



Twenty-Five Year Survival of Children with Intellectual Disability in Western Australia

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Objectives To investigate survival up to early adulthood for children with intellectual disability and compare their risk of mortality with that of children without intellectual disability.

Study design This was a retrospective cohort study of all live births in Western Australia between January 1, 1983 and December 31, 2010. Children with an intellectual disability (n = 10 593) were identified from the Western Australian Intellectual Disability Exploring Answers Database. Vital status was determined from linkage to the Western Australian Mortality database. Kaplan-Meier product limit estimates and 95% CIs were computed by level of intellectual disability. Hazard ratios (HRs) and 95% CIs were calculated from Cox proportional hazard regression models adjusting for potential confounders.

Results After adjusting for potential confounders, compared with those without intellectual disability, children with intellectual disability had a 6-fold increased risk of mortality at 1-5 years of age (adjusted HR [aHR] = 6.0, 95%CI: 4.8, 7.6), a 12-fold increased risk at 6-10 years of age (aHR = 12.6, 95% CI: 9.0, 17.7) and a 5-fold increased risk at 11-25 years of age (aHR = 4.9, 95% CI: 3.9, 6.1). Children with severe intellectual disability were at even greater risk. No difference in survival was observed for Aboriginal children with intellectual disability compared with non-Aboriginal children with intellectual disability.

Conclusions Although children with intellectual disability experience higher mortality at all ages compared with those without intellectual disability, the greatest burden is for those with severe intellectual disability. However, even children with mild to moderate intellectual disability have increased risk of death compared with unaffected children. (*J Pediatr* 2017;188:232-9).

Individuals with intellectual disability are known to have a shorter life expectancy than the rest of the population¹⁻³; however, most information reporting mortality or survival has not been derived from population-based studies. Intellectual disability is characterized by globally impaired cognitive functioning and significant deficits in adaptive functioning manifest before the age of 18 years.⁴ In Australia, the population prevalence of intellectual disability was recently estimated at 17.0 per 1000 live births,⁵ although in a recently published multicounty meta-analysis, the prevalence was estimated at 10.4 per 1000 live births.⁶

Many individuals with intellectual disability also have comorbid health conditions⁷ and are more likely to be hospitalized than those without intellectual disability.^{8,9} Despite improvements during the last few decades, in the early treatment of life-threatening conditions, such as for heart defects in infants with Down syndrome, concerns still remain about how well individuals with intellectual disability are able to access healthcare services.^{10,11} Initiatives to improve access to better healthcare for individuals with intellectual disability, predominantly within Australia, United Kingdom, and the US, have been shown to identify otherwise undiagnosed and often life-threatening conditions,¹² such as cancer and heart disease in this population.

The disparities in health experienced by those with an intellectual disability, particularly if mild or moderate,^{11,13} may also be compounded by increased social disadvantage.^{14,15} In Australia, the disparities in mortality for Aboriginal children have been well documented,¹⁶ and we also know Aboriginal children are over-represented among those with mild or moderate intellectual disability.⁵ Within high income countries, child survival and health outcomes, particularly for those with complex disability, are inextricably linked to healthcare, public health, and socioeconomic policies that reduce inequality.¹⁷ Although child and adolescent mortality has decreased over the last few decades, for all children there are overlaying factors related to relative poverty associated with increased child mortality.^{17,18}

aHR	Adjusted hazard ratio
HR	Hazard ratio
IDEA	Intellectual Disability Exploring Answers
ICD-10	<i>International Statistical Classification of Diseases and Related Health Problems, 10th Revision</i>
IQ	Intelligence quotient
POBW	Percent of optimal birth weight

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The intent of our study was to utilize a population-based dataset in Western Australia to describe the survival experience into early adulthood for children with intellectual disability compared with those without intellectual disability.

Methods

This was a retrospective cohort study of all live births in Western Australia between January 1, 1983 and December 31, 2010. Children with an intellectual disability were identified by linkage to the Intellectual Disability Exploring Answers (IDEA) database,¹⁹ a population-based register, which ascertains cases through the Western Australian Disability Services Commission and the Western Australian Department of Education. Children are considered eligible for IDEA if they are recognized to have an intellectual disability by the age of 18 years. Cases ascertained from the Disability Services Commission were considered eligible for the study if their general intelligence was estimated to be more than 2 SDs below the mean for their age (or their full scale intelligence quotient [IQ] was <70), and they had commensurate deficits in adaptive behaviors occurring before 18 years of age²⁰; or they had a condition known to be consistent with intellectual disability (such as Down syndrome). Young children who may not have been at an age to be tested on a formal measure of intelligence were eligible if a developmental test such as the Griffiths assessment scored <70, and they were considered vulnerable for intellectual disability.

Level of intellectual disability was defined as mild (IQ 55-69), moderate (IQ 40-54), or severe (IQ <40). Cases identified only through the education system were considered eligible if they had a level of intellectual disability defined as either mild/moderate or severe. The severity of intellectual disability for all individuals was, therefore, coded as either mild/moderate or severe, because education sources did not allow for differentiation between mild and moderate. Etiology of intellectual disability and level of intellectual disability were grouped as (1) autism with co-occurring intellectual disability, (2) known biomedical cause²¹ (such as Down syndrome, Fragile X, maternal alcohol, or postnatal injury), (3) unknown cause with severe intellectual disability, and (4) unknown cause with mild or moderate intellectual disability. Cases where there was a condition possibly associated with the intellectual disability but not a definite cause, such as prematurity or environmental deprivation, were classified as unknown cause. Cases identified only through education sources, where no medical information is provided, were also classified as unknown cause.

Linkage to the Western Australian Register of Developmental Anomalies was used to provide additional medical information on individuals with intellectual disability.

All births were linked to the Western Australian Death Registrations database to determine vital status (deceased, alive). Children not recorded as deceased were censored at the end of the study period, December 31, 2010.

Cause of death for all cases was coded from information on the Western Australian Mortality Database according to

International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) codes provided by the Australian Bureau of Statistics. In addition, for those with intellectual disability the underlying cause of death was coded using supplementary data such as autopsy reports. These were initially categorized as maternal, intrapartum, birth defect, prematurity, infection, accident, cancers, sudden infant death syndrome, other, or unknown,²² with further subclassifications for infection and birth defects as well as creation of 3 additional categories for epilepsy, renal failure, and thrombosis.

Data from the IDEA database were linked to the Western Australia Midwives' Notification System to obtain information about maternal and pregnancy characteristics. The Western Australia Midwives' Notification System²³ receives information from midwives about all births they attend in Western Australia for infants ≥ 20 weeks' gestation or ≥ 400 g. We obtained infant sex, birthweight (400-1499, 1500-2499, ≥ 2500 g), gestational age (24-31, 32-36, 37-42, >42 weeks' gestation), maternal race (Aboriginal, Caucasian, or other), maternal age (<20, 20-35, and ≥ 35 years), parity (no children (nulliparity), 1 child, 2 children, ≥ 3 children), and maternal marital status (not married, never married, separated, divorced, or widowed, and married). The percent of optimal birth weight (POBW), which is a ratio of observed birth weight to optimal birth weight expressed as a percentage, was provided²⁴ and categorized (<75%, 75%-85%, 85%-95%, 95%-105%, 105%-115%, 115%-125%, $\geq 125\%$).

We also included information from the Australian Bureau of Statistics on community-level social class using the Socioeconomic Indexes for Areas Collection District level data based on maternal residence postcode at time of birth. A Collection District is the smallest area unit for which socioeconomic data is provided and is roughly equivalent to a small group of suburban blocks in urban areas. Specifically, we used the Accessibility/Remoteness Index of Australia scores (major city, inner and outer regional, remote and very remote) to determine geographic remoteness and the Index of Relative Socioeconomic Disadvantage (10%, 25%, 50%, 75%, 90% and $>90\%$) for years 1996, 2001, and 2006. All data linkage was conducted at the Western Australian Department of Health by the Data Linkage Branch of the Western Australia Data Linkage System.

Statistical Analyses

Descriptive statistics were computed for continuous and categorical variables. The Kaplan-Meier product-limit method was used to determine survival probabilities and generate survival curves for the overall time period and for each level of intellectual disability group and cause of intellectual disability group. Children did not enter the follow-up period (left censoring) until 1 year of age to allow time for diagnosis of the intellectual disability; thus, deaths which occurred prior to age 1 year were not included in the analysis. The log-rank test was used to compare survival curves. Hazard ratios (HRs) and 95% CIs from univariate and multivariate Cox-proportional hazards regression models were used to determine the risk at specific time periods, conditional on reaching the minimum

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