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How much does intellectual disability really cost? First estimates for Australia

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Abstract

Background Given the paucity of relevant data, this study estimates the cost of intellectual disability (ID) to families and the government in Australia.

Method Family costs were collected via the Client Service Receipt Inventory, recording information relating to service use and personal expense as a consequence of ID. Government expenditure on the provision of support and services was estimated using top-down costing.

Results A total of 109 parents participated. The cost of ID in Australia is high, especially for families. Total economic costs of ID are close to $14,720 billion annually. Opportunity cost of lost time provided 85% of family expense. A comparison of family expense and social welfare benefits received suggests that families suffer considerable loss. This may impact on families' physical and emotional wellbeing.

Conclusions Monitoring of changes in expenditure is required. Policies should ensure that money devoted to ID is allocated in a rational, equitable, and cost-effective manner.

Keywords: *cost, intellectual disability, families*

Introduction

Costs associated with disability are a current focus of interest internationally. The World Report on Disability (World Health Organization, 2011) calls for "progress in … disability cost estimates and better data" (p. 42). In Australia, the government has asked the Productivity Commission to enquire about "the costs and benefits of replacing the current system of disability services with a new national disability care and support scheme" (Productivity Commission, 2010, p. 3). In designing the new scheme, its costs will need to be compared with the costs which currently apply.

An understanding of costs borne by families is also important in advocacy for equity in bearing the burden of care. Further, estimates of costs of care are a part of examining the cost-effectiveness of interventions.

For the above reasons, we sought to initiate research efforts to estimate the costs of intellectual disability in Australia.

These costs may include family expenditure on ID-related treatment (such as co-payments to GPs and pharmaceutical products) and care of their children; government expenditure on acute, primary, and population healthcare services; government expenditure on welfare, education, and disability support services; and nongovernment expenditure on services to support families with children with ID.

These costs will depend in part on the prevalence of ID. Estimates of prevalence vary as a consequence of different epidemiological methods employed. A useful review of this issue is provided by Leonard and Wen (2002). The Australian Institute of Health and Welfare (AIHW) used a national population

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survey in 2003 to identify 2.5% of the population under 65 years, or 436,200 people, as having ID (Australian Institute of Health and Welfare [AIHW], 2008a). Previous AIHW estimates had focused on people with ID who also needed ongoing support with activities related to self-care, mobility, and communication, and had concluded that a figure of 0.99% of the population was "perhaps the best figure to use for an overall estimate of the prevalence of intellectual disability in Australia" (Wen, 1997). Leonard, Petterson, Bower, and Sanders (2003) linked a state register and administrative data to identify a prevalence of ID of 1.42% among children in Western Australia aged 6–15 years. For the purposes of this report, we regard these figures as indicating a range of estimates of ID in Australia, differing probably because of variations in scope and levels of disability included, as well as other methodological differences. The relationship of the rate of 1.42% to register data, and the fact that it is relatively conservative, led us to adopt it for the present estimation task.

Estimates of the number of persons in Australia with ID above the age of 65 are particularly unclear. Further, in the older population, comorbidities become more common and isolating ID as a major factor becomes more problematic. Services for younger people with disability are sometimes identifiable whereas aged care services and supports are more generic. For these considerations we have confined this report to those with ID under the age of 65.

In a recent epidemiological study used to calculate the burden of disease, the statistical measure used was Disability Adjusted Life Years (DALYs; Murray, 1994), indicating years of healthy life lost through the impact of ID in Australia. In this study, the distribution of severity of ID, classified according to intelligence (IQ) scores, was 37% mild, 37% moderate, 19% severe, and 7% profound (Begg et al., 2007). In two separate reports, the authors estimate that ID was responsible for 1.7% of the total disease burden in all Australians and 5.5% of the total disease burden in Indigenous Australians (Begg et al., 2007; Vos, Barker, Stanley, & Lopez, 2007). In developing their burden of disease evidence, the authors note that people with ID live considerably fewer years than their counterparts, with length of life decreasing according to severity. For example, people with mild ID live an average of 78.9 years while those with profound ID are expected to live an average of 58.1 years. The quality of life (QOL) of people with ID is also considerably less than their counterparts. For example, the QOL of people with mild ID is considered to be 71% of optimal health (i.e., 100%), while QOL for people with profound ID is rated at 24% of optimal health (Begg et al., 2007).

There is a paucity of evidence quantifying the economic costs associated with ID. The majority of evidence focuses on costs to the healthcare system. For example, Lakin, Prouty, Smith, Polister, and Smith (2002) report an estimated annual per-person expenditure in 2001 of US$48,019 for people with ID receiving services through Medicaid. In the Netherlands, ID ranked first in disease-specific costs for the 0–64 year age group, accounting for 9% of healthcare expenditure (Polder, Meerding, Bonneux, & van der Maas, 2002). However, the costs of ID rest not only with the healthcare system but also have wide-ranging impact on the person, their family, and the broader society. A comprehensive assessment of costs should, in theory, consider all these viewpoints.

Intellectual disability impacts not only on people themselves but those caring for them, in particular their families. One aspect which contributes to impact is the high proportion of children with ID that display severe behaviour problems, which is nearly 3 times the rate in their counterparts (Einfeld & Tonge, 1996). The increased rate costs associated with high levels of behaviour disturbance in people with ID have recently been reported (Einfeld et al., 2010). Costs of care appear to vary with severity of ID. Knapp, Comas-Herrera, Astin, Beecham, and Pendaries (2005) found costs of care to increase with increasing severity of ID.

The more inclusive the cost estimates and the wider the perspective, the better able policymakers are to evaluate the benefit of interventions intended to mitigate the severity or financial hardship associated with ID. In estimating the cost of ID, it is important to identify actual expenditures, the value of opportunity costs, and the associated morbidity and premortality losses. The latter costs represent the value of pain and suffering, the loss of role performance and the loss of social participation. These costs are seldom included in costing studies given the assumptions required and lack of reliable data. Opportunity costs, however, are commonly included in costing studies. For example, a parent of a child with a disability may be unable to work due to their responsibilities as a carer and the absence of disability-sensitive child care arrangements. In a recent pilot study interviewing parents of children with autism, all 17 parents involved reported that their child's disorder had negatively affected their career and/or income (Järbrink, Fombonne, & Knapp, 2003). In Dobson and Middleton's (1998) study, parents estimated costs for the minimum services needed for their child with disability to participate as fully as possible in the world around them. The average expenses required to raise a child with severe disability were at least 3 times that of raising a child without a disability (Dobson & Middleton, 1998).

There are two common methods underpinning cost studies: the incidence-based approach and the prevalence-based approach. The incidence-based approach estimates the present value equivalent of known and expected costs, and values lost life and impaired health based upon an understanding of the nature and intensity of ID. The data requirements for such an approach are considerable and require an understanding of ID-specific incidence, morbidity, mortality, and life expectancies. Costs in the prevalence-based approach are the value of net resources which in a given year are unavailable to the community for consumption and investment purposes as a result of the effects of past and present ID (Luce, Manning, Siegel, & Lipscomb, 1996). In terms of direct costs, the prevalence-based approach involves a top-down assignment of the health sector costs to the subcategories according to their share in the overall prevalence of ID. The prevalence-based approach is favoured when comparing the costs of treatments in one time period, or when data is insufficient to conduct an incidence-based study.

There is a lack of Australian data on the costs associated with ID. The purpose of this study is to initiate a research endeavour to better understand these costs. This study had the goal of providing an initial exploration of these costs. We included in this exploration the following aspects: methodological issues in cost estimations; differences in costs for different ID groups; evaluation of nonmarket costs (e.g., opportunity costs) to carers; and costs borne by each of government and families.

Methods

A mixed methodology was adopted in this study. Family costs were derived using data on family expenditure, collected via a self-completed instrument, the Client Service Receipt Inventory (CSRI). This involved identifying the activities that families were engaged in, and costing these activities. Social welfare benefits to families with children with ID were estimated using a top-down costing approach that estimated government expenditure related to the provision of support and services for ID.

Family expenditure related to ID

Participants. The study was approved by The University of Sydney Human Research Ethics Committee. A wide range of ID associations across Australia were invited to advertise the study to the parents of children with ID. Interested families contacted the research team and were posted the CSRI. A total of 90 participants were sought (30 with mild ID, 30 with moderate ID, and 30 with severe/profound ID).

Measures. The Client Service Receipt Inventory (CSRI) is an instrument developed for collecting cost-related information about people with mental health problems for use in mental health service evaluations (Beecham & Knapp, 1992). The version of the CSRI for people with autistic spectrum disorder and their parents and carers (Järbrink et al., 2003) was adapted with permission from M. Knapp (personal communication, April 5, 2007). The CSRI was modified to the Australian context and used to collect information about the interviewee's use of health and social care services, accommodation and living situations, income, employment, and benefits. Key modifications to the instrument included tailoring the questions to the Australian context with a focus on services available in Australia. A copy of the revised survey is available from the corresponding author upon request. The questionnaire asks parents/carers to focus on those costs associated with the child's intellectual disability and/or behaviour problems, above the cost of raising a typically developing child.

Government expenditure on services provided for people and their families with ID

A top-down costing approach was undertaken to estimate additional expenditure by Australian governments in providing services and support for people with ID. The approach involved reviewing published reports associated with expenditure on services related to ID in the financial year 2005–2006. For the purpose of this study, expenditure was considered in four broad categories: income support; specialist disability support services; other disability-specific services, such as Home and Community Care Services (HACC); and relevant generic services such as education (where estimates of additional expenditure relate to extra expenditure arising because of a child's ID). These four categories have been used in Australia as a framework for providing a picture of the government funding and provision of services and assistance over the last two decades (see, for example, AIHW, 2007, pp. 169–191).

For all categories of expenditure, estimates were made by apportioning expenditure according to estimates of the proportions of people with ID receiving the services, in order to estimate additional expenditures relating to ID. These assumptions are made explicit in the results section of this paper, as well as being outlined here, with sources. Our estimates will tend to be conservative as when data on service

usage or additional expenditure on people with ID could not be obtained or reasonably inferred (for instance, for generic services such as health), the category was omitted.

For income support, disability payments and allowances include the Disability Support Pension (DSP; $8.26 billion in 2005–2006), mobility allowance, carer allowance and payment, with total expenditure of $12.513 billion in 2005–2006 (AIHW, 2007). Among DSP recipients in 2005–2006, 11.3% were reported as having an intellectual/learning "medical condition" (Australian Government Department of Families, Housing, Community Services and Indigenous Affairs [FaHCSIA], 2006). It is therefore assumed in our estimates that 11.3% of these expenditures relate to people with ID under 65 years of age.

Specialist disability services in 2005–2006 were funded under the Commonwealth State/Territory Disability Agreement (CSTDA) and included services for accommodation and support to people with disability; services that provide support in non-institutional settings; community access including services for social independence; respite services that provide a short-term and time-limited break for carers; and, employment assistance. These services are provided chiefly to people aged under 65 years (AIHW, 2008b). During 2005–2006, the total number of people who reported ID either as primary or significant other disability was 38.6% of all users of CSTDA services. In estimating ID-related expenditure on CSTDA services, we assumed 38.6% of all expenditure was related to users with ID. This is not likely to result in over-estimation of costs; for instance, people with ID were more likely to have "little or no effective communication" than service recipients with other disability (AIHW, 2008b, p. 27) and more likely to have multiple disabilities (AIHW, 2008b, p. 19), indicating the need for more assistance (AIHW, 2009b).

Of residential aged care users, 4.3% in 2005–2006 were aged under 65 years (AIHW, 2007, 2008b). Expenditure on residential aged care was adjusted to reflect this proportion and further adjusted to reflect that some 12.4% of clients aged under 65 had an ID (AIHW, 2009a). The Home and Community Care (HACC) program provides a range of community care services, targeting frail and older people with disability, as well as younger people with disability and their carers. Some 24.5% of all HACC users were aged under 65 years (AIHW, 2007). Expenditure on HACC services was adjusted to reflect this proportion and further adjusted to assume that, as with residential aged care, perhaps 12.4% of these clients aged under 65 had an ID.

In 2006, 3.9% ($N = 133,024$) of all school students in Australia had a disability (AIHW, 2007), with an estimated 43.8% ($N = 58,265$) of these having ID (AIHW, 2008a); that is, an estimated 58,271 students with ID in 2006. The method here is to multiply the number of school children reported by school authorities as having a disability in 2006 by the proportion of school children in the population with disability reported as having ID in 2003 to arrive at this estimate. This is a more conservative estimate than using the population data for both parts of the calculation. Although it was not possible, from published reports, to ascertain the additional expenditure made in schools on students with disability, unpublished estimates in NSW suggest that in 2009–2010 an allocation of $94.6 million supported over 14,800 students with disability in regular classes (G. Noonan, personal communication, September 2009). If this figure (rounded down including allowance for the different year) were used as the basis for an estimate of minimum per capita additional expenditure on students with disability nationally, then an estimated figure of $6,000 per student for 2005–2006 could be multiplied by the estimated number of students with ID.

Results

Family expenditure related to ID

A total of 109 parents completed the survey (100 mothers and 9 fathers). From the parents' responses 23 were classified as mild ID (12 males and 11 females), 38 as moderate ID (28 males and 10 females), 39 as severe/profound ID (28 males and 11 females). The severity of ID was unknown for 8 parents (6 males and 2 females) and data was missing for 1 female. The average age was 13 years (standard deviation [*SD*] = 7.6), 96% lived at home with their parents, and 44% had never been to mainstream school.

Table 1 provides an overview of information extracted from the CSRI. Service use increases according to severity of ID with people with severe/profound ID making an average of 45 visits to primary or community care services in the last 6 months compared to 25 and 40 visits for people with mild and moderate ID, respectively. Although not reported in the table, the results suggest that up to 28% of all services related to home help, 16% for speech therapy, 12% for case management, and 11% for occupational therapy.

A logical consequence of this utilisation of services and severity of ID is the time required each week to care for family members with ID. The data suggest

Table 1. Overview of key data variables by ID severity

	Mild ($n = 23$)	Moderate ($n = 38$)	Severe/profound ($n = 39$)	Not known ($n = 9$)
Service use				
Average number of ID-related admissions in past 6 months	0.13	0.35	1.13	0.38
Average number of visits to primary and community care services in the last 6 months	24.52	40.03	44.78	35.88
Average number of times required respite care in the last 6 months	6.04	8.21	17.54	4.00
Average number of times services by volunteer groups accessed in last 6 months	4.09	4.45	2.79	26.50
Family support				
Average hours of care per week provided by families	52	61	85	34
Proportion of families losing incomes in last 6 months due to ID responsibilities	64%	81%	66%	57%
Cost estimates				
Average out-of-pocket expenses for families in the last 6 months	$7,689	$12,533	$8,984	$13,546
Opportunity cost of time spent caring by families in the last 6 months	$31,817	$37,786	$52,494	$20,896
Total out-of-pocket expenses and opportunity costs for families in the last 6 months	$39,506	$50,319	$61,478	$34,442
Benefit from government				
Average government benefit received by families in the last 6 months	$2,825	$2,232	$3,349	$887
Cost-benefit				
Financial position for families in the last 6 months	− $36,681	− $48,087	− $58,129	− $33,555
Total population of Australia under 65 years in 2006 = 17,210,914	37% = 90,426	37% = 90,426	26% = 63,542	
Percent with ID = 1.42				
Number of individuals with ID below age 65 = 244,395				
National estimate for financial positions for families in the last 6 months	− $3,316,916,106	− $4,348,315,062	− $3,693,632,918	
Total cost to families (millions $)			11,359	

Note. ID = intellectual disability.

that families (i.e., parents, friends, and relatives) devote up to 85 hours per week on care for their dependant with severe/profound ID compared to 52 and 61 hours per week for individuals with mild and moderate ID, respectively. Nearly 70% of all families reported losing income or reducing the number of hours in paid employment as a consequence of the care they provide.

One of the questions on the CSRI asked respondents about out-of-pocket expenses in the last 6 months. These expenses include such items as the cost of replacing damaged toys and furniture, certain food, adaptations as well as expenses for care, medication, and transport. Although the survey did not ask respondents about their income, which would be useful to validate some of the out-of-pocket expenses, the data reported in Table 1 suggest that families with dependants with ID are thousands of dollars out of pocket each year. For example, in the last 6 months, the average family with a dependant with moderate ID was out of pocket over $12,000.

An estimate of the opportunity cost of family time spent caring for a dependant with ID has been calculated by combining estimates of average weekly earnings per hourly rate (i.e., $23.67 per hour) with reported number of hours of ID-related care provided by families each week multiplied by 26 to convert to a 6-month period. The results suggest that the value of time spent by families caring ranges from close to $32,000 to $52,000 for a dependant with mild and severe/profound ID, respectively. Combining out-of-pocket expenses with the value of opportunity cost of time spent caring reinforce the considerable family expense associated with a dependant with ID.

One question the CSRI asked respondents about was social security benefits they or the dependant receive.

The highest reported average benefits received was for dependants with severe/profound ID at $3,349 in the last 6 months, which is equivalent to $129 per week.

A comparison with expenses incurred with benefits received suggests that families with a dependant with ID suffer considerable economic hardship. The estimated net financial position ranges from a loss of $37,000 to a loss of $58,000 for mild and severe/profound ID, respectively. When adjusted for the estimated number of people aged under 65 years with ID by level of severity, the results suggest that ID cost families close to $11.359 billion each year.

Government expenditure on services provided for people and their families with ID

Total expenditure on services and assistance for people with ID is estimated at $3.361 billion in 2005–2006 (Table 2). Payments and allowances for ID comprise almost half of the expenditure with an estimated $1.414 billion allocated in 2005–2006. Services related to ID provided under the specialist disability support scheme were estimated at $1.525 billion (or 40%) of total expenditure. Education was the next most expensive category at 9% of total expenditure or $350 million.

Combined family expense and government expenditure

When extrapolated to the population, results from the CSRI suggest that family expenditure related to ID is estimated at $11.359 billion each year. Government expenditure on ID-related services is estimated at $3.361 billion each year. Aggregating these estimates suggests that ID costs the Australian society (i.e., government and families) $14,720 billion each year.

Discussion

Given the prevalence of ID within society, and the international literature suggesting ID is a considerable drain on families' time and resources (Lakin et al., 2002), this study attempted to estimate the economic costs associated with ID in Australia. The findings from this study offer a first approximation of the economic cost of ID in Australia. Before discussing the main findings, it is important to reflect on several potential limitations.

First, the limited funding available to conduct this research impacted on the scope of the project. For example, the recruitment process for the CSRI survey was opportunistic, so we cannot be sure that participants were representative. Indeed, children with mild ID are underrepresented compared with their prevalence as predicted by the distribution curve of intelligence in the community. However, this is in keeping with most studies in which the full range of ID is identified through administrative means. We do not know whether the mildest degree of ID, which tends to blend in with the rest of the community, also generates significant extra costs. With additional funding a more rigorous recruitment process could be adopted to ensure the sample is representative.

Table 2. Estimated government expenditure on services and assistance for people with ID and their families, 2005–2006

Expenditure activity	ID-related expenditure ($A millions)	Notes
Income support		
Payments/allowances	1,413.99	Total administered expenses $12,513.2 million (AIHW, 2007). Assume 11.3% of all expenses relate to people with ID aged under 65 years (FaHCSIA, 2006).
Specialist disability support services	1,525.24	Total expenditure on disability support services $3,951.4 million; 38.6% of users with ID as primary or significant other disability (AIHW, 2008b).
Other disability-specific services		
Residential aged care	29.96	Total expenditure on aged care $5,370.6 million (AIHW, 2007); 4.5% of clients aged under 65 and 12.4% had an ID (AIHW, 2009a).
Home and Community Care	41.84	Total expenditure on HACC services $1,408.9 million, with 24% of clients aged under 65 (AIHW, 2007). Again, assume 12.4% of these had ID (as for residential aged care).
Education	349.63	An estimated 58,271 students in 2006 with ID; an estimated expenditure per student of $6,000 (see text for explanation).
Total	3,360.66	

Note. ID = intellectual disability; HACC = Home and Community Care.

In our sample, 96% of the people with ID lived at home. This is slightly higher than the proportion of the same age group (89%) living at home as reported by Braddock, Emerson, Felce, and Stancliffe (2001).

Second, a prevalence-based approach was used to estimate costs. Costs in the prevalence-based approach include direct, indirect, and intangible costs. While this study has attempted to place a dollar value on direct costs and indirect costs to both families and the government, there is no consideration of intangible costs associated with the value of lost output, pain and suffering, the loss of role performance, and the loss of social participation. Future studies may consider integrating burden of disease estimates of reduced QOL associated with ID with monetary assessments of a QOL. Further, increased evidence on the parameters required for incidence-based costing may contribute to the economic costs generated in this report.

Third, the CSRI, although a valid and empirically tested instrument, was designed in the United Kingdom, and modified to the Australian context. Considerable scope exists to finetune this instrument to make it easier to complete and more relevant to Australian users. The CSRI may also be modified to include other aspects related to caring for a family member with ID such as impact on health, stress, or marital problems.

Fourth, the top-down study used existing sources to estimate expenditures related to ID. Data identified were in some respects insufficiently specific, which necessitated the use of assumptions. Further, the top-down analysis did not consider the full spectrum of government services or expenditure related to ID such as acute and other healthcare services utilisation, housing, equipment, or rehabilitation. A further study could broaden the scope to include these other services and include expenditure by non-government organisations. The lack of good quality economic data related to ID is not unique to this study and is a significant problem faced by other ID researchers (Forsyth & Winterbottom, 2002; Lakin et al., 2002; Polder et al., 2002).

Data obtained from the 109 participants who completed the CSRI suggest that service use and cost increases with the severity of ID. Families with a dependant with severe/profound ID made an average of 45 visits to a primary or community care service in the last 6 months compared to 25 visits for a dependant with mild ID. Families with a dependant with severe/profound ID devote up to 85 hours per week on care compared to 52 hours per week for a dependant with mild ID. The data suggest that over 70% of all families sacrifice work opportunities in order to have the time to care for their dependant. The opportunity cost of carer time over a 12-month period ranges from $63,364 to $104,988 for a dependant with mild and severe/profound ID, respectively. Combining annual out-of-pocket expenses ($15,378 for mild ID, $25,066 for moderate ID, and $17,968 for severe/profound ID) with the value of opportunity costs of time spent caring reinforces the considerable family expense associated with a dependant with ID estimated at an average of $48,073. The CSRI also asked participants about allowances received from the government. Based on responses, annual benefits received range from $4,464 for individuals with moderate ID to $6,698 for individuals with severe ID; families with dependants with mild ID reported annual benefits of $5,650. When multiplied by the number of individuals with ID below the age of 65, this amounts to $11.359 billion each year.

Although the CSRI asks for costs associated with ID additional to costs of care of raising a typically developing child, this difference could be better substantiated by directly measuring costs with a typically developing sibling, thus providing a control for our estimates.

When we estimated payments and allowances using the top-down approach, total expenditure was estimated at $1.414 billion, equivalent to $3,764 per individual with ID under the age of 65 years in Australia. Similarity in numbers provides evidence of convergence and face validity to our results. Total expenditure on services and assistance for people with ID is estimated at $3.361 billion in 2005–2006 or $13,751 per person with ID under the age of 65. Further work is needed to tease out the relationship between families' out-of-pocket expenses and government expenditure to identify the imbalance between government funding and family expense.

The results of this research suggest that the economic cost of ID in Australia is high, with families carrying the majority of the burden. Total economic costs of ID are estimated at $14,720 billion each year, with opportunity cost of lost time accounting for 85% of family expense. A comparison of family expense incurred with social welfare benefits received suggests that families with a dependant with ID suffer considerable economic hardship. The estimated net financial position ranges from an annual loss of $36,681 to a loss of $58,129 for mild and severe/profound ID, respectively. This hardship has implications beyond a measurable economic cost and is also likely to impact on families' physical and emotional wellbeing.

Further research is required to better understand the financial implications of caring for children with ID and the impact this may have on family wellbeing. Data are required to monitor changes in the prevalence of ID and expenditure on services for ID. Information is required on cost-effective strategies to

improve the care for those with ID and policies to ensure that money devoted to ID services are allocated in a rational, equitable, and efficient manner. Such information will be especially important as Australia considers the introduction of a long-term care and support scheme.

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