

Trends in prevalence of intellectual disability in WA

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idea

Intellectual Disability Exploring Answers



Importance of Research

Intellectual disability is a 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**



Counting intellectual disability into the future?

- In 2002 there was a restructure of Medical and Specialist Services within DSC in line with the Commission's policy to foster community based services
- Agreement and funding provision for Telethon Institute for Child Health Research to maintain an Intellectual Disability Database
- New protocols ensure named data are forwarded directly to the WA Data Linkage Unit at the Health Department and not retained at the Institute



Why do we need a data-base for Intellectual Disability ?

- to provide infrastructure for population-based epidemiological and genetic 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



What information do we need to collect?

- **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**



Sources of Ascertainment

**Disability Services
Commission**

**Department of
Education**

**Linkage at the WA Data Linkage
Unit, Department of Health**

**De-identified dataset
with unique ID for
each record is used to
update IDEA**



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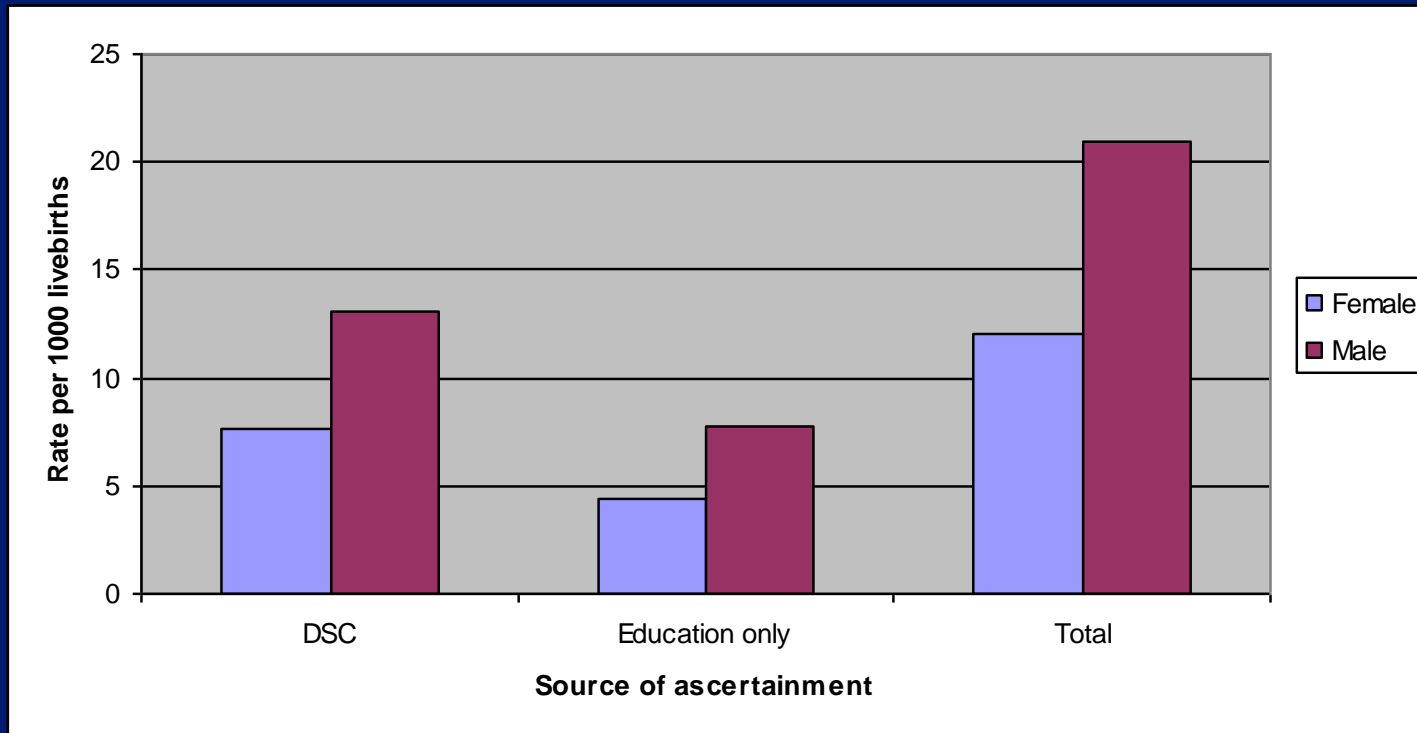
**DSC data on
level of ID,
DOB, diagnosis
etc is linked
using
IDEA_Key**

**Education
data on level
of ID and
DOB is
linked using
IDEA_Key**

**De-identified dataset
with unique ID for
each record is used to
update IDEA**



Prevalence of intellectual disability by source of ascertainment and gender



DSC

Education

Total

Prevalence Ratio

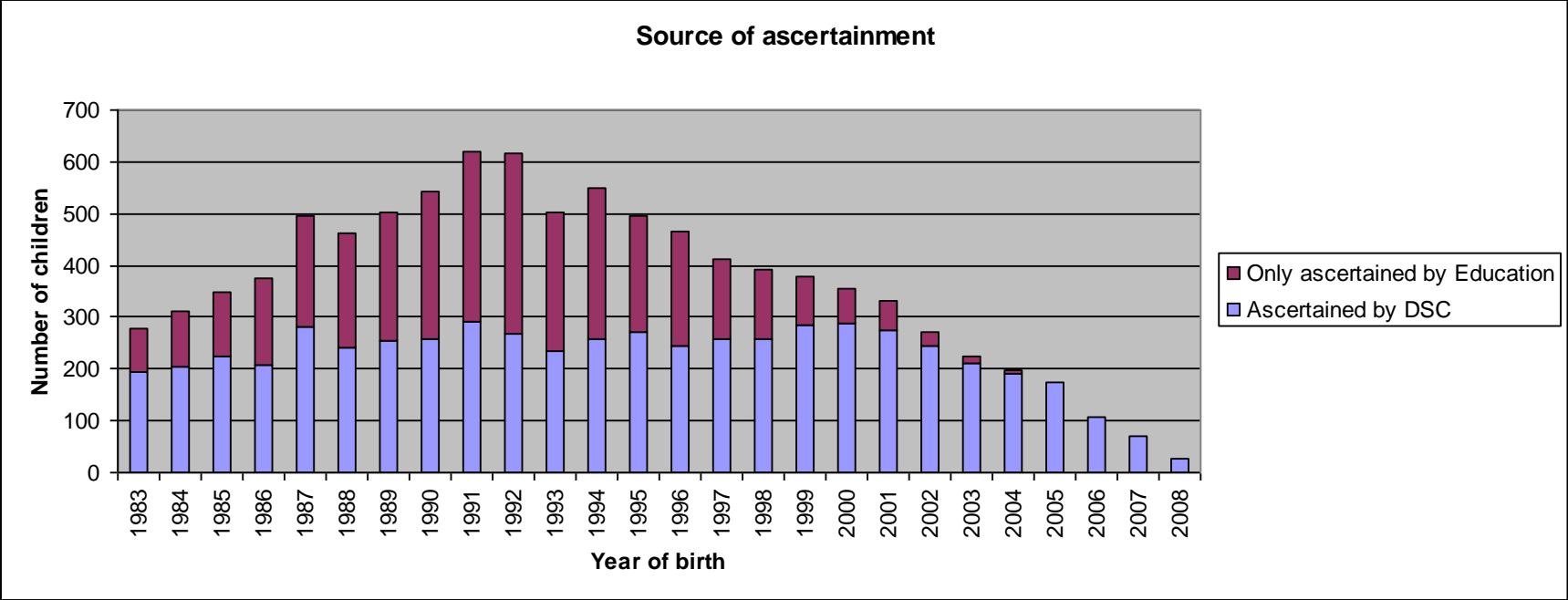
1.71

1.78

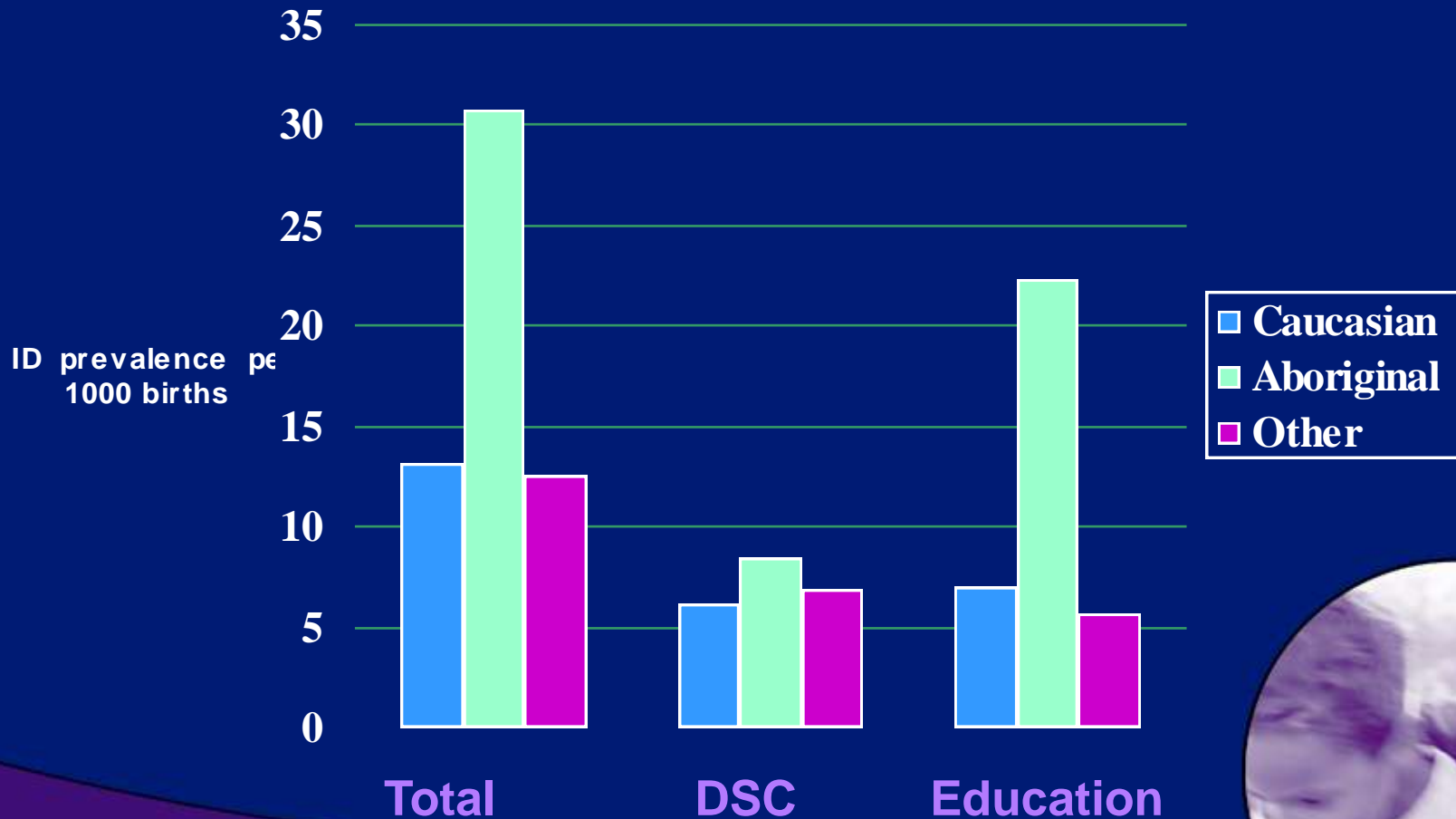
1.74



Number of WA born cases by birthyear and source of ascertainment

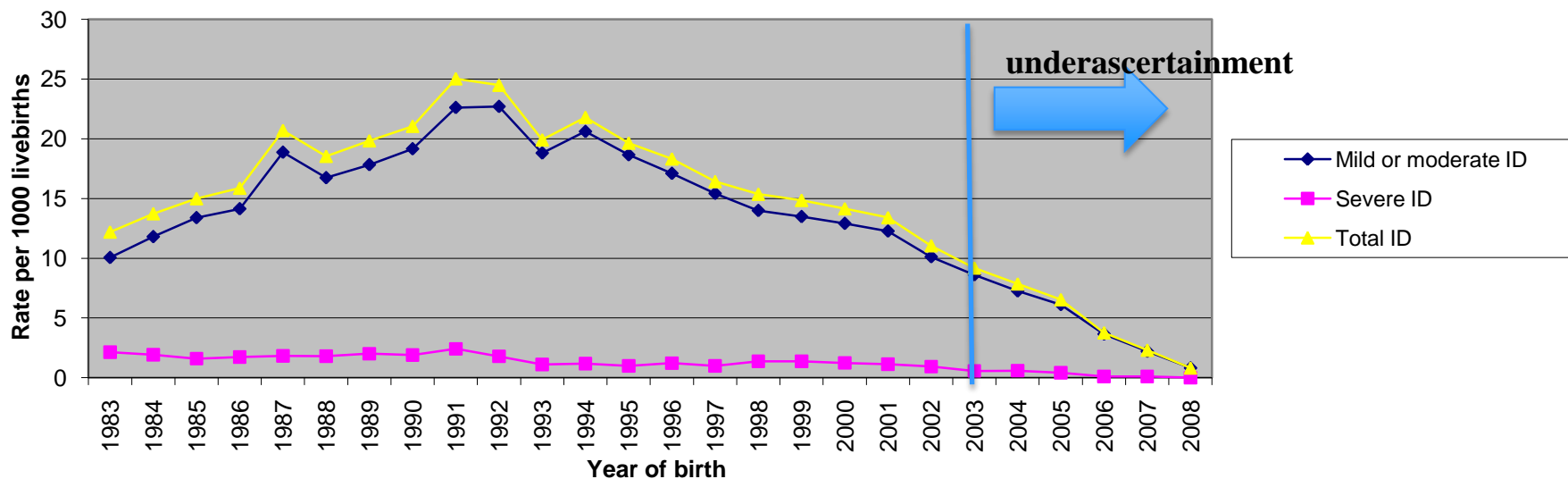


Prevalence of intellectual disability by source of ascertainment and race



Birth prevalence of intellectual disability by level of ID

Prevalence of intellectual disability by level



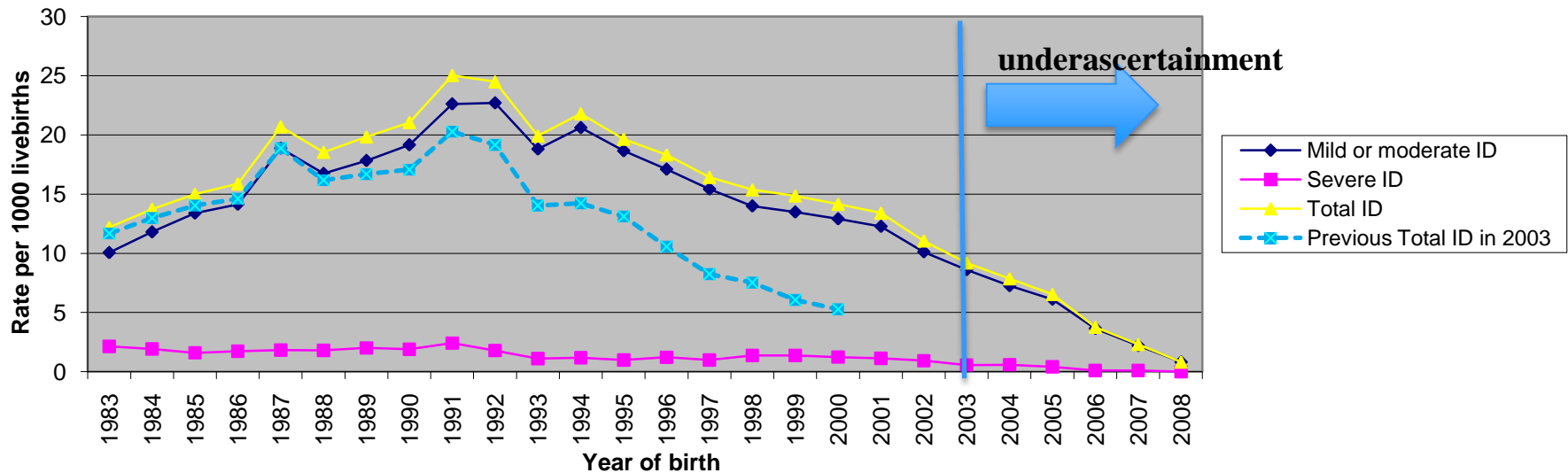
Restricting our estimates to birth years 1983-2003 which allows for the inclusion of children ascertained only through Education

Overall prevalence = 17.6/1000 livebirths



Birth prevalence of intellectual disability by level

Prevalence of intellectual disability by level



Restricting our estimates to birth years 1983-2003 which allows for the inclusion of children ascertained only through Education

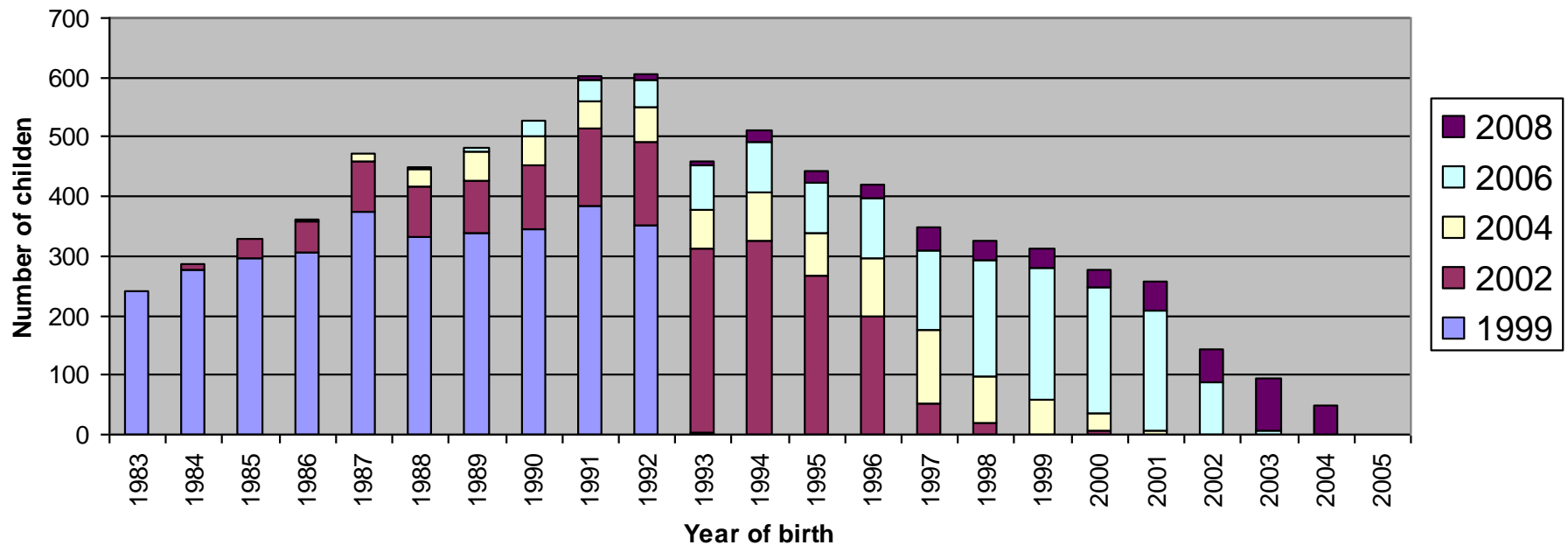
Overall prevalence = 17.6/1000 livebirths

Compares with previous estimates of 14.4/1000 livebirths

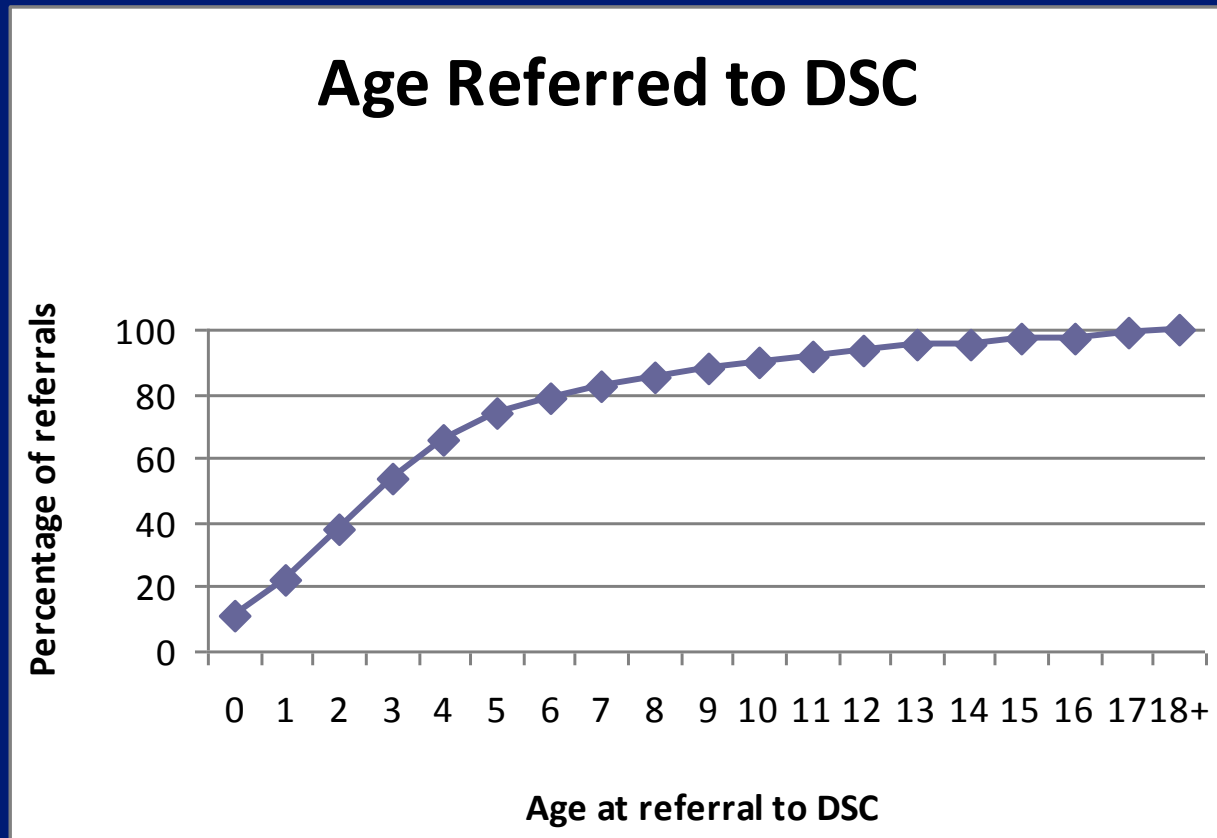


Year of ascertainment by birth year - All education cases

Year of ascertainment by Education



Age at referral to DSC



Determining Level of ID

Based on developmental or IQ tests

- DSC – mild, moderate, severe, unknown, based
- Education (up to 2004) – “mild or moderate”, severe
- Education (after 2004) – level of educational need (EN = 1-5)



Comparing previous level of ID with level of need in 2006 Education data

**Previous level of ID from
Education = mild or moderate
n=1784**



**Education level of need=4
N=1611 (90%)**

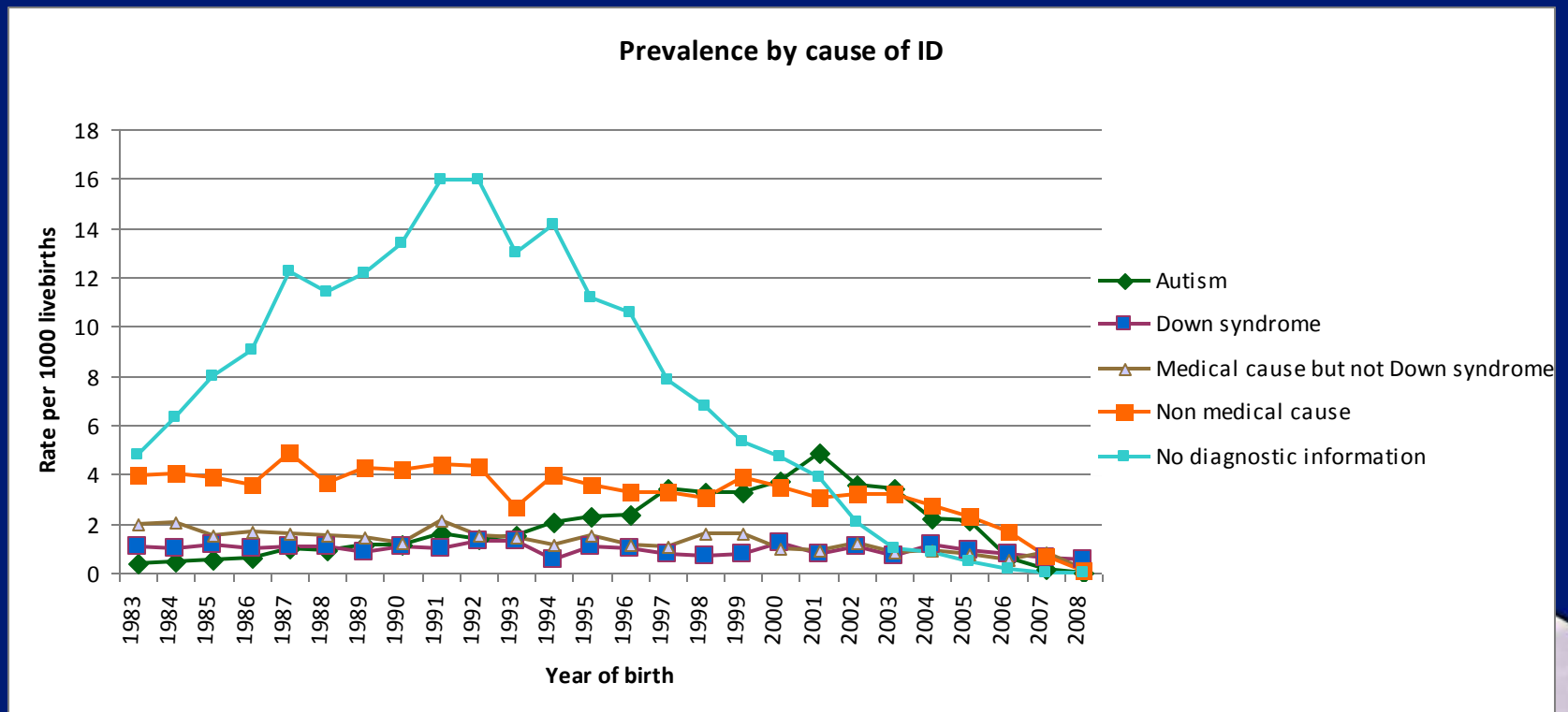
**Previous level of ID from
Education= severe
n=726**



**Education level of
need=5
N=604 (83%)**

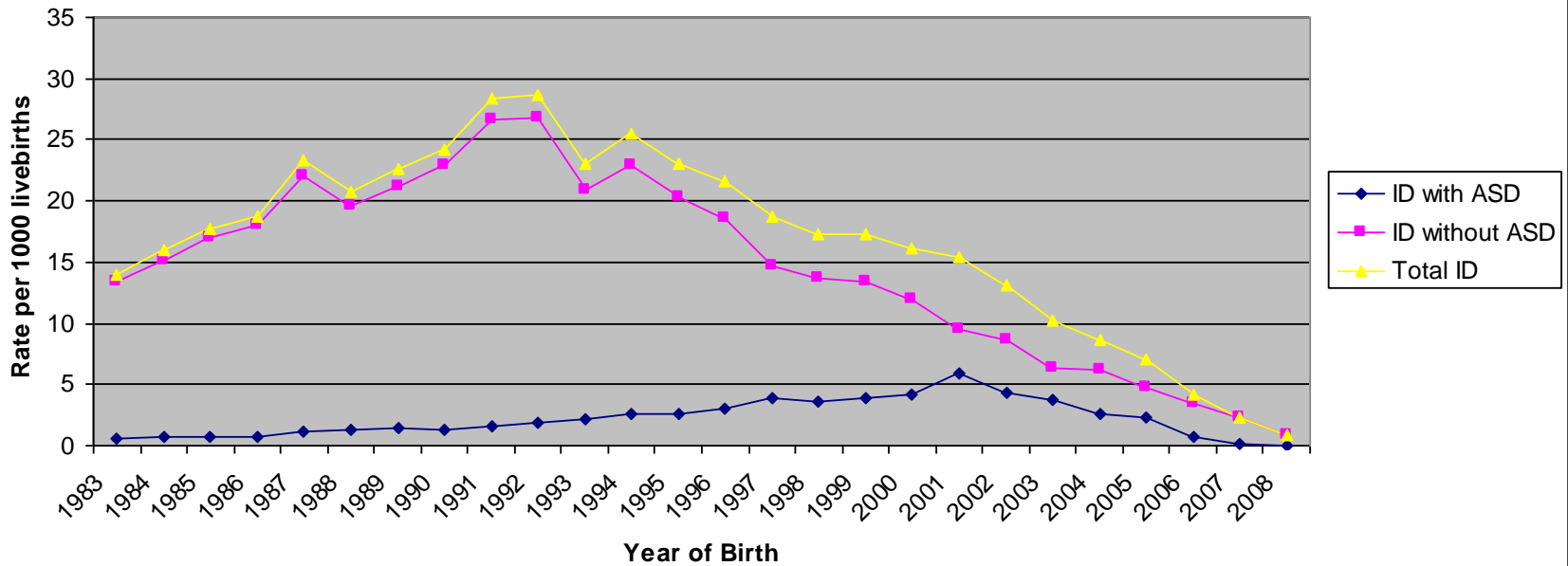


Prevalence by cause of intellectual disability



Trends in Autism diagnoses

Rates of intellectual disability with and without Autism Spectrum Disorder

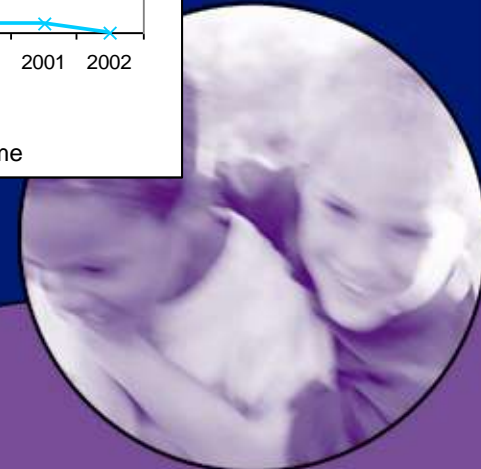
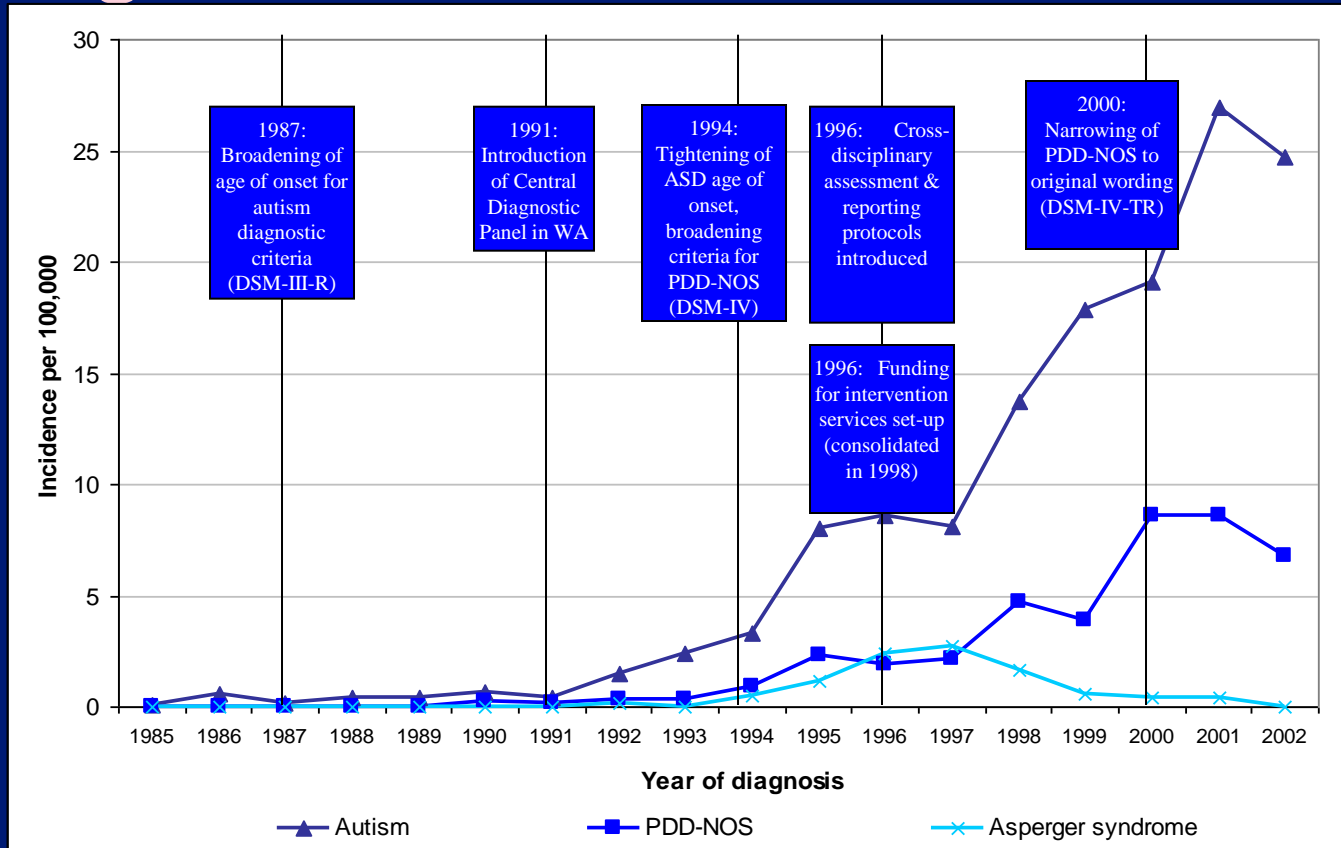


Factors impacting on prevalence of ASD diagnosis

- 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 ASD in WA 1985 - 2002



Studies using IDEA database

Currently 10 studies have received approval to link to the IDEA database, including studies into:

- the offspring of women with bipolar disorder and schizophrenia
- Intellectual Disability and Autism
- Early Causal Pathways of Mental Health Problems
- Pathways to health and education
- Child Abuse and Neglect:
- Alcohol in pregnancy
- Burden of genetic disease in the WA population
- Other tabular data



Results from studies linking to IDEA and other population databases

Study investigating child maltreatment in Aboriginal and non-Aboriginal families

- Children with an ID were found to be at increased risk of maltreatment substantiations in both Aboriginal and non-Aboriginal families.

Characteristics of non-Aboriginal and Aboriginal children and families with substantiated child maltreatment: a population-based study Melissa O'Donnell, Natasha Nassar, Helen Leonard, et al
International Journal of Epidemiology 2010;1-8



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...

- ◆ Peter Cosgrove
- ◆ Natasha Nassar
- ◆ Richard Sanders
- ◆ Staff at Disability Services Commission
- ◆ Department of Education
- ◆ Catholic Education Commission
- ◆ Association of Independent Schools

