How common is intellectual disability in WA?

Jenny Bourke,
Helen Leonard, Julie Marsh
Condition requiring life-long support for affected individuals and their families from:

- disability services
- health providers
- education providers
- and many other branches of both government and non-government sectors
Challenges and Limitations to Measuring Intellectual and all Disability

Inconsistency in how disability is defined

Lack of population-based data

Multiple disabilities: which is primary
The way forward

Provision of better and more comprehensive information on disabilities in order to:

- plan appropriate services
- monitor trends
- point the way to prevention

Important stakeholders are:

- people with disabilities & their families
- service providers
- health professionals
- policy makers
- researchers
Aims of IDEA

• To provide infrastructure for population-based epidemiological research into cause and prevention of intellectual disability

• To provide infrastructure for research into the health status and service needs of people with intellectual disability

• In conjunction with other childhood databases in WA to provide information on prevalence and predict trends for childhood disability

• To increase community knowledge about intellectual disability
Sources of Ascertainment

• **Currently**
  • Disability Services Commission
  • Department of Education

• **Future improvements**
  • Catholic education and independent schools
  • Direct notification from clinicians
Population Data sources relating to Childhood Disability

- IDEA
- WARDA
- School plus
- Mental health register
- Hospital Morbidity Data System
What information is collected?

- Basic demographic information-sex, place of birth
- Level of intellectual disability
- Medical information where available on the cause of the intellectual disability
- Associated conditions eg cerebral palsy, epilepsy
DSC Eligibility for Level 3 (ID) Services

DSC eligibility based on:
- deficits in adaptive behaviour
- level of ID coded
  - mild (IQ=55-69)
  - moderate (IQ=40-54)
  - severe (IQ<40)

Types of measures include
- Griffiths
- WPPSI
- WISC
- Leiter
- WAIS
- Vineland
- SIB
DSC Eligibility for IDEA
criteria for intellectual disability

IQ<70

Presence of a biomedical cause known to be associated with ID (eg Down syndrome) in the absence of IQ testing

Under 6 years* & classified as “Vulnerable” by DSC with a developmental score that is borderline or less

The aim is to reassess all children at age of six years to confirm eligibility for DSC
Education Department Eligibility

Education Department Eligibility for support determined from significant deficits in adaptive behaviour and IQ >2SD below mean

Children now categorised according to their level of educational need (EN) – rated 1 (low) to 5 (high)

Prior to 2006 categorised as ID level-mild/moderate or severe ID

Using previous known levels of ID (n=2515) we have determined

EN of 4 equates to mild or moderate ID in 90% cases

EN of 5 equates to severe ID in 83% cases
Criteria for eligibility

- IQ < 70
- < 6 years and classified as vulnerable by DSC
- Biomedical cause
- Children with ID, ASD or GDD
  - Education level 4-5
  - Mild/moderate to severe ID

Department of Education
Update of IDEA data

- Initial dataset included all DSC and Education cases identified in 1999 for births 1983-1992 and formed the basis of IDEA
Prevalence of intellectual disability by gender

Males = 65%
Prevalence ratio = 1.76
Prevalence of intellectual disability by Aboriginality

Overall Prevalence ratio = 2.4
Age of ascertainment for DSC and Education
Prevalence of intellectual disability by severity level: birth years 1983-2010
Prevalence of intellectual disability by severity level: birth years 1983-2000-with estimates to adjust for incomplete ascertainment
# Trends in prevalence of Intellectual Disability

<table>
<thead>
<tr>
<th>Rates (Birth years 1983-2005 (ascertainment to 2010), per 1000 live births)</th>
<th>Observed</th>
<th>Previous (Births 1983-1992)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild to Moderate ID (incl. unknown)</td>
<td>15.70 95% CI [15.38-16.02]</td>
<td>12.9 95% CI [12.3, 13.5]</td>
</tr>
<tr>
<td>Severe ID</td>
<td>1.16 95% CI [1.07-1.25]</td>
<td>1.4 95% CI [1.2, 1.5]</td>
</tr>
<tr>
<td>Total ID</td>
<td>16.86 95% CI [16.53-17.19]</td>
<td>14.3 95% CI [13.8, 14.7]</td>
</tr>
</tbody>
</table>

Based on conservative estimates of unascertained cases for births 1983-2005:
Prevalence = 21.13/1000 livebirths
Aetiology of Intellectual Disability

Heber classification system used by DSC medical staff based on medical records. The distribution of cases identified through DSC where medical information may be available:
Most common biomedical diagnoses
Prevalence of specific biomedical disorders
Prevalence of intellectual disability by autism status: birth years 1983-2005

![Graph showing prevalence of intellectual disability by autism status from 1983 to 2005. The x-axis represents the year of birth, and the y-axis represents prevalence per 1000 livebirths. Two lines are shown: one for ASD with and without ID, and another for ID but not ASD. The prevalence generally decreases over time, with a peak in the early 1990s.]

Proudly supported by the people of Western Australia through Channel 7's Telethon.
Factors impacting on prevalence of ASD diagnosis

- Improved clinical awareness
- Changing diagnostic criteria over time
- Changing diagnostic practices
- Gateway to early intervention funding
- Diagnostic substitution
Incidence and significant events in the diagnosis of Autism Spectrum Disorders between 1985 and 2002 among children up to eight years in WA

- 1985: Incidence per 10,000 child-years at risk
- 1987: Broadening of age of onset for autism diagnostic criteria (DSM - III - R)
- 1991: Introduction of Central Diagnostic Panel in WA
- 1994: Tightening of ASD age of onset, broadening criteria for PDD - NOS (DSM - IV)
- 1997: Cross-disciplinary assessment & reporting protocols introduced
- 1997: Funding for intervention services set up (consolidated in 1998)
- 2000: Narrowing of PDD - NOS to original wording (DSM - IV - TR)

IDEA Data: Strengths

Population–based and unique in Australia

Can be linked to other population-based databases

Opportunity to improve and confirm data on ID level using both sources of ascertainment

Has information on cause of ID for >65% of DSC referrals
IDEA Data: Weaknesses

No longer direct contact with patients

Information on co-morbidities may not be complete - without clear definitions information has varied over time depending on DSC medical officer

Depend on follow-up from DSC on eligibility testing at age 6 to confirm young “Vulnerable” children are actually ID
IDEA Variables

- Level of ID: mild, mild/moderate, moderate, severe
- Source of ascertainment: DSC, Education only
- Time of referral: DSC=year of registration
- Cause of ID: Heber diagnosis
- Associated condition: DSC data
Studies using IDEA database

- Studies which have received approval to link to IDEA data include the following topics:
  - Hospitalisations of children with intellectual disability
  - Offspring of women with bipolar disorder and schizophrenia
  - Intellectual Disability and Autism
  - Early Causal Pathways to Mental Health Problems
  - Child Abuse and Neglect
  - Alcohol in pregnancy
  - Burden of genetic disease in the WA population
Conclusions

• The IDEA database has an important function

• Data being used in a number of important studies including severe maternal alcohol use and child protection

• These preliminary results suggest that mild-moderate ID may be increasing even in the face of increasing ASD rates
IDEA Advisory Council

a reference group of stakeholders who both feed into and benefit from the use of the database

• Department of Education
• Disability Services Commission
• Health Department
  Child Development Centre
  Princess Margaret Hospital
  Private organizations and practitioners
• Consumer representative – parent
• Universities
Thanks go to...

- Staff at Disability Services Commission
- Education Department of WA
- Data Linkage Unit at WA Health Department
- Telethon Kids Institute