

**Every ninth
child in
Ontario:**

**A Cost-Benefit Analysis
for Investing in the Care
of Special Needs Children
and Youth in Ontario**

Nov 2015

**Supporting the voices
of children and youth
with special needs**

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Every ninth child in Ontario:

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Provincial Advocate
for Children & Youth



**Supporting the voices
of children and youth
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Summary

In the *Child and Family Services Act*, the Ontario Government defines special needs as:

a need that is related to or caused by a developmental disability or a behavioural, emotional, physical, mental or other disability.¹

About one child in nine in Ontario has special needs. The Ontario government is deeply involved in the lives of special needs children and shares responsibility for them with their parents and civil society. While all Ontario Ministries have a role in the lives of special needs children and youth, the Ontario government has a direct multi-faceted role involving the Ministries of:

- Health and Long term Care
- Community and Social Services
- Education
- Municipal Affairs and Housing
- Children and Youth Services

The Provincial Advocate for Children and Youth has a special role as a voice for children and youth with special needs. Everything we know tells us that their numbers are growing quickly with improvements in diagnosis, treatment, and intervention.

Ontario's government spends approximately \$5 billion on its 300,000 children with special needs. Various estimates place the actual cost of supports for special-needs children at more than \$10 billion, perhaps as high as \$12 billion.² This means that parents and non-profits are paying some of the \$5 billion deficit, while many needs are simply going unmet. If parents, family and civil society are able to meet half of the \$5 to \$7 billion deficit, governments can and should pay the remaining amount which we notionally calculate to be in the \$3 billion range.

Furthermore, we have limited data on whether the \$5 billion now being spent is being spent effectively. For some disability types, the costs and benefits of intervention are very clear. For many others, no data is available. This lack of data has made this paper almost impossible to write.

1. R.S.O. 1990, c. C.11, s. 26; 2001, c. 13, s. 5 (4).

2. See Footnote 88

Government and media are very good at telling us about the cost of programs and interventions to taxpayers. They are also good at telling us about the short-term success or failure of programs and interventions. But they fare less well when it comes to demonstrating long-term value and reduced future need for services. We do not hear about the value of enabling the beneficiaries of programs and interventions to contribute to our society and economy.

The purpose of this paper is to provide a framework that shows how government expenditure in this area can and will result in economic benefit to society as a whole. We make no claim to proving that interventions and programs produce a net profit or even break even. But we are able to show, using a limited dataset, that such interventions reduce the longer-term costs of disability over the life course of children and youth. Put another way, there is a cost to society and to the economy when expenditures are *not* made to diagnose, effectively treat, and supportively intervene in the environments of children and youth with special needs.

Our limited cost-benefit analysis illustrates the importance of just one type of intervention, the Individual Education Plan, primarily administered within the education system, on the well-being of children with special needs over the course of their lives. The findings indicate a return of \$0.47 for every dollar spent on interventions by the Ministry of Education for special needs youth in Ontario.

- In the course of a lifetime for one special needs child, the benefits would total \$400,625.23 in current year dollars, consisting of increased tax revenue and social assistance costs avoided.
- Given a cohort of about 14,000 special-needs children graduating every year, the benefits multiply out to \$1,246,871,173.
- The cost per year of special needs programs and interventions within the sphere of education is \$2,674,500,000.

This sample analysis provides child and youth advocates with a new line of inquiry and argument. It allows them to demonstrate

that the money we spend is worth it, not just because it is the right thing to do, but because it also makes good economic sense. A caveat: the assumption built into this model is that Individual Education Plans and other interventions are effective in enabling special-needs children and youth to complete high school. We are not speaking to the quality of the programs and services offered but rather to their intent. From what children and youth with special needs tell us, we know that positive outcomes are not always achieved and sometimes results are negative. In the words of one youth speaking with the Provincial Advocate, “I thought school was to be a mirror of what society could be but I found school to be a mirror of what society is.”³

In this paper, we have also attempted to give an overview of the current literature on approaches to children and youth with special needs. We show how these approaches have shifted to a social or ecological model that emphasizes the environments in which children move and their ability to enable a child to reach his or her full potential. We see how progressive ideas within the educational system lean toward taking individualized approaches not just to children with ‘labels’, but to all children.

In our review of disability, work, and income, we see that Canada is doing fairly well on integrating adults with disabilities into the workforce, compared to other OECD countries. Our success owes much to our country’s entrenched human rights standards and to the supports we put in place early, such as Ontario’s Individual Education Plans and other special interventions. But we can do much better. We are still just ‘in the middle of the pack’ of OECD countries.

As our society ages and our labour markets change, we know that we will need the talents of our special-needs children and youth and the contributions they can make. We know too that there is much we can do to help them make these contributions. The most successful northern European countries have recognized they will have future labour shortages and therefore consider very young children in the light of the job market and what they can be reasonably expected to do as adults. Their focus is on the life course of every child, and the integration of every possible child and youth into the labour force.

We know that early investment in children with special needs pays off. Cost analysis only considers the so-called ‘dead weight’ cost of raising a child, which is high for special needs children. The logic of dead-weight costs prevails only if we fail to weigh it against the economic benefits of productive citizens over their life courses. In this paper’s sample cost-benefit analysis of Ontario’s Individual Education Plans, we have sought to show a truer picture of our investments in children with special needs.

For a century and a half, the main societal and governmental response to children with special needs was to segregate them and warehouse them. Our approach was custodial and it too was expensive (both in spending and in lost opportunity). These are not the times we live in now. We know that governments, researchers, practitioners, and parents are harvesting the knowledge that with rare exceptions, special needs children can live successfully in our communities. We grossly underestimated what was possible for the lives of children with disabilities, and for societies that are inclusive.

Instead of a costly burden, we are riding a tsunami of success characterized by wonderful breakthroughs in diagnosis and achievements in treatment. But all our successes come at a cost. Government is meeting about one half of the costs of special needs while parents and non-profits are obliged to meet the other half—and cannot. That leaves many needs unmet.

We have been hard at work for many decades, moving special needs children from isolation and custody to inclusion and success. Children and youth are telling their Advocate that we are not there yet.

We have paid for the capital cost of the bridge from isolation to inclusion. We built it because we expected people to travel on it. Let us not have a bridge to the future on which we do not allow people to travel.

RECOMMENDATION 1: **The need for a government-wide strategy of inclusion**

There is no area of government that does not touch the lives of children and youth. Drawing on models from countries such as Sweden, the Netherlands, and New Zealand, Ontario should develop government-wide strategies to address the issues of special needs

youth. We need a comprehensive plan that supports all disabled children, to the greatest extent possible, within the mainstream. That includes the childcare system, the education system, after-school and summer programs, recreation, sports, and arts programs, and all other publicly funded activities that touch the lives of children and youth.

RECOMMENDATION 2: **The need to continue and expand supports**

For children who require supports over and above what is provided within mainstream systems, Ontario must improve these interventions, so that parents and caregivers no longer feel locked in perpetual struggles for adequate, robust support. If we assume that parents, caregivers, and non-governmental organizations are bearing half of the \$5 billion in unmet costs for children and youth with special needs, government should be contributing \$2.5 billion more than it is now.

RECOMMENDATION 3: **The need for a tracking system**

We need to be able to measure the outcomes of our interventions with special needs children and youth. Ontario should develop a comprehensive tracking system that can quantify in key areas where positive outcomes for supported children and youth have led to contributions and cost savings in our economy.

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The role of the Provincial Advocate

The Provincial Advocate for Children and Youth is an independent office of the Legislative Assembly. Their work is guided by the United Nations Convention on the Rights of the Child. A primary focus is to be an exemplar for meaningful participation of children and youth in all aspects of advocacy.

Under the legislation, the Advocate's Office must:

- Provide an independent voice for children and youth by partnering with them to bring issues forward.
- Encourage communication and understanding between children and families and those who provide them with services.
- Educate children, youth and their caregivers about the rights of children.

The children and youth who fall within the mandate of the Advocate's Office include those who are seeking or receiving services from the children's services sector in areas such as child welfare, youth justice, children's mental health, developmental services and children's treatment services. The jurisdiction of the Office also includes students of the provincial and demonstration schools, youth in court holding cells or being transported to and from court holding cells, First Nations children and youth, and children and youth with special needs.

The Office works in three areas of advocacy: individual rights, systemic advocacy, and community development.

The foundation of their work is in individual rights advocacy. Children and youth in Ontario's system of care often feel that they are invisible to the Province and that their voices go unheard. It's the Advocate's job to make sure that young people have a voice and that youth within the care of Ontario's residential services system know they have the right to speak to an advocate.

When they notice patterns or trends in the calls they receive from young people, they may decide to engage in deeper and closer scrutiny of an issue through systemic advocacy. When the Advocate's office speaks of "systems" they are referring to government policy, legislation and guidelines for service providers that determine the way an organization carries out its duties and obligations to children and youth. By "systems" they also mean agencies' own organizational policies and service practices. When conducting

systemic advocacy, the Office draws from the expertise of young people who have direct knowledge or experience with the issue and works with them to make recommendations for change at the level of policy, funding, or program delivery.

When an issue concerns local groups or specific populations of young people, the Office will undertake community development advocacy. In these situations, the Office engages young people and their natural supports and allies, and helps them become their own advocates by partnering with them to help create the change they wish to see. Community development plays an additional role by providing outreach and education.

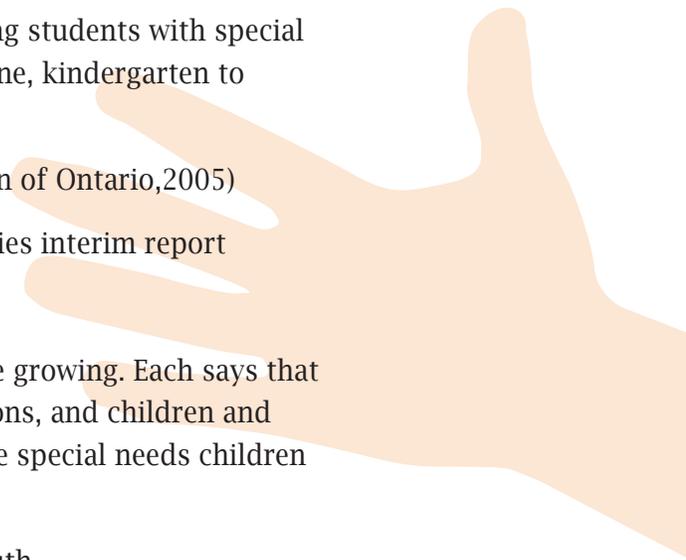
Part 1. A review of the literature on children and youth with special needs

Much advice has been given to government about Ontario's special needs children and youth. Examples of reports written since 2000 include:

- Children and youth with special needs (Canadian Council on Social Development, 2001)
- Services for children and youth with special needs in Ontario, and their families: Opportunities for improving their experiences and outcomes (Parliamentary Assistant, 2013)
- Fulfilling the promise (Elementary Teachers Federation, 2002)
- Caring and safe schools in Ontario: Supporting students with special education needs through progressive discipline, kindergarten to Grade 12 (Government of Ontario, 2010)
- Between a rock and a hard place (Ombudsman of Ontario, 2005)
- Select Committee on Developmental Disabilities interim report (Province of Ontario, 2014)

Each of these reports tell us that special needs are growing. Each says that governments, educators, parents, civil society organizations, and children and youth themselves believe that more can be done to enable special needs children to become:

- educated throughout their childhood and youth
- employed during both their youth and adulthood
- enabled, to the extent possible, to join the mainstream of community life.



The broader literature on children with special needs traces a long history of success in many areas that allow special needs children and youth to enter the mainstream.

The numbers

There are approximately 2.7 million children in Ontario age 18 or younger. The Ontario Ministry of Education estimated that as many as 300,000 children had special needs and/or one or more disabilities in 2007.⁴ The 300,000 relates to children with IEP's (Individual Education Plans).

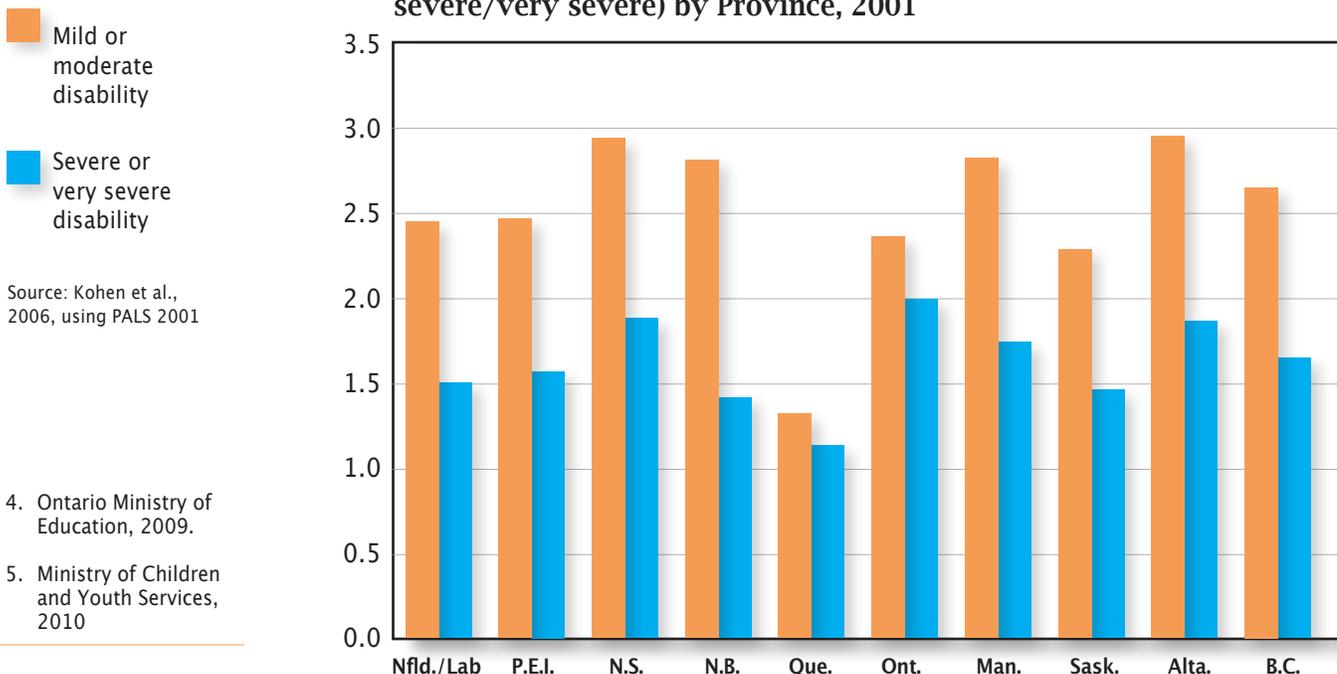
This makes the ratio of children with special needs to be 1:9.

This figure is exactly the same as the one in nine that generally applies to the whole of the disabled population reported through the Participation and Activity Limitations Survey (PALS) in 2006.

One in five of Ontario's children and youth has a mental health challenge that may or may not have been identified as a disability or special need.⁵ The most common challenges are anxiety, ADD/ADHD, depression, mood disorders, schizophrenia, and eating disorders.

According to the 2001 PALS survey, the proportion of children with a reported disability varies by province, especially for mild or moderate disability (Figure 1).

Figure 1: Percentage of children with a disability (mild/moderate and severe/very severe) by Province, 2001



Source: Kohen et al., 2006, using PALS 2001

4. Ontario Ministry of Education, 2009.

5. Ministry of Children and Youth Services, 2010

Most children with a disability experience a cluster of health and development problems, and the “diagnostic” label does not necessarily reflect the extent of children’s developmental or functional problems.⁶

From institutionalization to inclusion

Approaches to disabilities, particularly intellectual disabilities, have seen many shifts over the course of history. Religious or supernatural explanations dominated in the past, followed by the beginnings of medical explanations in the early 1800s. Interventions centred mainly on institutionalization, used in the US as recently as the 1970s. There have been periods of optimism and pessimism around capacity for “rehabilitation.”⁷

Institutionalization was based on low expectations about the ability of children with disabilities to participate in home, school, and community life. This approach was not only costly, but “served to limit educational policies, available services and programs, and the kind of research that was funded and conducted.”⁸

A recent review of practices across the world shows a shift from institutionalization to integration has occurred among half of the 147 countries reviewed. The shift began in Scandinavia in the 1950s. (No one in Sweden lives in an institutionalized setting today).⁹

Improvements in diagnosis

The literature shows that improvements in diagnosing disability have had several repercussions:

- It has changed our approaches to education (e.g. improved special education).
- It has begun to inform our approaches to social supports for children, and, to a lesser extent, for adults.
- It has increased the cost of interventions, because more children are being diagnosed.
- It has increased societal awareness and hence acceptance of disability.
- It has raised expectations on the part of families that there will be effective interventions.¹⁰

6 King et al., 2000

7 Mackenzie, Hurst, & Compton, 2009

8 Groark et al., 2011, p.184

9 Harbour & Maulik, 2010; Beadle-Brown, Mansell, & Kozma, 2007

10 Florian et al., 2006; McLaughlin et al., 2006

Shifting from a medical to a social or “ecological” model

People experience disability differently. The impact of a disability on their daily lives varies with socio-economic factors, family situations, access to resources, local infrastructure, and geographic location. Disabilities often involve multiple diagnoses and health conditions and there is variation within and across categories of disability, illustrating the importance of seeing each child as a unique individual.¹¹ Diagnostic labels may not adequately describe the unique needs and situations that accompany them.

For example, King et al. have shown that broad category labels such as “cerebral palsy” do not convey a sense of the complexity associated with these conditions. Cerebral palsy is a term used for a variety of disorders that primarily affect a child’s movements, but can also cause other developmental problems (mental retardation, seizures, language disorders, learning disabilities, and vision and hearing problems).

More and more, research, policy, and practice have attempted to reflect the complexity of disability. There has been a shift from a medical model to social and rights-based models of disability. The education system has moved away from categorizations that oversimplify disability. Research has shifted generally to a more “ecological” approach, recognizing parents as part of the “ecology” of a child with disabilities. It also recognizes parents as people with challenges of their own—financial, mental, and emotional.

11. For a full discussion on this, see Chapter 1 of the 2011 World Health Organization report on Disabilities: http://www.who.int/disabilities/world_report/2011/chapter1.pdf

12. King et al., 2000

13. Central figures in this shift include Saad Nagi, who in 1965 argued that disabilities could be defined by the human environments that failed to cater to the needs of all people, rather than by the characteristics of the individual, and Bronfenbrenner (Knestricht & Kuchey, 2009).

14. Mackenzie, Hurst, & Crompton, 2009, pp. 1 and 2

Mackenzie, Hurst, and Compton describe the medical model as:

... oriented towards clinical diagnosis, treatment, cure and prevention. It focuses on the individual in terms of their deficiencies, ailments or inabilities. The model is interested in medical facts whereby disability is caused by a physiological disease or injury resulting in a “damaged” body or mind that does not function in a manner considered normal for a human being.

... As such, it ignores the fact that society organizes itself based on certain assumptions, one of which is that everyone is able-bodied. Having to navigate through a world designed to meet the needs and convenience of the able-bodied can marginalize people who are not able-bodied, affecting their physical, social, political and financial well-being.¹⁴

The term “social model” is used more-or-less interchangeably with the term “ecological model,” which Urie Bronfenbrenner proposed in the late 1970s.

Knestricht and Kuchey describe it here:

In this framework, human development is seen as affected...not only... [by] person[al] characteristics (i.e. temperament, genetics and health) but also by external factors such as support systems, political and cultural influences. While the existing research on individual resilience describes an almost entirely 'within' person framework, the ecological model allows one to see things through a larger context that includes systems outside of the direct contact of the family. Bronfenbrenner envisioned a system of 'nested' environments that existed within each other with the metaphor of the model being that the environments or 'ecologies' exist within each other [and are] constantly interacting with each other...So that the "home" as ecology cannot help but be affected by the ecologies of the community, the country and the geo-political ecologies that surround it. It is this constant dynamic interaction that shapes the development of the child or, in this case, the family.¹⁵

Interventions within an ecological model are thus no longer limited to the child, according to the literature. They extend to the child's classroom, to the built form of a school, to a child's family, a child's community, and even more broadly, to the policy environment. While we may view the child as the central figure in this ecology, the approach also allows us to shift focus, so that we can focus on the needs and experiences of families, or the needs and experiences of classmates.

The social or ecological model is evident in the World Health Organizations definition of disability:

Disability is the result of complex interactions between a health problem or functional limitation and the social, political, cultural, economic, and physical environment. These, in combination with personal factors such as age, gender, and level of education, can result in a disadvantage—that is, a disability. Disability is [therefore] not defined merely as being the direct result of a health problem or any physical or mental limitation.¹⁶

Although the WHO definition is not included in the Convention on the rights of persons with disabilities, it has influenced education systems both in Canada and abroad. It is reflected in a growing literature on the role and experiences of families raising children with disabilities.

15. Knestricht & Kuchey, 2009

16. Human Resources and Social Development Canada (Galarneau and Radulescu, 2010)

Research into families and the community

The family is emerging as an important unit of study and intervention, as one of the “ecosystems” that in which a child with a disability lives. There is also increased interest in the economic ramifications of family care-giving, from two points of view:

- Accounting for and giving relevance to the contributions of people that are not typically quantified as part of a nation’s GDP
- Improving the economy by addressing the revenue lost to families, governments, and businesses as a result of family care-giving.

Most of these studies also describe some of the health and mental health problems that are associated with care-giving. Several are dedicated entirely to studying the social implications of raising a child with disabilities.

One study describes access to and use of services for children in Ontario, with some context around the experiences of their families. This study refers to a change in service delivery in Ontario that reflected a shift to an ecological model, from child-centred care to “Family-Centred Service (FCS). This approach, which emerged in the late 1990s, is described as:

*...a method and philosophy of service delivery for children and parents which emphasizes a partnership between parents and service providers, focuses on the family’s role in decision-making about their child, and recognizes parents as the experts on their child’s status and needs.*¹⁷

Other studies have begun documenting the emotional and mental impacts experienced by families. A 2012 Statistics Canada survey documents increased likelihood for depression and financial stress among parents providing care to children with disabilities.

While numerous programs and tax credits are available to children with disabilities and their caregivers in Canada, a common thread in the literature has been the gap between resource needs and resource availability, particularly for families on low incomes.

While people with disabilities, including children and youth, are still marginalized in their communities, the literature suggests that this is changing. Inclusive or universal design has become common practice. A Statistics Canada study suggests that stigma around people with disabilities is decreasing.¹⁸

There is still a ways to go, however. A study in New Zealand¹⁹ investigated the cost effectiveness of a spectrum of interventions for

17. King et al., 2000

18. Mackenzie, Hurst, & Crompton, 2009

19. Disability Resource Centre Auckland, Inc., 2010

people with disabilities, including personal care, equipment, services, and modifications to the built environment. They found that there was ample room to improve the delivery of these interventions, maximize autonomy, and reduce unnecessary costs. There has been no such study here yet, but many comparisons can be drawn between practices in New Zealand and Canada.

Despite evidence that stigma is decreasing overall, there is still evidence of prejudice when it comes to hiring people with disabilities and prejudices against specific kinds of disabilities.²⁰

Family resilience and socio-economic status

Studies have shown that parents with lower incomes often have fewer choices when it comes to accessing services for their children. In reviewing the literature, Knestrict and Kuchey found that families with disabled children are more likely to experience low income:

A study in the United States (Park et al., 2003) found that 28% of children with disabilities in the US, aged 3-21 years, are living in families whose total income is less than the income threshold set by the United States Census Bureau. They found that poverty impacted on families along five dimensions including health, productivity, physical environment, emotional wellbeing and family interaction. Moreover, when a family has a child with disabilities more stress is added to the micro-system of that family. Scorgie, Wilgosh and McDonald examined 25 studies of stress and coping in families of children with disabilities. They found that families with higher incomes have more choices available to help them cope. Yau and LiTsang (1999) found that higher income contributed to parental adaptability.²¹

Knestrict and Kuchey found that the most resilient families had the following characteristics:

- Designated as upper to upper-middle class
- Receiving Strategic Education Services (SES)
- Standard insurance provided by an employer for the entire family
- Living in a school district that adequately serviced special needs children as determined by SES
- Receiving a higher quality of uninterrupted insurance that delivered additional services not provided by the schools and allowed a high level of pre- and post-natal care

20. Gouvier et al., 2003; Bricout & Bentley, 2000

21. Knestrict & Kuchey, 2009

- Experiencing shorter wait times for services
- Having the autonomy and parenting skills to generate the rules, rituals and routines necessary for the child
- Having the transportation necessary to access services from doctors' and other appointments.²²

The less resilient families in the Knestrict and Kuchey study were the working poor—people working in jobs that provide minimum insurance or none at all. While local county, state, and federal programs could make up for low income in some instances, level of income was still the controlling factor in family resilience. It affected the family's ability to access resources, where they chose to live, the schools their children attended, and the type of medical care they had access to.

Knestrict and Kuchey describe the impacts this may have on children with disabilities:

If parents are struggling to meet the basic needs of family, there is little time to be reflective about their child's disability or to establish meaningful rules, rituals and routines. The conclusion in the literature is that adequate funding of support services, school districts, mental health services and prenatal clinics would allow all parents regardless of income, to be more reflective, to establish rules, rituals and routines and to develop a better understanding of their children's disability and their family's role.²³

The principle, then, is that children with disabilities may enjoy more success if they experience appropriate support from their families. Families' ability to support them, however, depends on their access to support services, which decreases along with socio-economic status.

The impact of caregiving on Canadian families

In 2012, 5% of family caregivers in Canada were providing care to children with a long-term health condition, or approximately 400,000 Canadians (1.4% of Canadians).²⁴ In Ontario, most of these caregiving families have only one child with a disability, and have other children.²⁵

22. Ibid

23. Ibid, p. 40

24. Turcotte, 2013

25. King et al., 2000

No studies similar to Knestrict and Kuchey's have been done in Canada to relate socio-economic status with the resilience of parents of children with disabilities. However, we do know that Canadian caregiving families report that they are struggling—both financially and emotionally. In a 2013 study by

Turcotte, families reported experiencing hardship related to raising children with disabilities, and difficulty accessing sufficient services.

Table 1: Characteristics of caregivers of children with disabilities in Canada

Characteristic	% experiencing this among caregivers of disabled children:	Comparisons with other caregivers:
Reported feeling depressed	38%	Caregiver of spouse: 34% Caregiver of parent: 21%
Reported financial difficulties	28%	Caregiver of spouse: 20% Caregiver of parent: 7%
Reported receiving financial assistance	30%	Caregiver of spouse: 14% Caregiver of parent: 5%
Would have liked more help than they received:	52%	Caregiver of spouse: 42% Caregiver of parent: 28%

Source: Turcotte, 2013

Among regular caregivers—those who spent at least two hours caregiving each week—caregivers of disabled children had the highest reported rate of depression and also reported more health and psychological problems, mainly because of the intensity of care provided.²⁶

Caregivers of children were also most likely to experience financial difficulties and most likely to be receiving government financial help. More than half reported needing more help.

Services accessed by families of children with special needs

A study by King et al. (2000), based in Ontario, shows that, as expected, several types of service are typically provided to meet the needs of each child with disabilities. Numerous services are provided regularly—once a month or more often. As the number of services increases, so does the number of locations parents must travel to access them, adding to travel time, expense, and stress.

The most frequently received services are occupational therapy, speech language pathology, and physiotherapy.

Most children with a syndrome, regardless of age, received many services from many different agencies. For example, for young children with cerebral palsy, 13.8% received three or fewer services, 27.6% received four to six services, and 58.6% received seven or more services.

Table 2: How many services were received by children with each primary problem?

Primary Problem	Number of Services Received			
	1 Service	2-3 Services	4-6 Services	≥ Services
Acquired brain injury (n=15)	0.0	0.0	40.0	60.0
Autism/Pervasive developmental disorder (n=25)	12.5	16.7	29.2	41.7
Cerebral Palsy (n=125)	0.8	18.4	28.0	52.8
Communication disorder (n=62)	37.7	23.0	31.1	8.2
Developmental coordination disorder (n=11)	9.1	36.4	18.2	36.4
Developmental delay (n=67)	9.0	17.9	26.9	46.3
Muscle disease (n=11)	0.0	9.1	36.4	54.5
Spina bifida/Hydrocephalus (n=32)	6.3	21.9	28.1	43.8
Syndrome (n=61)	1,6	18.0	24.6	55.7

For each Primary Problem, the percentages in the rows add to approximately 100% due to rounding.

Source: King et al., 2000

Table 3: What services did children receive and how often?

Services Received	n	% of total N	How Often the Services Was Received (in %)		
			Occasionally*	Once/month	> Once/month
Audiology	129	26.1	89.2	2.3	4.7
Augmentative communication	65	13.2	55.3	12.3	29.2
Dentistry (specialized)	81	16.4	87.6	3.7	3.7
Early childhood education	65	13.2	3.0	3.1	90.8
Family physician	242	49.0	78.1	9.9	6.2
Genetic counselling	43	8.7	95.4	0.0	0.0
Medical clinics/services	135	27.3	75.6	12.6	6.7
Nursing	39	7.9	23.1	2.6	74.4
Nutrition	50	10.1	66.0	14.0	16.0
Occupational therapy	335	67.8	40.6	20.9	34.9
Optometry	115	23.3	93.0	2.6	0.9
Orthotics/Prosthetics	145	29.4	89.7	2.1	2.8
Pediatrician	244	49.4	76.2	13.9	6.6
Physiotherapy	262	53.0	39.7	19.5	37.4
Psychology/Psychometry	44	8.9	77.3	6.8	9.1
Recreation therapy	63	12.8	17.4	7.9	66.7
Rehabilitation engineering	64	13.0	86.0	1.6	9.4
Resource teaching	140	28.3	7.1	6.4	78.6

Table 3 continued

Services Received	n	% of total N	How Often the Services Was Received (in %)		
			Occasionally*	Once/month	> Once/month
Serv. coordination/Case management	107	21.7	66.3	12.1	16.8
Social work or counselling	42	8.5	33.3	16.7	42.9
Special services at Home	148	30.0	2.8	4.7	85.1
Speech-language pathology	265	53.6	32.5	13.6	48.1
Technology access	17	3.4	64.7	5.9	29.4
Transition services	9	1.8	66.6	0.0	11.1
Other**	73	14.8	43.9	16.4	34.2

The percentages (reading across from columns “Occasionally” to “>Once/month”) add to approximately 100% due to rounding and missing data for some services.

* Two response options (“once a year or less” and “a few times a year”) were combined and called “Occasionally”.

** This category was created for responses that did not fit the options provided to the respondent.

Source: King et al., 2000

In a more recent study, Turcotte reports that mental health is the most common reason for providing care to a child in Canada, followed by a developmental problem, other neurological disease, and injuries resulting from an accident.²⁷

Table 4: Main reasons why family caregivers provide care to a son or daughter, 2012

Rank	Reason
First	Mental health problems (23%) For example, depression, bipolar disorder, manic depression or schizophrenia.
Second	Developmental problem or disability (22%)
Third	Other neurological disease (14%) For example, Parkinson disease, multiple sclerosis, spina bifida and cerebral palsy
Fourth	Injury resulting from an accident (6%)

Source: Turcotte, 2013

Special needs, disability and education

The question of how best to support learning for everyone—within a context of limited resources—is an ongoing conversation within the education system. The changing frame of disability, from a medical to a social or ecological model, has impacted theory and practice in the schools. Like the

family, the classroom is seen as part of the “ecology” of influences that contribute to a child’s experience of disability.

Over the last 60 years, especially in Sweden, the United States, the United Kingdom, Canada, and Italy, there has been a movement away from segregation in education toward increased integration and “mainstreaming.” There has also been a movement toward building a more nuanced, individualized approach to the unique needs of each child, whether disabled or not.²⁸

The concept of mainstreaming marks a dramatic shift from past perceptions:

*... as recently as the 1970s, children with disabilities were institutionalized based on low expectations about their ability to participate in home, school, and community life. Such low expectations and the tremendous costs of institutionalization were unfortunate, and they also served to limit educational policies, available services and programs, and the kind of research that was funded and conducted.*²⁹

Mainstreaming can be described as:

*... placing children with disabilities into regular classrooms. They usually have additional supports as well. Mainstreaming allows children with [intellectual disabilities] to receive education alongside their non-disabled peers.*³⁰

Reynolds et al. provide an overview of the benefits and drawbacks of mainstreaming children with intellectual disabilities. The benefits include:³¹

Opportunities for socialization:

Many children with [intellectual disability] have inadequate social skills. These social limitations ultimately hinder their success in life. Quite logically, social skills can only be learned and acquired in a social environment. A regular classroom provides the ideal social climate. For instance, students who have disorders such as Prader-Willie syndrome, Fragile X syndrome, and Down syndrome can develop excellent social skills through social imitation. These students truly benefit by observing and imitating their peers in a regular classroom.

Exposure to diversity:

Such diversity is naturally encountered in the real world. Whether or not a child has an [intellectual disability], children will eventually encounter many different people throughout their lives. Some people will be from similar cultures and backgrounds. Other people will not. A school setting is the ideal environment to notice and adjust to these differences. This real-world preparation is advantageous. It promotes the ability to

28. Beadle-Brown et al., 2007, Segal, P. & G. Maigne, 2003; Noury, 2003; McLaughlin et al., 2005; Florian et al., 2005; McLaughlin & Jordan, 2005.

29. Groark et al., 2011, p.184

30. Reynolds, Zupanick, & Dombeck, 2014, p.1

31. Ibid, p. 1. These concepts, well-summarized by Reynolds et al., are peppered throughout the literature, including in: Ruijs, Van Der Veen & Peetsma, 2010; Dessemontet & Bless (2013); Affleck et al., 1988; Baker, Wang, & Walberg, 1994; and Waldron & Cole, 2000.

embrace human diversity. These skills are critical for getting along with co-workers and neighbors.

Introduction to inspiration and challenge:

Without sufficient challenge, people do not develop and strengthen their abilities. A traditional classroom provides more opportunities for these challenging experiences.

Children without disabilities have been shown to benefit from mainstreaming as well, both socially and academically.³²

The drawbacks that Reynolds et al. noted in the literature include:³³

Negative stress on available resources:

As school budget cuts deepen, teachers are asked to do more with less. Public schools struggle to provide adequate education to those without specialized needs. Budgetary restrictions make it unrealistic to expect students with [intellectual disabilities] will receive the attention they need and deserve within a regular classroom. Moreover, many teachers in regular classrooms have not received training in specialized educational techniques.

Perception of unfairness to other students:

Some people also argue that mainstreaming is unfair to average students. This is because the teachers' time and attention is spent with the children who require more individualized instruction. This leaves the rest of the students to fend for themselves. Conversely, others argue that average students benefit from the inclusion of special needs children. It provides teaching and coaching opportunities to these more advanced students. This simulates a more natural environment for everyone.

The movement toward an individualized approach

A common thread in the literature is an emerging consensus on the need to move towards an individualized approach in teaching³⁴. While the potential benefits of mainstreaming are recognized, it is not seen as a blanket solution. Rather,

...the best educational setting is the one that best helps a child to achieve the goals of their [individual education plan]. Each child has different goals, abilities, and needs. ...Parents and educators must realistically appraise the learning environments and resources available in their communities. Then, they can make a wise selection that best matches the child's needs and circumstances.³⁵

32. Cole et al., 2004; Kalambouka, Farrell, & Dyson, 2007; Cosier, Causton-Theoharis, & Theoharis, 2013; Dessementet, Bless, & Morin, 2012.

33. Reynolds, Zupanick, & Dombeck, 2014, p.1

34. McLaughlin et al., 2006, Florian et al., 2006

35. Reynolds, Zupanick, & Dombeck, 2014, p.2

The practical challenges associated with mainstreaming have inspired a shift in the U.K., U.S., and Canada toward tailored approaches that recognize each child's complex needs.³⁶ Some authors contend that children's disabilities do not conform to discrete categories. Addressing these disabilities depends on the characteristics of the child, their peer group and the school environment, and the resources available.³⁷ Deciding which interventions to go with—including when and how much to mainstream—depends on the individual case.

In the U.S., this approach is rooted in Individual Education Plans (IEPs) and shaped by the Individuals with Disabilities Education Act (IDEA). IDEA requires that there be a continuum of placements available to students, according to their needs, extending from the classroom to residential settings. According to the Wisconsin Education Association Council, the law “intends that the degree of ‘inclusion’ be driven by the student’s needs as determined by the IEP, not by the district’s convenience or the parents’ wishes.”³⁸

Once again limited resources, including teachers and money, are listed in the literature as barriers to the effectiveness of the individualized approach.³⁹

Categorizing of disabilities in the school system

There is a debate within the school system over categorizing disability as opposed to simply establishing the level at which each individual child functions. Labelling can be stigmatizing for children with disabilities.⁴⁰

The original intent was to develop educational services and interventions rooted in categories of need.⁴¹ Categorizations were believed to help with:

- Identifying needs and appropriate interventions
- Explaining problems a child has to parents and helping them to secure appropriate services
- Protecting the rights of people with special needs along with the rights of those around them
- Allocating resources in an equitable way and accounting for funding decisions.

Categorizations tend to be supported by parents who understand that once their children are labeled, they are more likely to get access additional services and supports.

However, the literature suggests that categories cause problems when they are used to determine eligibility in special education programs. First, categorizations are removed from clinical diagnoses. McLaughlin et al. call

36. McLaughlin et al., 2006; Florian et al., 2006

37. King et al., 2000; Florian et al., 2006

38. Stout & Hudson, 2007

39. McLaughlin et al., 2006

40. McLaughlin et al., 2006

41. Florian et al., 2006

the process of categorization “messy”—influenced by many individuals, and occurring in a context of limited resources. They may not benefit the children who are classified, and could be used to prioritize the needs of the institution:

*Educators in both countries [U.S. and U.K.] have indicated a persistent lack of confidence in various classification schemes. For one thing, they view these schemes as inconsistent with the educational needs of children and as instructionally irrelevant. Labels applied to children or to programs result in specific actions that inevitably represent an attempt to balance program realities with child needs, but this cannot obscure the reality of individual differences among learners.*⁴²

In the U.K., McLaughlin et al. found that children requiring additional help in the school system were not always associated with a clinical diagnosis of disability. Conversely, children with diagnosed disabilities did not always need additional help. The categories “do not recognize the complexity of human differences.”⁴³

While categorization is seen throughout the literature as problematic, it is also recognized as difficult to avoid in a context of limited resources:

*“The reality is that educational classification policies, formal or informal, will always be required within a system in which individual needs and the broader social and community goals of education are competing priorities. However, as was argued in Florian et al., by understanding the mix of intentions that underpin these policies, as well as periodically reviewing the norms that establish them, it may be possible to move beyond a view of categories as fixed descriptors of people... The primary recommendation [is] that educational systems adopt a program of precisely describing educational characteristics of individual children that lead to education interventions for producing meaningful outcomes.”*⁴⁴

McLaughlin et al. suggest that education systems in the U.K. and U.S. (as well as Canada) have moved in the recommended direction—the UK being an early adopter, with quite progressive criteria for special education.⁴⁵

Similar recommendations come from work in Ontario:

The findings suggest that, due to the complex nature of their needs, it is important to continue to provide comprehensive and individualized services for children with disabilities. This further implies that therapists and clinicians require specialized expertise and experience to deliver effective services... As many service providers and managers are already aware, diagnostic labels often may not adequately describe the unique needs and situations of children. The information in this report could

42. McLaughlin et. al., 2006. p. 56

43. Ibid, p.

44. McLaughlin et al., 2006. p.57

45. The UK developed 11 categories of disability in its 1944 Education Act, but has since moved to eligibility criteria described as “non-categorical and needs based.” Access to special needs education is determined as follows:

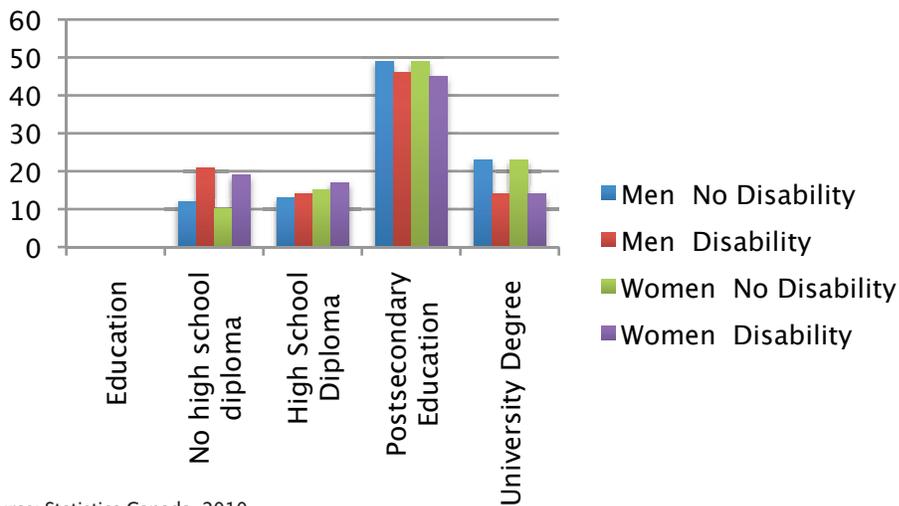
“The individual student has a greater degree of difficulty learning than the “majority of his peers” or requires some special intervention to ensure that he or she can access or benefit from the education. The provision of special education services is determined by a detailed non-categorical assessment and does not imply placement in particular schools, classrooms, or programs. Finally...membership in the special needs category does not imply a disability or medical condition; it only indicates that the student has difficulty. Medical conditions by themselves do not guarantee access to special needs education unless the conditions have educational implications.” (McLaughlin et al., p.49)

*be used to develop “profiles” of children’s needs and services that more adequately reflect the complexities.*⁴⁶

Disability and educational attainment

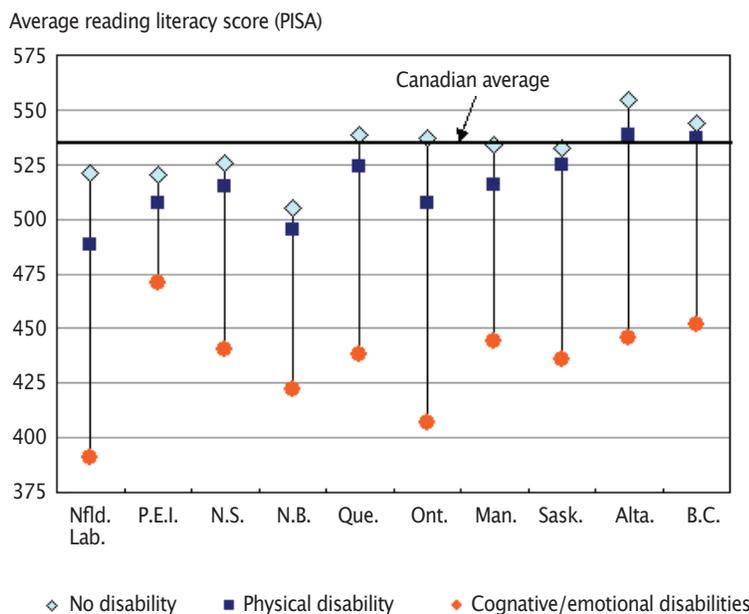
Differences in educational attainment for people with disabilities, compared to the average, are most evident in high school graduation and university degree achievement, as shown in Figure 2. Differences in literacy are also evident, as seen in Figure 3.

Figure 2: Educational attainment for persons with and without disabilities in Canada, men and women (%), 2006



Source: Statistics Canada, 2010

Figure 3: Literacy gap between disabled and non-disabled students, by province, 2000

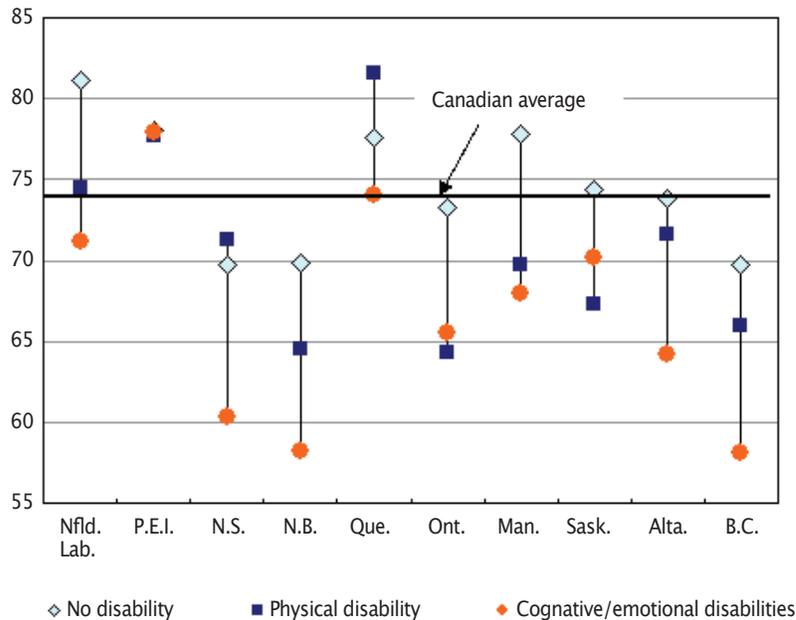


46. King et. al., 2006, p. 21

Source: Kohen et al., 2006, based on Statistics Canada and Human Resources and Skills Development Canada, Youth in Transition Survey, cycle 1; Organisation for Economic Co-operation and Development, 2000, Programme for International Student Assessment (PISA)

Parents of children with disabilities were less likely than the average parent to believe that schools were challenging their children to meet their potential, as seen in Figure 4.

Figure 4: Percentage of 15-year old students being challenged to work hard at school, from the perspective of parents

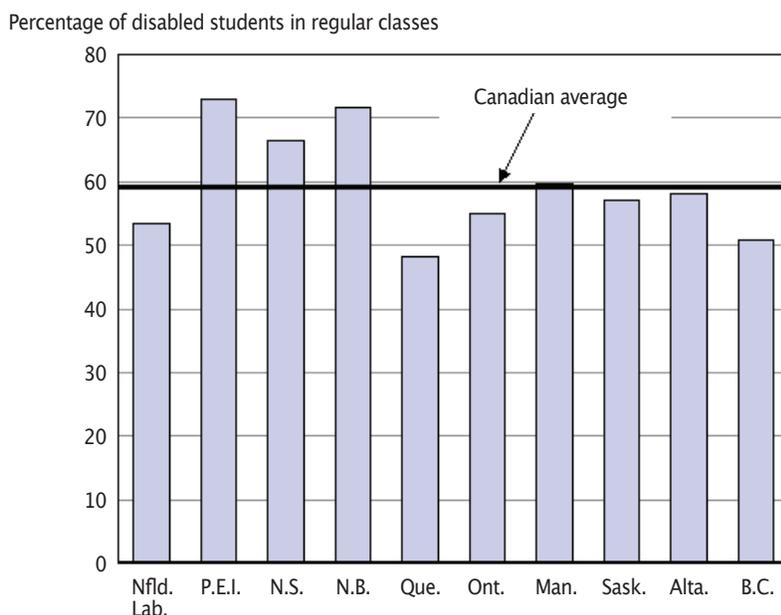


Source: Kohen et al., 2006, using Statistics Canada and Human Resources and Skills Development Canada, Youth in Transition Survey, cycle 1; Organisation for Economic Co-operation and Development, 2000, Programme for International Student Assessment (PISA)

The 2001 PALS survey investigated the experiences of children aged 4-14 in the education system, as well as the perspectives of their parents. Parents in Ontario were the most likely to report difficulties in accessing special education services.⁴⁷ Most often they reported insufficient levels of staffing or services as the reason. Other reasons included not being able to get an assessment and the unavailability of services locally.

Ontario also had the third lowest rate of special needs students in regular classes (Figure 5) but the second largest literacy gap (Figure 3). While literacy scores for children with cognitive and emotional disabilities tended to be lower, they were not significantly different from those in other provinces.

Figure 5: The percentage of disabled students in regular classes, by province, 2001



Source: Kohen et al., 2006, using Statistics Canada and Human Resources and Skills Development Canada, Youth in Transition Survey, cycle 1; Organisation for Economic Co-operation and Development, 2000, Programme for International Student Assessment (PISA)

Interestingly, Prince Edward Island and New Brunswick had the highest proportions of special needs students in regular classes, and also had the smallest literacy gaps between children with cognitive and emotional disabilities and children without disabilities. Moreover, parents in P.E.I. were the most likely to report that their children were being challenged to meet their potential.

Disability, work, and income

Income and employment in Canada

As a group, people with a disability earn less income and work fewer hours per year than the general working population.⁴⁸ Even when disabilities are temporary or episodic, work participation and annual work hours are lower, not only during the years of disability, but also during other years. Episodic disability affects capacity for continuous participation in the workforce, and that can affect capacity to succeed and advance.

When compared with people without disabilities, men and women disabled for six years report earnings differences of up to almost 20%.⁴⁹ These differences reflect, in part, a gap in hourly earnings that increases with every year of disability experienced. In 2004, the gap ranged from nearly zero for those with one year of disability to 20% and 23% for men and women respectively who reported six years of disability.

48. Galarneau and Radulescu, 2010, from the 2006 Survey of Labour and Income Dynamics (SLID)

49. Galarneau and Radulescu, 2010

Over a six-year period, the difference in the number of work hours between people with and without a disability can amount to one to 1.6 years of 'lost' work time. People with disabilities are not more likely to experience work interruptions such as a layoff, the end of a contract or seasonal job, a dismissal, a strike or a company relocation. They are, however, more likely to opt for reduced hours or not participate in employment, and slightly more likely to interrupt their work for health reasons.⁵⁰

A 2006 study showed that Canadians with disabilities were 2.4 times more likely to take extended leave, and experience lower pay as a result.⁵¹ Other studies have shown that absenteeism caused by a disability can lead to lower pay and reduced likelihood of promotion.⁵²

Table 5: Multiplier for risk of low-income for men and women with disabilities compared to men and women without disabilities, by number of years disabled

Number of years disabled	Risk of low-income multiplier
Men, 4-5 years	2x risk of men without disabilities
Men, 6 years	8x risk of men without disabilities
Women, >6 years	Not significant
Women, 6 years	4x risk of women without disabilities

Source: Galarneau and Radulescu, 2010

According to the 2006 Participation and Activity Limitation Survey (PALS), 42% of people between 15 and 64 years of age reporting a disability were unable to work. Those who were able to work appeared to benefit from recent employment growth. From 1999 to 2006, employment among men with disabilities grew more (from 48% to 56%) than employment among men without a disability (73% to 75%). Women with disabilities also saw an increase in employment from 39% employment to 46%—slightly more than for women without disabilities (61% to 65%).

In 2012, the employment rate for people with disabilities had risen to 51.3% compared with an overall figure of 81.8%, although this rate is likely not comparable to the 2006 figure, due to changing definitions of disability (See Appendix A).

Limitations in the workplace are more likely to relate to the severity of a disability, rather than the type. According to a study by Kapsalis and Tourigny, people who are limited at work due to their disabilities are at greater risk of experiencing low income and persistent low income.⁵⁵

50. Health reasons were cited for work interruption of respectively 6% and 8% of these men and women (no control for years of disability), compared with 0% and 1% for those without disabilities. (Galarneau & Radulescu, 2010)

51. Marshall, 2006

52. Harrison & Martocchio 1998; Yelin & Trupin 2003

53. Employment and Social Development Canada, 2014

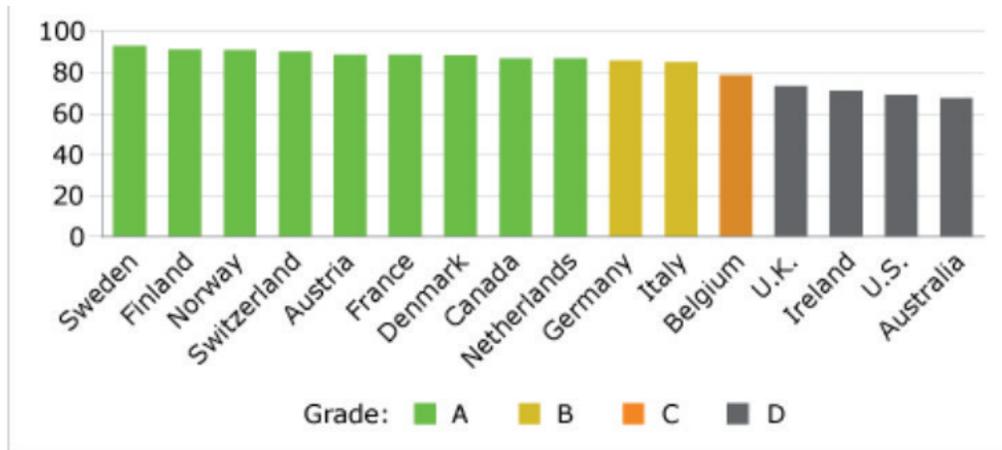
54. Hum & Simpson, 1996

55. Kapsalis & Tourigny, 2007

International comparisons of income and employment

According to the Conference Board of Canada, Canada ranked 8th out of 16 peers on income equity for people with disabilities in the mid-2000s.⁵⁶ People with disabilities were earning 87% of the average Canadian income, as seen in Figure 6. This leaves room for improvement—it is higher than Australia (68%) and the U.S. (69%), but lower than Sweden (93%). Nonetheless, Canada earned an “A” grade.

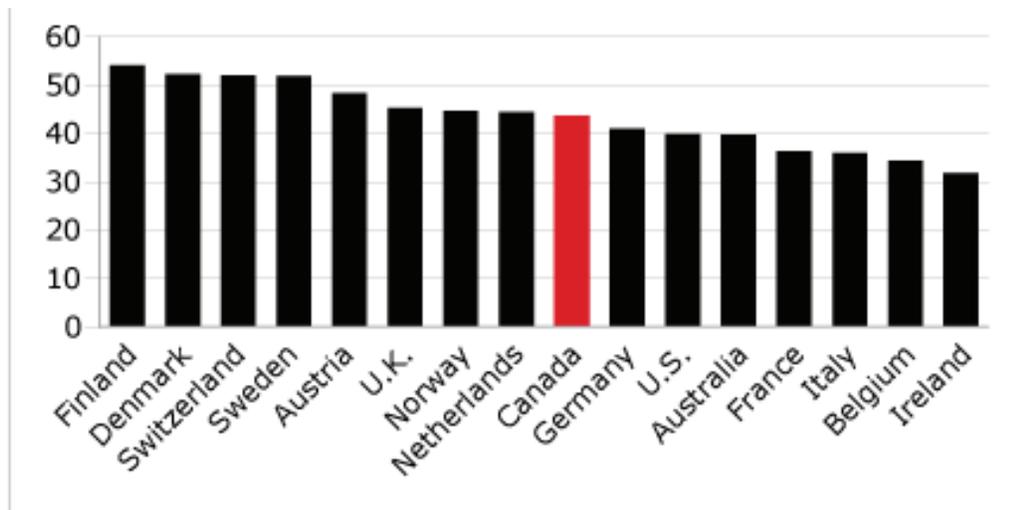
Figure 6: Income of people with disabilities (mid-2000s) as a share of income of people without disabilities



Source: Conference Board of Canada 2014

Canada was also in the middle of the pack for employment rates among people with disabilities, as seen in Figure 7. In 2005, 44% of working-age people with disabilities were employed in Canada. The best-performing peer country was Finland, with a 54% employment rate; the worst was Ireland, with a rate of 32%.

Figure 7: Employment rate of people with disabilities, mid-2000s (%)

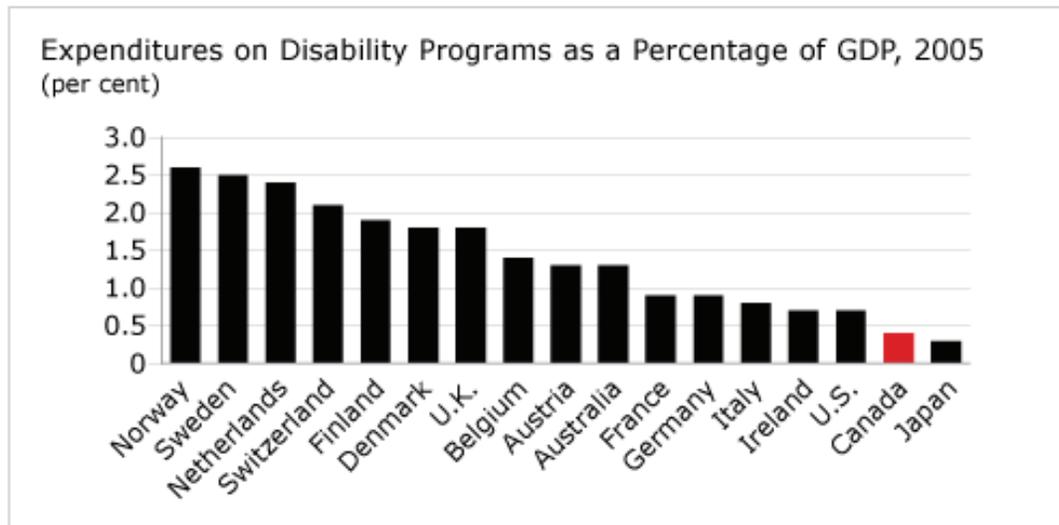


56. Conference Board of Canada, 2014

Source: Conference Board of Canada 2014

According to the Conference Board, Canada relies more on labour market integration of people with disabilities than on income transfers to achieve greater income equity. As a percentage of our GDP, our spending on disability programs is the second lowest among 16 peer countries, at 0.4% (Figure 8).

Figure 8: Expenditures on disability programs as a percentage of GDP, 2005 (%)



Source: Conference Board of Canada 2014

Frontrunners on income equity for persons with disabilities include Sweden, Finland, and Norway. Some criticize this success as resulting from generous cash benefits, rather than from employment integration.⁵⁷ However, the Nordic countries also boast high employment rates. Finland had the highest rate of employment in 2005, at 54%.

Research shows that there is a positive relationship between spending on disability programs and employment success. Canada appears to be an exception to this correlation. While we spend relatively little on disability programs, we nonetheless experience higher employment rates than 7 other countries that spend more.

Denmark and Germany focus more strongly on policies that promote integration into the labour force. Germany is in the middle of the pack on both employment and income, while Denmark is a frontrunner on employment, but middle of the pack on income. Norway and Sweden focus their efforts on both disability compensation and integration into the labour force. They come in first and second for income, and lower on employment: Sweden comes in 4th, and Norway 7th.

57. Hvinden, 2004.

The overall trend in OECD countries has been decreasing investments in compensation policies and increasing focus on integration policies. Strengthening integration policies is considered positive by the OECD, because of its implications for the economy, for creating inclusive communities, and for empowering and enriching the lives of people with disabilities. However, they suggest that more reform is needed to achieve this goal, including:

- introducing and fostering anti-discrimination legislation
- increasing employers' obligations toward people with disabilities
- streamlining administration and individualization of case management
- increasing work incentives for people with disabilities

The Conference Board of Canada further cautions that not all people with disabilities are capable of working, and fair compensation policies must remain available to those who require it to maintain their quality of life.

Part 2. The costs and benefits of meeting the special needs of children and youth

Cost-benefit analysis is not to be confused with cost effectiveness analysis, which also takes into account outcomes to which a dollar value cannot be assigned. In cost-benefit analysis, outcomes are all valued in economic terms. Understanding the impact of an investment in purely monetary terms can be a very valuable tool:

"If the central question of economic analysis is the trade-off of cost and benefits, then the central virtue of economic reason (and any decisions, policies or regulations associated with it) is efficiency. It is an explicitly moral claim, a statement about how the world should be: if we can do more with less by following a particular course of action, we are obliged to act in that way."⁵⁸

The literature on the costs and benefits of disability support

There is a robust literature on the economic **costs** of programs and services for people with disabilities. The problem is that there are almost no studies that look at both the costs and economic **benefits** of early interventions for children with disabilities.

58. Roscoe, 2014, p. 200

The World Health Organization categorizes the costs of disability in two ways: direct costs and indirect costs.⁵⁹ Direct costs are twofold. First, they account for costs that put families ‘out of pocket’ for expenses that come with having a child with a disability. Examples of these costs include: medical equipment, health services, personal assistance, transportation, and additional living costs.

Second, they account for the costs of programs, services, and benefits delivered by governments to support people with disabilities in achieving better social and workforce integration and a minimum standard of living.

Direct costs

Full and partial disability as well as early retirement schemes specific to disability or reduced work capacity account for an average of 1.2% of GDP spending in OECD countries. When sickness benefits are included, the share rises to 2% overall (5% in the Netherlands and Norway).⁶⁰

Canada’s share held steady at about 0.4% of GDP from 1990 to 2005 and 2% of public expenditure.⁶¹ The Conference Board of Canada reports that Canada’s spending on disability programs is the second lowest among peer countries. Nevertheless, Canada achieves employment rates among the disabled that are higher than seven peer countries that spend more.⁶²

The international is upward for both the number of recipients and costs of disability programs and services.⁶³ Canada’s rates, however, have stayed steady, up to 2007. That appears to be largely due to a significant increase in rejection rates for some types of disability claim.⁶⁴

Indirect costs

Analyzing indirect costs involves making some assumptions about what would have happened in the absence of the disability. This is measured in terms of lost economic output from labour and taxes. Few studies attempt to make this calculation, probably for ethical reasons. People with disabilities are full citizens exactly as they are, without achieving employment at the same rate as non-disabled individuals.

However calculating indirect costs can be useful in gauging the economic value of spending on programs, services and benefits. It can demonstrate the potential of investing in people with disabilities who are then able to return some of these investments in the form of economic contributions. A recent extensive review of costs of childhood disability included long-term costs associated with the child’s lifetime economic contributions.⁶⁵

59. WHO, 2011

60. Ibid, 2011

61. OECD, 2009

62. The Conference Board of Canada, 2013

63. WHO, 2011

64. OECD, 2009

65. Stabile & Allin, 2012

There can be no doubt that disabilities result in additional indirect costs to society, to families and to individuals with disabilities, but measuring the additional cost is a challenge. The World Health Organization reports estimated costs from the following countries:⁶⁵

- Australia estimated costs between 29% and 37% of income (depending on the degree of severity of the disability).⁶⁷
- Ireland estimated the cost varied from 20% to 37% of average weekly income, depending on the duration and severity of disability.⁶⁸
- Viet Nam estimated extra costs at 9%.
- Bosnia and Herzegovina estimated costs at 14%.⁶⁹

These studies are very important contributions to the literature as there are few comprehensive estimates of the cost of disability and no agreement on how and what to measure.^{70, 71} WHO explains:⁷²

Comprehensive estimates of the cost of disability are scarce and fragmented, even in developed countries. Many reasons account for this situation, including:

- Definitions of disability often vary, across disciplines, different data collection instruments, and different public programs for disability, making it difficult to compare data from various sources, let alone compile national estimates.
- There are limited data on the cost components of disability. For instance, reliable estimates of lost productivity require data on labour market participation and productivity of persons with disabilities across gender, age, and education levels.
- There are no commonly agreed methods for cost estimation.

Progress in the technical aspects of disability cost estimates and better data are required to achieve reliable national estimates of the cost of disability - for example, the cost of productivity losses because of disability, the cost of lost taxes because of non-employment or reduced employment of disabled people, the cost of health care, social protection, and labour market programs, and the cost of reasonable accommodation. The situation is better for data on public spending on disability benefits in cash, both contributory (social insurance benefits) and non-contributory (social assistance benefits), particularly in developed countries. But even for these programs, consolidated data at the national level are scarce.

The closest Canada has come is a 1998 study on economic burden of illness, which calculated the direct and indirect costs of illness by age, sex, and

66. WHO 2011

67. Saunders, 2006

68. Cullinana et al., 2010

69. Braithwaite & Mont, 2009

70. Saunders, 2006

71. Tibble, 2005.

72. WHO, 2011

73. OECD, 2009

province/territory. The Public Health Agency of Canada considered costs as follows:⁷⁴

Direct costs:

- Hospital care expenditures
- Drug expenditures
- Physician care expenditures
- Expenditures for care in other institutions
- Additional direct health expenditures

Indirect costs:

- Mortality costs
- Morbidity costs due to long-term disability
- Morbidity costs due to short-term disability

Literature that is primarily U.S.-focused generally categorizes costs in four groups—the costs:

- to families
- of health care
- of programs
- of specific disabilities.

The value of unpaid caregiver services in the U.S. was estimated at \$450 billion in 2009.⁷⁵ This gives an indication of the costs experienced by families whose caregiver could be spending his or her caregiving time in other activities, including work. Studies show that the benefits of decreasing the workloads of family caregivers extends to their employers, as well. In the U.S., the total cost of working family caregivers to U.S. businesses annually is estimated at \$4,933,816, 305. This includes the replacement cost of employees who quit, absenteeism, partial absenteeism, workday interruptions, and time taken to supervise employed caregivers.⁷⁶

Cost-benefit studies of interventions for children with disabilities

The literature on the economic impact of early childhood intervention for children with disabilities is very limited. The challenges of conducting such studies are threefold:

- incomplete data on costs of services
- diversity of children and programs
- the costs of the programs themselves, which are constantly changing and can become outdated quickly.⁷⁷

74. Public Health Agency of Canada, 1998

75. Family Caregiver Alliance, 2012

76. MetLife Mature Market Institute and National Alliance for Caregivers, 1997

77. Groark et al., 2011

However, a recent study from Australia reviewed the benefits of early intervention for children with five specific disabilities: autism, cerebral palsy, Down syndrome, hearing impairment and visual impairment.⁷⁸ The study sets out a framework for a cost-benefit analysis in five quantifiable areas: education, employment, living independence, health care, and quality of life. In the absence of sufficient evidence to estimate the returns of interventions, this study hypothesized a range of scenarios in which intervention could improve outcomes for children with disabilities.

Another study from Australia took a similar approach in estimating cost benefits for early interventions with people with mental health disorders and cognitive impairment.⁷⁹ This study hypothesized costs over a life course without early intervention and with early intervention to demonstrate the possible impacts and economic returns.

An earlier study conducted by Wood stated that:⁸⁰

...delaying intervention means more children requiring more services at higher costs, while providing early intervention for the same population means fewer children requiring high cost services.

In a review by Smith, four cost benefit studies were identified, including the one by Wood. One relates to pre-school education, known as the Perry Preschool project.⁸¹ It showed that investment in preschool services decreased the need for special education services. It projected cost returns in release time for mothers, public school costs, and lifetime earnings of children.⁸² The other two studies relate to early intervention services treatment and demonstrate a return on investment.^{83, 84}

A recent Ontario study calculated the cost-effectiveness of expanding intensive behavioural intervention to all autistic children in Ontario. It found that this expansion “represents a cost-saving policy whereby total costs of care for autistic individuals are lower and gains in dependency-free life years are higher.”⁸⁵

Early interventions with mental health disorders and cognitive impairments can also lead to decreases in costs to the justice system. An Australian study showed that people with such disorders in New South Wales were three to nine times more likely to be in prison than their non-disabled counterparts.⁸⁶ The cost of crisis supports and lives spent in prison could cost up to \$1 million per person per year. Successful initiatives, however, could improve outcomes for persons with mental health disorders and cognitive disabilities, saving 1.4 to 2.4 dollars for every dollar spent.⁸⁷

78. Synergies Economic Consulting, 2012

79. McCausland, Baldry, Johnson, & Cohen, 2013

80. Wood, 1981

81. Smith, 1988

82. Schweinhart & Weikart, 1980

83. Snider et al., 1974

84. McNulty et al., 1983

85. Motiwala et.al, 2006, p. 135

86. McCausland et al., 2013

87. Ibid

Estimating the costs of adequate intervention for special needs children and youth in Ontario

How much would it cost Ontario taxpayers if we fully funded all of the interventions needed to raise children with special needs to adulthood, maximizing their potential as contributing members of society and fully recognizing their human and individual rights to true inclusion?

Is there a way we can calculate that? Here's an attempt:

The cost to parents to raise and educate to adulthood a child who had **no** special needs has been estimated at about \$250,000. The cost of raising a child with special needs is four times that, or a million dollars.⁸⁸ For the first 18 years of life, that works out to \$55,000 a year. It is clear at present that most families cannot bear this full cost, leaving some needs simply unmet.

Let's assume that, in a fully civil society, the parent of the special needs child shoulders about as much of that cost as does the parent of a child with no special needs. That would be \$13,000 a year⁸⁹ plus further out-of-pocket expenses of \$2,000 a year.^{90 91}

That would leave governments and other civil society organizations paying roughly \$40,000 a year for the additional costs of each child with special needs. The Ministry of Education estimates that there are 300,000 children with special needs in Ontario. That would make the cost as high as \$12 billion a year. This amount would represent 9.4% of Ontario's budgetary expenditures, or 1.7% of Ontario's projected GDP.

This is not a 'sunk cost'. There is an economic return for raising special needs children and youth to be productive and integrated adults. We will continue to explore this return in this section of the paper. There is also the unquantifiable social benefit we all enjoy as a society that protects and includes everyone and values the rights of the individual child.

Is it possible to measure both the costs and benefits of meeting the special needs of children and youth?

To make this question intelligible, we must explain the frame, or point of view, that informs it. That frame has two aspects:

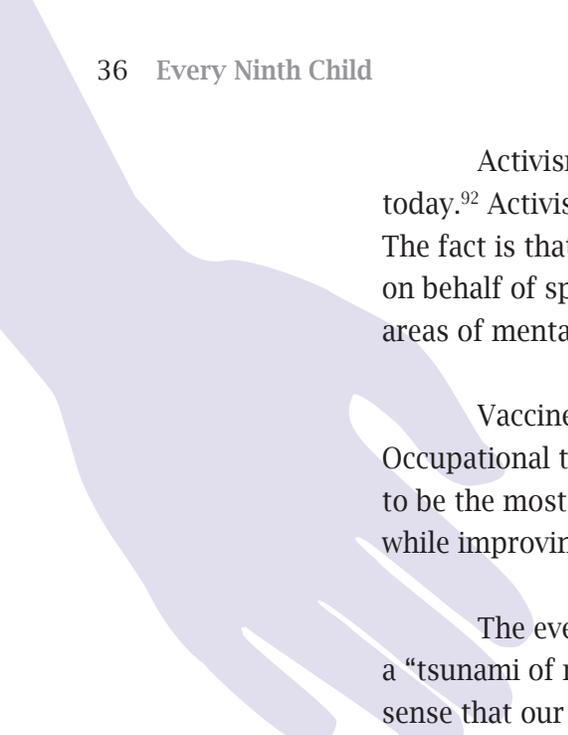
- confidence in the success of intervention
- an alternative perspective on the common arguments about resource scarcity.

88. Guillot, C., 2013, July

89. Yee, K. (Accessed 2014)

90. Burton, P. & Phipps, S., 2009

91. Anderson et al., 2009



Activism in the interests of children with special needs is unprecedented today.⁹² Activism would not be as strong as it is if intervention was unsuccessful. The fact is that special educational, therapies, and other medicinal interventions on behalf of special needs kids do work and often spectacularly--especially in the areas of mental and emotional health and in spectrum disorders such as autism.

Vaccines work. Special equipment works. Physiotherapy works. Occupational therapy works. Pharmaceuticals work. The postwar era has proven to be the most productive era in history in identifying and controlling disease while improving outcomes for special needs children.

The ever increasing effectiveness of diagnosis causes some critics to fear a “tsunami of need.” But such a tsunami is in fact a very good outcome, in the sense that our society is learning more and more about how we can improve the lives of children and thus their futures.

The argument over scarce resources is a familiar one. We have programs that work well but they are expensive. Governments are running long-term deficits and there is a general disposition to rein in taxation. The alternative frame attempts to assess the costs of inaction. Abandonment or curtailment of successful intervention will mean that 1 in 9 children will be left behind and they will not succeed as adults. Lack of success will mean that as adults, they will pay less tax, make fewer contributions to community life, and incur greater costs of intervention later.

Can we do a comprehensive cost benefit analysis of all interventions with special needs children? No, not with the resources at hand. There are literally thousands of types of sickness and disability among children and youth. There are an exponentially larger number of interventions and treatment regimens based on the severity of the disability. There are thousands of variations in the relative displacement of families caused by their children’s disabilities and treatment.

To do the job properly, researchers would have to conduct cost-benefit analyses on each of the interventions over a wide array of disabilities, considering an equal amplitude in family displacement scenarios.

All we want to do with this paper is focus on a limited number of interventions over a broad range of disability types. When deciding on which benefits to include, there were numerous choices available to us that we felt could be monetized. Of these, two benefits were ultimately selected to be included in this analysis: avoided social assistance and taxes resulting from employment. The costs were limited to the Ministry’s total allocation for students with special needs.

92. McLaughlin et al., 2006, among others, note an increase in parental activism beginning in the 1990s.

Ideally, all benefits and costs associated with interventions for youth with special needs could be included in such an analysis. Doing so with such a diverse population would be too vast an undertaking at this time, but we offer this limited analysis as a model.⁹³

Individual Education Plans: A sample cost-benefit analysis of one common intervention for children with special needs

Defining the population

Our cost-benefit analysis focuses on Ontario children and youth between the ages of three and 21 who have an Individual Education PLAN (IEP) in place. About 60% of these children and youth with IEPs are identified as “exceptional pupils,” defined as:⁹⁴

A pupil whose behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he or she is considered to need placement in a special education program...

Exceptional pupils are further identified in one of the following categories:

- behaviour
- communication
- intellectual
- physical
- multiple.

We also include children and youth who, although not formally assessed as “exceptional,” have IEPs because their performance “places them at risk of failure” and therefore their special education programs are also monitored by an IEP.⁹⁵ We exclude from the population children and youth who have been identified with “giftedness,” on the reasonable assumption they would not face any barriers to graduation, employment, or self-sufficiency in the absence of an IEP.

The premise and assumptions behind our sample model

IEPs and other interventions are integral to the success of students with special needs in graduating from high school. The purpose of this sample model is to illustrate the return on the Ministry’s allocation to youth with special needs in the education system. The premise is that without such funding in place, the likelihood of future employment for youth with special needs will be lower. This would increase their need for social assistance supports and decrease the potential tax revenues the government would receive through their employment.

93. We would have liked, for example, to include the interventions that relieve a caregiver from having to take time off work to care for a child with special needs, factoring in both the cost of the intervention and the caregiver’s recovered income, but decided to exclude this from the scope. This could perhaps be done using survey methods or by drawing inferences from market behaviour. See, for example, Multiple Sclerosis Society of Canada, 2008; MetLife Mature Market Institute and National Alliance for Caregivers, 1997; Family Caregiver Alliance, 2012; Lai, D.W., 2012. Also excluded are expenditures allocated to youth with special needs derived from other government ministries, including Health, Community and Social Services, and Children and Youth Services and the costs associated with post-secondary education.

94. Ontario Ministry of Education [Supply date of publication]

95. Sweet et al., 2012

The overarching assumption in the analysis is that without the Ministry's allocation to special needs education, it would be extremely difficult for many youth with special needs to graduate from high school. The funding is required to promote accessible learning and barrier removal within the education system.

Methodology

Most of the inputs to the model are based on actual data. A listing of the parameters used can be found in Appendix B.

A 3% discount rate is used to account for the decreased value of money over time. All dollar amounts are expressed in current year dollars, unless otherwise noted.

The estimates used to determine the size of each graduating cohort are based on the total number of youth with an IEP (excluding those identified as gifted) between the ages of three and 21. We assume an even distribution across the age groups, and so this number is divided by 19 (the number of years of education between ages 3 and 21) in order to determine the graduating cohort.

Without funding in place, it is assumed that youth with special needs will rely on support, in whole or in part, from the Ontario Disability Support Program (ODSP), the province's social assistance program designed for people with disabilities between the ages of 18 and 65. Social assistance benefits are based on income support payments for a single individual eligible for ODSP. Rates for future years have not been adjusted for increases in cost of living.

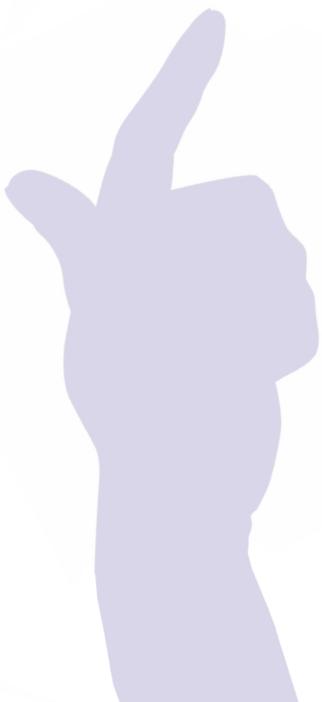
The estimates of benefits are based on the expectation that a youth graduating from high school will generate tax revenues for 40 years.

Education-related Information regarding youth with special needs was collected from the Ministry of Education and the Research & Information Services branch of the Toronto District School Board. Information about social assistance rates was sourced from provincial legislation. The average salary, employment, and labour force participation rates are taken from Statistics Canada.

Calculating the costs

The Ministry of Education reports that the total allocation for special education in 2011-12 was approximately \$2,547,900,000, including \$36,800,000 for full-day kindergarten special education programs.

The Ministry also notes that it provides school boards with funding through the Special Education Grant (SEG) to support the costs of the additional



programs, services, and equipment required for students with special educational needs. The SEG is not a reimbursement-based allocation. It is incremental to funding generated by all students, including those with special education needs, through foundation grants and other special purpose grants of the Ministry's education funding model, known as Grants for Student Needs ("GSN").

Calculating the benefits for one individual

In this analysis, we assume that reductions in special needs funding would result in a greater number of youth with special needs being unemployed or under-employed for most of their working years. ODSP would therefore be more prevalent as a primary source of income. Higher unemployment and under-employment would also result in foregone tax revenues from employment earnings.

We begin by considering the net benefit to society of one person employed versus being unemployed and relying on ODSP. We use the average salary provided by Statistics Canada of \$32,155, which is sufficient to reduce an individual's ODSP income supports benefits to zero.⁹⁶

The following chart summarizes the calculation of the net savings to society for one person working rather than receiving ODSP:

Discount Rate	3%
Average Salary	\$ 32,155
Average years of lifetime employment	40
Yearly ODSP	\$ 13,032
Annual tax contribution (before eligible deductions)	\$ 4,300
Value of lifetime ODSP saved plus tax revenue for one person	\$ 400,625

Calculating the benefit for each graduating cohort

We continue by applying the above savings identified for a single individual to a cohort of youth with special needs graduating from high school in any given year. We assume an even distribution of the 318,869 students with special needs in the education system between the ages of 3 and 21. The number of yearly graduates with special needs is estimated at 16,783, based on the Ministry's data. When we exclude "gifted" students, the number of annual graduates is 14,148.

Next, we estimate how many of the 14,148 are likely to become employed, thereby minimizing the need for ODSP income supports. We combine the labour force participation rate of working age adults with disabilities with a high school diploma (66%)⁹⁷ with the employment rate of 91%.⁹⁸ We estimate that 60% of the cohort of 14,148 of graduates with special needs will attain employment.

96. The threshold occurs at \$28,144 for a single individual.

97. See Appendix B, "Labour force participation rate of persons with disabilities with and without a high school diploma".

98. See Appendix B, "Employment rate of persons with disabilities".

Without the IEP, we estimate that 38% would have still achieved employment, (using a labour force participation rate of 44% and an employment rate of 87%). This yields a difference of 22%. That is, there would have been 22% less (or 3,112 fewer) individuals that would have achieved employment had they not had IEPs.

To recap, without the Ministry's allocation to youth with special needs, we estimate that 3,112 individuals per year would not achieve employment and pay taxes, and instead would have ODSP as their sole source of income over their 40 working years. This generates a net benefit to society of \$1,246,871,173 or a \$0.47 return on investment for every dollar spent on special needs education by the Ministry.

The following chart summarizes the calculation:

Total students with IEPs (based on 2011/12)	318,869
Age range (3-21)	19
Estimated size of cohort in one year (total IEPs divided by 19, assuming equal distribution)	16,783
Percent gifted	16%
Cohort graduating with special needs excluding minus gifted	14,148
With IEP, thus graduating	14,148
Labour force participation rate of working-age adult with a disability and with high school education	66%
Employment rate of adults with high school education	91%
Combined Rate (.66 x .91)	60%
No IEP, thus no high school graduation	
Labour force participation rate of working-age adult with a disability and no high-school diploma	44%
Employment rate within this group	87%
Combined rate (.44 x .87)	38%
Difference between the combined rates of the group with high-school graduation and the group with no high-school graduation (60% - 38%)	22%
Number of people from one cohort reaching employment who would not have without an IEP	3,112
Cost-benefit calculation	
Value of lifetime ODSP saved plus tax revenue for one person	\$ 400,625
Value for one cohort (\$400,625 x 3,112)	\$ 1,246,871,173
Return (Cohort value as a percentage of ministry costs, expressed as cents on the dollar)	\$ 0.47

Part 3. The dilemma—advocating for special needs while preparing children for life in the mainstream

*More and more children are being referred to special education and there seems no end to this increase.*⁹⁹

*Yes, he's a smart kid. No, he doesn't throw tantrums or flee from social interactions. But here's the flip side: He needs those supports, damn it. Speech therapy. Occupational therapy. Behavioural therapy. They're the keys to his success. And because they're underfunded, in demand, in terminally short supply, we—like all caregivers—are locked in a perpetual public relations battle...*¹⁰⁰

The success of activism

For a century and a half, the main societal and governmental response to children with special needs was to segregate them and warehouse them. Our approach was custodial and it too was expensive (both in spending and in lost opportunity). These are not the times we live in now. We know that governments, researchers, practitioners, and parents are harvesting the knowledge that with rare exceptions, special needs children can live successfully in our communities. We grossly underestimated what was possible for the lives of children with disabilities, and for societies that are inclusive. But we know that we can do more by listening closely to the voices of children and youth.

Instead of a costly burden, we are riding a tsunami of success characterized by wonderful breakthroughs in diagnosis and achievements in treatment. But all our successes come at a cost. Government is meeting about one half of the costs of special needs while parents and non-profits are obliged to meet the other half—and cannot. That leaves many needs unmet.

Activism in the interests of children with special needs is unprecedented today.¹⁰¹ Parents are more powerful and more active than they have ever been, with the internet a potent tool for information sharing and organizing.

Activism, especially in the areas of autism spectrum disorder, developmental challenges, and learning disabilities is both well-funded and effective. Parents have done very well in placing their issues before the public,

99. Levin, 2001

100. Rubinoff, 2014

101. McLaughlin et al., 2006, among others, note an increase in parental activism beginning in the 1990s.

with their appeals to officers of parliament such as the Ombudsman receiving wide-spread media coverage.¹⁰² Without parental activism, children in need would not be identified as well as they are and calls for intervention would not be as effective.

But parent advocates have mostly aimed their advocacy at starting and maintaining **special programs** as opposed to **improving mainstream education** to embrace the needs of their children. Advocating for exceptionality is an approach that governments have tended to oppose, because separate programs cost more. Nevertheless, parents and educators in Canada and the U.S. have successfully framed how special needs children are seen by the education system.

Today, special education has emerged as a priority and a whole system of services has grown up in that domain. Sincere, committed advocates for special needs kids have succeeded in carving out a place for Special Education in modern, state-funded education.¹⁰³

The importance of the life course of the child

OECD publications talk a lot about “the life course” and “life course policy.”¹⁰⁴ Rather than setting public policy for people at different stages of their lives, life course policymaking attempts to connect the various stages and improve the coherence of policies that promote successful and productive lives throughout adulthood.

We can’t afford to look solely at the short-term payoffs or effects of interventions we make in the lives of special needs children and youth. We need to think about how the things we do now will make things better down the road, not just for the child or youth, but for governments and the public at large.

Breakthroughs in medical diagnosis and treatment, various therapies, nutrition, and vocational rehabilitation mean that our special needs children are living longer. We need to ask how the interventions we make now will help the m 30, 40, or 50 years from now. We need to think more in the future perfect tense.

In our modern world, we have embraced human rights and rejected the idea that children with special needs should be institutionalized or kept at home. There is an expectation that once childhood ends, the special needs child will integrate into the adult world. We want them to be there, self-reliant and contributing.

102. Gordon, A., 2013, March

103. Bennett, P.W., 2011, May

104. ECD, 2007, Modernising social policy for the new life course

That means that we have to think carefully about the extent to which we remove children from the mainstream during their education. We also need them present in the mainstream to help teach children who don't have special needs that their world is not an enclave of 'normality', just as the adult world is not.

To the extent that we do separate children out, to provide for special needs and to prevent disruption in the classroom, we need to be constantly thinking of the life course consequences for both groups of children. We need to prepare both special needs children and children without disabilities to operate in a 'real world' in which inclusivity and diversity are not only the norm, but a contributing factor to the well-being and prosperity of our communities.

The tension between the need for special supports and programs and the need for integration and inclusion poses a real dilemma for the voice of disabled youth themselves. Do they wish to start the dialogue by saying:

- "We are just like you" or
- 'We are different from you'?

Perhaps they will wish to combine these two statements and say, "We are just like you *because* we are all different," and open up a conversation about the amplitude that characterizes normalcy and about accommodation as part of being normal as opposed to special.

The northern European model of workforce inclusion

Among the 29 richest countries, the Netherlands, Iceland, and Switzerland rank highest in social policies affecting children and youth, with the Netherlands ranking highest in child education, behavior and risks, and material well-being.¹⁰⁵

Canada, on the other hand, ranked below average on relative child poverty, overall child life satisfaction, and children and youth not in education, training, or employment. Canada and Ontario are behind northern Europe in this regard for a number of reasons, but many of the same factors that have influenced northern European policy making are relevant for us.

The Netherlands, Iceland, and Switzerland have populations that are aging faster than Canada. The OECD, whose members comprise the world's most affluent nations, predicts that there will be major workforce shortages in the future, with declining birthrates and an aging society.¹⁰⁶

105. UNICEF Office of Research, 2013

106. Brian Keeley, Human Capital: How what you know shapes your life, OECD Insights, 2007

This has caused Northern Europeans to look more closely at their children as an essential resource. They cannot afford to refrain from interventions on behalf of their special needs children – they need ‘all hands on deck’. That is why in the Netherlands, we see the employment assessment of young children with special needs at a very early age. In Canada, we tend not to seriously start this process until a child with disabilities turns 18.

In other words, these countries have come to see all their children as potential future resources. and investment in their future as obligatory.

Another reason why Canada may be behind northern European countries in investing in children and youth has to do with language. Indigenous languages like Icelandic, Dutch, French, German, and Italian are much more difficult to outsource to overseas service workers than service work in English. That means that jobs in fields such as accounting, telemarketing, copy work, and reception can't be sent overseas at low cost. Their own nationals must perform this work both now and in the future. This will create even more pressure on the job market, and a need to integrate as many children as possible into the workforce as adults.

In Canada, there is no national dialogue on our special needs children as a valuable resource for the labour markets of the future. But those national conversations are going on all the time in Iceland, Switzerland, and the Netherlands. The European Agency for Special Needs and Inclusive Education¹⁰⁷ has 28 full members, only one of whose national language is English.

In the future, there is every reason to believe that Canada and Ontario will be affected by the factors that have influenced these northern European countries. We too are getting older as a society. Our median age in 1967 was 26 and our median age now is 42. Our average age is even older. This means that Ontario will need as many of its children as possible in the labour force. We will have older people who will depend on the proportionally smaller workforce of the future.

Meanwhile, we will find it less easy to export jobs to emerging economies, as their low-cost labour pools are already demanding better working conditions and higher pay. In other words, we will need our children to perform the work we export to other countries today.

107. The European Agency for Special Needs and Inclusive Education, 2014.

Summing up: Three recommendations

In this paper, we have attempted to give an overview of the current literature on approaches to children and youth with special needs. We have seen how these approaches have shifted to a social or ecological model that emphasizes the environments in which children move and their ability to enable a child to reach his or her full potential. And we have seen how progressive approaches within the educational system lean toward taking individualized approaches not just to children with ‘labels’, but to all children.

In our review of disability, work, and income, we see that Canada is doing fairly well on integrating adults with disabilities into the workforce, compared to other OECD countries. Our success owes much to our country’s entrenched human rights standards and to the supports we put in place early, such as Ontario’s Individual Education Plans and other special needs interventions. But we can do much better. We are still just ‘in the middle of the pack’ of OECD countries.

The most successful northern European countries have recognized they will have future labour shortages and therefore consider very young children in the light of the job market and what they can be reasonably expected to do as adults. Their focus is on the life course of every child, and the integration of every possible child and youth into the labour force.

We know that early investment in children with special needs pays off. Cost analysis only considers the so-called ‘dead weight’ cost of raising a child, which is high for special needs children. The logic of dead-weight costs prevails only if we fail to weigh it against the economic benefits of productive citizens over their life courses. In this paper’s very limited cost-benefit analysis of Ontario’s Individual Education Plans, we have sought to measure this benefit. To show a true picture of our investments in children with special needs, we must open the door to considering the costs of failing to intervene.

Recommendation 1: The need for a government-wide strategy of inclusion

There is no area of government that does not touch the lives of children and youth. Drawing on models from countries such as Sweden, the Netherlands, and New Zealand, Ontario should develop government-wide strategies to address the issues of special needs youth. We need a comprehensive plan that supports all disabled children, to the greatest extent possible, within the mainstream. That includes the childcare system, the education system, after-school and summer programs, recreation, sports, and arts programs, and all other publicly funded activities that touch the lives of children and youth.

Recommendation 2: The need to continue and expand supports

For children who require supports over and above what is provided within mainstream systems, Ontario must improve these interventions, so that parents and caregivers no longer feel locked in perpetual struggles for adequate, robust support.

Recommendation 3: The need for a tracking system

We need to be able to measure the outcomes of our interventions with special needs children and youth. Ontario should develop a comprehensive tracking system that can quantify in key areas where positive outcomes for supported children and youth have led to contributions and cost savings in our economy.

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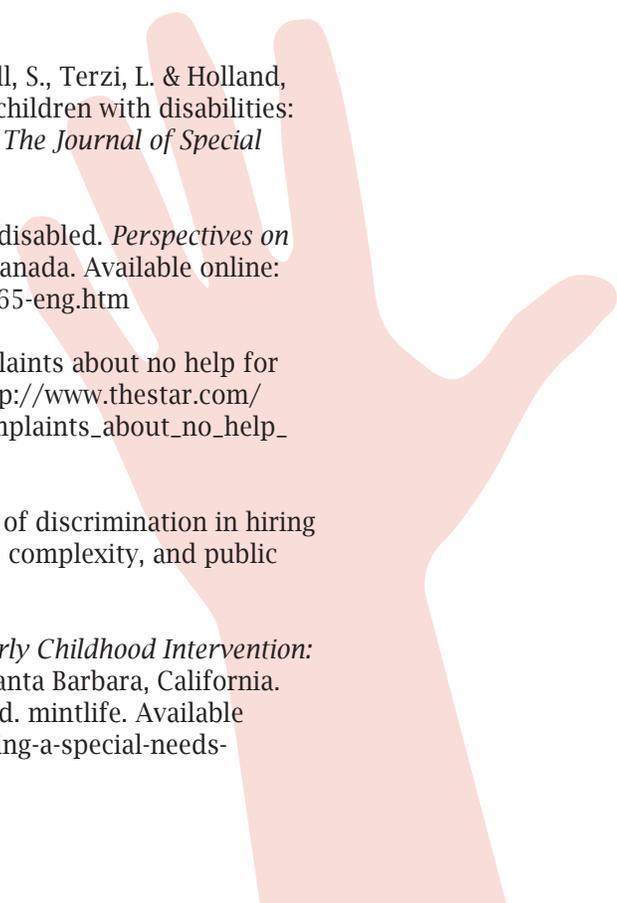
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Appendix A: Changes in data collection on disability in Canada

The collection of demographic data on persons with disabilities in Canada has been informed by shifting perspectives on disability. A new set of Disability Screening Questions were asked in the 2012 Canadian Survey, as compared with the now inactive Participation and Activity Limitation Survey (PALS), where a concerted effort had been made to reflect the social model of disability.

Surveys that provide information on disability demographics in Canada and Ontario include:

- PALS (1986-2006); frequency, occasional (1986, 1991, 2001, 2006);¹⁰⁸ now replaced by Canadian Survey on Disability
- The Canadian Survey on Disability (CSD) (2012-); frequency, every 5 years
- Survey of Income and Labour Dynamics (SILD) (collected annually January-mid-March); 1976-2011; now inactive, to be replaced by Canadian Income Survey?
- Census
- National Household Survey
- Canadian Community Health Survey (CCHS)

The definition of disability used in Canada since 1999 for the PALS survey, the census, the Canadian Community Health Survey and the Survey of Income and Labour Dynamics is borrowed from the World Health Organization, which uses the “bio-psychosocial framework”. It defines disability as:

*...the result of complex interactions between a health problem or functional limitation and the social, political, cultural, economic, and physical environment. These, in combination with personal factors such as age, gender, and level of education, can result in a disadvantage—that is, a disability. Disability is [therefore] not defined merely as being the direct result of a health problem or any physical or mental limitation.*¹⁰⁹

Canadian Survey on Disability (2012)

This survey gathers information on people aged 15+ whose “daily activities are limited due to a long-term condition or health-related problem.”¹¹⁰

108. Statistics Canada, 2013a

109. Human Resources and Social Development Canada, 2006 in Galarneau and Radulescu, 2010, p.5

110. Statistics Canada, 2013b

It collects information on: type and severity of disability, use of aids and assistive devices, help received or required, educational attainment, labour force status, experiences and accommodations at school or work, and ability to get around the community.

The CSD was distributed 16-20 months after the 2011 National Household Survey to respondents “pre-screened” in the NHS as having activity or participation limitations based on the same questions used in the 2006 Census.

The CSD has adopted the newly developed Disability Screening Questions (DSQ), used for the first time in 2012 to identify disability in Canada. Screening questions in the CSD more closely reflect a social model of disability than do the PALS screening questions. They are also consistent across all types of disabilities, unlike the PALS questions. As a result of these changes, data from CSD and PALS are not comparable.

The CSD is considered to be a step forward toward a social model of measuring disability. However, the methodology used in the 2011 National Household Survey to identify persons with disabilities for the CSD is the same as was used in the 2005 long-form census. This is considered problematic as the CSD may not include or may underestimate certain types of disability. As stated by Statistics Canada, “follow-up studies have shown that these filter questions do not adequately identify people with mental/psychological or cognitive disabilities.”¹¹¹

Disability by the numbers

The Canadian Survey on Disability tells us that in 2012, about 3.8 million people, or 13.7% of Canadians aged 15 and older, reported being limited in their daily activities because of a disability.¹¹² In 2012 in Ontario, 1,035,090 people had a disability, representing a prevalence of 15.4%. The prevalence is higher for women in both Ontario and Canada, at 16.8% and 14.9% respectively.

Table 1: Number and prevalence of persons with disabilities in Ontario and Canada (2012)

	Number of people with disabilities aged 15+	People with disabilities aged 15+
Canada	3.8 million	13.7%
Ontario	1,035,090	15.4%

Source: Statistics Canada, 2013

111. Statistics Canada, 2013c

112. Statistics Canada, 2013d

The prevalence of disability increases steadily with age. Nearly one in 10 working-age Canadians (aged 15 to 64) reported having a disability in 2012, compared with almost one-third of Canadian seniors (aged 65 and older). The most common disabilities experienced by each age group are listed in Table 2. Figure 1 shows the prevalence of disability types among adults with disabilities. The severity of disability experienced is listed in Table 3.

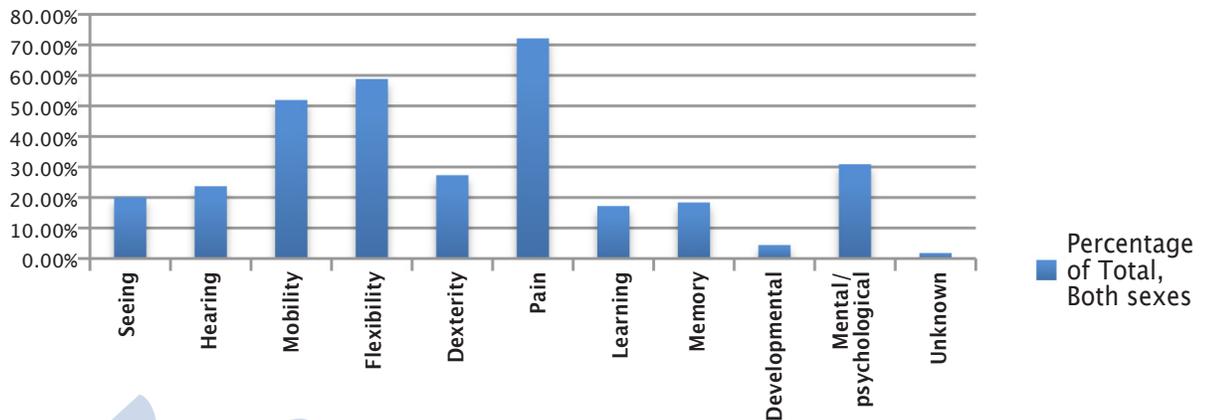
Table 2: Most common disabilities according to age group, Canada (2012)

Age group	Most common disabilities
15-24	Mental/psychological disabilities (2.2%) Learning disabilities (2%) Pain (1.9%)
45-64	Pain (12.7%) Flexibility (9.8%) Mobility (8.6%)
65+	Pain (22.1%) Flexibility (19.3%) Mobility (20.5%)

Source: Statistics Canada, 2012a, Canadian Survey on Disability, 2012

Figure 1: Prevalence of disability types among adults in Ontario (2012)

Percentage of Total, Both sexes, Ages 15+



Source: Statistics Canada, Canadian Survey on Disability, 2012 [Table 3.7]



Table 3: Severity of disabilities in Canada and Ontario, 2012

Severity	% of people experiencing this level of severity in Canada	% of people experiencing this level of severity in Ontario
Mild	31.7%	30.8%
Moderate	19.8%	19.1%
Severe	22.5%	22.2%
Very Severe	26%	27.9%

Source Statistics Canada, Canadian Survey on Disability, 2012 [Table 4.7] ¹¹³

Disability can be continuous, temporary, or episodic. From 1999 to 2004, 13% of people who reported a disability had been affected by it during all six years of the reporting period.¹¹⁴ The longer the disability period, the more likely it is that the people affected:

- have less education
- are women
- are older
- live alone
- have lower participation in the labour force.



113. Explanation of the four categories from Feng et al., 2009, p.43

114. Galarneau & Radulescu, 2010

Appendix B: Data parameters for the cost-benefit analysis model

Input/Parameter	Author	Underlying Source	Publish Date	Publication	URL/Page
# of students receiving SEN programs/ services	Ministry of Education				
Total allocation for SEN funding	Ministry of Education				
SEN incremental expenditure	Ministry of Education				
% of gifted youth	Research & Information Services, Toronto District School Board R. Brown, L. Newton, G. Parekh, H. Zaretsky		2013	Special Education in the TDSB and Ontario: An Overview, 2011-13	
Average salary for persons with disabilities	ESDC	Statistics Canada (PALS)	Modified in 2013	Disability in Canada: A 2006 Profile	http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=13#M_4
Years of employment					
ODSP rates		Ontario Disability Support Program Act			Maximum ODSP monthly amount.
Employment rate of persons with disabilities	ESDC	Statistics Canada (PALS)	Modified in 2013	Disability in Canada: A 2006 Profile	http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=13#M_4
Labour force participate rate of persons with disabilities with and without a high school diploma	ESDC	Statistics Canada (PALS)	Modified in 2013	Disability in Canada: A 2006 Profile	http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=13#M_4
Federal and provincial income tax rates for 2013	KPMG	Income Tax Act	2013	Federal and Provincial Income Tax Rates and Brackets and Surtaxes	http://www.kpmg.com/Ca/en/IssuesAndInsights/ArticlesPublications/PersonalTaxRates/Federal-and-Provincial-Income-Tax-Rates-and-Brackets-and-Surtaxes-9-30.pdf

