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# The Influence of Intellectual Disability on Life Expectancy

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***Background.*** To date, relatively few representative data have been available to health planners and advocacy groups on the life expectancy of people with intellectual disability. A study of trends in the survival profiles of people with intellectual disability was undertaken to assist in the planning of appropriate medical and support services.

***Methods.*** Since 1953, the Disability Services Commission of Western Australia has maintained a database of persons diagnosed with intellectual disability. The database was used to calculate survival probabilities on a total of 8724 individuals, 7562 of whom were still alive at the time of sampling in December 2000.

***Results.*** Kaplan-Meier survival plots showed a strong negative association between severity of intellectual disability and survival, with median life expectancies of 74.0, 67.6, and 58.6 years for people with mild, moderate, and severe levels of handicap. Significant negative associations also were observed with male gender, Indigenous Australian parentage, and individuals diagnosed with a specific genetic disorder.

***Conclusions.*** The findings indicate a major and expanding increase in the service requirements of this aging, intellectually disabled population during the past two generations.

THROUGHOUT the course of the 20th century, there was a consistent trend toward increased life expectancy in virtually all developed and developing countries. Although much of the research conducted on aging and life expectancy in the general population has been targeted toward assessing health and social needs, relatively little attention has been paid to disadvantaged population subgroups, including those with intellectual disability. On a global basis, 0.3% to 0.5% of children have been reported to be affected by severe intellectual disability (ID), with intelligence quotient (IQ) scores of less than 50 and deficits in adaptive behavior (1). Comparable figures for mild ID, with IQ levels between 50 and 70, show much greater variation and range from 0.2% to 4.0% (2). Estimates of ID in Australia show that between 1.7% and 1.9% of the population are affected (3). However, as in most countries, there may be some degree of underestimation, especially of mild cases and among those living in remote rural areas.

Evidence from the United Kingdom and the United States has indicated significant improvements in the life expectancy of persons with ID (4,5), and, for milder forms of disability, life expectancies are now almost comparable to those in the general population (6). The principal focus of the present study was to document changes in the age profile of those receiving services for ID within Western Australia during the past 50 years and to determine patterns of life expectancy based on severity and a number of other factors.

## Methods

### *Subjects*

The population of Western Australia is principally urban, with 74% of the population residing within the Perth metropolitan area where the provision of specialist diagnostic and care services is organized and based. Responsibility for the needs of people with ID has been vested in the Disability Services Commission (DSC), a state government agency established in 1952, and details of persons referred for services since 1953 are maintained in a computerized database.

The American Association on Mental Retardation classification is used to define ID (7), with services provided if IQ testing and an adaptive behavior assessment minimally indicate a mild level of ID (IQ $<70$), with symptoms manifest before 18 years of age. Wechsler intelligence scales are the preferred tool for assessing intellectual ability (mild ID, 55 to 69 points; moderate ID, 40 to 54 points; severe ID, $<40$ points). Other psychometric tests may be used if physical abilities or communication skills are impaired. Clinical diagnosis is based on a modification of Heber (8).

Information was abstracted from the DSC database for a range of variables, including background demographic characteristics, level of intellectual disability, clinical diagnosis, and the presence of genetic disorders. For deceased individuals, details were abstracted on the date and cause of death. These mortality data were supplemented through linkage with the Mortality Register maintained by the Health Department of Western Australia, which contains in-

formation derived from all death certificates issued in the state since 1969.

*Statistical Assessment*

A total of 9824 cases were identified. In 1100 cases, mainly children younger than 5 years of age, a formal ID assessment had not been conducted, and they were excluded from analysis. Survival estimates were calculated on the remaining 8724 persons, including 242 Indigenous Australians, who met the inclusion criteria, using date of birth as entry and date of death or December 31, 2000 as exit. Differences in survival were compared for gender, indigenous parentage, level of ID, and diagnosed genetic disorder, using Kaplan-Meier survival probabilities and log-rank tests to assess differences in the plotted curves. All data analyses were performed using Stata for PC version 7.0 (Stata Corp., College Station, TX).

## Results

The total numbers alive at the end of each decade are shown in Table 1. The mean age of individuals referred to and registered with the DSC in Western Australia increased from 11.2 years in 1953 to 32.0 years by 2000, with the oldest living person aged 96.4 years at the end of 2000. During the study period, 1162 individuals had died, with mean and median ages at death of 30.3 years ($SD = 22.3$) and 26.0 years.

Stratification by level of ID showed that 54.7% of individuals had mild ID, 27.8% had moderate ID, and 17.5% had severe ID (Table 2). There was a major gender difference in the numbers of recorded cases, with significantly more male individuals (58.4%) than female individuals (41.6%), and this pattern of sex differential occurred across all levels of ID.

In 22.9% of cases, a genetic disorder had been diagnosed, representing 16.0% of mild ID, 33.8% of moderate ID, and 27.5% of severe ID cases. Down syndrome was the most common genetic disorder, accounting for 1092 cases (12.5% of the total). Other major genetic causes of ID were autosomal cytogenetic defects ($n = 114$), Fragile X ($n = 64$), tuberous sclerosis ($n = 53$), and Prader Willi syndrome ($n = 46$).

The 50% survival probability for the whole ID population was 68.6 years. Comparable 50% survival probabilities in the general Australian population are 75.6 years for men and 81.2 years for women (9). Male participants in the study group had a shorter median lifespan, 66.7 years compared with 71.5 years for the female participants ($p < .001$). Survival also was significantly reduced for Indigenous Australians compared with non-Indigenous Australians ($p < .0001$).

Table 1. Distribution and Age Profile of Cases With Intellectual Disability, 1953–2000

| Year | Number Eligible | Mean Age, y | Median Age, y | Maximum Age, y |
|---|---|---|---|---|
| 1953 | 60 | 11.2 | 9.6 | 22.9 |
| 1960 | 769 | 13.5 | 12.4 | 53.0 |
| 1970 | 3178 | 17.7 | 15.7 | 70.0 |
| 1980 | 5175 | 22.6 | 20.7 | 78.7 |
| 1990 | 6258 | 27.8 | 27.5 | 86.7 |
| 2000 | 7562 | 32.0 | 44.6 | 96.4 |

Table 2. All Eligible Cases by Gender, Indigenous Status, Etiology, and Level of Intellectual Disability

| | Level of Intellectual Disability | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Mild | | Moderate | | Severe | | Total | |
| Characteristic | *n* | % | *n* | % | *n* | % | *N* | % |
| Gender | | | | | | | | |
| Female | 1903 | 21.8 | 1007 | 11.6 | 715 | 8.2 | 3625 | 41.6 |
| Male | 2870 | 32.9 | 1415 | 16.2 | 814 | 9.3 | 5099 | 58.4 |
| Etiology | | | | | | | | |
| Genetic | 763 | 8.7 | 819 | 9.4 | 420 | 4.8 | 2002 | 22.9 |
| Nongenetic/unknown | 4010 | 46.0 | 1603 | 18.4 | 1109 | 12.7 | 6722 | 77.1 |
| Ethnicity | | | | | | | | |
| Indigenous | 102 | 1.2 | 85 | 1.0 | 55 | 0.6 | 242 | 2.8 |
| Non-Indigenous | 4671 | 53.5 | 2337 | 26.8 | 1474 | 16.9 | 8482 | 97.2 |
| Total | 4773 | 54.7 | 2422 | 27.8 | 1529 | 17.5 | 8724 | 100.0 |

As shown in Figure 1, there was a highly significant negative association between survival and severity of ID ($p < .0001$), with 50% survival probabilities of 74.0, 67.6, and 58.6 years in persons with mild, moderate, and severe levels of ID, respectively. Finally, median survival was reduced in persons with a genetic disorder, 60.1 years, compared to 72.2 years where no genetic diagnosis had been made ($p < .0001$).

## Discussion

A number of limitations are associated with the application of centralized databases for a study of this type—in particular, the possibility of misclassification arising from the use of different diagnostic tools across the study period and the fact that people with mild ID are less likely to be registered. For these reasons, a deliberately conservative approach was adopted in selection of the study sample, by excluding all subjects for whom data were incomplete.

The issue of increasing life expectancy has taken on greater significance with the recent call, addressed to the World Health Organization, for research into practices that successfully promote longevity and healthy aging in persons with ID (10). Some studies have reported that morbidity patterns in people with ID do not differ markedly from those of the general aging population (4,5,11), which is reflected in the life expectancy figures obtained in this study (Figure 1). The specifically reduced life expectancy for Indigenous Australians with ID may primarily be indicative of the decreased survival experienced by the indigenous population in general (12).

By the time they reach middle-age, individuals with ID have a greater tendency toward obesity and decreased physical fitness compared with the general population (13,14). Enhanced predisposition to the development of psychiatric problems (4,15), osteoporosis (16), thyroid disorders, nonischemic heart disease, various forms of sensory impairment (17), and early onset of dementia (18), has been reported. With this in mind, the results of the present study should prove useful in evaluating the future health, residential, and care needs of this significant sector of the population, especially because substantial increases in life expectancy are occurring across the spectrum of ID severity.

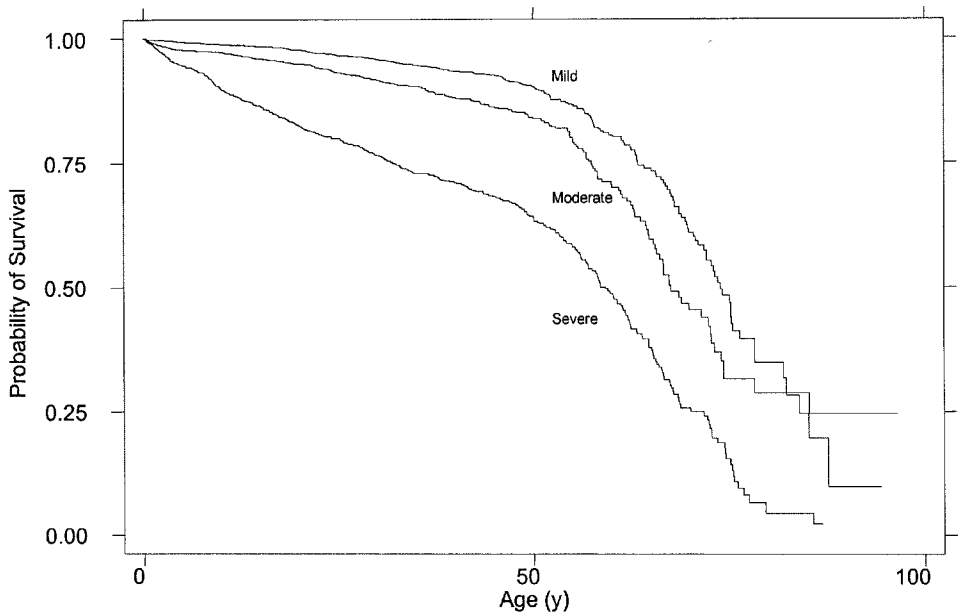


Figure 1. Survival by level of intellectual disability.

The changing patterns of service delivery introduced during the past decade for people with ID have placed an increasing emphasis on home and/or community care (19). Despite the policy of deinstitutionalization, the demands on health services are likely to increase over the coming years with a consequent need for the development of more comprehensive preventive and promotional health strategies.

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References

1. Durkin MS, Hasan ZM, Hasan KZ. Prevalence and correlates of mental retardation among children in Karachi, Pakistan. *Am J Epidemiol.* 1998;147:281–288.
2. Roeleveld N, Zielhuis GA, Gabreels F. The prevalence of mental retardation: a critical review of recent literature. *Dev Med Child Neurol*. 1997;39:125–132.
3. Wen X. *The Definition and Prevalence of Intellectual Disability in Australia*. AIHW catalogue no. DIS 2. Canberra, Australia: Australian Institute of Health and Welfare; 1997.
4. Day K, Jancar J. Mental and physical health and ageing in mental handicap: a review. *J Intellect Disabil Res*. 1994;38:241–256.
5. Janicki MP, Dalton AJ, Henderson CM, Davidson PW. Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disabil Rehabil*. 1999;21:284–294.
6. Patja K, Iivanainen M, Vesala H, Oksanen H, Ruoppila I. Life expectancy of people with intellectual disability: a 35-year follow-up study. *J Intellect Disabil Res*. 2000;44:591–599.
7. American Association on Mental Retardation. *Mental Retardation: Definition, Classification, and System of Supports.* Washington, DC: American Association on Mental Retardation; 1992.
8. Heber R. A manual on terminology and classification in mental retardation. *Am J Ment Defic*. 1959;64:1–111.
9. Australian Bureau of Statistics. *Population Projections, Australia—1999–2101*. Catalogue no. 3222.0. Canberra, Australia: Australian Bureau of Statistics; 2000.
10. Hogg J, Lucchino R, Wang K, Janicki M. Healthy ageing—adults with intellectual disabilities: ageing and social policy. *J Appl Res Intellect Disabil*. 2001;14:229–255.
11. Tait D. Mortality and dementia among ageing defectives. *J Ment Defic Res*. 1983;27:133–142.
12. Australian Bureau of Statistics. *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples.* Catalogue no. 4704.0. Canberra, Australia: Australian Bureau of Statistics; 2001.
13. Rimmer JH, Braddock D, Fujiura C. Prevalence of obesity in adults with mental retardation: implications for health promotion and disease prevention. *Ment Retard*. 1993;31:105–110.
14. Graham A, Reid G. Physical fitness of adults with an intellectual disability: a 13-year follow-up study. *Res Q Exerc Sport*. 2000;71:152–161.
15. Nottestad JA, Linaker OM. Psychiatric health needs and services before and after complete deinstitutionalization of people with intellectual disability. *J Intellect Disabil Res*. 1999;43:523–530.
16. Center J, Beange H, McElduff A. People with mental retardation have an increased prevalence of osteoporosis: a population study. *Am J Ment Retard*. 1998;103:19–28.
17. Kapell D, Nightingale B, Rodriguez A, Lee JH, Zigman WB, Schupf N. Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Ment Retard*. 1998; 36:269–279.
18. Janicki MP, Dalton AJ. Prevalence of dementia and impact on intellectual disability services. *Ment Retard*. 2000;38:276–288.
19. Ashman A, Suttie J, Bramley J. Older Australians with intellectual disability. *Aust N Z J Dev Disabil.* 1994;19:25–43.

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