The Many Faces of Caregiving: The Reality of Caregiver Parents in Gaspésie-Îles-de-la-Madeleine

Comité-conseil
santé des femmes
GASPÉSIE • ÎLES-DE-LA-MADELEINE

Table of Contents

Acknowledgements

The contributions of a number of people were essential to the completion of this report. First and foremost, we would like to acknowledge the contribution of the Associations de personnes handicapées de l'Estran, de Gaspé et des Îles-de-la-Madeleine, as well as Entraide Sein-pathique, in organizing the group discussions. Your mobilization was essential and invaluable to this project. We would also like to thank all our partners who helped distribute the questionnaire.

Many thanks to all those who took part in the group discussions and answered the questionnaire. The themes addressed could have required you to revisit more difficult moments, and to delve into the heart of very real challenges experienced at close quarters. You were very generous in sharing your experiences.

Explanatory note

The inclusive writing format in this tool varies between feminization when talking about caregivers and inclusive writing. The aim is both to give visibility to the women who make up the majority of caregivers (58%)[1] and to include the men who took part in the process.

Translation provided by Vision Gaspé-Percé Now with funding from Health Canada.

Introduction

Caregiving is a topic that is increasingly coming to the fore in Quebec. In 2023, the Quebec government passed a law to recognize and support caregivers [2] and, in 2021, it is proposing its first government action plan for caregivers (2021-2026) [3]. However, in the collective imagination, when we think of family caregivers, we often think of seniors, without seeing the diversity of people who may be concerned by this caregiver role. In the Gaspésie-Îles-de-la-Madeleine region, we have identified a group of caregivers about whom we still have too little information: parents with one or more children living with a temporary or permanent limitation (intellectual disability, autism spectrum disorder, Down's syndrome, physical handicap, etc.). This group of caregivers remains relatively unknown. The parent-child bond and parental responsibilities frequently screen out the underlying role of caregiver. It is therefore relevant to look at their specific reality as caregivers in our regional context.

The family caregivers who took part in this survey define family caregiving as sharing their daily lives by offering their presence and availability to the person being cared for. For these parents, the role of caregiver is to make the person's life more beautiful and enjoyable, helping them to flourish and gain autonomy despite the limitations they experience. In the case of parent caregivers, there seems to be a difficulty in perceiving themselves as such since, as mentioned above, their role and tasks are intrinsically linked to their role as parents, which seems to come naturally. They see themselves first and foremost as parents. However, they agree that the dependence of the child living with limitations on his or her parent is greater and requires a special response. The parents realize that the level of dependence that is perpetuated over time creates a caregiver relationship that is different from the parent-child relationship. This distinction is less marked in the child's early years.

Despite the fact that the majority of caregivers are women (58% are women and 42% men), we decided to solicit the participation of parents, both mothers and fathers, who are also caregivers [4]. Through this exercise, we wanted to understand how caregiving unfolds according to gender. In a recent analysis, the Conseil du statut de la femme pointed out that “[...] women's and men's involvement in caregiving is distinct, which contributes to the maintenance of gender inequalities [5]. A number of analyses and observations will therefore be raised throughout this document on how the gendered experience of caregiving is reflected in our region.

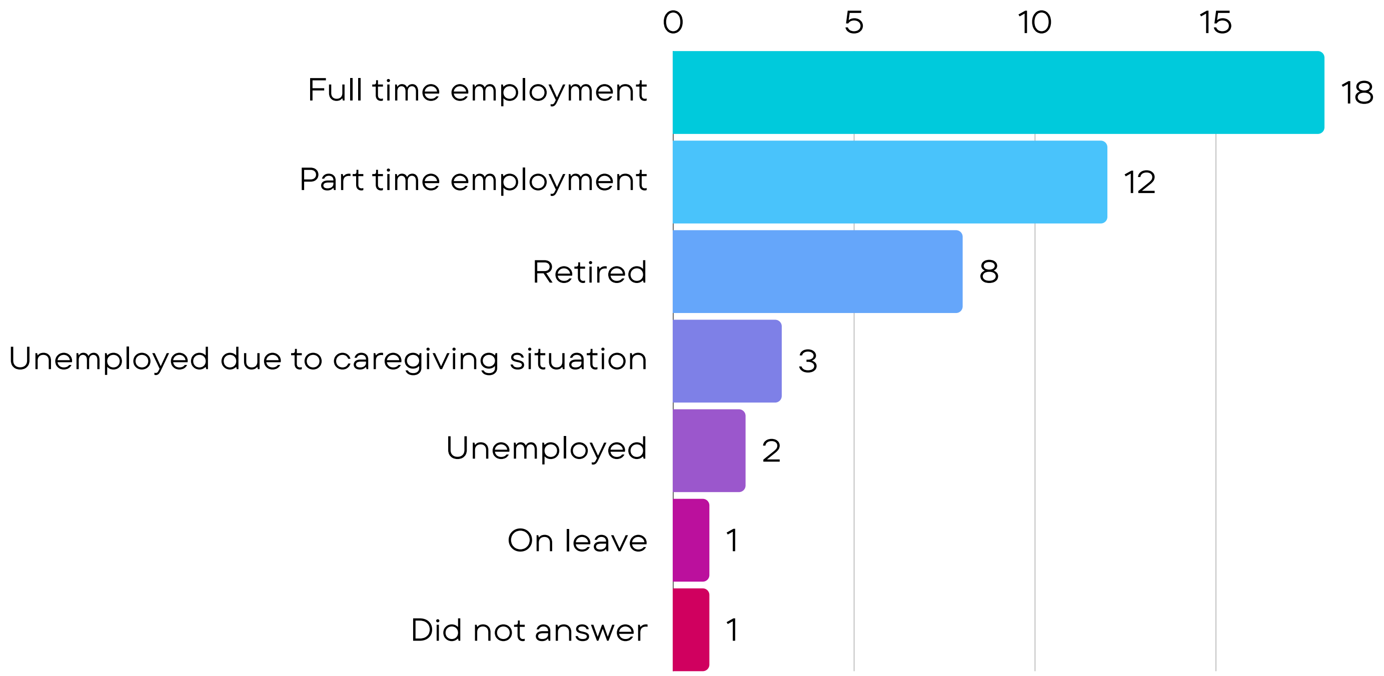
Methodology

The project was carried out in two main stages. Firstly, in collaboration with the partners, we organized **4 semi-structured group discussions** in which a total of 26 people took part. Then, **a questionnaire in French and English with a total of 27 questions** was sent to the partners and posted on our social networks. In all, 17 people responded to the French questionnaire and 2 to the English one. **A total of 45 caregivers took part** in the overall data collection.

Socio-demographic Context

Of the 45 participants, 38 were women and 7 men, aged between 30 and 88, and living in Gaspésie or the Magdalen Islands. Participants have been caregivers for an average of 17 years (2 years minimum, and up to 43 years for some).

Participants' occupation



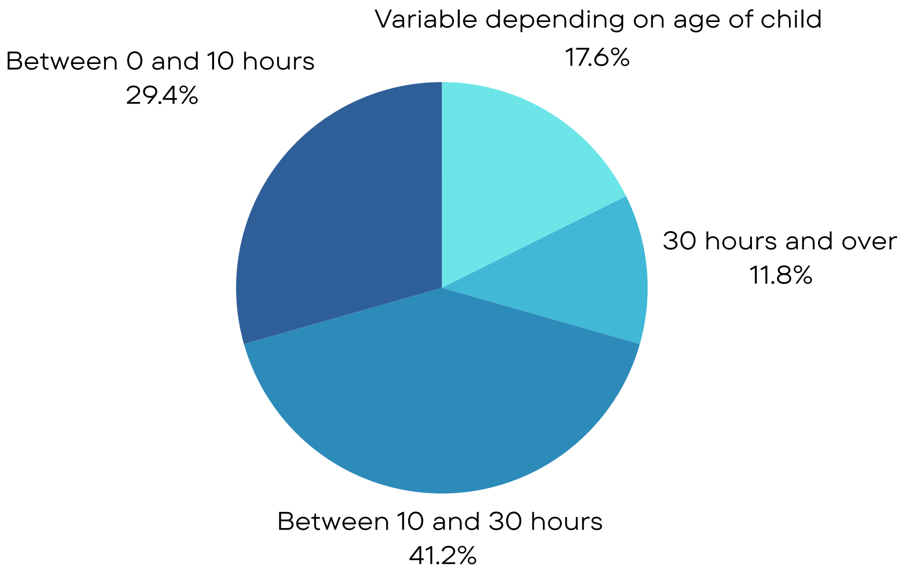
1. Role and tasks

A review of the literature carried out in 2020 revealed that the main responsibility for child stimulation and care rests on the shoulders of mothers. However, in the interests of fairness and to avoid overloading and eventually exhausting mothers who are close caregivers, the authors stress that greater involvement of fathers is essential [6].

We asked all the participants whether they shared the role of caregiver with the other parent or another person. Of these, 16 said they shared the role with the other parent, 5 with a spouse who was not the child's parent, 15 said they did not share the role with the other parent, and were therefore the main caregiver, and 6 said they shared the role with the other parent but were still the main caregiver. Of all participants, 3 did not answer this question.

- **Number of hours devoted to tasks**

The number of hours devoted to caregiving is difficult to calculate for the majority of those questioned, for several reasons: there are many such hours, and they blend in with other everyday tasks, and are also naturalized as part of parenthood.



The variability in the number of hours devoted to caregiving seems to be partly explained by the age of the child. This finding emerged in the group discussions as well as in the questionnaire. One respondent explained: “[...] as my child gets older, he learns to better develop his personal mechanisms for dealing with tantrums, for example. So I spend less time on it now than I used to.” The number of hours spent on caregiving tasks therefore depends on the child's degree of autonomy. Some children become more independent as they get older, while others will always be dependent on their caregiver.

- **Type of support**

Because of the diversity of tasks they have to perform, family caregivers develop great versatility over time. They become experts on their child's condition, nurses, psychologists, experts in clerical work and advocacy.

The type of support that all respondents to the questionnaire were unanimous about was emotional support, including listening, comforting, talking about emotions and so on. The next most common tasks performed by family caregivers are medical care, physical care and administrative management. In addition, many other tasks are performed by family caregivers, such as help with eating, household chores, cognitive support, hygiene care and maintenance.

  - **Emotional support**

Emotional support is central to the role of caregiver. Some mothers report that they are primarily responsible for emotional support, such as crisis management and reassurance, as their spouse feels unprepared in such situations. This inequitable assumption of responsibility for emotional support between mothers and fathers can be explained in part by the fathers' lack of exposure to crisis situations, particularly as they may be less involved in the child's daily life. What's more, the model of traditional masculinity places men in the role of provider, meeting the material needs of their families. This masculine model, however, leaves out everything to do with expressing and managing emotions, and everything to do with caregiving. As a result, fathers “[...] can quickly feel overwhelmed by caregiving contexts that offer few quick and effective solutions, and that may require them to learn new roles: listening, emotional support, taking full responsibility for domestic tasks, organization, and much more.”7 Learning to express and manage emotions starts in early childhood and, because of gender stereotypes, little boys learn very early that they shouldn't show their emotions, which is considered more feminine. If we encouraged boys from an early age to develop their emotional skills, adult men would feel less overwhelmed when faced with contexts that require listening, comforting and empathy, such as those experienced in caregiving situations.

  - **Administrative management**

Caregivers identify administrative management as a particularly onerous task. Administrative management includes managing bank accounts, financial aid applications, medical forms, multiple care plans, making appointments, tax credits, etc. Not only does this management add to the multiple domestic and daily care tasks, it also requires a certain level of literacy and access to the right information at the right time. Caregivers report that they often feel overwhelmed by bureaucracy and paperwork. What's more, information is not always easy to find, and the caregivers who can provide it are not always in a position to make the right referrals. What's more, when a child turns 18, additional legal steps have to be taken to ensure that parents can continue to act on their child's behalf, for example, to obtain a power of attorney, produce a will, and so on. Parents feel particularly overwhelmed by the complexity of these steps, most of which are also at their own expense. Many say they need legal expertise to help them through these steps. However, few lawyers have experience in situations where consent cannot be given in the usual way, such as with people living with an intellectual disability.

  - **Child’s autonomy**

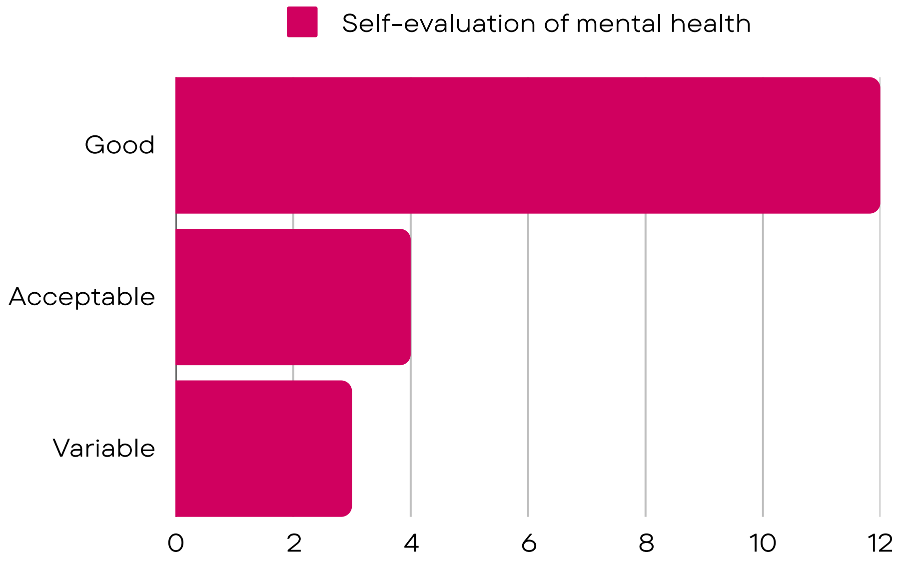
Many parents want to accompany their children to increase their autonomy, but taking the initiative requires a lot more time and supervision. What's more, autonomy often has its limits, i.e. the child can accomplish certain things on their own, such as many hygiene routines, but the parent has to make sure they are carried out properly. Increased autonomy therefore requires supervision and increases the mental load on primary caregivers. Despite this, many parents attach great importance to accompanying their child in this process.

2. Impacts of caregiving on parent caregivers

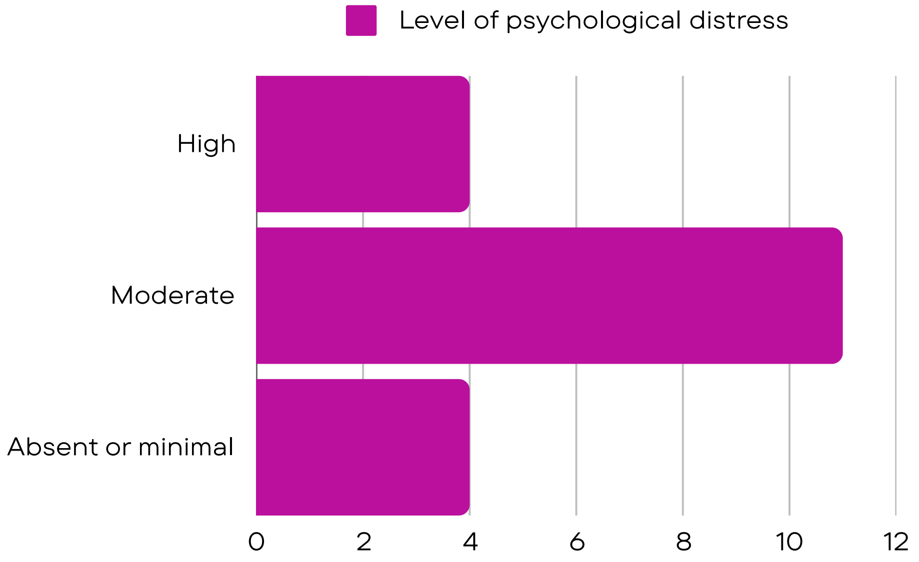
Caregiving has many impacts on parents caring for a child with limitations. We found that these impacts are multiple and take different forms. One respondent summed it up this way: “No time for myself, no time for my couple and no time for socializing, everything has to be organized, planned according to the availability of my other son to help us and give some time, but being a single father himself with full custody of his son, it's very complicated and difficult”.

- **Mental Health**

Through the questionnaire, we used two methods to assess the mental health status of family caregivers. First, we asked respondents to self-assess their mental health.



Secondly, we asked questions about the level of psychological distress experienced by family caregivers. To this end, we used the 6-item Kessler scale (K6) as a tool for measuring non-specific psychological distress, based on questions about symptoms of depression and anxiety experienced over the past 30 days [8].



79% of respondents expressed moderate to severe psychological distress, i.e. moderate to severe symptoms of depression or anxiety disorders. However, these worrying results are at odds with the answers obtained to the first question, where 63% of respondents rated their mental health as “good”. We therefore note that, when asked more specific questions, respondents revealed more serious symptoms of depression and anxiety than they indicated in their self-assessment. What's more, 58% of respondents said they needed psychosocial support.

This finding is also consistent with what we heard in the focus groups. A number of people mentioned that, overall, they were in good mental health, but when they spoke in more detail about their day-to-day reality and the stress of their caregiving role, they revealed significant effects on their mental health, such as insomnia, stress, chronic fatigue, feelings of hopelessness and so on. It seems that for many caregivers, the stress and anxiety they experience are such an integral part of their daily lives, that these states are normalized, so that parents no longer interpret them as elements that have an impact on their mental health.

> **When I stop, I cry.**

The effects mentioned by caregivers on their mental health are mainly depression, panic attacks, weight loss, loss of sleep and fatigue. Many say they feel they have no right to give up, because if they do, no one else will take over. The pressure for these caregivers is heavy on their shoulders. They also feel they don't have much leeway to do things that are good for them, because there are intervention plans to respect, recommendations to follow, routines to maintain, and so on.

> **Sometimes, I'd run away.**

But it is possible to be a caregiver and have good mental health. As one participant in a focus group explained: “My mental health is good because I've taken care of it”. She notes that it's giving oneself the opportunity to take care of one's mental health that really helps to preserve and maintain it. However, taking action to preserve one's mental health and take care of oneself is not accessible to everyone.

In fact, socio-economic status, including income, employment and the possibility of receiving help from family and friends, plays a central role in the ability of caregivers to preserve their mental health. For example, having a good household income enables some caregivers to work less, take a break, hire home help or get respite to avoid overwork and exhaustion. As this participant testifies: “If I hadn't had the opportunity to take off work, to have all that space to myself, to have the money to hire help, I don't know how I'd have managed at all.” Indeed, one way to lighten the daily burden of caregiving and act preventively is to have access to respite and home help. However, respite resources in the region are very limited and often far from where caregivers live. In the Magdalen Islands, for example, caregivers have to travel outside the archipelago to access these resources for a few days, which represents a significant expense and complex logistics. Without these resources nearby, access to respite time to care for one's mental health is complex. Some people are lucky enough to have family members ready to lend a hand. However, not all caregivers receive help from their loved ones. Sometimes, family and friends are not equipped to care for a child with a disability or intellectual impairment. Depending on the child's limitations, it can involve challenges that only professional help can meet. Consequently, in the absence of free, easily accessible public resources with a sufficient range of services, the use of paid professional help becomes for many the only feasible option for accessing respite or relief from daily tasks. A solution that only households with substantial incomes can afford. Considering that in Gaspésie-Îles-de-la-Madeleine more than half of single people do not reach a sustainable income in all localities, for a single parent caregiver, taking care of their mental health can quickly become a luxury they simply cannot afford [9].

> **I hate to go there, to be forced to have a break I'd have to go into psychiatry for a week or two...**

Although financial assistance is available for respite and home help, most caregivers said it was insufficient. What's more, to qualify, they have to undergo a mental health assessment which, depending on the outcome, will determine the amount they are entitled to. The worse the state of their mental health, the greater their chances of accessing the maximum amounts available. As a result, if at the time of their assessment, their mental health is fair or they are mitigating what they are actually experiencing, this has an impact on the amount of money they will be allocated. Participants report having to amplify their mental health status in order to access the funds they need to *prevent* burnout. One participant explains how this translates: “You realize over time that it's only when you're really at such a desperate point, at the end of your rope, at the end of all solutions, that there's something out there, someone out there who might be able to help.” What's more, the mental health of caregivers fluctuates greatly depending on how the child is feeling. It can change from day to day or week to week. However, they complain that to adapt to the CISSS form they have to report their mental health for the whole year ahead. This approach makes it impossible to take preventive action with caregivers and fails to take into account the changing nature of mental health.

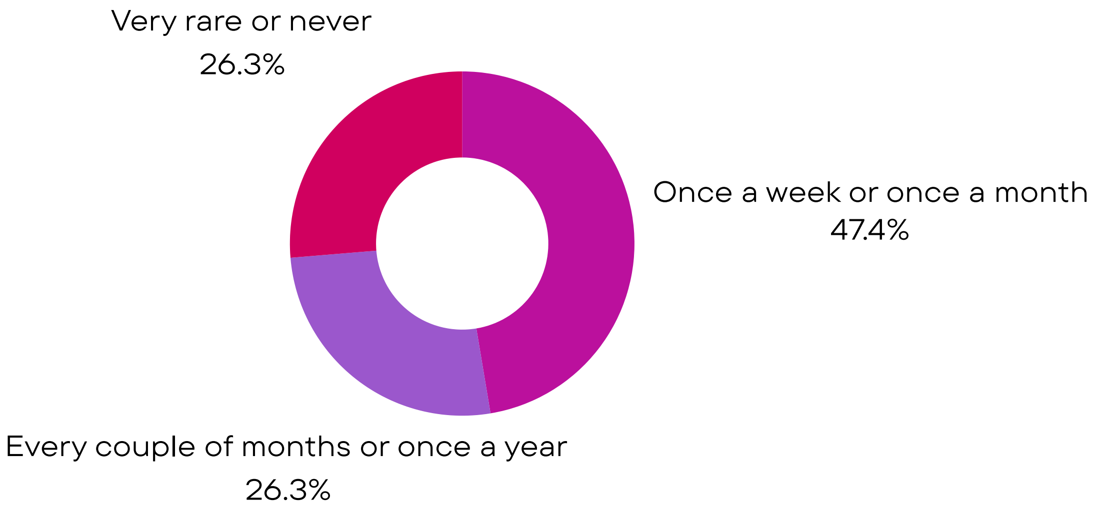
- **Life as a couple**

Focus group participants spoke of the difficulty of not forgetting the couple in a caregiving context. However, the impact on the couple's life did not seem to arouse as much interest in discussion as other subjects that seemed more urgent, more poignant.

Nevertheless, a number of studies have shown that the unequal distribution of caregiving tasks between mothers and fathers can create tensions within couples, and that many couples in caregiving situations have difficulty finding time to see each other. This finding resonates with some of the testimonials heard during the group discussions.

In the questionnaire and focus groups, participants mentioned on several occasions that separation was one of the impacts that caregiving had had on their family life.

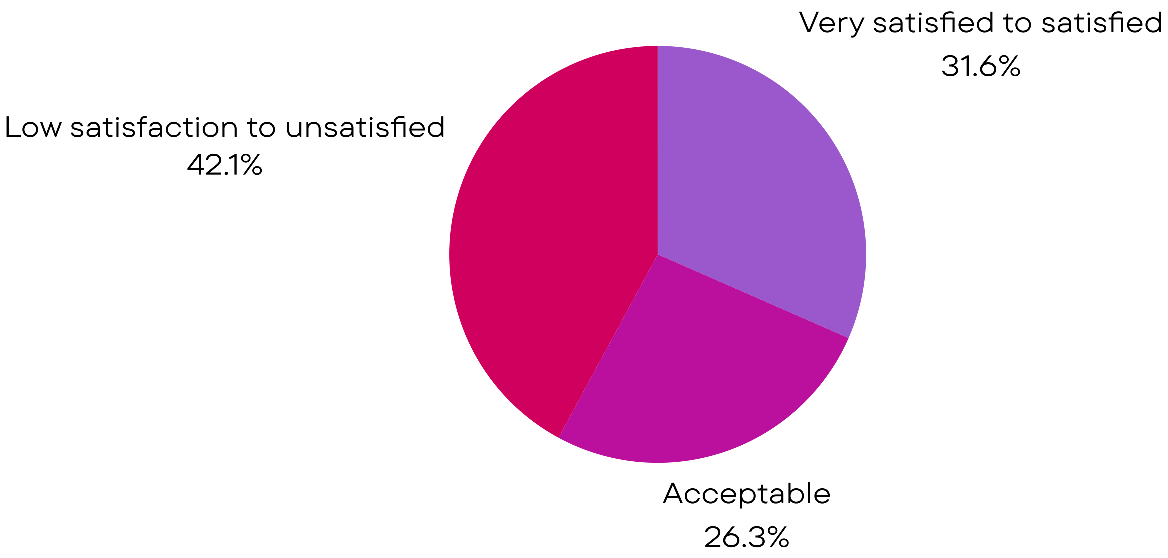
How often do caregiver manage to find time for themselves as a couple ?



- **Social life**

Parenthood already presents a challenge to maintaining a satisfying social life for those who experience it. For parents in caregiving situations, the challenge can be even greater.

Qualification of caregivers' social life



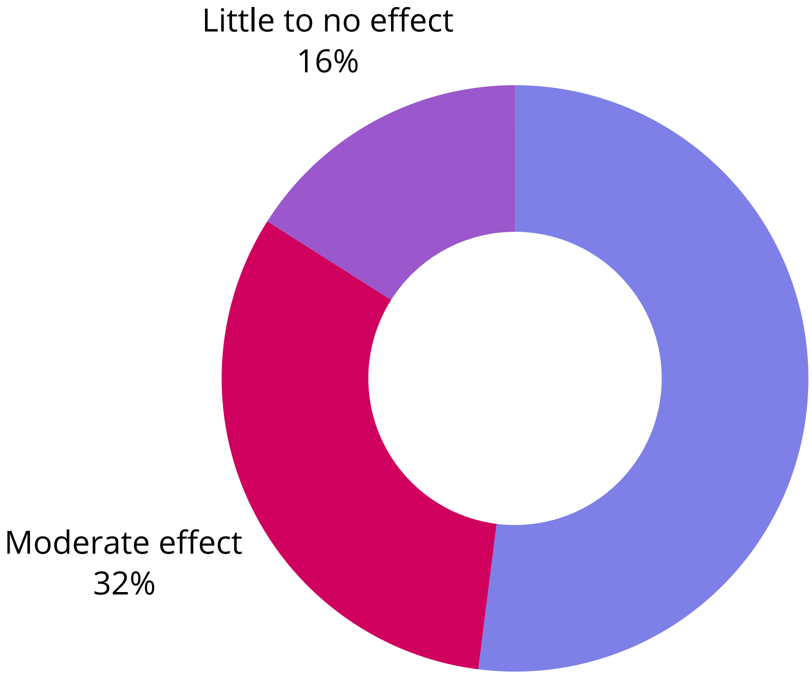
On the whole, parent caregivers report experiencing isolation and loneliness as a result of their role. Among other things, they may prevent themselves from going out or participating in social activities, since outings are in many cases more complicated to manage with their child. The lack of babysitting options also adds a further challenge. Some children are more difficult to care for and require more specialized intervention skills and abilities. On the other hand, some disabilities create behaviors that are difficult for friends and family to understand. The way these behaviors are viewed, misunderstood and judged by others can be socially difficult. As a result, parents can quickly find themselves cut off from their social life, and their support network can crumble.

One participant from the Îles-de-la-Madeleine said she needed to socialize with other moms who are caregivers and who are living a similar reality. However, in the Magdalen Islands territory, there are few support groups. In this case, social networks are an invaluable tool for breaking down isolation and finding a network of mutual support, exchange and information sharing.

- **Financial situation**

We find that the role of caregiver has a considerable impact on the financial situation of those concerned. More specifically, women are more likely to experience financial precariousness, since they reduce their hours of paid work to a greater extent or leave their jobs more than men [10]. In addition to the fact that women still earn less overall than their male counterparts, the impact that caregiving has on the careers of mothers puts them at greater risk of impoverishment [11].

Pressure exerted by caregiving on the financial situation of questionnaire respondents



Of the 10 people who answered that the pressure on their financial situation is “very important” or “important”, 7 work only part-time or are unemployed, mainly because of their role as caregiver, and the majority are primary caregivers. What's more, of the focus group participants and questionnaire respondents who were in the working population (of working age), 54% were either employed part-time or unemployed.

The financial pressure is therefore considerable for the majority of respondents, not only because of the caregiving role, but also because it often limits their ability to work full-time or at all.

- **Professional life**

For many people, the time-consuming tasks involved in providing care on a day-to-day basis make it impossible to hold a full-time work. If both parents work full-time, family organization suffers: household chores are not done, there's less time to spend with the children, and so on. Absenteeism from work is becoming a constant feature in the employment reality of the vast majority of people taking part in this survey. Indeed, respondents to the questionnaire report being absent from work between 3 h and 25 h per month due to their caregiving role. The number of hours of absence varies according to the child's age and level of autonomy. Caregivers report significant stress (panic attacks, anxiety, exhaustion, etc.) trying to work and meet their employer's expectations while carrying out their caregiving duties. The pressure of these expectations creates significant stress for caregivers, as well as guilt when they fail to meet them. The resulting overload leads many caregivers to burn out, affecting their mental and physical health, forcing them to take time off work or quit. Among the impacts most reported in the questionnaire on professional life, we find, in order: a feeling of guilt for not being able to meet expectations; a feeling of not being up to the job; work stoppages; repeated absences from work; a reduction in hours worked; working only part-time and taking unpaid leave. This reality was also noted during group discussions, where work stoppages were regularly reported as a reality experienced by caregivers.

- **Choice of job and professional retraining**

Many report that it is difficult for both parents to continue working full-time with one or more children with special needs. In such cases, it's usually the mothers who stay at home to be full-time caregivers, or who undergo professional retraining. Indeed, the reality of caregiving leads many mothers to reorient themselves towards a more supportive work environment, to engage in self-employment, to return to school or simply to stop working.

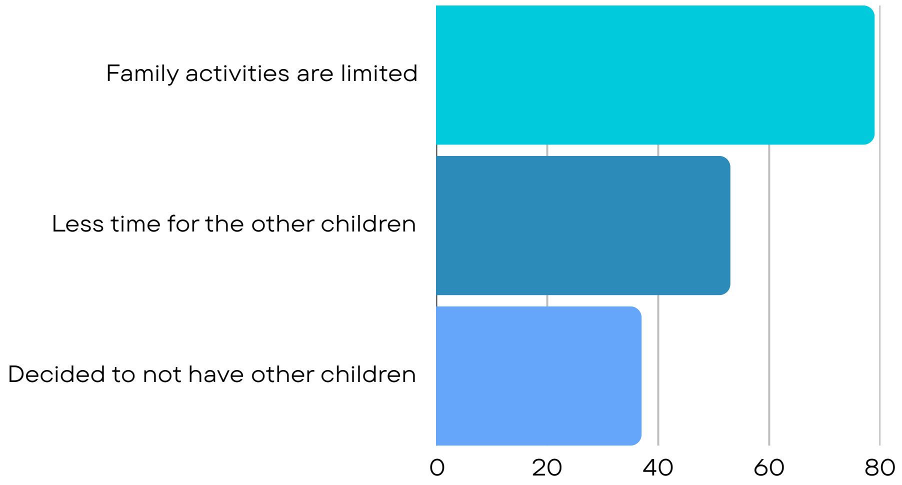
The large role played by caregiving in the lives of the people concerned is not compatible with all types of employment. As mentioned above, caregivers are leaving certain workplaces for more supportive employers. Most of these jobs are in the care sector, i.e. traditionally female-dominated. For example, orderlies, home helps or workers in organizations specializing in intellectual disabilities, autism spectrum disorders and working with disabled people. These are indeed more humane workplaces; however, it creates a situation where caregivers find themselves taking care of others in both their private and professional lives, which can accentuate the overload effect. What's more, caregiving jobs, where women are found in greater proportion, are emotionally and physically demanding, but are generally less well-paid than predominantly male fields [12]. Considering that women earn less overall than men, that caregiving puts pressure on the financial situation of those concerned, and that more mothers with caregiving responsibilities stop working or move into traditionally female jobs with lower pay, mothers with caregiving responsibilities are more at risk of financial insecurity. The Conseil du statut de la femme du Québec has found that women are more likely to be low-income caregivers [13].

Not surprisingly, caregivers gravitate towards areas of caregiving in which they have a sense of competence and extensive experiential knowledge. They spend many hours caring for their children, and become experts in their limitations. They want to understand their reactions and how their brains work. In the course of appointments with healthcare professionals, they acquire in-depth knowledge of what their children are going through. Some also take training courses to increase their understanding and improve their skills and interventions. However, while some have discovered a genuine interest in caring, many say they choose these jobs more out of spite, because of their reality as caregivers, than out of choice and real passion. One participant explains: “I didn't necessarily do the job I would have liked to do in life, but I learned to love it”.

The impact of caregiving on career choices is also reflected in the results of the questionnaire. In fact, 53% of respondents said they had had to choose a job that was adapted to their situation as a caregiver, and 21% said it was one of their main considerations.

- **Family life**

Participants noted that the family sphere is also impacted by the omnipresence of caregivers in their lives. Caregivers sometimes have to cope with the fact that they have several children and grandchildren. When asked about the impact of caregiving on their family life, respondents to the questionnaire identified the most preponderant impacts as (in percentages) :



On the other hand, they also report that family ties are sometimes strengthened in a caregiving context (32%).

Family equilibrium is also sometimes fragile. Some people feel they have no right to give up, because if they're not there, no one will take over. As one participant put it: “I'm the cornerstone in our home. If I'm ill, I worry a lot, it's a lot pressure”.

There are also repercussions for the extended family. Some family members lend a hand to caregivers to give them a break or to look after other children. However, family caregivers are concerned about exhausting family members.

3. The Needs of Caregivers

Among the needs most frequently mentioned in the focus groups and questionnaire were psychosocial support, respite, babysitting, financial assistance and transportation. We will elaborate on the items discussed in greater depth during the focus groups.

- **Respite**

The need for respite came up again and again during all the group discussions. It seems unequivocal that access to respite is an essential condition for the well-being, balance and health of caregivers. Moreover, 53% of respondents to the questionnaire identified it as a need.

In the GÎM region, access to respite is limited. In Gaspésie, the only facility offering respite for more than 24 hours outside the home is *Maison Gilles-Carle* in Sainte-Anne-des-Monts. Otherwise, in the Avignon area, the *Entre-tiens* Avignon organization offers in-home respite over several days, as referred by the CISSS. In the Magdalen Islands, the *Association des personnes handicapées des Îles* offers respite for short periods. Alternatively, some volunteer action centers, such as Côte-de-Gaspé and Îles-de-la-Madeleine, offer in-home respite for less than 24 hours. However, since demand is high and supply is still very limited, you have to be in the area served by these organizations to have access to this service. Indeed, some organizations are underfunded to meet all the demands they receive. There also seems to be a lack of respite on weekends, according to what we heard. Consequently, the lack of resources forces caregivers to travel long distances to access respite. For example, in the absence of a respite home in the Magdalen

Islands, some people fly to Quebec City to access respite for a few days. In Gaspésie, a person living in Grande-Vallée has to make a 3-hour round trip, possibly twice in the space of a few days, to reach the *Maison Gilles-Carles* in Sainte-Anne-des-Monts. A caregiver in Côte-de-Gaspé would have to drive a 5-hour round-trip to access the same resource. For older parents or those with mobility issues (no access to a car, reduced mobility, etc.), distance is an obstacle to accessing this resource. The size of the territory, the lack of available resources and distance are therefore determining factors in access to respite care in the region.

- **Transportation**

Transportation is an essential service for families with one or more children living with a disability. It enables these children to take part in activities, socialize and, in some cases, attend school. Depending on the area, transportation services vary. In Côte-de-Gaspé, for example, paratransit services are often cancelled at the last minute due to staff shortages. On the other hand, to access certain services, such as school, regular transportation doesn't go to all areas. For Grande-Vallée residents, the only schools able to offer services to people living with a disability or intellectual impairment are in Gaspé. However, regular transportation does not serve this part of the Estran. As a result, this lack of transportation service makes it very difficult for these people to attend school and socialize.

In the Magdalen Islands, air travel is often necessary to access certain services and care. However, some caregivers report that travel is complex with the airlines serving the region. A great deal of communication with the airline is required to ensure that the needs of both the child and the caregiver are taken into account.

- **Financial assistance**

According to the responses to the questionnaire, 47% of respondents said that financial assistance was lacking. In fact, several issues concerning existing financial aid were raised by caregivers as a whole, notably the inadequacy of reimbursements and the obsolescence of the amounts available. Many complained that the reimbursements offered do not take into account the real costs of accommodation and meals. This needs to be updated, so that reimbursements keep pace with inflation. Participants also strongly criticized the fact that expenses for accompanying adults are not reimbursed. For example, if the child is hospitalized, the caregiver is not reimbursed for expenses such as meals and accommodation. Caregivers also criticize the fact that the reimbursement of travel expenses does not take into account the days of travel that people in remote regions and living on islands have to make to access services and care. Nor can appointments always be condensed into a single day, which can prolong the stay. A participant from the Magdalen Islands explains how this translates: “If your appointments are for two days and you're gone for four, they just reimburse two days. They don't take into account travel days.” Considering that many resources are not available in the region, travel to Quebec City in particular is frequent. The absence of certain resources nearby should not financially penalize communities in remote regions.

Caregivers also report difficulty in finding information and knowing where to go for it. Once the information has been obtained, access to available help still seems uneven. Networking is *the* main source of information for caregivers. It is through other caregivers with similar experiences that they obtain much of the information on the financial aid to which they are entitled. For example, not all caregivers know about the supplement for disabled children, and mention that caregivers sometimes talk about it too late: “If you don't get informed, if you don't know what you're entitled to and you don't ask for it and don't take the trouble to get it”. The same applies to the tax credit for caregivers. It was also mentioned that “Unemployment for caregivers is only for 15 weeks, which isn't much”. Moreover, during the discussion groups, many were learning for the first time about the existence of certain financial aid schemes, and it was a moment of exchange and sharing.

On the other hand, to receive the financial aid available, caregivers feel they have to give the “right” answers during their assessment with the health and social services network. One participant denounced the situation: “You have to know the right things to say... at one point, I stopped saying that my network was present. My network is exhausted too.” Caregivers need to become expert advocates of their own rights.

> **Seriously, if you don’t have any money, you’re screwed.**

- **Babysitting**

Access to babysitting allows family caregivers to have access to short moments of respite. 32% of respondents to the questionnaire answered that babysitting is a need. Moreover, the subject was raised in most of the focus groups.

Babysitting for children living with a disability is quite different from babysitting for children living without limitations. Because babysitting can be so demanding, parent/caregivers need to find trustworthy people who know how to work with children who have one or more limitations or an intellectual disability. Many say they have difficulty letting someone into their family and into their privacy. This makes it difficult to find a babysitting resource to go out on a weekend or weeknight spontaneously. However, babysitting is essential to enable caregivers to take care of themselves, have time for the couple and maintain social and family ties.

Participants reported that the financial assistance offered by the CLSC for babysitting is insufficient. When converted to an hourly rate, the amount is well below the minimum wage. The amounts do not appear to have been revised for many years, and should be updated.

- **Needs inherent in the role of caregiver**

When you spend most of your life caring for someone else, especially someone with limitations, it can be difficult to connect with other experienced relatives. This bond not only helps to break the isolation that can be experienced within the family sphere, but also provides a healthy comparison with other relatives. As a result, 53% of respondents to the questionnaire expressed a need for recognition of their parenting skills and validation of their role.

In order to fulfill their role, some parents also mentioned the need for coaching and training to better understand their child's reactions and be able to react in the best possible way.

We can see here a need to strengthen caregivers' self-esteem, but also a strong desire to do things right, to react appropriately and professionally to their children.

Aging as caregivers

Many aging family caregivers are very concerned about what will happen to their child when they die, if they have an accident, or when they are no longer able to care for their child as themselves. The participants deplore the fact that, at the moment, responses come mainly when an emergency arises, and not enough in the way of prevention. This situation causes immense stress and distress for all concerned. Parent carers would like to see more prevention, which would reduce some of the stress associated with the uncertainty of what will happen to their child.

“The rest of us are getting older too, what happens if we have an accident tomorrow?”

At present, there aren't many solutions, or only imperfect ones. For example, sometimes places are offered in retirement homes. However, these are not places dedicated to people living with an impairment or disability. It's a solution to the lack of alternatives. Instead, there is a need for homes for disabled seniors.

The importance of prevention was raised several times during the group discussions. The bereavement of one or both parents, the loss of a family nucleus, moving house and adapting to a new living environment are major upheavals for the children we help. When all this happens at the same time, it can have serious consequences for their mental health and psychological well-being. To preserve the mental health of children and caregivers, it's vital to prepare for the “aftermath”.

The two resources discussed below are part of the solution. They should be considered in future prevention efforts.

“All I ask of God is to live long enough for my little one to go before me.”

4. Children’s Needs

To be able to fulfill their roles as both caregiver and parent, parent caregivers need easy access to services and resources adapted to their child's reality. The need for housing, in particular, was raised several times during the focus groups. Two resources seem to be the most pressing: adapted housing and foster families.

- **Adapted housing or supervised apartment**

The availability of adapted housing or a supervised apartment is essential for increasing the autonomy of certain children. The opportunity to live in a supervised environment outside the family nest enables many children to develop their full potential and autonomy. Indeed, some children could eventually live in a supervised apartment, but parents need them to develop their autonomy before they're too old. However, supervised apartments are either not yet available in the region or are located far from where the parents live. In addition, participants report that there is a lack of opportunity to assess whether children would be able to live in supportive housing, as well as a lack of 24-hour educators.

- **Foster care**

Foster families are an essential resource, especially when aging parents are no longer able to care for their children, or when they die. The presence of foster families is central in these situations, and can be part of the solution for planning the “aftermath”. In Gaspésie and the Magdalen Islands, however, this resource is rare.

- **Schooling**

A number of issues relating to schooling were raised by those questioned. It seems that, despite the good will of professionals, the situation is problematic for many children living with limitations.

In general, some testimonies seem to indicate that the school is sometimes unable to respond or respond adequately to the needs of these children. Diagnoses are sometimes misunderstood, and some children report feeling uncomfortable at school. What's more, staff turnover can destabilize children who need a sense of direction. In the Magdalen Islands, there is a lack of expertise among special education technicians in autism spectrum disorders (ASD). The lack of professional staff to support children with special needs is also an issue in the context of their schooling. Consequently, the lack of adapted resources, or when the school considers the child unsuitable for school, can lead to expulsion. Some parents mentioned feeling a disconnect between school and services adapted to their children.

The need is to find support in schools with professionals who understand the issues faced by children with ASD, intellectual disabilities, etc., and to make school a safe space for socialization and empowerment. Children living with limitations benefit greatly from social mix spaces.

5. Resources for caregiver parents in the GÎM region

- **Difficult access**

As we've mentioned on several occasions, access to resources can sometimes seem like an obstacle course. A large number of participants mentioned that they had to work very hard to gain access to services and benefits. For example, one participant mentioned that she had to insist on access to an employment-service cheque in order to be able to offer financial compensation to her father, who was helping her. This benefit seems to be managed unevenly across the province, particularly when it comes to children with disabilities, as the program is designed primarily for seniors.

The particular situation of English-speaking people

Only two English-speaking women responded to the English-language questionnaire, which means that we cannot draw any conclusive conclusions about their situation. We note, however, that the same difficulties experienced in the French-speaking community are present: difficulty in finding time for oneself, little or no time for the couple, choosing a job based on the caregiving situation, and so on.

What stands out in particular is the difficulty of obtaining information on government assistance programs, and of receiving the help requested. It is also difficult to find specialized resources in the English language, which complicates the children's care journey, as well as affecting the financial health of caregivers.

- **Access to information**

In the questionnaire, we asked participants how easy it is to find information on available help and government assistance programs, with 37% answering “yes” or “most of the time”, 26% saying only “sometimes” and 37% answering “rarely” or “no”. In response to this question, the two English-speaking respondents answered “rarely” and “no”. The first step to getting the help you need, however, is to have access to the right information. What's more, when we asked them whether, once they had obtained the information, they were able to *easily* access the help offered by these programs, only 24% answered “yes” or “most of the time”, 35% answered “sometimes” and 41% answered “rarely” or “no”.

These responses are worrying in that they reflect barriers to access on two levels. On the one hand, there are barriers to accessing information on available help programs and resources, and on the other, even when these resources are known, there are still barriers that make it difficult to access the help available.

Literacy level on access to available help resources

Literacy levels have an impact on people's knowledge of their rights and their ability to assert them. Indeed, one participant testified that she had to write numerous letters and go back to the drawing board several times in order to access a service and allowance essential to her role as a caregiver and to her child's well-being. This process is intellectually demanding, requiring knowledge of one's rights and oral and written communication skills that some people with lower literacy levels are unable to deploy.

What's more, some participants mention that there is less support from organizations working in the field of caregivers, since the subject is associated mainly with seniors. As a result, they are less able to respond to the needs of family caregivers.

- **Missing resources**

With regard to the resources available in the region, we surveyed respondents to the questionnaire to find out whether the resources meet their needs. Of the 19 responses, only 2 said "yes", 11 said "partially" and 5 said "not at all".

To go a step further, we asked them if they have easy access to the resources their child needs, such as occupational therapy, physiotherapy, speech therapy and other specialties. Of these, 63% said that when they did find resources, they were not available in the region or had a long waiting list, while 21% said that the resources they needed were only available privately. One person replied that resources were not available in their mother tongue.

○ Gaspésie

In the Gaspé Peninsula, access to resources is uneven across the territory. Resources are often far from home, requiring considerable logistics to reach them. For example, in Grande-Vallée, which lies at the end of the MRC, there are not enough resources nearby. Caregivers often have to travel to Gaspé, where services are centralized, or to Chandler for certain examinations. Adapted education is not available in Grande-Vallée. At age 20, they have to leave school or go to Gaspé (with no organized transportation).

○ Îles-de-la-Madeleine

Many specialized resources and services for children are not available in the archipelago. More specifically, there is a reported lack of psychiatric care for children with suicidal ideations and depression. The psychiatry department at the Îles-de-la-Madeleine hospital is reportedly not equipped to meet the specific needs of these children, resulting in a lack of prevention and intervention on their part. In addition to not having a pediatrician or neurologist, medical teams with a low exposure rate do not develop their expertise and are caught unprepared for certain disabilities. What's more, many medical tests are not covered on the islands, forcing parents to travel off-shore to access them. For example, to get a diagnosis for your child, you have to travel outside the archipelago. One participant mentioned that she was thinking of moving to be closer to services and resources, because the lack of resources on the islands is so hard on her and her family. One participant mentioned having to talk about her child's suicidal ideations to obtain services, medication and care.

○ Lack of specialized resources

To support children living with a disability or intellectual impairment, parent caregivers need access to specialized resources. The parent caregivers who participated identified resources that are either unavailable in the region or difficult to access for a variety of reasons:

1. **Occupational therapists**: a service named several times. However, the waiting list in the public sector is very long, and there are also delays in the private sector. It is reported that the wait can take several years. Needs have time to evolve and change by the time parents receive the call;

2. **Psychologists, social workers and psychiatrists**: parents need these resources to be available and specialized to work with neuroatypical children, living with a handicap or intellectual disability;

3. **Specialized educators**;
4. **Physiotherapists**;
5. **Adapted sports and activities**.

Some parents mention that they would benefit from family rather than individual care for their children. In other words, sometimes several children in the same family need the same service, but the children are taken into account separately. In such cases, it would be easier to envisage the whole family being looked after. On the other hand, many participants mentioned that they felt they were working at cross-purposes to access local resources for their children. Many felt overwhelmed and disillusioned by a system that failed to meet their needs. The cumbersome nature of the process sometimes gets the better of their tenacity.

The contribution of community organizations

It's important to point out that a number of organizations in the region, such as the *Associations des personnes handicapées*, are dedicated to the support, socialization, social participation and inclusion of people living with a disability or intellectual impairment. Despite inadequate funding for their missions, these organizations work very hard to put in place a range of services and activities that meet the needs of local populations. Their contribution is essential for caregivers and their children.

6. Caregiving between women and men

A gender-based analysis of caregivers in Quebec conducted by the *Conseil du statut de la femme* in 2021 revealed that female caregivers invest more time in caring for their loved ones, tasks that are emotionally demanding and require personal commitment. The analysis also highlights that the tasks taken on by women caregivers come with a significant daily mental load, such as transportation, domestic chores, making appointments, emotional support, hygiene care, etc. [14]

The findings of this analysis echo the testimonies gathered during focus group discussions with family caregivers in the region. The weight of the mental burden does indeed seem to rest mainly on the shoulders of mom carers. The latter testify that they are responsible for managing appointments and administrative tasks such as filling out numerous forms and keeping track of intervention plans, which are sometimes multiple. The region's caregivers also play a major role in providing emotional support and carrying out care-related tasks. The focus groups also revealed that mothers are more proactive on several fronts. They read up on forums, train themselves to better understand their child, and seek out the help they need for themselves and their family. When they share caregiving responsibilities with the other parent, most of them are more proactive than their spouse. For example, some of them mention that when their spouse wants to give them the evening off, it represents a certain amount of organization for them, since they have to plan a meal, remind them of the routine, etc.

This investment of time and energy, as well as their personal commitment to their role as mother-helpers, has a major impact on their lives, which fathers don't seem to experience to the same extent [15]. In fact, caregiver mothers experience more consequences, particularly in terms of their professional lives. This observation was raised several times during the group discussions. As we pointed out, many of them have to quit their jobs and/or retrain. This puts them at a financial disadvantage in both the short and long term, contributing to their economic insecurity.

- **Fathers’ involvement**

A portrait based on a review of the literature carried out in 2020 highlights the importance of encouraging fathers' involvement and the need to better understand their needs and the difficulties they experience, in order to propose intervention methods that encourage them to participate more fully in family life [16]. Indeed, during the group discussions, the importance of giving fathers the chance to experience situations or crises was mentioned, so that they gain confidence. The fact that they are less involved and generally not the main caregiver means that they are less at ease and have fewer tricks up their sleeves to deal with these situations.

On the other hand, some mom carers have mentioned that their spouses are unable to understand all the work and energy they put into caring for their children and family. Since the hours spent caring for children and doing household chores are not part of a paid job, some spouses don't understand why their partner is overworked and exhausted. One participant describes how this translates into her married life: “My partner doesn't understand when I'm depressed either, he doesn't understand what it's like. Often, it's more like bickering.” She also mentions that it's only when she goes for psychiatric help that the people around her and her partner take her condition seriously. It's also difficult when the two parents don't have the same vision of what should be done for their child. Sometimes, the father is more resistant and refuses to accept his child's reality, which complicates the process of obtaining a diagnosis and assessment to access help resources. This finding is consistent with recent data showing that men are less inclined than women to seek help [17]. However, this resistance prevents the family from obtaining assistance and benefits, which, among other things, adds to the burden of caregiving mothers. For example, to access the daycare integration allowance program for children with a significant and persistent disability or incapacity, the child must be assessed, which means accepting that the child has special needs.

7. Recommendations

To conclude, we offer a few recommendations based on the testimonials we've received and the discussions that have taken place between these parents. We feel it is vital to take action, as some parents are experiencing great psychological distress and feel helpless or abandoned. There are specific aspects to the caregiving experience of parents that need to be taken into consideration. There are also unavoidable questions: who will take care of these children if not their parents? And the task is greatly complicated when the support network is tenuous, exhausted or even non-existent. Here are just a few of the ways in which these parents can find the respite they so desperately need.

1. **Focus on prevention**
    - o Act upstream to prevent crises. It's vital not to wait until caregivers are exhausted before providing them with financial assistance;
    - Know which families need a support plan in case of death, so we can act now to find solutions.

2. **Improve services and resources on the territory**
    - Call on the CISSS to take the lead in setting up respite care projects, adapted housing and other resources that are lacking in the region. The people concerned, who are already overburdened and/or elderly, are unable to take on these projects, but are waiting for an initiative to provide support;
    - Find new host families in the region;
    - Solicit municipalities to set up initiatives for adapted housing projects or respite homes on their territory.

3. **Facilitate access to information**
    - Create a bank of resources including financial assistance, programs, respite and homecare services, and provide this information rapidly when a diagnosis is made;
    - Demonstrate transparency in the allocation of financial assistance to caregivers in the region;
    - Share information and keep staff well informed;
    - Create a bank of resources for respite care and babysitting.

4. **Encourage spousal involvement**
    - Promote education for men and boys on understanding and managing emotions;
    - Organize discussion groups for spouses and caregivers;
    - Promote variability in domestic tasks.

5. **Encourage the creation of discussion forums**
    - o Enable parents to meet and share their successes and challenges, thereby reducing isolation and fostering a sense of parental competence;
    - o Promote children's autonomy and socialization by offering mixed-gender activities where children with disabilities or intellectual impairments can socialize with children without disabilities or impairments;
    - Encourage twinning with organizations that integrate children with disabilities into mainstream activities (e.g., dance classes).

Conclusion

The data gathered in this overview gives us a glimpse into the reality of family caregivers in the Gaspésie-Îles-de-la-Madeleine region, a reality that has remained little documented until now. Without pretending to be exhaustive, this report gives us a better understanding of what these caregivers are going through, and provides food for thought and recommendations to better support them in their caregiving role.

This overview was built up thanks to the invaluable testimonials collected during the group discussions and through the questionnaire. It is these testimonies that provide an insight into the experience of caregiving for a parent in our region. However, it should be noted that no focus groups were held in Baie-des-Chaleurs, Rocher-Percé or Haute-Gaspésie. It is therefore possible that elements concerning these sectors appear to be missing from the document for this reason, and not by deliberate omission. It would be interesting to meet with caregivers in these areas at a future survey.

References

Conseil du statut de la femme. (2018, mars). *Les proches aidantes et les proches aidants au Québec : Analyse différenciée selon les sexes.* https://www.csf.gouv.qc.ca/wp-content/uploads/por_proches_aidants20180419_web.pdf.

Couturier, E. (2020). Économie 101 : qu'est-ce que l'écart salarial? *L'Institut de recherche et d'informations socioéconomiques.* https://iris-recherche.qc.ca/blogue/inegalites/economie-101-qu-est-ce-que-l-ecart-salarial/.

Gouvernement du Québec. (2021). *Plan d'action gouvernemental pour les personnes proches aidantes 2021-2026.* https://publications.msss.gouv.qc.ca/msss/fichiers/2021/21-835-11W.pdf.

Groupe des aidants du Sud-Ouest. (2020, mai). *Être un vrai homme ou l'obstacle imposé des émotions.* https://www.gaso.ca/post/%C3%AAtre-un-vrai-homme-ou-l-obstacle-impos%C3%A9-des-%C3%A9motions.

Handfield, C. (2024, 12 mai). Devant l'adversité, les hommes réagissent autrement. *La Presse.* https://www.lapresse.ca/societe/sante/2024-05-12/sante-mentale/devant-l-adversite-les-hommes-reagissent-autrement.php.

Loi visant à reconnaitre et à soutenir les personnes proches aidantes, 2023, chapitre R-1.1, https://assets.websitefiles.com/650860654a94d70a1cd4cf6f/650860654a94d70a1cd4cfc1_R-1.1.pdf.

Painter S., des Rivières- Pigeon C. et Séguin A. (2020, mars). *Les besoins des parents d'un enfant ayant un handicap au Québec. Portrait à partir d'une recension des écrits.* https://espace.inrs.ca/id/eprint/12735/1/Rapport_Besoins_parentsPH_20_final1.pdf.

Simandl, M. (2022, décembre). *Kessler Psychological Distress Scale 6 (K6) and Kessler Psychological Distress Scale (Past Week; K6W).* https://confluence.camh.ca/pages/viewpage.action?pageId=55083964.

Tremblay-Boily, G. (2023, septembre). *Le revenu viable hors grands centres : données pour la Montérégie, Gaspésie-Îles-de-la-Madeleine et la Côte-Nord.* IRIS. https://iris-recherche.qc.ca/wp-content/uploads/2023/09/RVHorsCentre-20230925-WEB.pdf.

Notes

1 Conseil du statut de la femme. (2018, mars). *Les proches aidantes et les proches aidants au Québec : Analyse différenciée selon les sexes.* https://www.csf.gouv.qc.ca/wpcontent/uploads/por_proches_aidants20180419_web.pdf

2 *Loi visant à reconnaitre et à soutenir les personnes proches aidantes*, 2023, chapitre R-1.1,https://assets.website files.com/650860654a94d70a1cd4cf6f/650860654a94d70a1cd4cfc1_R-1.1.pdf

3 Gouvernement du Québec. (2021). *Plan d'action gouvernemental pour les personnes proches aidantes 2021-2026.* https://publications.msss.gouv.qc.ca/msss/fichiers/2021/21-835-11W.pdf

4 Conseil du statut de la femme. (2018, mars). *Les proches aidantes et les proches aidants au Québec : Analyse différenciée selon les sexes.* https://www.csf.gouv.qc.ca/wpcontent/uploads/por_proches_aidants20180419_web.pdf

5 *Ibid.*

6 Painter S., des Rivières- Pigeon C. et Séguin A. (2020, mars). *Les besoins des parents d'un enfant ayant un handicap au Québec. Portrait à partir d'une recension des écrits.* https://espace.inrs.ca/id/eprint/12735/1/Rapport_Besoins_parentsPH_20_final1.pdf

7 Groupe des aidants du Sud-Ouest. (2020, mai). *Être un vrai homme ou l'obstacle imposé des émotions.* https://www.gaso.ca/post/%C3%AAtre-un-vrai-homme-ou-l-obstacle-impos%C3%A9-des-%C3%A9motions

8 Simandl, M. (2022, décembre). *Kessler Psychological Distress Scale 6 (K6) and Kessler Psychological Distress Scale (Past Week; K6W).* https://confluence.camh.ca/pages/viewpage.action?pageId=55083964

9 Tremblay-Boily, G. (2023, septembre). *Le revenu viable hors grands centres : données pour la Montérégie, Gaspésie-Îles-de-la-Madeleine et la Côte-Nord.* IRIS. https://iris-recherche.qc.ca/wp-content/uploads/2023/09/RVHorsCentre-20230925-WEB.pdf

10 Painter S., des Rivières- Pigeon C. et Séguin A. (2020, mars). *Les besoins des parents d'un enfant ayant un handicap au Québec. Portrait à partir d'une recension des écrits.* https://espace.inrs.ca/id/eprint/12735/1/Rapport_Besoins_parentsPH_20_final1.pdf, page 56

11 *Ibid.*

12 Couturier, E. (2020). Économie 101 : qu'est-ce que l'écart salarial ? *L'Institut de recherche et d'informations socioéconomiques.* https://iris-recherche.qc.ca/blogue/inegalites/economie-101-qu-est-ce-que-l-ecart-salarial/

13 Conseil du statut de la femme. (2018, mars). *Les proches aidantes et les proches aidants au Québec : Analyse différenciée selon les sexes.*
https://www.csf.gouv.qc.ca/wpcontent/uploads/por_proches_aidants20180419_web.pdf

14 *Ibid.*

15 Gouvernement du Québec. (2021). *Plan d'action gouvernemental pour les personnes proches aidantes 2021-2026.* https://publications.msss.gouv.qc.ca/msss/fichiers/2021/21-835-11W.pdf

16 Painter S., des Rivières- Pigeon C. et Séguin A. (2020, mars). *Les besoins des parents d'un enfant ayant un handicap au Québec. Portrait à partir d'une recension des écrits.*
https://espace.inrs.ca/id/eprint/12735/1/Rapport_Besoins_parentsPH_20_final1.pdf, page 30

17 Handfield, C. (2024, 12 mai). Devant l'adversité, les hommes réagissent autrement. *La Presse.*
https://www.lapresse.ca/societe/sante/2024-05-12/sante-mentale/devant-l-adversite-les-hommes-reagissent-autrement.php