td>
<td>27.7</td>
<td>45</td>
<td>3.1</td>
<td>5</td>
<td>9.0</td>
</tr>
<tr>
<td>Chakrabarti &amp; Fombonne 2001</td>
<td>16.8</td>
<td>26</td>
<td>8.4</td>
<td>13</td>
<td>2.0</td>
</tr>
</tbody>
</table>
# Recent surveys of PDD

<table>
<thead>
<tr>
<th>Age</th>
<th>Rate / 10,000</th>
<th>M / F ratio</th>
<th>% IQ normal</th>
<th>Rate / 10,000</th>
<th>M / F ratio</th>
<th>% IQ normal</th>
<th>Rate / 10,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDC, 2000</td>
<td>3-10</td>
<td>40.5</td>
<td>2.2</td>
<td>37</td>
<td>27.0</td>
<td>3.7</td>
<td>51</td>
</tr>
<tr>
<td>Baird et al, 2000</td>
<td>7</td>
<td>30.8</td>
<td>15.7</td>
<td>60</td>
<td>27.1</td>
<td>4.5</td>
<td>-</td>
</tr>
<tr>
<td>Chakrabarti &amp; Fombonne, 2001</td>
<td>4-7</td>
<td>16.8</td>
<td>3.3</td>
<td>29</td>
<td>44.5</td>
<td>4.3</td>
<td>94</td>
</tr>
</tbody>
</table>
### Staffordshire surveys

<table>
<thead>
<tr>
<th></th>
<th>92-95 cohort</th>
<th>96-98 cohort</th>
<th>Combined samples</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=15,500</td>
<td>N=10,903</td>
<td>N=26,403</td>
</tr>
<tr>
<td>N</td>
<td>P</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------------</td>
<td>--------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Autistic disorder</td>
<td>26 16.8</td>
<td>24 22.0</td>
<td>50 18.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>95% CI 14.1-25.0</td>
</tr>
<tr>
<td>PDD NOS</td>
<td>56 36.1</td>
<td>27 24.8</td>
<td>83 31.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>95% CI 25.0-39.0</td>
</tr>
<tr>
<td>Asperger</td>
<td>13 8.4</td>
<td>12 11.0</td>
<td>25 9.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>95% CI 6.1-14.0</td>
</tr>
<tr>
<td>CDD</td>
<td>1 0.7</td>
<td>1 0.9</td>
<td>2 0.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>95% CI 0.1-2.7</td>
</tr>
<tr>
<td>All PDDs</td>
<td>96 61.9</td>
<td>64 58.7</td>
<td>160 60.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>95% CI 51.6-70.7</td>
</tr>
</tbody>
</table>

1: One girl with Rett syndrome has been excluded

Chakrabarti & Fombonne, (2005)
Montréal Survey

• Sample
  – Largest school board (LB Pearson) for Anglophone children in West Montréal
  – 55 schools; 27,749 pupils from K to grade 11
  – Children with PDD identified through special education code (ASD) that provides extra funding to the school
  – 180 children with PDD identified on October 1st 2003

Fombonne et al., 2006
## PDD prevalence

**Montréal Survey: 180 subjects**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Prevalence (1/10,000)</th>
<th>95% CI (Lower, Upper)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>21.6</td>
<td>16.5 - 27.8</td>
</tr>
<tr>
<td>PDD NOS</td>
<td>32.8</td>
<td>26.4 - 40.2</td>
</tr>
<tr>
<td>Asperger</td>
<td>10.1</td>
<td>6.7 - 14.6</td>
</tr>
<tr>
<td>CDD</td>
<td>0.4</td>
<td>0.0 - 2.0</td>
</tr>
<tr>
<td>All</td>
<td>64.9</td>
<td>55.8 - 75.0</td>
</tr>
</tbody>
</table>

*Fombonne et al., 2006*
New Montreal survey

- Sample
  - English Montreal School Board (EMSB) for Anglophone children
  - 71 schools; 23,635 pupils from K to grade 11
  - Children with PDD identified through special education code (ASD) that provides extra funding to the school
  - 187 children with PDD identified on April 1st 2008

*Lazoff, Fombonne et al., (2010) (Can J psych)*
## New Montreal survey

<table>
<thead>
<tr>
<th>Condition</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
<th>Prevalence /10,000 (95% confidence interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PDD -NOS</td>
<td>88</td>
<td>15</td>
<td>103</td>
<td>43.6 (35.2 – 52.0)</td>
</tr>
<tr>
<td>Autistic Disorder</td>
<td>50</td>
<td>10</td>
<td>60</td>
<td>25.4 (19.0 - 31.8)</td>
</tr>
<tr>
<td>Asperger</td>
<td>19</td>
<td>4</td>
<td>23</td>
<td>9.7 (5.8 – 13.7)</td>
</tr>
<tr>
<td>CDD</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0.4 (0.0 – 1.3)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>158</td>
<td>29</td>
<td>187</td>
<td>79.1 (67.8 - 90.4)</td>
</tr>
</tbody>
</table>

*Lazoff, Fombonne et al. (2010) (Can J Psych)*
ADDIM Strengths

- Common case definition
- Common case identification approach in majority of sites
- Multiple sites: geographic and community diversity
- Large population base
  - 10% of US 8-year olds in 2002*
    *varies by study year
- Ongoing
ASD Prevalence in 8-yr olds: 6.6 per 1000
ADDM 2002

- Health Sources Only: 5.1 per 1000
- Education Sources: 7.2 per 1000

CDC
SAFER • HEALTHIER • PEOPLE™
Prevalence of ASD, USA 2006

Prevalence per 1000

Alabama, Florida, Missouri, Pennsylvania, Wisconsin, Arizona, Colorado, Georgia, Maryland, North Carolina, South Carolina, USA

Health records only, Health and education records, USA

0.9%
Outline

• Past and recent prevalence surveys
• **Best current estimate for ASDs**
• World wide efforts on ASD epidemiology
• Time trends: is there an epidemic?
Recent review of surveys

- **63 published surveys**
  - 50 on AD, 14 on ASP, 12 on CDD, 26 on PDD
  - Half published since 2001
  - AD: 2.2/1,000
  - ASP: 1/1,000
  - CDD: 2/100,000
  - PDD: ~ 7 to 9/1,000

- **Some studies have PDD rates over 1%**
  - 1.1% in NJ-USA (CDC, 2007)
  - 1.3% in Arizona (CDC, 2009)
  - 1.2% in the UK (Baird et al. 2006)
  - 1.3% in some birth cohorts (Lazoff, Fombonne et al., 2010)
  - 1.8% in Japan (Kawamura et al. 2008)

Fombonne et al 2011
Equivalences

\[
\frac{90}{10,000} = \frac{9}{1,000} = 0.9\% = 1 \text{ child in 110}
\]
Correlates of ASD

- The proportion of children with cognitive functioning within the normal range is 30% for autistic disorder and 55% for all PDDs.

- Consistent male overrepresentation for autistic disorder (4.4:1), CDD (9:1), and all PDDs (5.5:1).

- Association between higher proportion of normal IQ subjects and a higher male/female ratio (Spearman’s r: 0.53; p = .007).

- Regression, or loss of skills, occurs in about 1 in 4 children with PDD.
Autism Surveys: Other findings

- no association with social class in post 1980 surveys
- association with immigrant status or ethnicity: largely unsupported
- geographical variation in prevalence
  - methodological variation between studies confounds comparisons
  - limited evidence not in favour of between-countries variations in rates.
Table 1: Details of the cluster of seven families.

<table>
<thead>
<tr>
<th>Case number</th>
<th>Father</th>
<th>Occupation</th>
<th>Mother</th>
<th>Residence</th>
<th>Relation to autistic child</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A</td>
<td>Teacher</td>
<td>B</td>
<td>Home</td>
<td>Son</td>
</tr>
<tr>
<td>2</td>
<td>C</td>
<td>Engineer</td>
<td>D</td>
<td>School</td>
<td>Daughter</td>
</tr>
<tr>
<td>3</td>
<td>E</td>
<td>Doctor</td>
<td>F</td>
<td>Clinic</td>
<td>Niece</td>
</tr>
<tr>
<td>4</td>
<td>G</td>
<td>Teacher</td>
<td>H</td>
<td>Home</td>
<td>Niece</td>
</tr>
<tr>
<td>5</td>
<td>I</td>
<td>Lawyer</td>
<td>J</td>
<td>Office</td>
<td>Niece</td>
</tr>
<tr>
<td>6</td>
<td>K</td>
<td>Engineer</td>
<td>L</td>
<td>School</td>
<td>Nephew</td>
</tr>
<tr>
<td>7</td>
<td>M</td>
<td>Teacher</td>
<td>N</td>
<td>Home</td>
<td>Nephew</td>
</tr>
</tbody>
</table>

Figure 1: Map of the area showing apparent cluster of autism cases. Street names have been removed to preserve confidentiality.

A map showing the geographical distribution of cases with the major diagnosis of autism. The children were all assessed by the same clinician (G.C.).
14 ‘villages’
10,500 Inuit inhabitants
4,500 under age 18
An unusual observation amongst Inuits from Northern Quebec

- Based on N~4,500 subjects under age 18, we expect ~30 subjects with ASD
- One would reject the hypothesis of equal prevalences if $N_{obs} < 21$, but we found *no* case
- Specificity: the curious case of Kujjuarapik where half the village is Cree and they have ASDs
- Not attributable to migration, differential mortality, cultural expression,..
- Pre- and post-natal exposure to neurotoxicants (including methylmercury) is high
Outline

• Recent prevalence surveys
• Best current estimate for ASDs
• World wide efforts on ASD epidemiology
• Time trends: is there an epidemic?
Nations with autism prevalence estimation studies completed, in process, or in planning stages

![Map of Nations with Autism Prevalence Studies](image_url)

- **High Income**
- **Developing**

**CDC**

**Autism Speaks**
Korean Autism Study (KAS)

Research Design

• Total Population Study
  - No sampling

• Mechanisms to Identify Children
  1. Mandatory Educational System
  2. Home Schooling
  3. Disability Registry

• Two Stage Design
  1. Multi-Informant Screening
  2. Confirmative Dx with ADOS & ADI-R
Cultural differences: Autism versus Reactive attachment disorder?
Objective: Experts disagree about the causes and significance of the recent increases in the prevalence of autism spectrum disorders (ASDs). Limited data on population base rates contribute to this uncertainty. Using a population-based sample, the authors sought to estimate the prevalence and describe the clinical characteristics of ASDs in school-age children. They found a 2.64% prevalence (95% CI=1.91–3.37) in the general population sample and a 1.89% prevalence (95% CI=1.43–2.36) in the high-probability group. ASD characteristics differed between the two groups: the male-to-female ratios were 5.1:1 in the general population sample and 2.5:1 in the high-probability group, respectively, and the ratios of autistic disorder to other ASDs were 0.56:1 and 0.94:1, respectively.

### TABLE 3. Prevalence Estimates of Autism Spectrum Disorders (ASDs) in a South Korean Community

<table>
<thead>
<tr>
<th>Measure</th>
<th>Prevalence (%)</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total population</td>
<td>2.64</td>
<td>1.91–3.37</td>
</tr>
<tr>
<td>General-population sample</td>
<td>1.89</td>
<td>1.43–2.36</td>
</tr>
<tr>
<td>High-probability group</td>
<td>0.75</td>
<td>0.58–0.93</td>
</tr>
<tr>
<td><strong>ASD Type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any ASD</td>
<td>2.64</td>
<td>1.91–3.37</td>
</tr>
<tr>
<td>Autistic disorder</td>
<td>0.94</td>
<td>0.56–1.34</td>
</tr>
<tr>
<td>Other ASDs</td>
<td>1.70</td>
<td>1.08–2.32</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3.74</td>
<td>2.57–4.90</td>
</tr>
<tr>
<td>Female</td>
<td>1.47</td>
<td>0.60–2.37</td>
</tr>
</tbody>
</table>
Issues in survey data analysis: weighting for non-response

Target Population

N=20,000

Normal: 19,000
Special needs: 1,000
Screening phase: sampling fractions, and participation rates

N=20,000

Normal 19000

Special needs 1,000

Screen negative

1,710

Screen positive

190

Screen negative

100

Screen positive

100

Screen negative

100

Screen positive

190

Screen negative

100

Screen positive

200

Screen negative

250

Screen positive

50%

80%
Diagnostic phase: sampling fractions and participation rates

N=20,000

Normal 19,000

Special needs 1,000

Screening

Screen negative

1710

Screen positive

1900

Screen negative

1710

Screen positive

190

Screen negative

250

Screen positive

100

Screen negative

100

Screen positive

25

ASD - 425

ASD + 2

ASD - 18

ASD + 1

ASD - 5

ASD + 35

ASD - 18

ASD + 2
Prevalence estimation in the special needs population

\[ P = \frac{ASD\, response\_rates}{N} \]

\[ P = \frac{(35, 0.8, 2, 0.8, 4)}{1000} \]

\[ P = 49\% \]
Study objectives

To provide the first estimate of the prevalence of ASDs in a representative sample of Mexican children aged 8

To identify clinical, educational, cognitive, familial and social correlates of ASD in Mexican children

To describe retrospectively the developmental trajectories (first symptoms, first contacts and responses with health care/educational professionals, delays and barriers in accessing diagnostic and treatment services,..) of children confirmed with an ASD diagnosis in order to identify targets for service improvement in Mexico
Study area

State of Guanajuato, one of the 32 states of Mexico. On a number of socio-economic indicators, this state is adequately representative of Mexico in general.

City of Leon:
- total population of about 2 million inhabitants, economic activity centered around the shoe fabrics, cattle industry and services
- presence of a local autism team from CLIMA with expertise in autism

Target population

1) residing in the Leon area at the survey date (1st October 2010);
2) enrolled in grade 2, born in 2003 (N= 35,500)
Case identification

Two-stage approach.

Stage 1 screening the entire population using multiple data sources.

screening with SRS in normal schools
record abtraction +SRS for subjects in contact with services

Stage 2, children and their parents will be invited to a diagnostic confirmation stage using the ADI-R and the ADOS, and supplementary questionnaires to document the developmental and medical history, and the history of access to different services of the index child since birth.
Screening for Autism in Mexico

Eric Fombonne, Carlos Marcin, Ruth Bruno, Cecilia Manero Tinoco, and Christian Diaz Marquez

In order to conduct the screening phase of the first epidemiological survey of autism spectrum disorders (ASDs) in Mexico, we needed a screening tool to detect autistic symptomatology in a large sample of school-age children. We used the Spanish version of the Social Responsiveness Scale (SRS). We recruited a clinical sample of 200 children (81% males; mean age: 7.4 years) with a confirmed diagnosis of ASDs and a sample of 363 control children (59.5% males; mean age: 8.5 years) without ASDs. Three-way analyses of variance (ANOVAs) identified a main effect of clinical status (ASDs vs. controls) for both parent and teacher scales, but no gender or age effect. The mean total and subscale raw scores were significantly different between the clinical and control groups for the parent and for the teacher SRS (P < 0.001). The internal consistency of the SRS was excellent. Receiver operating characteristic (ROC) analyses showed excellent discriminant validity of the SRS in the Mexican sample (area under the curve: 0.962 for the parent, 0.960 for the teacher). ROC curves were also used to determine which cutoff would provide the best trade-off between sensitivity and specificity. Mexican SRS scores were significantly higher than in the U.S. and German population for typically developing children but comparable for clinically referred subjects. The SRS is an acceptable screening instrument for epidemiological studies of ASDs in Mexico. Its psychometric properties are excellent and comparable to those derived from North American and other samples. *Autism Res* 2012, **:**--**:** © 2012 International Society for Autism Research, Wiley Periodicals, Inc.

Table 1. Mean Raw Score SRS Parents by Age and Gender

<table>
<thead>
<tr>
<th>Age</th>
<th>Both</th>
<th>Boys</th>
<th>Girls</th>
<th>Both</th>
<th>Boys</th>
<th>Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>4-5</td>
<td>56</td>
<td>104.3 (26.5)</td>
<td>101.7 (27.9)</td>
<td>115.0 (16.4)</td>
<td>37</td>
<td>35.9 (18.4)</td>
</tr>
<tr>
<td>6-7</td>
<td>62</td>
<td>97.7 (25.9)</td>
<td>95.2 (25.1)</td>
<td>106.1 (28.1)</td>
<td>72</td>
<td>43.8 (20.2)</td>
</tr>
<tr>
<td>8-9</td>
<td>42</td>
<td>102.8 (29.7)</td>
<td>101.8 (30.1)</td>
<td>108.8 (28.7)</td>
<td>140</td>
<td>41.8 (13.9)</td>
</tr>
<tr>
<td>10-11</td>
<td>19</td>
<td>115.3 (33.0)</td>
<td>113.7 (30.5)</td>
<td>123.7 (51.8)</td>
<td>102</td>
<td>41.0 (18.5)</td>
</tr>
<tr>
<td>12-13</td>
<td>21</td>
<td>96.8 (35.7)</td>
<td>92.8 (32.5)</td>
<td>113.8 (48.7)</td>
<td>12</td>
<td>53.9 (35.7)</td>
</tr>
<tr>
<td>All</td>
<td>200</td>
<td>102.2 (28.9)</td>
<td>100.0 (28.6)</td>
<td>111.3 (28.7)</td>
<td>363</td>
<td>41.8 (18.2)</td>
</tr>
</tbody>
</table>

SRS, Social Responsiveness Scale; PDD, pervasive developmental disorder; SD, standard deviation.
Figure 2. Receiver Operating Characteristics (ROC) curves for the Social Responsiveness Scale (SRS) by informant.
Other ongoing studies/projects

- Venezuela, Brazil,..
- India
- Africa: South Africa, …
- Asia: Vietnam,…
- Middle East: Qatar, Oman, Saudi Arabia, Israel,
- …
Value of an epidemiological survey

- Get an estimate of the magnitude of the health problem
- Get a baseline useful to monitor time trends
- Provide information to decision-makers re. service needs and planning
- Provide data on risk factors/correlates
- Evaluate access to services and factors that influence it
- Generate a representative case series from which to sample for further studies (ie case-control, outcome studies, etc…)
- Generate data on trajectories of ASD subjects in the local health/welfare system
- Develop up-to-date screening and evaluation techniques
- Increase awareness, involve professionals, develop expertise
Outline

• Past and recent prevalence surveys
• Best current estimate for ASDs
• World wide efforts on ASD epidemiology
• Time trends: is there an epidemic?
Broadening of PDD concept
Historical note - 1

• 1943: a new disorder or existed before?
  – Prior descriptions abound
    See U. Frith

  – Article in 1926 by Schussareva et al.
    Translated in Eur J Ch Adol Psych

  – Descriptions medical literature of 19th century
  – By design, first descriptions applied to the most severe part of the phenotype
Broadening of PDD concept

Historical note - 2

Parallel with autism: Fetal Alcohol Syndrome (FAS)

- Described recently, 1969/71
- Initially rare, $p<0.001$
- Severe phenotype

- Broadening of phenotype
  
  Fetal Alcohol Effects

- Checklists of diagnostic criteria, shift away from categorical disorder departing massively from normal range

- Prevalence is now 1% or more
Time trends in autism

- Problems:
  - prevalence *versus* incidence rates
  - changes in case definition / case finding
  - secular changes in age at diagnosis
  - statistical power issues
prevalence = 50 / 100,000

“true” prevalence = ?
Approaches used to evaluate time trends in autism

- referral statistics
- comparison of prevalence surveys over time
- repeat surveys in defined areas
- trends in rates in consecutive birth cohorts
- incidence studies
The 1990’s

Minnesota, USA – Gurney et al., 2003

Denmark – Madsen et al., 2003

Japan – Honda et al., 2005

United Kingdom – Taylor et al, 1999
Prevalence and access to services

Population

Low access to services

High access to services

Same prevalence

Services
Trends in Minnesota

Individual with Disabilities Educational Act (IDEA)

DSM-III-R

ICD-10

DSM-IV

Gurney et al., 2003
"age" effect

1991-92 birth cohort as it ages
Prevalence of autism and MR of unknown cause in California

King & Berman’s replication (*Int J Epi, in press*):

25% of DDS caseload of Autism is due to shift from MR to ASD

Croen et al., 2001
Diagnostic ‘substitution’: from Language disorders to Autism

- 38 subject (31 M, 7 F), diagnosed with developmental language disorder (20 PLI, 18 SLI)

- re-evaluated as adults (age 15 to 31) with autism specific instruments (ADI-R and ADOS-G)

<table>
<thead>
<tr>
<th></th>
<th>SLI N=18</th>
<th>PLI N=20</th>
<th>ALL N=38</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autistic disorder on both ADI and ADOS</td>
<td>0</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>-</td>
<td>(40%)</td>
<td>(21%)</td>
</tr>
<tr>
<td>PDD on both ADI and ADOS</td>
<td>2</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>(11%)</td>
<td>(55%)</td>
<td>(34%)</td>
</tr>
<tr>
<td>PDD on either ADI or ADOS</td>
<td>6</td>
<td>19</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>(33%)</td>
<td>(95%)</td>
<td>(66%)</td>
</tr>
</tbody>
</table>

Bishop et al. 2008
<table>
<thead>
<tr>
<th>Study</th>
<th>Definition for other PDD</th>
<th>AD</th>
<th>PDD NOS</th>
<th>Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lotter (1966)</td>
<td>behaviour similar to autistic children</td>
<td>4.1</td>
<td>3.3</td>
<td>0.8</td>
</tr>
<tr>
<td>Brask (1970)</td>
<td>‘other psychoses’ or ‘borderline psychotic’</td>
<td>4.3</td>
<td>1.9</td>
<td>0.4</td>
</tr>
<tr>
<td>Wing et al (1976)</td>
<td>socially impaired</td>
<td>4.9</td>
<td>16.3</td>
<td>3.3</td>
</tr>
<tr>
<td></td>
<td><em>(triad of impairments)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hoshino et al (1982)</td>
<td>autistic mental retardation</td>
<td>2.3</td>
<td>2.9</td>
<td>1.3</td>
</tr>
<tr>
<td>Burd et al (1987)</td>
<td>‘autistic-like’</td>
<td>3.3</td>
<td>&gt; 7.8</td>
<td>2.4</td>
</tr>
<tr>
<td>Cialdella &amp; Marmelle (1989)</td>
<td>other forms of ‘infantile psychosis’</td>
<td>4.5</td>
<td>4.7</td>
<td>1.0</td>
</tr>
</tbody>
</table>
### Impact of diagnostic criteria on rate estimation: example of the Northern Finland survey

<table>
<thead>
<tr>
<th>Age</th>
<th>N</th>
<th>Population</th>
<th>Criteria</th>
<th>Rate /10,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 – 18</td>
<td>9</td>
<td>39,216</td>
<td>Kanner</td>
<td>2.3</td>
</tr>
<tr>
<td>15 – 18</td>
<td>28</td>
<td>39,216</td>
<td>Autism ICD-10/DSM-IV</td>
<td>6.1</td>
</tr>
<tr>
<td>15 – 18</td>
<td>30</td>
<td>39,216</td>
<td>Autism Spectrum ICD-10</td>
<td>7.6</td>
</tr>
</tbody>
</table>

*Kiellinen et al., 2000*
### Study design impact on prevalence

Example of 4 recent UK surveys

<table>
<thead>
<tr>
<th>Location</th>
<th>Size</th>
<th>Age Group</th>
<th>Method</th>
<th>PDD Rate /10,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baird et al. 2000</td>
<td>South East Thames 16,235</td>
<td>7</td>
<td>Early screening + FU identification</td>
<td>57.9</td>
</tr>
<tr>
<td>Chakrabarti &amp; Fombonne 2001</td>
<td>Stafford 15,500</td>
<td>2½ - 6½</td>
<td>Intense screening + assessment</td>
<td>62.6</td>
</tr>
<tr>
<td>Fombonne et al. 2001</td>
<td>England &amp; Wales 10,438</td>
<td>5 - 15</td>
<td>Household survey</td>
<td>26.1</td>
</tr>
<tr>
<td>Taylor et al. 1999</td>
<td>North Thames 490,000</td>
<td>0 - 16</td>
<td>Administrative records</td>
<td>10.1</td>
</tr>
</tbody>
</table>

Six-fold variation in estimates
Prevalence of ASD, USA 2006

- 3 fold variation

- Prevalence of ASD, USA 2006

- Health records only
- Health and education records
- USA
Stafford Surveys

Rate /10,000

Chakrabarti and Fombonne, 2005
Prevalence rates by birth cohorts (1972-1985) in two surveys

Fombonne et al. 1997

Smeeth, Fombonne et al., 2004
Time trends: conclusions

- Most epidemiological studies are not informative to gauge trends over time

- There is evidence that methodological factors account for a substantial part of the observed increase in prevalence

- Prevalence rates have gone up but this trend cannot be interpreted as evidence of a secular increase in the incidence

- The hypothesis of an increased incidence is not ruled out, but it remains to be tested with adequate epidemiological data
Take home messages...

- ASDs are amongst the most frequent child neurodevelopmental disorders

- Increasing numbers/prevalence occurred with changes in diagnostic criteria and improved awareness and services

- Surveillance should be developed in order to detect future changes in the incidence