THE LIFETIME COSTS ASSOCIATED WITH LIVING WITH A DISABILITY

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Introduction

In 2013 the CDPA was contracted by the Human Resources and Skills Development Canada to undertake a literature review on lifetime costs associated with disability as part of the scheduled legislative review of the Registered Disability Savings Plan (2011). This paper represents a portion of the information generated for the government in that process. It was embargoed by the previous federal government, and no portion of it could be shared, despite the CDPA's mandate to generate and mobilize knowledge. With the recent change in government, we are now able to hare this information. Admittedly it is now 2 years out-of-date; however, we feel there is still considerable useful information contained herein that may be of interest and of use to our constituency. We release it at this time in the hopes that it will be helpful.

This review of literature used a scoping review methodology to assemble knowledge from international peer-reviewed and grey literature on the methods and results of estimates of the lifetime cost of disability. The scoping review was conducted according to the five-step approach outlined by Arksey and O'Malley: question specification, search design, article selection, data organization, reporting (Arksey & O'Malley, 2005; Levac, Colquohoun & O'Brien, 2010).

(1) The question addressed in the review was: ***What is currently known about the extraordinary expenses associated with living with a disability?***

(2) The search design employed electronic health and social science databases, with the following keywords: *Disability, disabilities, disabled; savings, financial security, assets, wealth; costs, supports, lifetime costs, burden.* Keywords were combined systematically in an iterative fashion as the search proceeded. In addition to bibliographic databases, web-based searches were conducted of key national jurisdictions and consumer / advocacy organizations representing disability issues.

(3) Articles were included in the review if they were: written in English or French; published between 2006 and 2012; related to the research question. Articles were excluded from the review if they did not pertain directly to disability. Both authors critically reviewed the final set of articles and documents.

(4) & (5) Articles were organized and reported according to four approaches to estimating costs: direct estimates of lifetime costs, indirect estimates; human capital approaches and asset poverty approach.

1. Direct estimates of costs

Lifetime costs of disability can be estimated as costs to individuals and families, or as costs to society. The following studies used a variety of methods to estimate overall lifetime or annualized costs to individuals and families in the UK, the US, Australia and Canada.

- Knapp, Romeo, and Beecham (2009) found that the lifetime costs of caring for adults with Autism Spectrum Disorder (ASD) in the UK were £796,050 for those with no co-morbid intellectual disability, and £1,234,044 for those who also had an intellectual disability. These costs included special education, health and social care, respite care, accommodation costs for children not living with their families, and foregone employment income. They do not include informal care or foregone employment income by family members.
- Centres for Disease Control (2004) in the US found that the average lifetime medical and non-medical costs (assistive devices, home and automobile modifications, special education, losses to employment income) were $1,014,000 for persons with “mental retardation”, $921,000 for persons with Cerebral Palsy, $417,000 for people with hearing loss, and $566,000 for people with visual impairments. The cost of special education alone could range between 42%-82% of the total direct costs incurred by families caring for a child with an intellectual disability.
- US estimates of the lifetime cost related to traumatic brain injury (TBI) came in between $85,000 to $3 million USD depending on severity. This study included medical costs, foregone employment income, and costs related to the care of the individual post injury (Brain Injury Institute, 2012).
- A study in the United States (Ganz, 2007) included costs for home modifications, special education and employment supports. This study estimated lifetime costs at $3.2 million USD, and found that the non-medical costs were much larger than the medical costs.
- An Australian study estimated the cost of disability at 29% of household income for families with any person with a disability, and 37% for households where the head of household experienced disability (Saunders, 2007). The study also found that each point in four point severity scale accounted an additional 10% in the cost of disability to households. The cost of a moderate restriction was estimated at 30% of household income, a severe disability at 40% and a “profound” disability at 48%.
- Between 1995 and 2001, the cost of disability in Ireland increased from 20 to 30% of disposable income (Stapleton, Protik & Stone, 2008).

- Recent Canadian estimates of the lifetime cost of spinal cord injury (Kruger, 2011) estimated $1.6 million for people with paraplegia and $3.0 million for people with tetraplegia. This study included direct costs (i.e., health care and prescription drugs, equipment and modifications, long-term care), and indirect costs (i.e., morbidity, premature mortality, unpaid caregiving costs).
- A Canadian study using 2001 PALS data (Burton & Phipps, 2009) estimated the overall mean outlay by families at $1,159 per year. When multiplied by the average life expectancy of 83 years used in the CDSP program architecture (Styan, 2012), the average lifetime out-of-pocket cost of disability in Canada is $96,197. This conservative estimate only included direct out-of-pocket costs and truncates costs at the top end.
- Based on differences in standard of living between households, Cullinan and colleagues (2011) estimated the cost of disability in 2001 at 22.8% of average family income/. This translates to $7,634 CAD per year, or $633,628 over a lifetime. For families with a child who has "some limitation", lifetime costs were estimated between $564,151 and $842,058 CAD. For those with a severe limitation, lifetime costs were estimated between $908,755 and $1,036,592 CAD.
- Sobsey and Calder (2006) observed that in Canada, the economic impact of many extraordinary costs associated with disability is mitigated by government programs, private insurance and service from charitable organizations. Further they note that some of the typical costs of child-rearing are reduced when a child grows up with a disability; for example, post-secondary education and car insurance.

Several studies estimate the <u>cost to society</u> of living with a disability or caring for a person with a disability, including social spending, medical costs and lost productivity:

- Dow and Meyer (2010) estimated that 6 million Americans, 6 million Britons and 2.6 million Australians provide informal care to family members. They estimate that 74% of all care provided in Australia is provided informally, accounting for $30.5 billion per year in savings to society. They similarly estimate savings of $87 billion / year in the UK (approximately equivalent in value to the National Health Service), and $257 billion in the US.
- An Australian study estimated the overall cost of caregiving at AU$ 968 per household per week, or $49,818 per year (Access Economics, 2010).
- The market value of family caregiving in the US was estimated at $304 billion in 2004 (Fujiura, 2010).

2. Indirect estimates of cost

Difficulties in quantifying the impact of disability and corresponding labour market disruptions have led to the development of indirect methods of capturing the cost of disability. In comparison to direct approaches where researchers tally consumption expenses (direct survey approach, expenditure diary approach, budget standards approach), indirect approaches use econometric models and large datasets to reach conclusions about the financial well-being of individuals and families affected by disability compared to their peers (Cullinan, Gannon & Lyons, 2011, Saunders, 2007). The Material Hardship approach looks at the ability to afford a standard basket of consumption items considered necessary to function in contemporary society (Emerson et al., 2010; Emerson & Hatton, 2007; Parish et al., 2008). This approach does not estimate specific disability-related costs, but rather reports the odds that individuals and families with disability will experience greater material hardship than other families. Indirect estimates of the cost of disability suggest that 30-48% of disposable income is spent on disability-related expenses, depending on severity of disability and other household demographic factors.

There are of course limitations to indirect approaches, such as disagreements about the indicators that should be included, cross-cultural comparisons of basic needs for everyday living, and need to control for many factors associated with household composition (Emerson & Hatton, 2007); nevertheless, these studies offer a useful perspective on the total cost of disability to individuals and families, particularly in relation to comparable households that do not live with disability. These approaches will no doubt be refined over time, but they are already an important development in measuring the cost of disability. Indirect methodologies have been recognized and endorsed as the best way forward in terms of measuring the cost of disability (Stapleton, Protik and Stone, 2008).

Another emerging area of research includes attempts to quantify "spillover effects" on family members living with an individual with a disability (Witt et al, 2011; Edwards et al. 2008). This research recognizes the additional stresses placed on families caring for people with disabilities, and the possible adverse effects on health, medical costs, disability days, sick leave and mental health of family members. Family-level variables can add considerable cost to individual estimates of the costs associated with disability, especially if families do not have adequate medical insurance. Economic consequences due to higher rates of family separations and delayed launching can also be included in these spillover effects that can adversely affect the financial wellbeing of families (Emerson et al., 2010; Parish, Rose et al., 2010b).

3. Human capital approaches

Another way to examine the costs of living with a disability is to consider the presence or absence of capital. In this approach, four types of capital are usually considered (Robson & Nares, 2006):

- Human capital – education, skills, health
- Physical capital – housing, transportation, business assets
- Social capital – networks, connections
- Financial capital – income and assets.

In terms of human capital, individuals with disabilities are unquestionably less likely to accrue human capital by means of advanced education and training (McColl, James, Boyce & Shortt, 2006; Statistics Canada, 2008). Particularly if the onset of disability occurs prior to the completion of education, there are significant effects on lifetime educational attainment, occupational choices and employment potential. Recent Canadian estimates show that 10% fewer disabled men and women attain post-secondary qualifications than their non-disabled counterparts (men: 11.7% disabled, 21.1% non-disabled; women: 9.1% disabled vs. 19.6% non-disabled)(Canadian Human Rights Commission, 2012).

Differences in physical capital lead to structural economic inequalities that are deeply rooted in society. Take for example home ownership – perhaps the most basic indicator of economic security and wealth. Robson and Nares (2006) notes that in Canada, housing is the most significant asset owned by families, representing 38% of all assets. (Second is retirement savings, accounting or 12% of wealth). According to Emerson and Hatton (2007), only 55% of families with a disability in the UK were able to own their own home, compared to 72% of other families. In the US, only 4% of disabled adults own a home, compared to 70% of non-disabled adults (Soffer et al, 2010). In the absence of relatively lucrative paid employment, the costs of home ownership are simply out of reach. Similar deficiencies are evident when exploring the ability of people with disabilities to raise capital for business enterprises, to pursue advanced or professional education, and to save for retirement.

With regard to social capital, Soffer and colleagues (2010) refer to "gateway assets" to describe social capital that contributes positively to economic security – assets like personal and family contacts, expert advice, private transportation, excellent health care and health maintenance. These supports permit individuals to obtain advanced education, to be socially and geographically mobile, and to obtain optimal employment – in short, to be well off. Putnam and associates (2005) note that people with disabilities are less likely to have opportunities that lead to the development of social capital. They refer specifically to advanced education and employment experiences, and the subsequent development of beneficial contacts and connections.

In terms of financial capital – particularly savings and investments, 46% of families with a child with a disability had no savings at all. They were 68% more likely than their peers to be entirely without financial assets. For those who had savings, families with a disabled child had significantly less than other families (£1,200 vs £3,000) (Emerson & Hatton, 2007). Dufflo and associates (2007) showed that people with incomes less than $40,000 are very unlikely to be able to save. Given an average income of $19,000 for people with disabilities (compared to $27,500 for non-disabled), it is clear that saving would be a particular challenge (Statistics Canada, 2008). Buckland (2010) notes the difficulty for low income families to obtain bank credit of any kind, particularly a mortgage. Instead, they are often forced to rely on "fringe credit" sources, such as private loan and cheque cashing services. These financial agencies are notoriously expensive and unregulated. It is no surprise then that parents with a disabled child find themselves concerned about their ability to save for future financial needs of that child (Shulman, 2009).

4. Asset ownership

Recent literature suggests that even more limiting than lack of income in terms of social inclusion and citizen participation is the lack of wealth (Sherraden, 1991). Wealth is defined as not only the presence of income, but also the ownership of assets. Assets most commonly include real property (home and land), business assets, and savings and securities (Parish et al., 2010a). Assets are often classified as short-term (or liquid) assets, such as bank accounts and investments, and long-term, such as real estate and retirement savings (Rothwell & Goren, 2011). People with disabilities have significantly fewer assets than their non-disabled counterparts, especially if they also have low incomes. They are unable to afford the basic elements of economic self-sufficiency, such as advanced education, home ownership, small business capital, assistive devices, and architectural modifications (Putnam et al., 2005).

Assets are at the root of social stratification, and are considerably more influential than pure income for determining who will flourish and who will not (Sherraden, 1991). The ownership of assets permits individuals to think about the future, to take risks and to make commitments (Boshara et al., 2006; Soffer et al., 2010). Assuming that younger people will be net borrowers while older people are net savers, asset-holding permits families to smooth out lifetime consumption and ensure a stable standard of living (Buckland, 2010; Robson & Nares, 2006; Williams, 2006). Assets mitigate economic strain, and provide a cushion against economic disruption. They act both directly and indirectly to affect individual well-being and family functioning (Conger, Rueter & Rand, 2000; Rothwell & Goren, 2011).

Parish and colleagues (2010) found that mean asset accumulation was on average 15% lower for families with at least one working aged adult (18-64) with a disability than for a comparison group of families where no adults had a disability. This study captured multiple disability types and activity limitations, and demonstrated that a family's ability to save is related to family composition. Net worth was lowest for households where the head of household was a member of a visible minority, did not have a high school diploma, or was a single woman.

Asset poverty occurs when a family's total assets minus total debts are not sufficient to meet their basic needs for three months (Haveman & Wolff, 2005). Asset poverty among families affected by disability is a result of lower income, higher costs, and children not "launching" from the home at the same time as children in other families (Selzer & Krauss, 1994, 2001). Families that experienced income poverty were 60% more likely to transition into asset poverty in the subsequent year, and less likely to transition out of hardship in the future (Selzer & Krauss, 2001).

Asset poverty rates were found to be 2-4 times greater for families affected by disability compared to other American families (Parish et al., 2010a; Rank & Hirshl, 2010). High asset poverty rates were pervasive across age cohorts. Fifty-five percent (55%) of parents under 45 with disabled children experienced asset poverty, compared to 38% of all US families. Forty-two percent (42%) of parents with disabled children remained in asset poverty into their retirement years, compared to 11% of all US families (Rank & Hirschl, 2010; Parish et al., 2010a).

In terms of debt, Emerson and Hatton (2007) found that families in the UK with a child with a disability were more than twice as likely to be in debt, and to have trouble paying off debts than the reference group. Furthermore, they had approximately 50% more total debt than other families.

Discussion and Conclusions

In order to support the development of effective disability policy, credible estimates are needed at both the individual and societal levels of the costs associated with living with a disability.

Based on the literature reviewed, costs associated with living with a disability appear to consume between ¼ and ½ of annual household income for individuals or families affected by disability. Extraordinary expenses attributable to disability are estimated in this literature between $100,000 and $3 million (CAD) per capita, depending on the severity of disability and the subsequent requirements for personal care, health care, and specialized housing and equipment. The data on costs to society are considerably more sparse, but a very general estimate based on the information available might be about $30 billion per year for Canada, or $1000 per capita per year.

The literature also points to the importance not only of income as an indicator of economic well-being, but also the ownership of assets. Assets provide individuals and families with a stake in the economy, a degree of security against future extraordinary expenses, and a sense of economic agency and self-sufficiency. The literature clearly shows that individuals and families affected by disability experience asset poverty at greater rates than their non-disabled counterparts. Out-of-pocket costs, combined with lost productivity, render many families unable to afford basic household goods and services, let alone to save for the future.

According to Park, Turnbull and Turnbull (2002), a government has at its disposal a number of policy options to address the issue of extraordinary disability-related costs. For example, it could increase the disability tax credit. It could increase incentives for retirement saving, with a provision for intergenerational transfers of those resources. It could make mortgage payments tax-deductible as a means of encouraging home ownership as a fundamental asset. It could extend family medical leave to permit a more active role in the care of a disabled family member. It could extend tax benefits to employers to augment Employee Assistance Programs.

Karlsson and associates (2007) describe a continuum of social welfare policy based on the distribution of financial risk between individuals and the state. At one extreme are countries where the individual bears the full risk of future financial and long-term care needs. Under this system individuals must maximize savings to cover all future expenses. Incrementally more moderate are states where individuals purchase private insurance to cover long-term care expenses, states where private insurance is supplemented by public sector support, and states where tax-based public resources support those in financial need. At the opposite end of the spectrum are states where social insurance provides a universal standard of long-term care to all its citizens.

On a continuum like this, Canada has typically found itself closest to the end where the state assumes the greater proportion of the risk for those in financial need. Recent literature however, suggests that Canada is transitioning from the social welfare economy developed in the post-war period to reflect collective values, to an asset-based economy similar to that of our American neighbours (Williams, 2006). Through the accumulation of assets, individual Canadians are being motivated towards ownership and building wealth (Boshara et al., 2006). Rather than ensuring a basic income stream for people with disabilities, as was done in the past, a number of federal policy initiatives are intended to encourage economic self-sufficiency. Pension planning is an example where there has been a steady devolution of responsibility in recent years from state to individuals, with increasing emphasis on private employment- or investment-based options to supplement the government's old age pension (Buckland, 2010).

The gap between the wealthy and the poor in Canada has widened considerably in the past ten years – a development that is usually regarded as a signal of an economy in decline (Moscovitch & Germain, 2006). With regard specifically to disability policy, the Organization for Economic Cooperation and Development (OECD, 2010) has recently evaluated the disability policy environments of its member nations (particularly as they relate to provisions for disabled workers). Using 2007 data, they rated their 28 member countries on the generosity of benefits, and on how actively they promote integration. On the compensation scale, Canada was third from the bottom. Only the USA and Korea were less generous in terms of compensation levels for disabled workers. On the integration scale, Canada scored just below the median (comparable with Belgium and Luxembourg), suggesting that policy efforts to integrate or include people with disabilities in mainstream society are only moderate. These ratings placed Canada in the lowest cluster, characterized by stringent eligibility criteria, low benefit levels, and under-developed rehabilitation systems. Other countries in this cluster included the US, UK, Japan, Korea, Australia and New Zealand.

In summary, this review has shown the strained economic circumstances of individuals and families affected by disability. The evidence is robust that there are extraordinary costs, particularly in the areas of health and medical expenses, environmental adaptations and transportation. This literature is complex and difficult to summarize because of different methodologies, different costs included, different currencies, different years and different types and severities of disability. The literature suggests that Canada is on the cusp of a paradigm shift in domestic economic policy – from one based on income to one based on assets (Boshara et al., 2006).

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