

Brief Report

Costs of caring for children with an intellectual developmental disorder

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Abstract

Background: Caring for a child with intellectual developmental disorder (IDD) is expensive for the medical system, for the family, and for society in general. Whereas the health care costs of IDD have been described, the societal and parental costs of IDD have been less well documented.

Objective: Our goal was to estimate the out-of-pocket costs to parents, and the non-health system costs to society, of raising a child with IDD.

Methods: We used an online retrospective survey, previously developed by our group, to collect parental and societal costs to families of 80 children who presented with IDD of unknown etiology in British Columbia, Canada.

Results: Median annual parental costs of caring for 80 children with IDD was CAD\$44,570 (range CAD\$2245–\$225,777). The largest contributors to parental costs were income loss and caregiving time costs. Median annual societal costs (excluding health system costs) were CAD\$27,428 (range CAD\$0–\$119,188). In school age children, the largest contributor to societal costs was a per child school subsidy. Both parental and societal costs increased with increasing IDD severity. Parental costs were not adequately compensated by government benefits received.

Conclusions: Although medical care is universally available through Canadian provincial health systems and social assistance is provided to the families of children with IDD, parents continue to bear a substantial financial burden beyond that associated with raising an unaffected child. © 2015 Elsevier Inc. All rights reserved.

Keywords: Costs; Disability; Intellectual developmental disorder; Parents; Society

Intellectual developmental disorder

Intellectual developmental disorder (IDD) is a broad term describing an array of developmental conditions characterized by life-long deficits in cognitive functioning and adaptive skills.^{1,2} Individuals with IDD frequently require numerous therapeutic appointments, medications and equipment, and more caregiver time than typically developing children of the same age. This has significant economic impact for the health care system, caregivers, and society. Whereas the health care costs of IDD have been described in the literature^{3,4} the societal and parental costs

of IDD have been less well documented. Assessment of the economic burden for parents has been described as an equity issue for these families^{5,6} and anecdotal evidence from affected parents indicates that the impact can be profound.

Information on uncompensated costs of raising children with IDD is necessary to determine whether the children and their parents are being adequately supported by community and governmental programs. Economic evidence is also needed to measure the financial impact of social support and interventions for these children. Information on health care costs paid by socialized systems, such as Canada's, is more readily calculable from government databases and is not the focus of this study.

To the best of our knowledge, there has been no Canadian study to document costs of IDD, and few studies, worldwide, on parental or societal costs of caring for a child with IDD. A recent Australian study examined the parental costs of raising a child with IDD above those required for caring for typically developing children. The mean annual increase in parental out-of-pocket expenses and lost opportunity costs (e.g.,

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parental income loss)⁶ was estimated as USD\$84,277.^d Recent studies of parental costs of caring for children with autism, with or without co-morbidities, demonstrate the variability and difficulty in estimating annual costs. Median costs of some typical studies range from USD\$7613 to USD\$54,884 per year^{7–9} depending on the geographical area, disease severity¹⁰ and in particular whether or not the costing model includes lost opportunity.^{5,11}

Anderson et al.⁵ provide a conceptual model that was used in our study for defining costs for children with disability. This model consists of two factors, one describes “personal factors” (the phenotype of the affected child), and the second describes costs incurred by parents and society. Parental costs come from a variety of sources including caregiving time, income loss, specialized equipment, therapy, transportation to appointments, and others. Examples of societal costs include government benefits, tax rebates, educational supplements, transportation subsidy, and respite care.

In this study, we estimated the out-of-pocket costs to parents, and non-health system costs to society of raising a child with IDD for 80 children who presented with IDD of unknown etiology. Information on severity of IDD was included in an attempt to address the influence of “personal factors,” as defined by Anderson’s conceptual model.⁵

Methods

Recruitment & setting

This study received ethical approval from the UBC Research Ethics Board. A convenience sample of 206 British Columbian parents, each with a unique identifier, were recruited in July 2014 through the TIDE-BC study,¹² and were invited to participate by conventional or electronic mail. The TIDE-BC study includes children aged 1 through 18 years, referred to Children’s & Women’s Health Centre of British Columbia with confirmed IDD of unknown cause.^{2,12,13} British Columbia (BC) has a population of about 4.6 million, just over half of whom live in the Greater Vancouver area, the location of BC’s only tertiary care children’s hospital. BC residents have a universal health insurance plan for medically-required services/procedures provided by physicians and allied health professionals as well as all hospital based therapies and medications.¹⁴ Many residents carry private insurance that varies considerably, but may pay for additional expenses including out-of-hospital medications and community based therapy that is not covered by the provincial plan.

SCOPE online survey

We developed a web-based online survey called “SCOPE” (Studying the Costs of Parental Expenditures)

to document non-health insured expenses paid during the past 6 months by parents or society for a child with IDD, that are over and above that required to care for a typical child. The SCOPE Survey was adapted by our group from an Australian survey,⁶ that in turn was based on the well-validated Client Service Receipt Inventory that collects information on service use and family support.¹⁵ Our adaptation was pilot tested in a series of children with Down syndrome,¹⁶ with minor modifications made prior to use in the current study. SCOPE was implemented through REDCap,¹⁷ and participants completed the survey online through a secure internet connection.

The SCOPE survey asks the primary caregiver a series of questions relating to their child regarding appointments, care needs, extra expenses, governmental and other benefits over the previous six months, as well as documenting effects on parental employment due to the child’s condition. At the end of the survey, parents indicate whether or not the researchers may contact them if necessary for clarification of their survey answers. Parents who completed the survey were offered a \$25 honorarium. (Please see Supplemental Table 3 and Fig. 4 for survey details).

Cost estimates

All costs are expressed in Canadian dollars.^e For directly reported costs, such as government benefits received, costs were taken at face value. The opportunity costs of time lost, including caregiver and volunteered care time, were calculated using a market-replacement method based on job classification.^{5,10,18} Costs of non-hospital therapies, such as speech therapy, were calculated using a ‘cost per encounter’ method¹⁹ using labor-market average wages for the position.^{20,21} Travel costs reimbursed by government (e.g., mileage subsidies) were considered to be societal costs; unreimbursed travel costs were assigned to families. Non-parent volunteered caregiving (e.g., care by friends or extended family) was assigned the labor-market average rate of \$17/hour, under the assumption that this time would have to be paid for if it had not been provided by a volunteer.

Income loss by the parents was derived from reduced working hours and unpaid time off, and was calculated from an hourly wage or yearly income based on their current or most recent occupation. These were assigned as a parental cost whereas paid time off (e.g., to attend a medical appointment) was assigned as a societal cost. Respondents who declined to provide their current wage had the option of stating their occupation, which can be used to find a labor-market average wage, although nobody chose this option in the current study.

In BC, educational supplements for special needs children (either \$18,300 or \$36,600 per year) are provided to

^d Costs have been converted to USD at September 2014 rates, for ease of comparison.

^e 1 CAD ≈ 0.90 USD ≈ 0.71 EUR ≈ 0.55 GBP ≈ 1.03 AUD in September 2014.

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