

Background of the IDEA system

The IDEA system originated from a dataset of individuals with intellectual disability receiving support from the Western Australian government, was established in 1953 and maintained by successive state governments performing this role. In 2002, the IDEA system was moved and currently is homed in the Telethon Kids Institute (Western Australia) and is a permanent population-based data linkage surveillance system.

Intellectual disability case definition

Disability Services Commission

A person is considered to be intellectually disabled if they have scored more than two standard deviations below the mean on a recent formal assessment of intellectual functioning (within the past 3 years); or scored more than two standard deviations below the mean on a recognised measure of adaptive functioning with demonstrated deficits in two or more of the following skill domains conceptual, social or practical; or if their clinical presentation is consistent with an intellectual disability. The onset of these conditions needs to have manifested prior to 18 years of age.¹

Department of Education

Intellectual disability is determined through a diagnostic report which has had all components completed within six months and has considered factors such as language, cultural background, learning opportunities, disabilities, motivation and cooperation.² Determining intellectual disability includes an assessment of adaptive functioning using both clinical evaluation and standardised assessment with a significant impairment defined as two standard deviations below the mean on a standardised, culturally relevant assessment in at least one domain across multiple environments (e.g. home, school, community and work). Results and interpretations of assessments demonstrate a significant sub-average intellectual functioning of an intelligence quotient <70 on an individually administered appropriate IQ test; and evidence that academic achievement and progress is limited in comparison to age expectations.

Prior to 2006, confirmed cases from the Department of Education were included if the assigned level of ID was 'mild or moderate' or severe. In 2006, the level of ID provided by the Department was modified to represent the child's educational level of need, rated from 1 (low need) to 5 (high need). In the absence of availability of information on ID level, cases with an educational need of 4-5 were considered to have an ID. An analysis of the correlation between the previously assigned level of ID and the level of educational need has shown that an EN score of 4 is correlated with a mild or moderate ID, and EN score of 5 with a severe ID.³ In 2016 the level of educational need was replaced with an Individual Disability Allocation (IDA) which was rated from 1 (mild ID) to 7 (severe and comorbid ID) and used to estimate level of intellectual disability. Further enhancement of data is undertaken by a medical officer, located at DSC, using the four digit AAMR system to assign the most appropriate cause of ID to cases⁴ which can be later grouped into broader categories. The onset of these conditions needs to have manifested prior to 18 years of age.

Supplementary Table 1: Data variables for IDEA surveillance system

Variable	Description
Unique ID	Unique identifier that can be used with other data linkage studies
Ascertainment source	Whether cases were ascertained through Department of Communities or Department of Education
IDEA eligibility	Described as Eligible, Eligible EDWA, Eligible Vulnerable, not eligible. 1. Note: "Eligible EDWA" are cases where there is insufficient information from Department of Communities to determine IDEA eligibility but sufficient information from Education is available. 2. "Eligible Vulnerable" are Department of Communities cases where level of ID is unknown but case has been deemed Vulnerable to ID.
ID level	Mild, mild or moderate, moderate, severe, unknown, Unknown but intellectually handicapped, borderline, Not intellectually handicapped
Sex	Male or Female
DOB Month	Month of birth
DOB Year	Year of birth
Client diagnosis	numeric Heber code for diagnosis – up to four can be recorded
Client diagnosis description	text description of diagnosis - up to four can be recorded
Autism Spectrum Disorder identified	Identifies clients with an autism spectrum disorder diagnosis
Cause of ID	Provides the broader group cause of ID if available. Described as biomedical, not medical – unknown, autism spectrum disorder with ID, insufficient information.

Note: ID (intellectual disability) and intellectual handicap are used interchangeably

References

1. Disability Services Commission. Eligibility Policy for Specialist Disability Services funded or provided by the Disability Services Commission Perth: Government of Western Australia, 2012.
2. Department of Education. Individual disability allocation: intellectual disability. Perth: Department of Education Western Australia, 2017.
3. Leonard H, Glasson E, Bebbington A, et al. Chapter Eight - Application of Population-Based Linked Data to the Study of Intellectual Disability and Autism. In: Urbano RC, ed. International Review of Research in Developmental Disabilities: Academic Press 2013:281-327.
4. Heber R. A manual on terminology and classification in mental retardation. *Am J Ment Defic* 1959;Suppl 64(2):1-111. [published Online First: 1959/09/01].