

# **Review of Extra Costs Linked to Disability<sup>i</sup>**

## *Research Notes<sup>ii</sup>*

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*The complete research report is available online in French at [www.larepps.uqam.ca](http://www.larepps.uqam.ca)*

*The research notes are available online in French and English at [www.larepps.uqam.ca](http://www.larepps.uqam.ca)*

## Background

For over two decades, organizations of people with disabilities, governments, and researchers have been wondering how to compensate the costs of disability and how much money this would require. In 2009, the Québec government launched the “À part entière” policy, which aims to increase the social participation of people with disabilities. In this regard, this study proposes to identify the additional costs incurred by people with disabilities and their families<sup>1</sup> in overcoming the limitations caused by their impairments, disabilities, and handicap situations<sup>2</sup>. Furthermore, the idea of fair compensation for people with disabilities is increasingly seen as an essential component of any strategy to fight poverty, as successive population surveys reveal, unsurprisingly, that people with disabilities are poorer than other sections of the population (Crawford, 2005 and 2013; PALS, 2006).

At the request of the OPHQ (Office des personnes handicapées du Québec), the LAREPPS (Laboratoire de recherche sur les pratiques et les politiques sociales) conducted an empirical investigation for the purpose of documenting and quantifying disability costs (DC) in Québec in relation to major parameters, such as type of impairment<sup>3</sup> and the person’s degree of disability, socioeconomic status, and region of residence. This study differs from previous work on this issue by its span: it takes into account a variety of situations related to daily life<sup>4</sup> in a variety of households. Indeed, many studies focus on a category of disability, a limited region, a specific age group, or a type of daily life habit (e.g., employment, community life, or transportation). Using a qualitative methodology, this study collected data from 50 participants through focus groups and individual interviews conducted with people with disabilities or parents of children with disabilities, in three distinct urban and rural regions of the province of

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<sup>1</sup> This study conducted interviews with both adults with disabilities and parents of children with disabilities belonging to various age groups.

<sup>2</sup> The issue of additional costs figures among eleven priorities set out by the government through its policy.

<sup>3</sup> Four disability categories were selected: situations of motor impairment; sensory impairment; multiple disabilities; and problems related to mental health, intellectual disabilities, and pervasive developmental disorder (PDD).

<sup>4</sup> The data covers a wide range of situations and sectors of activity, defined by a grid of thirteen life habits developed by the IRDPQ (l’Institut de réadaptation en déficience physique) (Fougeyrollas *et al.*, 1998) and encompassing all types of disabilities listed by the OPHQ. The lifestyle habits selected are the following: nutrition, body condition, personal care, communication, housing, transportation, responsibilities, interpersonal relationships and community life, education, work, and leisure activities.

Québec: Montréal, Montérégie, and Côte-Nord. Over the two-year investigative process, the research team had the support of an advisory committee of researchers and stakeholders in the disability studies field and of a monitoring committee at OPHQ.

## **Defining Disability Costs**

In line with the orientations set out by OPHQ, this study distinguishes two categories of disability costs (DC): *specific* additional costs (SAC), and non-specific or *general* additional costs (GAC). Non-specific disability costs or general additional costs (GAC) refer to expenses that are not compensated by any public programs or services. These costs are vague enough and so difficult to account for that no government programs exist to cover them; yet, such costs are real and, in the long run, create social and economic inequalities between disabled people and other sections of the population. For example, having to pay a more expensive rent for a building with an elevator or located close to shops and services qualifies as a general additional cost: no public program covers that type of expense. In contrast, *specific* additional costs (SAC) refer to extra expenses incurred to offset inadequate allocation or delivery of services within existing programs for the disabled. For example, using one's own money to supplement a grant provided for home adaptation is considered a specific additional cost.

## **Measuring Disability Costs: Research State of the Art**

In the last twenty years, several western countries became interested in the issue of the cost of disability, i.e., the money a disabled person has to pay to be able to enjoy the same standard of living as a person without disabilities (Indecon, 2004). The studies we have consulted on this matter were mainly conducted by economists and government agencies in the Anglo-Saxon world. These studies sought to assess and quantify disability costs by discussing the advantages and limitations of various methodological approaches. The diversity of methods and approaches, as well as a wide range of definitions of additional costs, make it difficult to compare results from one study to another (Tibble, 2005). For example, while some studies measure additional costs for goods and services actually acquired, others are interested in the potential costs related to reported needs. Therefore, due to the diversity of approaches, the level of additional costs measured in these studies

varies considerably. Yet all studies agree on one thing: households in which one or more persons with disabilities live have relatively lower incomes than other households, particularly because they incur additional costs due to disability (Stapleton, Protik, and Stone, 2009). In other words, with the same income, people with disabilities have a lower standard of living than people without disabilities (Zaidi and Burchardt, 2003). Studies generally show that additional costs vary according to the type of disability and its severity. Many other factors also influence costs, including the household size and its total income. Regarding the latter factor, both the actual costs and reported needs identified in these studies increase according to household income, thus revealing the relative nature of a cost estimate. Moreover, studies show that people with disabilities who have insufficient income neglect their everyday needs (Martin and White, 1998; Zaidi and Burchardt, 2003; Tibble, 2005).

In Québec, the issue surrounding compensation for the needs of people with disabilities dates back to the 1980s. Unlike international research efforts, few studies done in Québec have addressed the issue from an econometric point of view. Québec studies have instead focused on political or sociological approaches assessing the conceptual issues and elements of compensation for disability costs. Three major reports have fueled discussions: the report of Groupe DBSF conducted for the COPHAN (Confédération des organismes de personnes handicapées) in 1991–1992; the report conducted by Fougeryrollas and his team in 1999; and the report of Blais, Gardner, and Lareau in 2004. In addition, two large-scale studies—the EQLA (Québec’s survey on activity limitations) in 1998, and the PALS (Participation and Activity Limitation Survey) in 2006—have examined the actual costs incurred by people with disabilities, particularly regarding health care and social services, medication, technical aids, and transportation (Camirand, Aubin, Audet, *et al.*, 2001; Camirand, Dugas, Cardin, *et al.* 2010). None of these studies, however, distinguished between general (GAC) and specific (SAC) additional costs.

## **A Subjective Approach**

In light of the strengths and weaknesses of the different approaches available for calculating additional costs (Tibble, 2005) and of the resources at our disposal, our

research team chose to use a subjective approach, through interviews. We carried out a relatively high number of interviews with people with disabilities, asking them to identify and estimate the additional costs they incur (actual and potential) compared to non-disabled people. At the expense of statistical representativeness, we made a selection of cases to maximize the diversity of situations so as to learn about the needs—fulfilled or unfulfilled—and the budgetary strategies of a diversified sample of people with disabilities or their families.

### **Two Categories of Disability Costs Intertwined in Real Life Experience**

Despite this exploratory study's initial objective of strictly focusing on general additional costs (GAC), it quickly became clear that a rigorous analysis was required to determine, concurrently, the specific additional costs involved. It appears that these two categories are closely related when the experience of people with disabilities is scrutinized; respondents are struggling to address specific (SAC) and general (GAC) additional costs separately. It is therefore in the interest of methodological integrity that both categories of findings are discussed in the present study.

## Findings

This study's main objective is to identify what additional costs arise according to both lifestyle habits and types of disability, these two variables being at the heart of the analytical framework. As a second objective, the study attempts to determine if other factors—such as the socioeconomic status of the individuals, household, place of residence, age, or household composition—influence the variety, recurrence, and prevalence of a given additional expense, and whether it can qualify as a specific or a general disability cost. Finally, our study proposes a new typology<sup>5</sup> of general additional costs based on the characteristics of such costs rather than lifestyle habits or categories of needs.

### **Disability Costs and Types of Disability: What Kind of Relationship?**

According to study data, housing, health care, and transportation are areas of life habits that qualify most often as situations of additional costs. These areas encompass costs that are both specific and general and are reported by our respondents in varied and recurrent ways. Additional costs are not as present in the areas of work, education, communication, nutrition, leisure, and social/family responsibilities. This can be explained in part by the fact that housing and health care, for example, involve needs deemed essential by people with disabilities and parents of children with disabilities, and also because they reflect everyday needs recurring at every stage of one's life.

Not unexpectedly, this study shows that the variety and recurrence of additional costs, both general and specific, are linked to the type of disability and special needs related thereto. Thus, people with motor disabilities frequently incur specific (SAC) and general additional costs (GAC) related to lifestyle habits, such as transportation, body condition, health care, and housing. On the other hand, people with sensory disabilities incur more additional costs (SAC and GAC) in terms of communication, work integration, leisure, and housing. Other features identified among people with intellectual disabilities,

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<sup>5</sup> For example, lost opportunities, rewards for caregivers, incidents, expenses that are not compensated by public programs, extra expenses incurred because of public service limitations, and default billing of a standard service.

pervasive developmental disorder (PDD), and mental health problems should be distinguished herein. For people with an intellectual disability or PDD, the additional costs mainly concern support for personal care, nutrition, and housing. However, for people living with a mental health problem, additional costs reported are few, and mainly relate to nutrition and civic responsibilities. As for people struggling with multiple disabilities, our study shows their costs to be associated mainly with personal care, housing, transportation, and nutrition.

### **What Else to Say about Specific Additional Costs (SAC)**

Specific additional costs are often incurred to cover shortfalls or lack of access to homecare services that are supposed to be delivered through social programs. Situations of people having to pay full price to hire domestic help provided by a social economy enterprise are typical, as are situations in which people hire staff “under the table” or pay parents and relatives. As for housing, the same “informal rule” applies, as extra amounts are committed for heavier work and dwelling repairs by many respondents in our study. Additional amounts that are spent on materials and labour that supplement home adaptation programs are also frequently mentioned. For transportation, people with disabilities often incur additional costs for both short and long trips. Many respondents highlight the involvement of families and the use of taxis for medical appointments or regular trips. In this regard, the inadequacy of paratransit is often pointed out, as some people report having waited up to three hours to be served. This situation poses particular problems for people with disabilities who work outside their home. The cases of Paul<sup>6</sup>, 29, and Irene, 32, who need more time at night and in the morning to travel to and from work are examples. Furthermore, the current organization of paratransit forces people with disabilities to plan everything in advance. Irene, who uses a wheelchair, told us, “People have to plan 48 hours in advance, and how long their appointments will be.” Thus, unpredictable situations quickly become problematic for people with disabilities. Lastly, when health conditions require medical or rehabilitative treatments, people and their families often have to make up for limited amounts of money provided by public programs.

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<sup>6</sup> These are fictitious names, also used in the research report.



## **What Else to Say about General Additional Costs (GAC)**

According to our study, the most recurrent general additional costs are related to housing, physical condition, and health care. We found very common cases where people incur additional rental costs because they need to live in apartments located near shops and services or in apartment buildings providing adaptations. Regarding their health, many respondents declared that they had to pay extra fees for over-the-counter (OTC) drugs or for the use of essential paramedical care and services. In spite of a province providing public insurance for prescription drugs, fees for OTC drugs can add up significantly each month. Cindy's case is an example: visually impaired, she receives Social Solidarity benefits every month, but has to pay herself for certain drugs that are not covered. She takes sedatives and anti-inflammatory tablets for her migraines that cost about \$45 a month.

## **The Value of Additional Costs**

Although this study did not seek to quantify the value of general additional costs, the data collected, however, allows for a rough estimate of the costs reported for a one-year period by our respondents and their families. The documented cases show that GACs can total up to \$7,000 annually for one family, while some other families and adults reported no GACs at all. The median value we calculated for our sample would be about \$750 a year. Please note that these costs do not include lost wages or loss of opportunities if we stand by our definition, although both elements were most likely to create additional costs according to the people we interviewed. This methodological caveat of the approach should be pointed out.

## **Additional Costs Related to Lost Wages**

This study retained some loss of income among the general additional costs, although it does not technically fall under "expenses" per se. For instance, the study considers the reduction of weekly working hours or job abandonment as a real cost, whether they result from choice or coercion, and whether they concern a caregiver or person with disabilities. Lost wages are among the most important general additional costs reported in this study,

and, for one family in our sample, they can reach tens of thousands of dollars annually. They become significant especially in the case of parents who act as caregivers to their children or spouses. Oscar's parents certainly know about that. They both gave up their jobs for a long time because their son was hospitalized. Today, Oscar's father is in a career shift, and his mother takes care of Oscar full-time.

### **Influence of Socio-Economic and Socio-Demographic Factors**

The study data confirms what the literature on the issue of additional costs already evoked: the socio-economic status of individuals or household income remains the key determinant of the prevalence and level (low, medium, or high) of additional costs. Our data on prevalence confirms this trend for specific and general additional costs.

On another matter, household composition is a factor the literature suggested exploring. The inclusion of families with children with disabilities in our sampling strategy is actually reflected in the study results. Indeed, parents of children with disabilities seem to incur significant additional costs. The type of disability seems to play a less important role than family income when considering the variety and prevalence of additional costs. Thus, the higher the household's income, the more its expenses diversify across life habits and the higher are its additional costs, as discussed above. Finally, the region—a variable included in the sampling of the research project—seems to have little impact according to the data collected.

As for the severity of the disability, which was identified in the literature as a factor associated with high costs, the study data makes it difficult to form a judgment. This finding may be explained theoretically and methodologically by two considerations: the purpose of this study is not to measure cost level, but to identify the variety and forms of general additional costs. Moreover, the wide diversity of needs covered by programs in Québec (whether repaid in part or in full) would balance out situations more in accordance with families' socioeconomic status than severity of the disability.

### **Additional Costs Vary According to Social Class**

This study shows that people with the lowest income, living alone, and not benefitting much from family resources, are those who are least likely to incur specific or general additional costs. Conversely, those who incur the most expenses, whether specific or general, themselves have comfortable incomes or receive financial support from their families. The poorer a person is, the less he or she incurs additional costs, a trend already observed in studies on the costs related to disabilities (Martin and White, 1998; Tibble, 2005). If this situation seems paradoxical, it still is logical: the concept of additional costs *de facto* implies some financial leverage that is not available to people living in poverty.

When one looks more closely at the analysis of respondents who reported the fewest specific and general additional costs, one finds out that they are mostly those with mental health problems. They appear as having more obstacles limiting their social participation. For instance, despite their abilities, Luc, Sylvain, and Marc, three participants in this study, are on welfare and live in a state of great poverty. Their everyday needs are met not without difficulties, while their family networks are unlikely to help them financially. More than that, many of their more important specific needs, such as social and professional integration, remain unmet. Consequently, other needs, such as socialization and participation, are ignored for lack of sufficient income. In this regard, the case of Luc is obvious. In his 50s and diagnosed with a serious mental health problem, his condition has now stabilized, and he attempted to return to employment a few years ago. However, his employer had not, in his opinion, respected the employment conditions negotiated with the employment integration service: “The employer took the grant, but I was left to myself, without guidance, onboarding, or adaptations. I lost my health because of this and since that time, I have a very modest living... and have to make do with that.” Luc lives alone in a modest room in town, has no computer, sacrifices a lot with regard to leisure activities, and says he “lives like a hermit.”

Our data thus validates one of the results of the recent study of the Disability Resource Centre Auckland (2010), which highlighted the high costs incurred by people with mental health problems. This lead merits further investigation in future research.

## **Budgetary Strategies Related to Additional Costs**

Few are the people with disabilities and their families who do not feel the additional economic burden related to their disability situations. Only five out of the 33 participants met individually declared that their additional costs are easy to absorb or that these costs have little or no effect on their standard of living. By contrast, for most cases in the study, people choose budgetary strategies that require cutting expenses while incurring some additional costs to meet the specific needs they deem essential. Mylène's situation is a good example. In her 40s, she is blind and suffers from a chronic disease. Mylène had to decrease her work hours because of fatigue, but was soon forced to take a second job, from home, to make ends meet. With revenues of less than \$30,000 a year, she explained that her house maintenance and some repairs are neglected. She also cut her Meals on Wheels services.

Our study revealed several cases that are illustrative of what Fougeyrollas (1991) calls the impoverishment resulting from the Disability Creation Process, or, in other words, that for the same income, people with disabilities have a lower standard of living compared to the rest of the population (Tibble, 2005: 27; Zaidi and Burchardt, 2003; Stapelton, Protik, and Stone, 2009).

## **Contribution of Families**

Furthermore, the study shows the importance of the families' financial contributions. The additional costs incurred by parents are often among the highest. Parents of minor children appear to be the most directly affected by the loss of income and professional opportunities. Losses sometimes amount to thousands of dollars when one parent, often the mother, temporarily or permanently leaves the labour market. This is the case of Oscar's mother, who, following the hospitalization of her 12-year-old son, had to leave her job in order to provide appropriate care for her child. Other parents reduce work hours or take several unpaid days off a year to accompany their child to medical appointments, school, or a rehabilitation centre. The mother of three-year-old Adèle explains how she has to sacrifice a half-day's pay each week to accompany her daughter

to her speech therapist. “Sometimes you can get those hours back in the evening, but most of the time, this time remains unpaid.”

This study shows that family responsibilities take other forms when it comes to “children” who are now adults, but whose need for support continues beyond the normal stages of the development of autonomy. This is the case for Cindy, 29, who suffers from a degenerative disease. Sharing a modest house with her father, she said that her parents have taken on “more than their share” so that she can have some autonomy. Indeed, until recently, Cindy’s parents paid all costs related to her subsistence and tuition so she could finish her college education. It should be noted that the involvement of many parents continues well beyond the home: parents help their children financially even if they no longer live with them in the same household.

## Place of Residence and Types of Disability

The study looked at the region of residence of people with disabilities to verify if the distance of specialized services and resources can generate more additional costs. The analysis first shows that the “region effect” is low and varies according to the nature of special needs (which are related to the type of disability). Thus, some people are not much affected by the fact that they live far from urban centres, because they are unlikely to use specialized services and they have access to the services they need fairly close to home. For respondents for whom the place of residence has an impact, the effects of being far from Québec or Montréal translate more in terms of missed opportunities (due to accessibility constraints) than actual additional costs. This implies that people are less likely to use rehabilitation activities and leisure services or have opportunities to socialize because of the travel distance to service points or shops.

## Towards a New Typology

This study helped us develop a new typology of general additional costs not based on lifestyle or categories of needs, but on cost characteristics. Six categories were extracted from our findings and may be used as tools to sketch a new portrait of additional costs.

	<b>Main Types of General Additional Costs (GAC)</b>
<b>1</b>	<b>Loss of income and lost opportunities related to consumption</b>
<b>2</b>	<b>Donations, tips, and rewards</b>
<b>3</b>	<b>Incidents</b>
<b>4</b>	<b>Unrecognized special needs</b>
<b>5</b>	<b>Additional expenses or expenses related to services</b>
<b>6</b>	<b>“By default” billing without access to a standard service</b>

The first category refers to loss of income and loss of opportunities related to consumption. For example, it refers to the narrowing of options, variety of choices, and

buying opportunities due to a disability. Another category includes general additional costs, such as donations, tips, and rewards that people with disabilities are paying to different people as compensation for services rendered. This is the case for Ginette, 40, who is not eligible for domestic help because it was considered that her roommate and family can satisfy her needs. She compensates their support by giving them gifts.

A third category comprises the cost of losses, breakage, or other incidents related to a disability situation. A fourth category lists the costs associated with unrecognized special needs, such as money paid by a participant to attend a promising research protocol about his or her disability. Additional expenses or costs related marginally to actual services, such as costs of renting accommodations located on the first floor, or the use of a more expensive grocery store offering delivery service, constitute a fifth category. Finally, the category “By default billing without access to a standard service” reflects situations like the one of a deaf participant who has to pay additional fees for a plan that includes voice messages he cannot hear.

Upon examination, this categorization enables us to recognize and describe a series of situations resulting in general additional costs that had not been identified or addressed in previous work on this issue. Now that the veil has been lifted, investigative work remains to be done.

### **In Spite of Numerous Public Programs, a Broad Range of Inequalities**

In this study, a wide variety of specific additional costs have been identified, even though our main task, at the origin, was to paint a portrait of general additional costs. Although the line between the two categories is thin, the recurring issue of specific additional costs suggests that even though compensation programs are extensively deployed in the province of Québec, the “disabilities regime of compensation” still meets some difficulties and fails to significantly reduce social and economic inequalities between people with disabilities and people without disabilities. Although there are more than 200

programs covering special needs in Québec, they appear to have insufficient resources to meet the needs of people with disabilities.

Therefore, our findings lead us to stress the existence of very extensive specific additional costs (SAC), along with a set of general additional cost (GAC) subcategories. Indeed, our approach allows us to believe that many programs offer insufficient resources to eligible people. The mismatch between people's needs and the public resources at their disposal is partly due to the fact that some programs are regionalized and thus implemented differently depending on location, and that the programs operate according to lists with excessive waiting times. In addition, the mediocrity of some services drives programs recipients to use alternative services, resulting in additional costs that this research had to take into account.

It should be noted that, due to a lack of knowledge about the available programs, people incur many specific additional costs that they could have been spared otherwise: the number of programs and complexity of the public social services network might explain this reality. As several respondents testified, mastering "access to services is a full-time job."

It was generally easier to sub-categorize the general additional costs (GAC) than specific ones (SAC). However, some cases of general additional costs put forward the issue of recognizing or not the special needs that a program should provide, as much expenditure for services with effects deemed beneficial by people themselves or their families were not recognized through actual programs.



## **Listing the Incalculable**

During the interviews conducted for this study, it was often difficult for participants to address the issue of additional fees without evoking certain non-monetary costs, such as loss of amenities and missed opportunities. Thus, a number of respondents, especially parents, spoke of sacrifices, big and small; complex grieving to do; moral costs; anxiety; loss; and sadness. Non-monetary costs that this study classifies as GAC can result in lost opportunities such as total withdrawal from the labour market for people or their parents. Although unavoidable, non-monetary costs remain extremely difficult to identify and calculate.

## **A Final Word: Gaps among People with Disabilities**

The issue of additional costs highlights a gap between wealthy and poor people with disabilities. Although we have not favoured a quantitative method, our data suggests a quasi-proportional link between the variety and level of actual additional costs and the income of individuals and households. Thus, the poorest households (for equivalent needs or for the same category of disability) report less specific and general additional costs, but also more deprivation.

The study of additional costs emphasises how much special needs vary; needs depend on the social and family environment and can illustrate withdrawal, resourcefulness, or a fighting spirit. If it is legitimate to assume that expenditures reflect our values and family environment, this logic does not apply to poor people with disabilities. Additional expenses are in their case transformed into a larger number of obstacles to their social participation, rather than a set of subjective choices between various opportunities.

This study helps identify situations in which the existence of additional costs is more than a hindrance to the emancipation of disabled people; disability costs cause significant negative impacts on the social and professional integration of individuals. In a context of fiscal austerity in which not only the services to the most vulnerable citizens are threatened but also the allowances to the middle classes, recognition of general and

specific additional costs by the government would be a strong symbol: a concrete lever for social participation of people with disabilities and, at the same time, an acknowledgement of their right to self-determination.

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<sup>i</sup> Translation of the French document "Identification des coûts supplémentaires généraux liés aux déficiences, incapacités et situations de handicap assumés par les personnes handicapées et leur famille".

<sup>ii</sup> Quotations have been translated from French.