Office of the Citizens' Representative
Newfoundland and Labrador

# By a Thread

## A Report about the Challenges of Parents and Caregivers of Medically Complex Children

October 2023

Why is providing support to family caregivers so important?

Children with complex health care needs will grow to become adults with complex health care needs. The need for high levels of health, social, and educational support for these individuals continues throughout their life and health trajectory.

As a result, parents and family caregivers face a lifetime of physical, psychological, financial and emotional burdens. This is a public health issue. Many family caregivers are overwhelmed and face financial, emotional, and psychosocial risks that increasingly result in a decline of their own health and wellness. Caregivers of children with complex care needs may also experience social isolation. [1]

*"I have always been strong for my daughter and family and have fought hard for her to the detriment of my own mental health and well-being. We all need help."*

Written submission – Family Caregiver

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[1] Academic Pediatrics. Volume 23, Issue 2, March 2023, Pages 236-243

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# Introduction

"I stand by his bed and apologize to him constantly."
"The job that I'm doing is not parenting, it is nursing."
"I'm covered in bruises and my husband has been questioned again."
"I know hundreds of people yet I'm so lonely."
"I pay about $35,000 a year out of pocket for respite."
"They told my husband and I to separate and go on social services."
"We never openly plan anything because anything could happen. Siblings can't be promised anything because those promises keep getting broken."
"I don't want to die and make her siblings have to assume her care."
"The time for lip service is over."
"Please, after I'm dead, I beg you, Government, to put something in place that is nice for my child. You can have my estate. I need to die in peace. My last breath will be in concern for her."

Parents and caregivers of medically complex children in Newfoundland and Labrador are hanging on by a thread.

In the fall of 2021, the Office of the Citizens' Representative (OCR) was approached by a caregiver who outlined in great detail the near impossible circumstances faced by her family, which struggles to provide 24/7 care for a non-verbal child with multiple disorders including daily seizures, and an inability to be nourished by anything other than feeding tubes. This caregiver is not only a parent and consistent emotional support to the child, but also functions as a personal care attendant and nurse. Respite is hard to come by. There are no breaks, no vacations, no outings.

I elected to investigate the issue of supports for family caregivers of medically complex children and adults under the own initiative provisions of the **Citizens' Representative Act**. Our consultations with parents and caregivers showed they are isolated, exhausted, and in many cases, have premature failing health. Many are financially unstable. Some describe little to no semblance of what our society associates with normal child rearing. They struggle to maintain the overall health of the family unit, including their own mental health and the mental health of siblings of the medically complex child. They have legitimate, daily fears of what happens to their children when they pass on.

Still, they dig deep every day for the strength to persevere with limited support and respite, some extended familial help, and/or some support from the province, primarily during times of extreme crisis.

Our investigation of these concerns, via the Department of Health and Community Services ("HCS") and the four regional health authorities, found:

1. Silos exist in the provision of services and programs.

2. Parents and caregivers are often confused about, or unaware of eligibility for federal and/or provincial government assistance.

3. Parents and caregivers are relying on social media to learn about services and connect with each other.

4. There is no discernable central contact point to access support.

5. There are extremely limited programming options with long waitlists, especially after the child reaches adulthood.

6. Some parents and caregivers are experiencing extreme financial hardship.

7. Parents and caregivers assume significant medical care responsibilities.

8. Parents and caregivers have a general lack of respite hours.

9. Parents and caregivers toil even harder in crisis situations, such as acute care stays involving their medically complex children, their spouse or other children in the home.

10. Private insurance coverage, especially for equipment, is expensive and problematic to obtain. These costs may require one parent to be out of the home to maintain employee coverage, thus reducing the amount of care the parent or caregiver can provide.

11. There is a lack of supportive housing or residential accommodation for more functional adults.

12. There is an impending lack of supportive housing or residential assisted living arrangements for a generation of children whose parents are aging and will no longer be able to physically take care of them.

All of these problems are compounded in cases involving no diagnosis or rare diseases.

This report is a clarion call to the Government of Newfoundland and Labrador, and the people of our province, to prepare for a time in the near future when these parental and caregiver supports become increasingly unavailable as a generation approaches retirement age.

We have a collective responsibility to work together to make sure family caregivers are supported; to make sure they receive the benefits and services they require in a fair, timely and efficient manner; and, have a plan for their future.

Our province must prepare to take care of these children when their families no longer can, and we must brace for the next generation of medically complex adults. As a province, we have a moral imperative to act, and act now.

What is promising, however, is that HCS recognizes these problems and has assured us it is working to rectify them.

We received nothing but cooperation from the public officials in the Department and the Health Authorities who work every day with these families. There was no static from these public bodies; only an understanding and an expressed desire to be able to do more.

I would like to thank all staff of this Office for a true team effort: everyone employed here took some element of the investigative and reporting process as their own. Systemic reviews in small offices are difficult when individual complaint volumes climb or even stay the same.

I would like to especially thank Amie Richards who, after the passing of her little girl, took a personal and academic interest in the betterment of conditions for parents and caregivers of medically complex children. Ms. Richards' knowledge and assistance in this investigation were invaluable. Special thanks as well to Susan Green for her commitment of time and energy in advancing the concerns of many parents and caregivers.

Finally, I want to thank the parents and caregivers themselves, who found time in their schedules to meet with us, call us, or write to us to share their deeply personal stories and experiences.

Bradley J. Moss
Citizens' Representative

## Recommendations

1. (**HCS**) Develop policy for acute care admissions of medically complex children (adult children included) that requires a family consult as soon as practicable. This consult would identify the specific needs and required supports of the child to ensure a continuity of care; consider all available supports; and mitigate additional care burden for the caregiver.

2. (**HCS**) That home support workers be introduced to acute care admissions to provide optimal support for the family. While Personal Care Attendants in acute care settings are indeed valuable members of the health care team, home support workers bring instant familiarity and a significant parental trust factor to the acute care admission. This provides respite to families who have to manage issues outside of the hospital; get adequate rest to continue to provide care and tend to sibling and household needs; and allows Personal Care Attendants to be deployed elsewhere as needed.

3. (**HCS**) Respite care should be based on the needs of the child and not family income. Developing a standard criteria for assessing each medically complex child for symptoms and medical needs, (including those with undiagnosed or rare diseases), and funding based on needs, not income, would make this support system more equitable.

4. (**Education**) Engage with post-secondary institutions on the potential to review and develop curriculum to professionalize respite work in the area of medically complex citizens. This training exists in Canada in the form of Developmental Service Workers, a two-year program at Algonquin College in Ontario. Graduates of this program bring skills to families in areas such as basic pharmacology, awareness of psychological, social and cultural issues, physiology and recreational supports.

5. (**HCS/Education**) Engage with Memorial University on the existence and/or potential development of a co-operative program that would provide a work term for students to work with families who have children with complex needs. Faculties/ programs to consider could include Social Work, Psychology, Kinesiology and/or Music.

6. (**HCS**) Report to OCR semi-annually on its study of the upcoming residential support needs for medically complex children and adults, together with results on cross-jurisdictional research on innovative models that exist elsewhere.

7. (**HCS**) Conduct consultations with those affected by rare disorders to work toward better standardization of eligibility criteria to include persons without diagnoses and who have rare disorders, in order to promote inclusion and better serve this population.

8. (**HCS**) Facilitate the creation of a Ministerial Advisory Committee with significant parental/caregiver representation to establish clearer lines of communication between parents, caregivers and policymakers.

9. (**HCS**) Undertake a meaningful study and develop an action plan on programming options for medically complex adults and increase support for the community sector to develop and deliver enhanced programming. Likewise, the provincial government should look favourably on any other existing or emerging community-based or business organizations that can fill these existing gaps in services to medically complex children and adults.

10. (**HCS**) Resources need to be found and allocated to increase the availability for therapeutic counselling and referral options for parents and family caregivers who are facing burnout.

11. (**HCS**) To augment Recommendation 8, HCS should develop a central internet hub for information for this subset of our population. A provincial care and special needs support system where all resources and links for all associations and organizations that offer programs and supports for medically complex children, their parents, and caregivers, can be found.

12. (**HCS**) Work to draft and sponsor Caregiver Recognition Act legislation that raises awareness and recognition of caregivers and to support them in their role. We regard Quebec's "Act to Recognize and Support Caregivers" as the current national benchmark legislation.

## The Investigation

Caregiving for medically complex children and adults is a multifaceted activity involving multiple systems. This investigation considered the following issues:

1. The alleged need for additional supports in areas such as:

    I. Crisis situations
    II. Quality respite care
    III. Future planning
    IV. Navigating systems
    V. Inclusion
    VI. Therapeutic services

2. The alleged need for connection/broad family caregiver support in terms of avenues to collectively share their unique experiences, needs and challenges.

3. The impact the culmination of these concerns has on family caregivers.

Over the course of several weeks in late 2022, we invited written submissions from family caregivers. We met with several of them privately. We conducted focus groups with community service providers, interest groups and parents/caregivers of medically complex children.

- ► We conducted a literature review.

- ► We conducted cross-jurisdictional research.

- ► We invited submissions from HCS, each of the four Health Authorities and the Department of Children, Seniors and Social Development (CSSD).

- ► We met with the Minister of Health and Community Services.

We recognize and acknowledge the limited scope of this investigation. It did not explore:

1. Issues related to the education system and the barriers caregivers experience in that system.

2. Issues related to the education system and the barriers medically complex children experience in that system.

## Crisis Situations

It is an unfortunate fact that crisis is unavoidable in the course of life. Commonly, we lose loved ones and we suffer health setbacks. We also experience setbacks in the health of those close to us. We tend to measure these situations in hours or days. In all of these situations we try to develop mechanisms to cope and in most cases rely to some extent on others to assist us until the crisis settles out.

But what happens if the crisis doesn't really settle out? What happens when the measurement of hours and days becomes the norm? Ask parents and caregivers of medically complex children and adults.

COVID-19 alone presented significant additional challenges to this subset of our population, as evidenced in the 2020 Statistics Canada study entitled *"The impact of the COVID-19 pandemic on Canadian families of children with disabilities."* [2]

> *The impact of the COVID-19 pandemic may have been particularly hard for these families because of school closures, reductions in services, and the additional challenges related to caring for children with disabilities…including but not limited to attending clinic and therapy appointments, receiving respite and rehabilitation services, and obtaining medical equipment, which may have been further amplified during COVID-19.*

Pandemic aside, the responsibilities of caring for medically complex young children or adult children, which are exceedingly high in comparison to other children, increases when there is an unexpected health crisis in the family or an acute care hospital admission involving the person with complex needs.

Imagine for a moment you are the parent of a child who requires around the clock observation and care and your spouse is rushed to hospital. Think about being the parent of three children, one of them with multiple co-morbidities who is admitted for an extended acute care stay. Your hard-forged coping mechanism for managing crisis has to adapt, and adapt quickly.

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[2] https://www150.statcan.gc.ca/n1/pub/45-28-0001/2020001/article/00066-eng.htm

A case in point: Don and Judy [3] relayed that the moment their adult, non-communicative child was admitted to hospital, their funding for home support was cut. It was nearly a week before a Personal Care Attendant (PCA) was assigned to their room and from that point on, a series of new PCAs with varying abilities to effectively care for the child attended sporadically at the bedside.

> *We felt mentally and physically exhausted when our (child) was hospitalized. We had to be with (child) constantly. Funding for workers gets cut the day they are admitted.*

When hospitalized, children with complex care needs may need constant supervision, especially when the child has limited or no ability to communicate verbally. Caregivers feel they have to be vigilant, resulting in the caregiver being constantly at the bedside to be able to communicate and answer questions; receive updates; monitor the pre-existing health issue(s) and the health issue at hand; monitor the mood and feelings of their loved one as only they can; and answer questions about the child's level of functioning and/or communication patterns.

Safety is also a significant concern for these caregivers, especially in cases where the child does not recognize or understand danger, lashes out, fears strangers, attempts to get out of bed, or attempts to remove medical devices.

Some caregivers also identified poor communication and information sharing with health care staff, which only heightened families' concerns about safety problems, potential for medication errors, poor pain management, and feeding/toileting concerns. Situations are further aggravated if there are other siblings left at home needing care. In all of these cases, unexpected hospitalization places significant physical and emotional burdens on caregivers.

An additional perspective, that of caregiver hospitalization, places further stress on the family. Brian wrote:

> *The only system to help that seems to be in place at the moment is removing the disabled child when there is a crisis and placing them in group homes (where there is 24 hour care by workers) or in foster care. Ironically, there is a respite system in place and financial assistance to support the foster parents of these children yet no help to maintain these children in their own homes.*

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[3] Names have been changed throughout this report to protect the identity of contributing family caregivers.

Crisis situations are not limited to in-patient admissions. For parents and caregivers of medically complex children and adults, any disruption in the family routine can be problematic. Many of those interviewed in this investigation told us that interruptions to the family routine by internal or external crisis places additional stress on the family unit. There are feelings of guilt when they have to reach out to their retired parents and relatives who are already shouldering a load. They take pains to avoid asking their personal friends, but sometimes have no other choice. In response to this issue, HCS stated:

> *The needs of family caregivers you noted in your letter regarding ease of access to home support, emergency situations and after-hours specialized care options, as well as improved service accessibility options, will be further considered by HCS.*

We offer the following recommendations to reduce barriers in crisis situations:

**Recommendation 1**

(**HCS**) **Develop policy for acute care admissions of medically complex children (adult children included) that requires a family consult as soon as practicable. This consult would identify the specific needs and required supports of the child to ensure a continuity of care; consider all available supports; and mitigate additional care burden for the caregiver.**

**Recommendation 2**

(**HCS**) **That home support workers be introduced to acute care admissions to provide optimal support for the family. While Personal Care Attendants in acute care settings are indeed valuable members of the health care team, home support workers bring instant familiarity and a significant parental trust factor to the acute care admission. This provides respite to families who have to manage issues outside of the hospital; get adequate rest to continue to provide care and tend to sibling and household needs; and allow Personal Care Attendants to be deployed elsewhere as needed.**

## Quality Respite Care

Family caregivers provide care from birth into adulthood until the family caregiver is no longer able to provide the level of care required. For them, respite care that affords an opportunity to attend to normal and routine aspects of daily living such as banking, shopping, home maintenance; and attending to the educational, social and recreational needs of siblings is a crucial requirement. It helps to prevent social isolation. It relieves stress and pressure. It allows some time for rest and can rejuvenate patience. In Newfoundland and Labrador, respite care for parents of medically complex children is related to financial need and not related to the child's level of disability or need.

In order to qualify, a family must be below the minimum financial threshold or in crisis to receive respite care.

One contributor to our research, citing scholars on this issue, wrote:

> *With the increased level of care associated with parenting such children, parents often report feeling as though they are always "on duty;" always caring for and monitoring their child. Associated with this, parents also experience poorer quality of life in general and lower levels of sleep quality in particular. Parents are sometimes able to alleviate some of this burden by using in-home caregivers to provide care for their child; however, this also leads to decreases in privacy. Additionally, choosing and allowing someone into your home also requires considerations related to how that person will fit with the family and how they will view and interact with your child.*

Elizabeth told us:

> *(My child is a teenager) in Grade 11. She has a form of CP, Autism and OCD. She has been followed by the Rehab team at the Janeway since she was a year old. I have been given more support through the Rehab Department than the provincial government. I had applied early in (child's) life for respite care and was approved, but I found the application process very invasive. The application alone is over 10 pages. They require every bill you have paid in the last 12 months, they want a record of your bank statement for the last 12 months. Any money you may have in stocks, bonds, or RRSPs have to be cashed and used before any funding can be given.*
>
> *If you have any amount of savings you are required to use that before funding is available. It would also include a lengthy home visit to see if (child) actually requires respite. I find it very degrading and insulting… I feel that parents and caregivers of*

*(Cont'd)*

> *special needs children are being given another stressor in trying to provide quality of life to our kids....I also have (another child) and I think that is not fair to him and our family to have to use all our resources, savings and time and effort for my daughter and not have any for the rest of my family. We didn't ask or plan to have our life this way and it is a lifestyle adjustment to us and a very hard one at that.*

Michelle wrote:

> *I am a single mom to a 9 year old with complex medical needs... I have a very happy life with my daughter and it is full of love and joy. We are very lucky that she has been acutely well within her chronic health needs. I am personally lucky that I also have a mom and sister nearby. While our life is a happy one it is also fraught with the stresses and challenges that come with special needs parenting: financial, emotional and physical. We do receive 12.5 hours a week in respite via SCWA. This is a massive necessity as I use this for grocery shopping, my own essential appts, etc. I would not thrive without these hours. Could they be increased? YES! Would that be of benefit to us? YES! Is it easy for this to happen; NO! It is very difficult to find "good help"; qualified, trustworthy, compassionate people to work unusual hours for 15$/hr. We have been lucky to have had success over the years with university students, as we have more of a part time need.*
>
> *I hate having to defend the reasons I need this respite. I wish it could be more, and I am grateful I do not have a parental contribution towards the pay for the respite. But I could use so much more and it would benefit my child so much more.*
>
> *During the summer months, there is no programming available (paid or funded) that is suitable for her needs. She is not able to be immersed into typical kid's camp due to behavior needs and intellectual disability. There are respite workers or 'babysitters' that can be hired but none would have the training/experience needed for her complex needs and would require 4-6 weeks of on the job (ie. Paid) training from us her parents.*

John told us:

> *There are no day camps or programs for lifelong learning or respite for children/teens/adults with special needs. If my child needed a camp or day program, I would be required to pay out of pocket for a respite worker to attend as well as the cost of the camp or day program. While I do not have any issue with paying for a much*

> *(Cont'd)*
> *needed service, the activities/structure/function/environment of offered camps and day programs available are not appropriate for my child and a respite worker would not have the skills necessary to assist my child in navigating eating, activity and transitions.*

Kelly said:

> *…the Government recognizes that these children require more expensive care than most other children and also recognizes that respite from the daily caring of these children is essential.*

Doubling back to the issue of crisis, a submission from Bonnie stated:

> *It is my understanding that when a parent/ family is in crisis, the only resources available to these parents is (Janeway hospital) counselling. This is a good solution but hardly helpful when the problem which has created the crisis in the first place is that there is no respite care…so that it is impossible for parents to juggle the medical needs of their disabled child and the needs of their other children. But how does a parent attend a counselling session to talk about the problem of respite care – if the respite care cannot be provided so that they can attend counselling?*
>
> …
>
> *As a society, we have closed our institutions which would have provided respite care for these children and shifted the burden of their care to their families without any assistance for that care unless the family is on social assistance, or the family is "in crisis".*
>
> …
>
> *We are dealing with these caregivers in a reactive way, having to respond to their health care needs exacerbated by the physical demands and stress caused by years of caring for their loved ones. Does it not make sense to intervene proactively by providing respite care that will allow these family caregivers to pause and give them some small respite from this lifetime burden of care?*
>
> …
>
> *One parent in our province was advised by a Social Worker that they would be better off if the couple divorced because then the mother, as a single parent, could go on social assistance and receive the financial help needed to meet the child's daily requirements and the respite care they so desperately needed. Is this honestly the best we can do in our province?*

It is not the best we can do, and when asked, HCS said that they would consider unmet family caregiver needs related to ease of access to home support, emergencies and after-hours specialized care options, as well as improved service accessibility options.

(**Appendix 1** contains all submissions received from HCS, CSSD, and the Health Authorities).

We offer the following recommendations related to quality respite care:

**Recommendation 3**

**(HCS) Respite care should be based on the needs of the child and not family income. Developing a standard criteria for assessing each medically complex child for symptoms and medical needs, (including those with undiagnosed or rare diseases), and funding based on needs, not income, would make this support system more equitable.**

**Recommendation 4**

**(Education) Engage with post-secondary institutions on the potential to review and develop curriculum to professionalize respite work in the area of medically complex citizens. This training exists in Canada in the form of Developmental Service Workers, a two-year program at Algonquin College in Ontario. Graduates of this program bring skills to families in areas such as basic pharmacology, awareness of psychological, social and cultural issues, physiology and recreational supports.**

**Recommendation 5**

**HCS, in partnership with the Department of Education, engage with Memorial University on the existence and/or potential development of a co-operative program that would provide a work term for students to work with families who have children with complex needs. Faculties/programs to consider could include Social Work, Psychology, Kinesiology and/or Music.**

## Future Planning

Children and youth with complex care needs are among the most vulnerable populations served by our health and social care systems.

Without exception, every parent interviewed expressed fear and dread on the subject of care for their medically complex child after they are no longer physically able to provide care and/or pass on. These feelings are internalized and ever-present. Family caregivers provide care throughout the continuum of their children's lives, from birth into adulthood until the family caregiver is no longer able to provide the level of care required. Caring for a child with complex care needs never stops.

Thinking about the future, however, can be frightening. Caregivers shared the following comments,

> *What happens when I am no longer able to care for my child? Who will care for them?*
> *I hope they pass away before I die.*

Creating future plans for children with complex care needs is a multifaceted process. Parents must consider many aspects of caretaking for their children including, but not limited to:

- Who will care for my child when I am gone?
- Where will my child live?
- Who will ensure my child receives proper medical/mental health treatment? Who will make decisions if they are unable? Should we consider guardianship?
- Who will manage my child's care?
- Financial security, wills and trusts – how do we ensure these are in place?

Caregivers have to consider and try to coordinate responses to all of these questions in addition to tending to the needs of everyday living. Positioned high on family caregivers' lists of concerns for future planning were housing and care after parents pass away.

The Government of Canada recognized the peril facing members of the disability community who need and seek independent housing in its national housing strategy.

> *People with disabilities face unique challenges in accessing affordable and appropriate housing. Inadequate social supports, insufficient financial assistance and inaccessibility of housing units all contribute to the difficulties they may face in their quest to live independently. People with disabilities are more than twice as likely to live on low incomes as those without a disability…*[4]

Caregivers identified a need for inclusive housing for their medically complex children to allow them to live independently, when possible, and with the community support to thrive and live with integrity and dignity.

Linda asked:

> *Why don't we have a communal residency program like other provinces? About 10 years ago the community tried to get something on the go but another non-profit group put an end to it stating it wasn't inclusive (the residents didn't have a choice, etc.). Do they have a choice about living in substandard boarding houses that are dirty and be taken advantage of or worse? Is this better than a formally run residence?*
>
> *We can leave money and our homes to our children, but upkeep and running the home may be out of their scope. We need an accountable and trusted place for our children so that we can at least die in peace.*

In relation to the topic of future planning and residential options, HCS said,

> *A review of residential supports is ongoing as a joint initiative between HCS and CSSD. The review is examining residential options available in Newfoundland and Labrador for children, youth and individuals with various conditions requiring supports, receiving input from stakeholders including family caregivers and individuals with lived experience, and exploring residential models from other jurisdictions and the research literature. Once completed, the recommendations from the review will be used to inform the future direction of residential supports in this province, including supportive options for individuals experiencing complex needs and their families.*

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[4] https://assets.cmhc-schl.gc.ca/sf/project/placetocallhome/pdfs/canada-national-housing-strategy.pdf?rev=7d7a4713-2f37-4cf0-a13e-68d278867630

**Recommendation 6**

**HCS should report to OCR semi-annually on its study of the upcoming residential support needs for medically complex children and adults, together with results on cross-jurisdictional research on innovative models that exist elsewhere.**

Another area of concern identified during our engagement with families related to future planning was the transition from children's services to adult services. The needs of children with complex health care needs do not go away when they reach the age of 18.

> *Once my child exits school, there is nothing available for programming (paid or funded) year-round. Should she require admission to long term care, she will be sedated and restrained; there are no centers with caregivers or facilities/equipment that would be able to safely engage her into activities of daily living or provide meaningful and therapeutic benefit. At present she is on no medications and receives sensory regulation for behavior management at school and home, as prescribed by OT.*
>
> Written submission: Yvonne

## Navigating Systems

Family caregivers told us their children need more and varied health and social care services than average families, as well as a high degree of coordinated care.

Family caregivers have difficulty navigating health and social care systems to identify and access the programs and services that are available on a federal, provincial and community level. System navigation is even more challenging when the child with complex needs does not have a diagnosis or the diagnosis is rare.

Joy expressed her "dream" for system navigation:

> *A team of experienced parents/caregivers/health care professionals that can act as a contact point for provision of navigating the pediatric health care system, provide planning/insight for school planning/programming and to provide the overarching umbrella that links all programs/facilities/organizations/agencies.*

The need for advocacy and assistance in navigating the various service systems was a predominant theme we heard. Families told us 'silos' exist at many levels.

On a provincial level, these systems include three separate Departments (Education; HCS; and CSSD) and other community and private services. Each system brings with it an array of programs and eligibility criteria. Family caregivers described the need for a contact person they could call with questions about available services to help ensure they are connected to the right people.

Some caregivers referred to what they called the “Backdoor doctor or backdoor health care provider”. These individuals often step outside their normal role and go above and beyond to try to support caregivers in accessing the support they need. Caregivers said they do not get the help they need because they did not know who to ask or where to get the information. Even worse, the service is not available; they do not meet the eligibility criteria; or there are long waitlists.

Families of children living with rare diseases have a more challenging time navigating health and social care systems. They can have a difficult time finding accurate information and effective treatments. It is even harder if they don’t have a diagnosis. The Canadian Organization for Rare Disorders (CORD), says there are estimated to be more than 7,000 rare conditions identified in Canada. Rare diseases affect one in 12 Canadians, many of whom are children.

Rare diseases often place a profound burden on individuals and families and, with few exceptions, there is a lack of specialized and/or accessible social services, such as therapeutic recreation programs and respite care. This stems, in part, from a lack of awareness among providers of social services.

Many rare diseases have limited medical interventions (of 7,000 known rare diseases, fewer than 5% have effective therapeutic interventions) and many require ongoing care. As noted in the CORD survey, most community-based services (such as education, disability and employment) are perceived as having little awareness or knowledge about rare diseases, making access to services limited. Worse again, when patients and families apply, there are challenges to recognizing their needs because the disease may not be identified as one eligible for assistance or other benefits.

In an April 2019, CORD national survey of patients and their caregivers[5], CORD found:

* Almost 80% of rare disease caregivers suffer from mental health issues as a result of their caregiving responsibilities.
* 68% reported that caring for someone with a rare disease has negatively impacted their work performance.

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[5] https://www.raredisorders.ca/canadas-rare-disease-caregivers-under-immense-stress-struggling-with-mental-health-issues-isolation-and-financial-burden/

- 63% have taken on debt because of their caregiving responsibilities.
- 70% feel that their caregiving role has put a strain on their marriage/intimate relationships.

Family caregivers dealing with rare diseases said they face multiple unmet needs because of the lack of care coordination and support. They also expressed the need for support in accessing services and navigating the complex health care and social care systems.

The standardization of criteria for assessment of medically complex children based on symptoms and medical needs, especially those with rare or unknown diagnoses, is a consistent theme we heard from parents and caregivers. Exclusion from program eligibility based on a subject not "ticking all the boxes" has led parents and caregivers further away from being able to adequately cope with the challenges they face. This exclusion deprives these children and adults, particularly those with rare disorders, from accessing meaningful therapeutic opportunities.

### Recommendation 7

**HCS should conduct consultations with those affected by rare disorders to work toward better standardization of eligibility criteria to include persons without diagnoses and who have rare disorders, in order to promote inclusion and better serve this population.**

HCS acknowledged the challenges experienced by families of children and adults with complex needs, and said they have been working to address these concerns. On the subject of System Navigation, HCS stated:

> *Publicly funded services for children with complex care needs are primarily funded through the Department of Health and Community Services (HCS).*
>
> *The Regional Health Authorities (RHAs) are funded to manage the administration and delivery of services*[6].

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[6] We acknowledge that in the intervening period, the province's four former regional health authorities transitioned to become NL Health Services, the province's single, provincial health authority.

> *(Cont'd)*
> *HCS is responsible for the development of health care policies and strategic direction, while the RHAs are responsible for the delivery of health care services. HCS works collaboratively with the RHAs to support implementation and monitoring of programs and services, but does not directly provide any intervention or supportive services to individuals or families.*
>
> *There are a number of health programs and services offered in our current system to support children, youth, individuals and their families, including those with complex needs. Financial supports, respite and home support options, early intervention and therapeutic programs, behavioural intervention, mental health supports, medical equipment and supplies and residential options are available to help address and support various components of care. Despite this broad array of services, numerous reports and action plans, including the content of your letter, have raised concerns with the current system and have highlighted the need for consistent intake processes, equitable access, additional services, quality service delivery, increased parent and caregiver supports, coordination of services and collaborative support planning.*
>
> *To be responsive to these systemic issues, substantial change is required to transform the way community health services are delivered to children, youth and individuals with complex needs and their families. As such, significant work is underway at HCS, in collaboration with other government departments, the regional health authorities and community organizations, to develop new models of care that incorporate and streamline existing programming, and offer new programs intended to address diverse health and support needs. Understandably, all of the necessary systemic changes cannot be introduced simultaneously but must be integrated methodically over time, and thus are at various stages of implementation within the RHAs.*

The submissions found in **Appendix 1** provide an inventory of the existing programming (including those offered by RHAs); descriptions of new services under development; and additional planned improvements to services available to children, youth and adults requiring supports, and their families.

HCS said they recognize that eligibility for and access to programs can be limited, acknowledging that some programs are only available to certain age groups, diagnoses, and/or income levels. HCS also said they recognize there have been gaps in the system regarding crises and therapeutic/peer support for family caregivers, which is affecting the health and well-being of those with complex needs and their families.

Specific to the issue of navigation, HCS further acknowledged that the current model of health service delivery is complex, fragmented and inefficient with significant barriers to information sharing and collaborative practice for family caregivers. They identified that under the new Child and Youth Community Health (CYCH) model and Supporting Abilities program, many of the provincial programs will be updated to ease navigation and to be more inclusive and responsive to the needs of children, youth, individuals and families.

**Appendix 1** also provides information on the CYCH model and the Supporting Abilities program. Within this framework, HCS outlines how service navigation within the CYCH model will be addressed.

HCS highlighted that existing provincial policy manuals for many programs and services are dated and new standards are under development. Eligibility criteria for the new provincial CYCH model and Supporting Abilities program is also under development and will be integrated in the RHAs over time.

In addition to the CYCH and Supporting Abilities initiatives underway, HCS has approved new system navigator positions to work with the existing mental health navigator to establish a provincial navigation network for community-based services across a person's lifespan. These navigators will act as an access point for community-based services; support individuals and families to navigate the health system, government departments, community organizations, and external private providers (e.g. home care agency operators); facilitate referrals to appropriate services within the health system and in community; and, seek to remove service barriers for individuals and families. Planning is underway for the navigator program, with implementation expected in the near term.

The Model for the Coordination of Services to Children and Youth is a framework whereby partner departments and their respective agencies provide coordinated supports and services to children and youth in the province. We found that family caregivers face shortcomings navigating the system with regard to the connections within and among the networks involved in helping children with complex care needs. An Individual Support Services Plan (ISSP) is central to the current model of service provision for special education. With respect to both the ISSP and the Model for Coordination of Services, HSC said:

> *The ISSP and the Model for Coordination of Services has been revised and the new Coordinating Supports for Children and Youth Process is being finalized. This is a streamlined process to coordinate supports for children and youth with complex needs. It highlights one comprehensive plan with clearly defined roles and responsibilities for the members of the child/youth team. This process is inclusive of all child-servicing departments, agencies and partners, and includes an information sharing protocol and shared consent. There are regional and provincial committees for oversight embedded into this process.*

The Department of Children, Seniors and Social Development (CSSD) advised it has minimal involvement providing direct programs and services to children with complex needs or their caregivers. CSSD is responsible however, for Child Protection and In-Care (including Foster Parent and Kinship programs); Disability Policy Office (DPO); Income Support; and, the Division of Seniors and Aging.

CSSD brought forward some concerns regarding children with complex needs transitioning out of the school system. They said the Disability Policy Office has heard concerns regarding limited programming for adults with complex needs, as well as a lack of access to full-time programming. CSSD also said when children leave school, they are required to be placed on waitlists in order to access the limited supports available to them, as opposed to having a transition period where there would be no gap in service.

We are encouraged by the intention to create the System Navigator Program. We offer the following recommendation to augment it:

### Recommendation 8

**Government, via HCS, should facilitate the creation of a Ministerial Advisory Committee with significant parental/caregiver representation to establish clearer lines of communication between parents, caregivers and policymakers.**

## Inclusion

Yet another gap exists in the availability of day programs, summer camps, or other enrichment activities for children and young adults with special needs.

For parents of medically complex children and adults, the worry about the care and well-being of their children never ends. Unlike other children who will become independent adults, their children will be dependent adults, at which time they will be limited to the confines of the nuclear or extended family because there is little or no provision for daycare or activities as they age.

> *In our province, Vera Perlin provides daycare and activity services for 75 disabled adults, with a waiting list of 100, some of whom have been on that list for 30 years. (The organization) is aware of about 200 more individuals that have no services and (it is) aware of the incredible stress this causes to the aging caregivers of these adults. Many professionals that (the organization) has talked with within the system have said this is a looming crisis.*
>
> Written submission: Jason

According to the Vera Perlin Society website:

> *As part of its mission statement, the Society seeks to work with other affiliated agencies in fostering the development and happiness of individuals with a developmental disability in our community.*
>
> *Today, the Vera Perlin Society provides services in areas of:*
> * *Career Development*
> * *Employment*
> * *Administration*
> * *Case Counselling*
>
> *In addition, the Society provides outlets for socialization and even entertainment via the Perlin Players.*

Inclusion Canada Newfoundland and Labrador also has a presence in our communities:

> *Inclusion Canada Newfoundland and Labrador is a non-profit organization that works with and on behalf of persons with intellectual disabilities and their families. Inclusion Canada Newfoundland and Labrador promotes a vision of communities where everyone belongs and has a rightful place; where families support a person's right to full citizenship.*

These organizations and others are well-positioned to assist this subset of our provincial population, and their families. Bolstering the ability of the community sector to serve medically complex children, adults and their caregivers, will be of key importance moving forward.

**Recommendation 9**

**HCS should undertake a meaningful study and develop an action plan on programming options for medically complex adults, and increase support for the community sector to develop and deliver enhanced programming. Likewise, the provincial government should look favourably on any other existing or emerging community-based or business organizations that can fill these existing gaps in services to medically complex children and adults.**

## Therapeutic Services

Family caregivers told us they are without therapeutic services to support their emotional and mental health needs while managing very complex care requirements of their children.

In the absence of a high level of support to family caregivers, there is burnout. Family caregivers told us that burnout is the trigger point for crisis, which precipitates intervention by the province. The services that become available from the province are provided in the short term to mitigate the crisis, and then are generally unavailable in the long term, resulting in another inevitable path to burnout.

Family caregivers who shared their experiences with our Office spoke of the great solace they take in online peer support. While many use the internet and social media as recreational outlets, family caregivers spend most of their time online seeking support. They conduct research; connect with others who are living the same experience; and provide advice based on lived experience, especially to parents of very young medically complex children who are embarking on their health care journey.

Many of them referenced “Welcome To Holland” by Emily Perl Kingsley, (reproduced with permission of the author on the back cover of this report) as a source of inspiration at times when they feel like they can’t go on.

According to Statistics Canada:

> *Even though this caregiving is generally considered beneficial because of the savings achieved and the well-being of the care recipients, taking on such responsibilities can have consequences for caregivers. In particular, those who care for their child or spouse are more likely than others to be experiencing difficulties as a result of their tasks. In addition, they are more likely, because of their caregiving responsibilities, to experience psychological consequences, health effects, pressures on their personal finances and possible consequences in their career.* [7]

During our focus groups we heard many parents describe the physical and emotional toll that caring for their children can have. Although most parents described the same feelings, some admitted to feeling guilty about voicing these complaints as if it was a negative reflection of their parenting.

We also heard that the attitude from some government staff would also reinforce this guilt, such as comments like "this is your duty as a parent" when parents would seek help and supports.

Leanne stated:

> *"The last time I voiced my concern over the financial aspect of autism is when [a service provider] visited our home with [another service provider] at the time. I told her that the cost of autism was overwhelming, she replied 'well you knew that there would be expenses involved when you decided to have children." I am not asking for a handout. I am asking for the assured wellbeing of my children after I am gone. It's a basic human right.*
>
> …
>
> *I have back issues, high blood pressure and high cholesterol; I am only 38 years old. I feel my body is overworked with lifting, organizing, planning, in a way most mother's my age do not. I feel this is a reality for many parents acting as caregivers. I hardly have the time to take care of myself physically, which of course leads to more stress about who will care for my child when I am gone. If I had more supports for myself as a caregiver, I could take care of myself better and in essence be healthier for my child.*
>
> Written submission: Jacqueline

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[7] https://www150.statcan.gc.ca/n1/pub/75-006-x/2013001/article/11858-eng.htm

**Recommendation 10**

**(HCS) Resources need to be found and allocated to increase the availability for therapeutic counselling and referral options for parents and family caregivers who are facing burnout.**

## Impact

Family caregivers of medically complex children and adults face an ever-present and obvious threat to their financial security. According to the Royal Bank of Canada[8], the cost of raising children in Canada can vary between $10,000 – $15,000 per child per year. Of course, costs differ contingent on choice of lifestyle and where you choose to set up a home; but the broad cost to a family including food, shelter, clothing, schooling and preparing the home for the arrival of a child remain the same.

Families of children with complex needs have financial needs that far exceed what would be considered the norm. Respite care, medical supplies, equipment, insurance premiums and therapeutic supports are among those needs. The ability of families to earn an income that would reasonably attend to these needs is challenged by the level of daily personal care that these families must provide to children. These do not wane with age. In fact, they may increase if a medical situation becomes more complex or acute.

Some family caregivers shared they have been left with no choice but to sacrifice their careers and ambitions to provide the level of care their child requires.

Hannah told us:

> *I have sacrificed my career over the years and worked in high stress jobs for benefits mostly…I stayed in my entry-level job and was able to go part time to make sure that my child was able to go to the many appointments that were weekly. So I decreased my income so that he could get to every appointment and service out there.*

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[8] https://discover.rbcroyalbank.com/the-cost-of-raising-a-child-in-canada/#:~:text=According%20to%20several%20published%20estimates,broad%20costs%20remain%20the%20same

Julia told us:

> *The government does not provide any of the necessities of looking after a child with complex needs unless the family has an income that is below the financial threshold. This means that unless the family has insurance coverage through a work plan, the entire burden of the care requirements for that child are borne by the parents. Many health plans cover a minimum of items per year.*

Rachel wrote:

> *Once your child attends school, things like physio, occupational therapy and speech therapy is more with the school system and not very often. Even though my child still needed the services, they were disappearing. So we pay for private in all of those so he has the opportunity to excel.*
>
> *We applied with the province and were told again we "looked too good on paper"…but we were drowning in bills. Special equipment costs a lot and are never covered by insurance. There is so much never covered by anyone. Even when we were approved for some respite we have a huge co-pay each month. Over the years we were told if we were divorced, we would get more services from the province in help with respite and supplies. Yet that will impact our child who needs both of us.*
>
> *One parent I know was advised by a social worker they would be better off if the couple divorced because the mother, as a single parent, could go on social assistance and receive the financial help needed to meet the child's daily requirements and the respite care they so desperately needed.*
>
> *We had to get a van because a car is not big enough for the wheelchair, walkers and equipment that is needed for basics. So we pay a fortune in gas.*
>
> *Psychologically, the lack of help for parents of disabled children/adult children with complex needs make them feel overwhelmed, with a life sentence of physical demands with little support and without the necessary equipment that would help.*
>
> *They often feel that there is something wrong with them when they feel unequal to the task and feel overwhelming guilt that they cannot manage this unrelenting care that their disabled child/adult requires.*

The financial requirements imposed on family caregivers do not afford stability for most of the families who shared their stories with us. Some self-identified a sense of negative self-worth.

Family caregivers also move daily between two very different roles: parent and caregiver. One family caregiver stated they simply no longer feel like a parent, only a nurse. Nursing was a common theme heard throughout our interviewing process. While the system generally refers to the parenting role, the daily medical care they are taught to provide must be acknowledged.

In *Continuity of Care for Children with Complex Chronic Health Conditions: Parents' Perspectives*[9] the authors cite the experiences of parents providing parental and medical duties. Forty-seven parents took part. One parent of a child with Duchenne Muscular Dystrophy stated:

> *Not only are you dealing with your child, you're dealing with the disease. You're dealing with the frustration of trying to get some kind of help, guidance, expert advice and it's like two big jobs. You're finding out as much as you can about the disease and looking after your family, but you're also having to search, in all these different areas for help.*

In addition, the authors speak to informational continuity; specifically, how information regarding their child's health becomes lost in translation between various service providers, or being required to act as the person who is expected to understand, remember and explain information from one service provider to the next that is involved in their child's care. This requires vigilance over and above the disease/disorder or the daily management of symptoms and heightened vigilance in acute hospital settings, as stated earlier in this report.

Over and above the financial toll and assuming the dual role of parent and nurse, family caregivers shared that their experience of providing a high level of care to a child with complex needs has an overall impact on the social and developmental well-being of the whole family. Family caregivers self-identified as isolated, as it is more challenging for them to participate in active and meaningful spousal relationships, friendships, and family and community gatherings.

In their own words, here is some of what we heard:

> *I also have a son, and I think that it is not fair to him and our family to have to use all of our resources, savings and time and effort for my daughter and not have any for the rest of my family.*
>
> …

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[9] https://pubmed.ncbi.nlm.nih.gov/20025770/

> *We are given 15 hours a week respite, which is used mostly to buy groceries and run around getting what my child needs. There is no date nights. There is no time for myself and my husband to just be a couple. That is long gone. Instead it is all about our child and what they need.*

A submission we received from an extended family member of a medically complex child gave a third party account of one family's situation:

> *There is no family time because one parent must always be feeding or monitoring. Suppertime and bedtime can be an ordeal especially if the other children have activities around those hours. There needs to be two people during this time period because important anti-seizure medication and sleeping medication are administered during this time and supper needs to be prepared and (the sibling) put to bed…The disabled child has nighttime seizures and vomiting so needs to be monitored through the night by one parent – which means interrupted or limited sleep for both on alternate nights…I do not know how other parents, caring for children with complex needs, manage without extended family support… Unfortunately, things will not get better but get worse as grandparents are no longer able to physically help.*
>
> …
>
> *There is seldom family time because of our child's feeding schedule, which requires difficult to transport equipment. Family members babysit to allow doctor's appointments, teacher interviews etc. – all the necessary things one has to do raising a family. There is seldom any time to allow for personal care for either parent. Nor is there any time for them to spend with each other because of the constant demands for care. They have no social life because they are using extended family to help them do what is essential….Extended family are used so much for helping with the essential that asking for further time for non-essential activities makes them feel guilty. Any socializing must be done in their home because accommodating their disabled child's needs in someone else's home is impossible without the required equipment. Often, they are just too exhausted to make the effort to invite others over.*

Family caregivers are expected to dedicate their time, finances and medical knowledge to the care of their medically complex children at the expense of the social and developmental well-being of the family as a whole. This 24/7 care comes at a cost of social isolation and compromised relationships; deterioration in physical and mental health; and redefined family roles resulting in harm to the development of the family unit as a whole.

**Recommendation 11**

**(HCS) To augment Recommendation 8, HCS should develop a central internet hub for information for this subset of our population. A provincial care and special needs support system where all resources and links for all associations and organizations that offer programs and supports for medically complex children and their parents and caregivers can be found.**

## A "Caregiver Recognition Act"

The provinces of Quebec (2020) [10], Manitoba (2011) [11], and Ontario (2018) [12] have passed Caregiver Recognition Acts. We recognize that caregivers in this province go beyond parental caregivers to medically complex children and adults and include those giving care to seniors and others in their homes.

Each of the provinces referenced above include general principles relating to caregivers and designate a day or week in the calendar for caregiver recognition. In addition, Quebec and Manitoba especially enshrine consultation, reporting, and in Quebec's case, a national policy for caregivers and an action plan to implement it.

Manitoba's explanatory note succinctly implies their intent:

> *This Bill sets out general principles relating to caregivers and proclaims the first Tuesday of April in each year as Caregiver Recognition Day. The government is to promote the general principles and to consider them when developing, implementing, providing or evaluating caregiver supports.*

The minister is to consult with caregivers and others, and may establish an advisory committee to provide advice. Every two years the minister is to provide a report on caregivers, which is to include an inventory of caregiver supports.

We believe a natural sponsor of such legislation would be HCS. Passage of such legislation can only be of public value, and in no way a detriment.

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[10] Appendix 2 https://www.legisquebec.gouv.qc.ca/en/document/cs/R-1.1

[11] Appendix 3 https://web2.gov.mb.ca/laws/statutes/2011/c03211e.php

[12] Appendix 4 https://www.ola.org/sites/default/files/node-files/bill/document/pdf/2018/2018-11/b059_e.pdf

**Recommendation 12**

**HCS work to draft and sponsor Caregiver Recognition Act legislation that raises awareness and recognition of caregivers and to support them in their role. We regard Quebec's "Act to Recognize and Support Caregivers" as the current national benchmark legislation.**

## Canadian Home Care Association ("CHCA") Report (2016)

Our office conducted scans of previous research and reports related to issues of family caregivers. One report that was particularly relevant to the issues identified in this report was conducted by the CHCA. The CHCA is a national non-profit membership association dedicated to ensuring the availability of accessible, responsive home care, and community supports to enable people to safely stay in their homes with dignity, independence and quality of life. Members include governments, health authorities, administration organizations, service providers and researchers.

During 2015, the CHCA conducted a pan-Canadian review to gain an understanding of the programs available in each province and territory for children with complex care needs. Their 2016 report, entitled "Home and Community Based Services and Supports: Children with Complex Needs" [13]stated:

> *Children and youth with complex care needs are among the most vulnerable populations served by our health and social care systems. Life-saving interventions and advances in medical technology enable children with complex care needs to live well into adulthood and beyond. The often-complicated health and social systems require parents and other family members to learn a variety of skills and develop incredible stamina to enable their child to remain safe at home and active in the community.*
>
> *Community and home-based care programs provide many opportunities and advantages for children with special needs. They often require an array of health education, social and other services to live safely at home, with their families, and in their communities. While there are many innovative programs currently in place in provinces and territories across the country to support children at home and at school, many obstacles inhibit children with special needs and their families from obtaining the necessary aids and devices, treatment, financial assistance and support they require.*

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[13] https://cdnhomecare.ca/wp-content/uploads/2020/02/CHCA-Children-with-Complex-Care-Needs.pdf

Although this report is eight years old, it was very informative for purposes of our investigation. Chief among the concerns we have is that many of the same gaps and challenges identified in the report's section on the province of Newfoundland and Labrador still resonate with end users of these systems.

Examples include:

1. Defining children with complex care needs: a lack of common definition impacts eligibility for programs, planning for these children and measuring the success of program outcomes [14].

2. Accessing data: there is still limited data to monitor, evaluate and improve home care services to a population the government can't quantify.

3. Parent challenges: parents and caregivers need respite, information, training and financial support.

4. Fragmented services: limited coordination of care and services across multiple government ministries and programs.

5. Rural and remote access: limited expertise, support and resources as care moves away from the urban pediatric hospital.

6. The need for increased specialized pediatric training and education for home support staff.

7. Pay scales for home support workers do not reflect the differences in responsibilities and care requirements for those providing care to children with complex care needs.

8. Complicated and prolonged funding procedures and processes for families requiring support services.

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[14] To date, "complex care needs" remains undefined.

The gaps identified by CHCA in 2016 echo what we heard in focus groups conducted late in 2022. These gaps were also acknowledged by HCS which advised:

> *(HCS recognizes) eligibility for and access to programs can be limited, since some programs are only available to certain age groups, diagnoses, and/or income levels. (Also) recognize there have been gaps in the system regarding crisis situations and therapeutic/peer support for family caregivers, which is affecting the health and well being of those with complex needs and their families. The current model of health service delivery is complex, fragmented and inefficient with significant barriers to information sharing and collaborative practice, contributing to the concerns you have brought forward on behalf of family caregivers.*
>
> ...
>
> *To be responsive to these systemic issues, substantial change is required to transform the way community health services are delivered to children, youth and individuals with complex needs and their families. As such, significant work is underway at HCS, in collaboration with other government departments, the regional health authorities and community organizations, to develop new models of care that incorporate and streamline existing programming, and offer new programs intended to address diverse health and support needs.*

## Conclusion

The Office of the Citizens' Representative will monitor the recommendations contained in this report via annual follow-up, and it will advise the House of Assembly of the progress of their implementation. We recognize these are not immediate short-term fixes; however, it is imperative that the work progress for these parents, caregivers, and medically complex children and adults. It is our assessment that this is a looming public health problem.

The vast majority of parents and family caregivers who shared their individual circumstances with us have faith that government has the resources and talent available to fix the problems both they, and the government acknowledge exist. Until these drastically important changes are made, they will continue to hang on by a thread.

# Acknowledgement

The Departments of Health and Community Services; Education; Children, Seniors and Social Development; and NL Health Services were provided with a draft copy of this report with an invitation for commentary.

The Department of Education agreed to engage with post-secondary institutions and Memorial University to work towards improving a quality of respite care available to families.

The Department of Health and Community Services acknowledged the challenges experienced by families of children and adults with complex needs stating: "We have been continuing to work on various initiatives to address these systemic concerns and remain committed to taking further action to address them."

The Department of Children, Seniors and Social Development (CSSD) provided the following commentary:

> *Through the Disability Policy Office, CSSD's on-going connection with the community of and for persons with disabilities continues to highlight the gaps in appropriate programs and services for medically complex individuals, especially as they transition into adulthood and across the life span. The community of and for persons with disabilities continue to express concern regarding aging parents and caregivers of adults with medically complex needs...CSSD remains supportive of all improvements in programs and services that positively influence the inclusion of persons with disabilities.*

Further, in response to a quote from a caregiver (p.8) which suggested that the only system in place to support a family in crisis is to remove the disabled child and place them in a group home, CSSD stated:

> *While we recognize this perception exists based on the experience of caregivers and parents within the healthcare system, CSSD does not support this approach. When the department is made aware of situations where this is occurring, we have addressed this concern in the moment.*

We thank these entities for the attention given to this investigation and report. Their feedback and ongoing commitment to family caregivers is necessary and valued.

# Appendix 1

**Submissions from Departments and Regional Health Authorities:**

Department of Health and Community Services
Department of Children, Seniors and Social Development
Eastern Health
Central Health
Western Health
Labrador-Grenfell Health

Newfoundland Labrador

Government of Newfoundland and Labrador
**Department of Health and Community Services**
Office of the Deputy Minister

COR-2022-180710/01

October 21, 2022

Bradley Moss
Citizen's Representative
Office of the Citizen's Representative
citrep@gov.nl.ca

Dear Mr. Moss:

I am writing in response to your correspondence from August 11, 2022, regarding your office's "own initiative" investigation pertaining to supports, services and programming for family caregivers of children with complex needs. My apologies for the delay in sending this response. The Department of Health and Community Services (HCS) acknowledges the challenges experienced by families of children and adults with complex needs, and we have been working to address these concerns.

There are a number of health programs and services offered in our current system to support children, youth, individuals and their families, including those with complex needs. Financial supports, respite and home support options, early intervention and therapeutic programs, behavioural intervention, mental health supports, medical equipment and supplies and residential options are available to help address and support various components of care. These programs are described in detail below. Despite this broad array of services, numerous reports and action plans, including the content of your letter, have raised concerns with the current system and have highlighted the need for consistent intake processes, equitable access, additional services, quality service delivery, increased parent and caregiver supports, coordination of services and collaborative support planning.

To be responsive to these systemic issues, substantial change is required to transform the way community health services are delivered to children, youth and individuals with complex needs and their families. As such, significant work is underway at HCS, in collaboration with other government departments, the regional health authorities (RHAs) and community organizations, to develop new models of care that incorporate and streamline existing programming, and offer new programs intended to address diverse health and support needs.

Understandably, all of the necessary systemic changes cannot be introduced simultaneously but must be integrated methodically over time, and thus are at various stages of implementation within the RHAs. In light of current initiatives underway, and in response to the information requested, I am providing information on existing programming, descriptions of new services under development, and additional planned improvements to services available to children, youth and adults requiring supports and their families.

1. **Information about any existing programs and supports available for family caregivers specific to the Department of Health and Community Services.**

HCS is responsible for the development of health care policies and strategic direction, while the RHAs are responsible for the delivery of health care services. HCS works collaboratively with the RHAs to support implementation and monitoring of programs and services, but does not directly provide any intervention or supportive services to individuals or families. Therefore, in this correspondence I will provide high-level information about provincial programs and services that support family caregivers of children with complex needs, and the RHAs will be responding to you with complementary information specific to service delivery in their regions.

Currently, Community Supports Services (CSS) are available for children, youth, adults with disabilities and their families to assist with living at home or in a community setting, and information is available at https://www.gov.nl.ca/hcs/personsdisabilities/fundingprograms-hcs/. CSS programs include:

- **Special Child Welfare Allowance (SCWA)**, which provides assistance with the cost of services and supports for a child or youth (under the age of 18 years) with a physical or intellectual disability living at home. Eligibility for this program is in the process of being expanded beyond diagnosis of physical or intellectual disability and will include children and youth assessed as requiring supports to function well in their daily lives, including those with Autism Spectrum Disorder (ASD) and complex needs. This expanded eligibility criteria is in the process of being implemented across the RHAs.

- **Intervention Services**, which consists of two programs to support families in managing challenging developmental and/or behavioural concerns:
  - The **Direct Home Services Program** provides individualized skill teaching and behavioural strategies to families with infants and preschool-aged children who display or are at risk for significant developmental delay, with the goal to achieve positive gains in the child's development. This program also includes the intensive Applied Behavioural Analysis (ABA) home therapy program that is available for children with a diagnosis of ASD up to Grade 3.
  - The **Community Behavioural Services Program** is available for individuals school-aged and older who are diagnosed with an intellectual disability and demonstrate significant behavioural concerns. The program provides intervention and support to individuals and family caregivers to address and manage challenging behaviours within home and community environments.

- **Therapeutic and Professional Services**, which provides speech-language pathology, occupational therapy, physiotherapy, psychology, social work, audiology, dietetics and nursing services to children, youth and individuals requiring supports.

- **Provincial Home Support Program**, which provides personal care, household management, respite and behavioural supports at the minimal level for adults with disabilities to maintain individual independence. These services are intended to supplement, but not replace, care provided by the individual's family caregivers and/or support network. Services are delivered from an approved agency or by an individual hired by the family.

- **Special Assistance Program**, which provides basic medical supplies and equipment to eligible families to assist with activities of daily living for children, youth, and adults requiring supports. While this is not a direct family caregiver support, it can reduce the financial burden for families when supporting their children, youth and adults with disabilities. Examples of medical supplies and equipment provided by the program include:
  - Medical supplies (such as dressings, catheters and incontinent supplies);
  - Oxygen and related equipment and supplies;
  - Orthotics such as braces and burn garments; and,
  - Equipment such as wheelchairs, commodes or walkers.

- **Residential Options**, which provide supports for adults with disabilities to reside in home settings in the community. There are several residential support options available including Board and Lodging Supplement, Alternative Family Care, Cooperative Apartments, and Individualized or Shared Living Arrangements. The residential option most relevant to family caregiver support is the Board and Lodging Supplement, which is a funding supplement available to adults 18 years of age and older with psychiatric, physical and/or intellectual disabilities who reside with relatives or non-relatives and have identified needs that require a higher board and lodging rate to remain living in these arrangements.

Additionally, there are many programs that provide mental health and addictions supports and services across the province, which include:

**Provincial Services**

- Janeway Outpatient Psychiatry services are available for individuals 18 years of age and younger.
- The Hope Valley Treatment Centre is for individuals ages 12-18 with addictions issues.
- The Tuckamore Treatment Centre is for individuals ages 12-18 with complex mental health and behavioural issues.
- The HOPE Program is for individuals 15 years of age and older with eating disorders. The program is a provincial intensive outpatient program and provides specialized group-based and individual therapy, provided by an interdisciplinary team of health professionals, including nursing, psychology, social work, occupational therapy, clinical nutrition, physiotherapy, a consulting medical practitioner and psychiatry. Outpatient counselling for individuals with eating disorders under the age of 15 is also available in all RHAs, in consultation with a pediatrician.
- The Recovery Centre is for individuals 16 years of age and older who need help withdrawing from alcohol, drugs or gambling.
- There are 23 youth outreach workers located throughout the province who provide supportive services to children and youth in schools.

- There are over 60 Doorways walk-in clinics throughout the province that provide counselling services for ages 12 years and older. Seven clinics are located in high schools with plans to expand to more high schools.
- A Child and Adolescent Trauma Team offers case consultation for clinicians working with children, youth and parents related to intergenerational trauma, such as physical, sexual and emotional abuse, as well as online abuse.
- The Provincial Mental Health and Addictions Systems Navigator helps individuals navigate and connect with mental health and addictions services in the province.

**Online Services (all of which are located on www.bridgethegapp.ca)**
- Therapy Assistance Online (TAO), for individuals 16 years of age and older.
- BreathingRoom, for individuals 13 years of age and older.
- MindWell-U 30-Day Mindfulness Challenge, for individuals 16 years of age and older.
- Strongest Families Institute (SFI) positive parenting programs for parents of children up to four years old, and anxiety and behavioural health programs for children ages three to 17 years.
- SFI ICAN (Conquer Anxiety and Nervousness) program, for ages 18 years and older.
- Kids Help Phone (1-800-668-6868)
- Crisis Text Line (686868)

**Regional Services**
<u>Eastern Health:</u>
- Child and Youth Central Intake allows for one central phone number for those interested in self-referring to any mental health and addictions services.
- Janeway Family Centre provides individual and family-based therapy.
- The Bridges Program serves 13 to 18 year olds, and provides short-term psychotherapy, family therapy, group work and psychiatric consultation.
- The Connect Team serves young people with complex needs, and coordinates services with other youth-serving organizations.
- The Psychosis Intervention and Early Recovery Program (PIER) is for individuals aged 16 years and older.

Central Health
- Generalist counsellors see individuals across the life span.
- A psychologist at the Hope Valley Treatment Centre provides assessments in the community, when capacity allows.
- There is currently no child and adolescent psychiatrist in the region. A clinical associate overseen by a psychiatrist will see younger clients, otherwise referrals are made to Child/Adolescent programming at the Janeway.

Western Health:
- Children and youth are seen in all six mental health and addictions offices across the region.
- Blomidon Place provides mental health promotion, education and prevention services, consultation, coordination, assessment and counseling services to children and youth (under 19 years old) and their families.

- Psychiatry for children and youth is accessed through the Janeway for individuals up to age 16. Individuals who are 17 years and older are seen by adult psychiatry.
- Early Psychosis program provides early recognition, identification, assessment and treatment of first episode psychosis for people aged 16 years and older.

Labrador-Grenfell Health:

- Generalist counsellors see individuals across the life span.
- One psychologist provides counselling and assessments across the life span.
- Psychiatry for children and youth is accessed through the Janeway.
- An Interdisciplinary Diagnostic Clinic for ages eight to 18 years offers consultation, assessment, and diagnosis, as well as education on the effects of Fetal Alcohol Spectrum Disorder (FASD) and how to best care for someone with FASD.

I recognize eligibility for and access to programs can be limited, since some programs are only available to certain age groups, diagnoses, and/or income levels. I also recognize there have been gaps in the system regarding crisis situations and therapeutic/peer support for family caregivers, which is affecting the health and well-being of those with complex needs and their families. The current model of health service delivery is complex, fragmented and inefficient with significant barriers to information sharing and collaborative practice, contributing to the concerns you have brought forward on behalf of family caregivers. However, under the new Child and Youth Community Health (CYCH) model and Supporting Abilities program, many of the provincial programs noted above will be updated to ease navigation and to be more inclusive and responsive to the needs of children, youth, individuals and families. An overview of the CYCH model and the Supporting Abilities program is provided below as a response to question #6.

2. **Information about any policies and procedures related to programs and supports available, including criteria for access.**

RHAs will provide you with information regarding the processes to access existing services. Please note that existing provincial policy manuals for many programs and services are dated and new standards are under development. Eligibility criteria for the new provincial CYCH model and Supporting Abilities programs is under development and will be integrated in the RHAs over time. The draft policies and standards can be shared with you should you wish to review them. Further information on the CYCH model and Supporting Abilities program can be found in the response to question #6.

3. **Information about any policies and procedures related to financial assessments necessary for determination of eligibility for services**.

Information regarding financial assessment and eligibility for services is available at https://www.gov.nl.ca/hcs/files/publications-policy-manual-income-test.pdf.

4. **Statistical information in your control or possession on;**
    a. **the number of children with complex needs in Newfoundland and Labrador;**
    b. **the number of families providing care to a child with complex needs;**

c. **the number of children with complex needs who are eligible for services under existing programs;**
d. **the number of children with complex needs who are in receipt of services under existing programs.**

Currently, data to capture these statistics is not collected through the provincial health system, as there is no consistent definition of complex needs currently in use in the system. The following new initiatives will improve data collection and are currently being finalized or are in various stages of implementation:

- A new provincial standardized assessment tool and software platform;
- A new central intake process for child and youth community health programs; and,
- Data collection to track uptake of the new process for coordinating supports for children and youth experiencing complex needs (see response to question #8 for further details).

The Canadian Institute for Health Information (CIHI) released a national report in 2020 regarding characteristics, health care service use, and care needs of children and youth with medical complexity in Canada. The rate of medical complexity varied by province and territory, with Newfoundland and Labrador showing the highest age-adjusted rate at 1,447 per 100,000 children and youth. This rate is above the national age-adjusted rate of 948 per 100,000 children and youth.

5. **Information about any partnerships with other public bodies and/or community agencies to provide services and supports to family caregivers.**

There are various parent supports provided through Family Resource Centres, and through many other community agencies across the province. It is recommended that you connect with the Departments of Education and Children, Seniors and Social Development to find out additional information on these supports as they are not within HCS oversight.

Development of the new CYCH services model and the Supporting Abilities programs (see response to question #6) has involved contribution from a variety of professionals, including individuals working with the Departments of Education and CSSD, RHAs, school districts, community agencies, Indigenous governments and organizations and others. As these programs and services are delivered to children, youth, individuals and their families, mechanisms for information-sharing, collaboration and service coordination among partners will be embedded into operational considerations.

6. **Information about any new initiatives that are being considered to support family caregivers.**

The CYCH services model and the Supporting Abilities program are under development to address the needs of children/youth and adults, respectively, who require support to function well in their everyday lives at home and in educational and community settings. Through these programs, some existing services will be coupled with new services to help ease navigation and improve access to holistic and needs-based supports for families. Each service will include direct family caregiver support. These initiatives are described in further detail below.

The CYCH services model will be available to children and youth aged 18 years and under (or 21 years and younger if remaining in high school), and will be implemented across home, school and community settings. It will consist of four provincial programs to address the needs of children and youth and to support family caregivers as follows:

- **Mental Health, Behavioural and Social Emotional Support (MH-BASES)**, which will provide a flexible continuum of timely and appropriate mental health, behavioural and social emotional supports to children, youth and their families. In addition to existing mental health services and behavioural intervention from the Community Behavioural Services program, new services being implemented within this program include:
    - Incredible Years School-age/Dinosaur Social Skills Program, which is an 18 to 22 week intervention group for parents and their children (ages four to eight years old) who demonstrate challenging behaviours, including non-compliance to adult requests, disruptive/aggressive behaviour and social behaviour difficulties. The program teaches children positive communication skills, problem-solving and emotion management and regulation, and promotes self-esteem and positive social skills. It also helps parents to develop strategies to reduce parental stress, improve parent-child relationships and lessen child disruptive behaviour.
    - Coping Power, which is a group-based intervention for parents and their children (ages nine to 14 years old) that addresses deficits in social cognition, self-regulation, peer relations and positive parental involvement. The intervention focuses on improving coping with anger, social problem-solving, and practicing skills to resist peer pressure, which can reduce the number and severity of behaviours that may impact functioning. Parents are supported by facilitators and peers to learn and implement coaching strategies with their children.
- **Developmental Health Services**, which will provide services to support cognitive, communication, physical and social emotional areas of child development to children and youth who are at risk of, or are experiencing, developmental health concerns that affect their functioning at home, in school or in community settings. In addition to the Direct Home Services and Therapeutic and Professional Services listed above, new services being implemented in this program include:
    - Incredible Years Toddler and Preschool intervention, which involves group-based supports for parents and caregivers whose preschool aged children display non-compliant, disruptive and aggressive behaviour. Incredible Years promotes positive behaviour in children and helps parents to develop strategies to reduce parental stress, improve parent-child relationships and lessen disruptive behaviour.
    - Responsive Interactions for Learning (RIFL), which is a parent training intervention that supports parent responsivity to their child by exploring parents' ability to correctly

assess the knowledge and state of mind of their child while cooperating to reach a shared goal. RIFL also emphasizes the parent's ability to expand their child's ideas and knowledge by asking questions and providing their child with appropriate challenges and support through scaffolding of skills. This service has been developed to increase parent responsivity and engagement, which have been linked to improved socio-emotional and language development in children.

- **Provincial Autism Services and Supports (PASS)**, which will provide social communication and behavioural supports and services to children and youth diagnosed with ASD. Children and youth indicated for PASS must present with demonstrated indicators or have a diagnosis of ASD to be eligible for services. In addition to the intensive ABA home therapy program noted above, new services being implemented in this program include:

    - Joint Attention, Symbolic Play, Engagement and Regulation (JASPER), which is a social communication intervention for children nine years old and younger that targets the foundations of social-communication: joint engagement, joint attention skills, imitation, and play. JASPER can be delivered to children by trained clinicians, or parents/caregivers can receive coaching support to implement JASPER strategies with their child.

    - Children's Friendship Program, which is a group-based intervention for parents and their children in Grades 2 to 6 who have trouble making or keeping friends. Children are taught various skills and parents are supported to coach and reinforce the friendship-making skills their child learns.

    - PEERS® (Program for the Evaluation and Enrichment of Relational Skills) for Adolescents, which is a group-based parent-assisted social skills intervention for teens in junior and senior high school who have friendship concerns, and are motivated to learn about making and keeping friends and/or handling conflict and rejection. In this intervention, teens are taught friendship skills that they practice in their daily lives, while their parents/caregivers are taught coaching skills to support their teen to develop and maintain friendships.

- **Supportive Services for Children and Youth (SSCY)**, which will be the revised SCWA program referenced above. This program will provide enhanced clinical case management to explore the strengths of the child, their family, and the community to develop a support plan and facilitate access to required services. If the support plan includes services and resources that require additional funding (e.g. respite services, medical supplies), and there are assessed financial barriers, a subsidy may also be coordinated through SSCY. Children and youth receiving services from SSCY must demonstrate financial eligibility and have confirmation that they have a disability resulting in functional limitations in activities of daily living. Please note that a financial assessment will not be required to access intensive case management supports from the SSCY program.

SSCY will encompass specific supports, yet other programs also provide supports for children and youth with complex needs and their families, based on their presenting concerns. For example, within Developmental Health Services, perinatal and preschool social emotional development will be one of the core areas of development targeted for intervention. HCS is partnering with the University of Toronto to support the implementation of a Parent Responsivity and Social Emotional Support Program into an existing home visiting program for preschool children experiencing developmental delays. Demonstration sessions for this initiative are underway, with findings intended to inform broader implementation in the winter of 2022. There will be new parenting interventions embedded within the MH-BASES programs, as well as planned behavioural in-home support available for children and youth experiencing complex behavioural needs. As other provincial programs are integrated, additional supportive services may be determined to be appropriate for children, youth and their families, depending on the nature of the concerns.

Service navigation within the CYCH model will be accessible through a provincial central intake. A standardized assessment tool, the interRAI Child and Youth Mental Health (ChYMH) tool, will be used in conjunction with discussions with the family to comprehensively assess and prioritize the functional support needs of children and youth, as well as identify strengths and support needs of the parents and family. This information will be used to determine appropriate services, indicate urgency for services, improve service coordination and inform transition planning. Clinicians within the RHAs are currently being trained to use this tool to enhance clinical decision-making and support planning.

The Supporting Abilities program is the new adult disability support program under development, which will be available to adults 18 years of age and older who have disability-related support needs. Many of the services within this program are currently available within the RHAs, but will be streamlined under the Supporting Abilities program to ease navigation and support transition planning, along with expanded services to provide the expertise necessary to support the unique needs of adults with disabilities and their family caregivers. Navigation to appropriate services and supports for this population will be informed by a new assessment tool, the interRAI – Intellectual Disability (ID), which is comparable to and compatible with the ChYMH tool for children and youth. This will enhance transition planning from pediatric to adult programs. The Supporting Abilities program will consist of:

- **Case Management Support**, which will be parallel to the SSCY program described above, to support individuals and families with acquiring services and resources, including medical supplies, and respite and home supports.

- **Behavioural Support**, which will be parallel to the Community Behavioural Services program, with expanded eligibility beyond intellectual disability to be more inclusive of individuals assessed as requiring behavioural supports to function well in their daily life, including those with ASD and complex needs.

- **Life and Social Skills Support**, which will support adults and their family caregivers with activities of daily living and promoting independence. A new service being implemented in this program includes:

  - PEERS® for Young Adults, which is a group-based peer/caregiver-assisted social skills intervention for young adults who have friendship and relationship concerns, and are motivated to learn about making and keeping friends, dating and/or handling conflict. In this intervention, young adults learn social relationship skills that they practice in their daily lives, while their peer or caregiver adopts the role of social coach to support them to develop and maintain positive social relationships.

- **Residential Options**, as described in the response to question #2.

A review of residential supports is ongoing as a joint initiative between HCS and CSSD. The review is examining residential options available in Newfoundland and Labrador for children, youth and individuals with various conditions requiring supports, receiving input from stakeholders including family caregivers and individuals with lived experience, and exploring residential models from other jurisdictions and the research literature. Once completed, the recommendations from the review will be used to inform the future direction of residential supports in this province, including supportive options for individuals experiencing complex needs and their families.

In addition to the CYCH and Supporting Abilities initiatives underway, HCS has approved new CSS system navigator positions to work with the existing mental health navigator to establish a provincial navigation network for community-based services across the lifespan. These navigators will act as an access point for community-based services; support individuals and families to navigate the RHAs, government departments, community organizations, and external private providers (e.g. home care agency operators); facilitate referrals to appropriate services within the health system and in community; and, seek to remove service barriers for individuals and families. Planning is underway for the navigator program, with implementation expected in the near term.

Finally, the needs of family caregivers you noted in your letter regarding ease of access to home support, emergency situations and after-hours specialized care options, as well as improved service accessibility options, will be further considered by HCS.

7. **Information on any reports, draft reports, consultations, etc. by the Department that address recognition, assistance, support and engagement with family caregivers.**

There have been multiple reviews and reports containing recommendations for enhanced supports for family caregivers. These are contained in multiple Office of the Child and Youth Advocate reports, the Autism Action Plan, the Education Action Plan, the Towards Recovery Action Plan, and Health Accord NL reports. There have also been external reviews of Child and Youth Services and a Residential Review which have helped inform needed improvements. All recommendations laid the foundation for the strategic direction found within the draft CYCH services model and the Supporting Abilities program.

8. **Information on the status, process and/or outcome of the review of Newfoundland and Labrador Model for the Coordination of Services to Children and Youth with Special**

**Needs as per the recommendations of the ISSP/Pathways Commission Report of June 2007.**

The ISSP and the Model for Coordination of Services has been revised and the new Coordinating Supports for Children and Youth Process is being finalized. This is a streamlined process to coordinate supports for children and youth with complex needs. It highlights one comprehensive plan with clearly defined roles and responsibilities for the members of the child/youth team. This process is inclusive of all child-servicing departments, agencies and partners, and includes an information sharing protocol and shared consent. There are regional and provincial committees for oversight embedded into this process.

I trust the foregoing to be satisfactory. My officials are available to meet with you if you wish to discuss additional concerns that have not been addressed. Please contact Annette Bridgeman at (709) 729-3773 or annettebridgeman@gov.nl.ca should you wish to arrange a meeting.

I appreciate your advocacy on behalf of family caregivers, as it informs our work as we strive to improve services for individuals with complex needs and their families.

Sincerely,

**Andrea McKenna**
Deputy Minister

cc: Annette Bridgeman, Director of Regional Services, HCS

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Newfoundland
Labrador

Government of Newfoundland and Labrador
**Department of Children, Seniors and Social Development**
**Office of the Deputy Minister**

COR-2022-00755-04

October 12, 2022

Mr. Bradley Moss
Citizens' Representative
Office of the Citizens' Representative
4th Floor, Beothuk Building
20 Crosbie Place
PO Box 8400
St. Johns, NL A1B 3N7

**Re: Notification of Investigation**
**Own Motion Investigation – Family Caregivers**

Dear Bradley Moss:

On August 11, 2022, your notification was received regarding an own motion investigation being undertaken by the Office of the Citizens' Representative concerning family caregivers. Pursuant to Section 31(1) of the **Citizens' Representative Act**, the following information was requested:

1. Information about any existing programs and supports available for family caregivers specific to the Department of Children, Seniors and Social Development.
2. Information about any policies and procedures related to programs and supports available, including criteria for access.
3. Information about any policies and procedures related to financial assessments necessary for determination of eligibility for services.
4. Statistical information in your control or possession on:
    - the number of children with complex needs in Newfoundland and Labrador;
    - the number of families providing care to a child with complex needs;
    - the number of children with complex needs who are eligible for services under existing programs; and
    - the number of children with complex needs who are in receipt of services under existing programs.
5. Information about any partnerships with other public bodies and/or community agencies to provide services and supports to family caregivers.

6. Information about any new initiatives that are being considered to support family caregivers.

7. Information on any reports, draft reports, consultations, etc. by the Department that address recognition, assistance, support and engagement with family caregivers.

8. Information on the status, process and/or outcome of the review of Newfoundland and Labrador's Model for the Coordination of Services to Children and Youth with Special Needs as per the recommendations of the /SSP/Pathways Commission Report of June 2007.

## CSSD Response

As discussed during a meeting with CSSD officials on August 19, 2022 with lead investigator, Sharon Samson, CSSD has minimal involvement providing direct programs and services to the population identified. As noted in our meeting and the request for information, many of these queries would be better suited for the Department of Health and Community Services (HCS), the Regional Health Authorities (RHA), as well as the Department of Education.

1. **Existing programs and supports available for family caregivers specific to the Department of Children, Seniors and Social Development.**

### Child Protection and In Care

The Protective Intervention Program (PIP) is a mandatory program that provides services to families whose children are, or who are at risk of, being maltreated either through omission or commission by the parent. The PIP promotes the safety and well-being of children and assists families in addressing issues that create risk to their children. Social workers work closely with families to determine child protection concerns, assess safety and risk to the child, identify family strengths and needs, and determine which least intrusive interventions will reduce risk. Where available and appropriate, families are connected with supports and services designed to maintain, support, and preserve the family unit when it is in the best interests of the child.

Within the PIP, regional staff refer to HCS to access services for children with complex needs. The following supports can be provided to caregivers for the purpose of enhancing a child's safety and reducing the risk of maltreatment: childcare, day camp, babysitting and respite.

Referrals can also be made on behalf of children to internal services such as: Intervention Services (BMS) for assistance with behavioural concerns, parenting supports (Triple P Parenting Program), and the Family Services Program (FSP) which offers counselling and psychoeducational sessions. Behavioural aide services may also be approved for families who require this service to enhance the safety of their children.

These same services are provided to children involved in the Kinship Services Program. The Kinship program is intended to provide supportive and financial services to an approved kin who is willing and capable of providing care to a child in need of protective intervention who requires an out-of-home living arrangement. This is a voluntary and collaborative arrangement and agreement between the child's parents, the kinship caregiver, and the social worker whereby the parent transfers care of the child to the kinship caregiver via a Kinship Care Agreement (KCA). It is a protective intervention service that is an alternative to removal. The child does not come into the care or custody of a manager as a result of this arrangement.

A monthly basic rate is paid to the kinship caregiver. This rate is equivalent to the foster home basic rate (discussed further below). Other services (e.g. health and medical services, tutoring, child care, respite and counseling) may be provided if necessary to meet the child's needs or support the placement, and the service is not available from an external source or other government department (i.e. MCP, NLPDP, HCS, RHA).

The In Care program is invoked when a child is placed in a foster home or other CSSD approved placement option (e.g. a family based care home). This may happen by way of a court order or voluntary agreement with the parents where a kinship placement is not available. Monthly financial compensation and other supports are provided to foster parents, family based caregivers and/or the children placed with them, as needed.

As discussed in the meeting on August 19, 2022, it is not the goal to have children with complex needs placed in care for the sole reason that their caregivers are unable to manage their needs due to a lack of supports (financial, emotional, etc.). However, if a child with complex needs has been deemed in need of protective intervention and is placed in care, there are supports available for their foster parents or caregivers during that time. The Protection and In Care policy and procedure manual defines "Caregiver" as follows, "*An individual recruited and assessed by a family-based licensee to provide a safe and stable family-based placement for children and youth in care.*"

In order to become an approved regular foster parent through CSSD, each applicant must complete Parent Resources for Information, Development and Education (PRIDE) training. Relative/significant other foster parent applicants can obtain an approval without completing PRIDE training; however, in order to become eligible to receive financial support through the level fee, PRIDE training is required. Depending on the specific needs of the child, a foster parent may require additional training such as nonviolent crisis intervention training (NVCI), applied suicide intervention skills training (ASIST), and module 1 of the specialized foster parent training. This training is provided by CSSD, either directly or through an outside source, and paid for by CSSD. In accordance with the Children, Youth and Families Regulations under the Children, Youth and Families Act, family based placement provider licensees can recruit, assess and train family based care providers. Training provided to family based caregivers must comply with the training requirements outlined in departmental policy. Consistent with training requirements for foster parents, family based caregivers also complete PRIDE training as well as other specialized training based on the needs of the child(ren) in the placement.

Foster parents are entitled to a basic foster care rate, block funding, and a level fee (depending on the complexities of the child, in addition to the foster parents training). The rates provided also vary depending on the age of the child, as well as their geographic location (i.e. remote Labrador). Block funding is intended to include monies for respite and social/recreational expenditures. Family based placement provider licensees enter into funding agreements to receive payments from CSSD. The licensee shall cover all costs for children in family based placements with the exceptions of vision care, dental care, prescription medications, medical equipment, exceptional transportation, post secondary tuition, and fees associated with personal identification as these costs are covered by CSSD.

CSSD can provide funding for the cost of minor repairs, equipment or renovations for a foster home to accommodate a child or youth with a disability or other special needs (as recommended by a qualified health practitioner). Special items/equipment, and prescription medications required to meet a medical or special need can only be provided if they are not covered by another external source (i.e. MCP, HCS, RHA).

Other services that may be provided include: dental care, vision care, special diet, and other health services (i.e. counselling, occupational therapy). Child care costs may also be provided if it is required for employment or educational purposes, or to care for a child that requires child care to meet an identified special need as assessed by a health practitioner and supported by the social worker.

The specific funding amounts for foster parents can be found in the Protection and In Care Policy and Procedure Manual, which are outlined in the response to Question 2.

**Disability Policy Office (DPO)**

The DPO does not oversee programs and services, and is not primarily a funding source. The role of the DPO is to work with all government departments and agencies to assist in the development of policies and programs that include people with disabilities, and ensure these are barrier free. As per the **Accessibility Act**, the DPO is required to examine and review measures, policies, practices and other requirements to improve opportunities for persons with disabilities, support others to develop and implement public education and awareness on the purpose of the Act, as well as identify and study issues of concern to persons with disabilities and recommend action where appropriate. The DPO also provides administrative support for the Accessibility Standards Advisory Board.

However, the DPO does administer Accessible Vehicle Funding. This funding was established to reduce costs associated with disability and provide an accessible transportation option to individuals and families throughout the Province. The program supports individuals or families to acquire or adapt personal vehicles for accessibility. This could include the following retrofits: customized seating, hand controls, left-foot gas pedals, lifts and ramps, roof floor and door alterations, steering devices, wheelchair securing systems, shipping and instillation costs, as well as maintenance of equipment no longer under warranty.

**Income Support**

CSSD, through the Income Support division, provides financial benefits and other services to eligible low income individuals and families to assist in meeting daily living expenses. These benefits can include basic benefits to cover the cost of food, clothing, personal care, household maintenance and utilities, as well as non-basic benefits which can include eye exams, prescription glasses, housekeeper's allowance, transportation and private childcare.

Social workers also assist in a variety of roles with income support recipients, which includes supporting staff in delivering services to clients with complex needs. An explanation of the various roles Social Workers fulfil within the Income Support division is outlined in Chapter 16 of the Income Support Policy and Procedure manual.

**Seniors and Aging**

Similar to the DPO, the Seniors and Aging Division does not administer front-line services. While Seniors and Aging is responsible for the administration of the **Adult Protection Act**, this Act is implemented on the front line by the Regional Health Authorities. The Provincial Advisory Council on Aging and Seniors is responsible for advising government in preparing for an aging population by ensuring a senior's perspective is reflected in policy development and in planning for future service delivery.

**2. Information about any policies and procedures related to programs and supports available, including criteria for access.**

The overarching policy and procedure manual for the Child Protection, Youth Services, In Care and Adoptions programs can be found online - https://www.gov.nl.ca/cssd/files/Protection-and-In-Care-Policy-and-Procedure-Manual-August-12-2021.pdf The specific policies which may be relevant to this investigation are as follows:

**Child Protection and In Care**

Protective Intervention Program
Childcare – 1.19
Day Camp – 1.20
Babysitting – 1.21
Respite – 1.22
Behavioural Aide – 1.23
Triple P Positive Parenting Program Services – 1.34

Kinship Services Program
Program Eligibility – 1.13
Basic Rate – 1.18
Child Care – 1.18
Vision Care – 1.18
Dental – 1.18
Respite – 1.18
Counselling – 1.18
Other Medical Services – 1.18
Prescription Medications – 1.18
Special Items/Equipment – 1.18

In Care
Basic Rate – 3.25
Block Funding – 3.26
Level Fee – 3.27
Respite – 3.28
Minor Repairs/Equipment/Renovations – 3.23
Special Items/Equipment – 3.23
Prescription Medications – 3.21
Dental Care – 3.21
Vision Care – 3.21
Special Diet – 3.23

Other Health Services – 3.21
Child Care – 3.29
Specialized Foster Home Approval – 4.7

**Disability Policy Office**

The Accessible Vehicle Funding Policy Manual can be found online - https://www.gov.nl.ca/cssd/files/Accessible-Vehicle-Funding-Policy-Manual-2022-1.docx This policy outlines the criteria for access.

**Income Support**

The overarching policy and procedure manual for the Income Support can be found online - https://www.gov.nl.ca/cssd/policymanual/incomesupport/ The specific policies which may be relevant to this investigation are as follows:

Chapter 2 – Eligibility
Chapter 5 – Basic Benefits
Chapter 6 – Shelter Benefits
Chapter 7 – Transportation Benefits
Chapter 8 – Health Benefits
Chapter 9 – Special Needs Benefits
Chapter 16 – Social Work Services

**3. Information about any policies and procedures related to financial assessments necessary for determination of eligibility for services.**

There are no financial assessments necessary for the Child Protection, Youth Services, In Care, Adoption, or Seniors and Aging programs.

**Disability Policy Office**

As noted above in question 2, the policy manual for the Accessible Vehicle Funding can be found online - https://www.gov.nl.ca/cssd/files/Accessible-Vehicle-Funding-Policy-Manual-2022-1.docx. Appendix A details the sliding scale calculation, while Appendix B outlines Disability-Related Costs which can be considered in the determination of financial eligibility.

Applicants with an annual net income of $46,500 or less may be eligible for 100% funding up to $25,000, while partial funding may be available for applicants with annual net incomes between $45,600 and $64,000. Applicants are required to provide a Notice of Assessment from the Canada Revenue Agency.

**Income Support**

The policies and procedures related to financial assessments necessary for determination of eligibility for services can be found in Chapter 2 – Eligibility, of the Income Support policy and procedure manual.

**4. Statistical information in your control or possession on:**

- **the number of children with complex needs in Newfoundland and Labrador;**
- **the number of families providing care to a child with complex needs;**
- **the number of children with complex needs who are eligible for services under existing programs;**
- **the number of children with complex needs who are in receipt of services under existing programs.**

CSSD would not be responsible for, or have access to, these statistics. If you require statistics on the number of children in care or receiving kinship services, these data are available quarterly on the Department's website at https://www.gov.nl.ca/cssd/childprotection/

HCS is responsible for compiling data relevant to any overlap between those who receive funding from HCS or a RHA that is supplemented by ISS (or vice-versa). We would suggest that you request these data and statistics from HCS or the RHAs.

**5. Information about any partnerships with other public bodies and/or community agencies to provide services and supports to family caregivers.**

**Child Protection and In Care**

CSSD has strong partnerships with many community agencies. In particular, Daybreak, Waypoints, Amal, Key Assets, and the Newfoundland and Labrador Foster Families Association (NLFFA).

Waypoints provides the Supporting Foster Parents Program and offers additional virtual training sessions for foster parents. All foster parents are also referred to the NLFFA for support after they have been approved as foster parents. The NLFFA provides support to foster families through education, retention, and advocacy.

Waypoints also offers the Family Support Program, which is a family-centered, strengths-based service designed to support families in a capacity that aims to enhance family relationships and overall family functioning. Daybreak offers the Home Visitation Program, which is an initiative that helps enhance the skills and knowledge of parents and improve child development while contributing to the overall health and well-being of children and their families within their communities. Additionally, other community agencies provide services to CSSD families, such as Amal and Key Assets, who provide Family Intervention Services, an intensive therapeutic service option for children with complex needs and challenging behaviours. These services are all either financially supported through grant funding, contractual funding, or individually paid for per client on a case-by-case basis by CSSD.

In addition to these community agencies, CSSD front-line social workers may also assist with connecting the child/caregiver to other services that are not offered through CSSD but are offered through other government departments such as HCS, RHAs, Education or the community.

### Disability Policy Office

Many government departments and agencies work together to make sure their services and programs include people with disabilities. Ministers and senior management meet regularly to plan how best to remove barriers and achieve inclusion.

The DPO works regularly with the Coalition of Persons with Disabilities NL, as well as the Network of Disability Organizations which is chaired by the Coalition.

### Income Support

Income support recipients may be eligible for benefits and services offered by other Government departments and agencies. Financial eligibility for these may be determined by CSSD, however, individual departments determine the extent of these benefits and services. This includes the Prescription Drug Card offered by the Newfoundland and Labrador Prescription Drug Program (NLPDP), Medical Supplies and Medical Equipment offered by the Special Assistance Program from HCS, and Medical Transportation provided by HCS.

### Seniors and Aging

The Seniors and Aging division often collaborates with SeniorsNL, the Office of the Seniors' Advocate, the NL 50+ Federation, as well as the Seniors' Coalition.

**6. Information about any new initiatives that are being considered to support family caregivers.**

CSSD is continuously reviewing best practices to consider the implementation of new programs, services and training. However, at this time, there are no new initiatives being considered that are relevant to this specific OCR investigation. However, we would recommend that your office consult with HCS regarding their Individualized Funding Pilot Program.

**7. Information on any reports, draft reports, consultations, etc. by the Department that address recognition, assistance, support and engagement with family caregivers.**

While there are no reports specific to family caregivers, all publications can be found on the Department's website - https://www.gov.nl.ca/cssd/publications/. This includes annual reports, activity plans, strategic plans, and others.

**8. Information on the status, process and/or outcome of the review of Newfoundland and Labrador's Model for the Coordination of Services to Children and Youth with Special Needs as per the recommendations of the /SSP/Pathways Commission Report of June 2007.**

As this report was addressed to the Minister of Education at the time, and ISSP is an initiative coordinated through the Department of Education, it would be best to consult with the Department of Education on the status, process and/or outcome of the review of this report and associated recommendations.

While this matter is primarily health related, our Department has heard concerns regarding similar topics. The DPO has heard concerns regarding the Inclusion Program, facilitated through the Department of Education. The Inclusion Program provides assistance to regulated child care services to include all children, including those with exceptionalities. However, concerns have been voiced to the DPO regarding the assignment of inclusion workers to specific child care centres, as opposed to being assigned to specific children. In turn, it has been alleged that this creates issues with recruitment and retention of inclusion workers, and therefore, the accessibility of child care services to children with complex needs.

Additionally, the DPO has heard concerns regarding children with complex needs transitioning out of the school system. Concerns have been raised regarding limited programming for adults with complex needs, as well as a lack of access to full-time day programming. When children leave school, they are required to wait on waitlists in order to access the limited supports available to them, as opposed to having a transition period where there would be no gap in service.

Newfoundland
Labrador

The Department recognizes that complex needs and family caregiving are important systemic issues. I trust you will find the above satisfactory. If you have any questions, please do not hesitate to contact me.

Sincerely,

**Alan Doody**
**Deputy Minister**

Eastern Health

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October 20, 2022

Bradley Moss
Citizens' Representative
Office of the Citizens' Representative
4th Floor, Beothuk Building
20 Crosbie Place, St. John's, NL, A1B 3N7

Dear Mr. Moss:

Re: Citizens' Representative File #: 524CF22 – Own Initiative Investigation – Family Caregivers

In response to your letter to Mr. Dave Diamond, CEO, dated October 11, 2022, giving notice of your office's own initiative investigation re: family caregivers, pursuant to Section 31(1) of the Citizens' Representative Act, Eastern Health offers the following response, structured to respond to the items identified in your request:

1. **Information about any existing programs and supports available for family caregivers specific to Eastern Health.**

   Following is a list of programs, services, and supports:

### Children & Women's Health Program

**Direct Home Service Program (DHSP)**
https://cwhp.easternhealth.ca/children-and-youth/child-development/direct-home-services-program/

Child Management Specialists (CMS): home based skill teaching to parents of preschool children with developmental delay(s)

The Incredible Years®: evidence-based programs for parents and children, and supported by over 30 years of research. The goal is to prevent and treat young children's behavior problems and to promote their social, emotional, and self-control skills. The programs are used worldwide in schools and mental health centers, and have been shown to work across cultures and socioeconomic groups. The Regional Health Authorities began to rollout The Incredible Years® in the summer of 2022. At Eastern Health two virtual groups (preschool and toddler) were offered: Parents of children 3 years old to school entry age were offered the 16 week preschool group, and parents of children up to 3 years old were offered the toddler group. New groups are offered this fall with plans to offer fall and winter sessions. See link: https://incredibleyears.com.

Autism Services: 2-day monthly training for caregivers, one-on-one caregiver education/intervention tailored to their child's needs.

JASPER-Clinician Led or JASPER-Parent Implemented: a play-based intervention that teaches social communication skills to young children with autism.

CPI Nonviolent Crisis Intervention®: provides tips to help caregivers respond to difficult behaviors in the safest, most effective way possible.

**Janeway Child Development (JCD)**
https://cwhp.easternhealth.ca/children-and-youth/child-development/child-development-team/

Children and Youth up to age 18 with significant developmental delays are assessed and treated by a pediatrician and allied health professionals.

Intake: The JCD Intake Coordinator reviews referrals to the department (pediatricians and allied health services) and triages for placement on the appropriate waitlist, contacts referral agents/parent for clarity, when required.

Parent education/groups for caregivers of children with development disabilities: Attention Deficit information session, Parenting Young Children, Parenting Your Anxious Child.

Speech language pathologist (SLP) treatment for preschoolers and Hanen Parenting programs: Depending on the child's communication/language delay, one of the Hanen programs for parents led by Hanen Certified speech-language pathologists (SLPs) may be offered. Treatment may also be consultative or a one on one 6-8 session block. This is for preschool only as the school system provides SLP services to school age children.

OT, SLP, Social Work, Psychology: Development and learning and behavioural pediatricians, occupational therapists, physiotherapists, clinical social workers or psychologists treat children/youth with complex developmental conditions/disorders that struggle with cognitive, communication, motor, learning, social, self-help and behavioural disorders as it interferes with their daily living.

**Janeway**

Provincial Perinatal Program, specialty services e.g., ophthalmology, neurology, audiology, diagnosis specific clinics (e.g., Down's Syndrome), Music Therapy.

For those eligible, Wheelway transportation to and from Child Development/Rehab appointments, Interpreting Services.

**Janeway Rehabilitation Program**
https://cwhp.easternhealth.ca/children-and-youth/child-rehabilitation-services/

The Janeway Children's Health and Rehabilitation Centre offers child rehabilitation services. The Janeway Rehabilitation Team is a specialized team that assesses, treats and completes follow-up for individuals under the age of 18 with complex conditions that create a significant level of physical impairment.

The nursing unit of the Janeway Rehabilitation Team is often the first contact point for families, providing assistance with navigation throughout the system.

**Janeway Lifestyles Program**
https://cwhp.easternhealth.ca/children-and-youth/pediatric-outpatient-services/jlp

The Janeway Lifestyle Program works with families whose children have been identified as having a risk factor for the development of a chronic disease such as high cholesterol, high blood sugars, high blood pressure, liver disease and weight concerns, providing a safe social space and non-judgmental service. The focus is on reducing barriers to lifestyle changes while improving nutrition, physical activity, and self-esteem for all children. The goal is to help children and their families enjoy a healthy life.

**CAYAC (Children and Youth in Alternate Care) clinic**
https://cwhp.easternhealth.ca/children-and-youth/outpatient-services/cayac-clinic/

The Janeway Children's Health and Rehabilitation Centre offers the CAYAC clinic. This is a multidisciplinary, multiagency clinic that aims to address the physical and mental health needs of children/youth in alternate care in the Eastern Region.

## Mental Health and Addictions

### Janeway Family Centre, Bridges, Outpatient Psychiatry Clinic

Eastern Health's Mental Health & Addictions Program provides outpatient counselling services to children, youth and their families who are experiencing emotional, social or behavioral challenges. These services are provided through the Janeway Family Centre, the Bridges Program and the Outpatient Psychiatry Clinic at the Janeway. These services are for children (and their families) up to the child's 18th birthday.

In addition to individual and family counselling, our interdisciplinary teams also offer a number of groups to support parents/caregivers of children and youth. These include:

- Parenting Your Anxious Child
- Parenting your Adolescent (PYA)
- Partnering with Parents (for parents of children and youth with complex mental health diagnosis)
- ADHD information group and support groups
- Parenting your younger child (PYC):
- It's Okay (for parents who have gone through separation and divorce)
- Soul Guardians (for kinship caregivers of children who have experienced trauma, not biological parents)

### Doorways

Doorways' clinics throughout the Eastern Health region provide easy and rapid access to mental health and addictions counselling services 'one session at a time.' No referrals are necessary. These services are available via phone, video or in-person.

### Provincial Mental Health and Addictions System Navigator

The mental health and addictions patient navigator has knowledge of all mental health and addictions services provided by the health authorities and the community. The navigator will help callers to consider options and find the right mental health and addictions service for individuals and their family.   The provincial Mental Health and Addictions System Navigator will provide services to individuals, families and professionals of any age within Newfoundland and Labrador.

### Tuckamore Centre

Tuckamore is a residential treatment centre for youth (aged 12-18 years) with complex mental health challenges. Tuckamore Centre offers support to family caregivers of resident youth through 24/7 access to Child Youth Care Counsellors for support, advice, crisis intervention. Family Caregivers also have access to their child's primary clinician and participate in therapeutic sessions where clinically indicated.  Tuckamore offers a DBT skills group to all family caregivers so they may learn the same regulation/coping skills their child has learned during their stay in the program.

For more information about the centre, please refer to the following link: https://mha.easternhealth.ca/wp-content/uploads/sites/7/2020/02/BR_Paradise-Youth-Treatment-Centre_2014_09.pdf.

## Community Supports Program (CSP)

### Supportive Services for Children, or SSCP (formerly Special Child Welfare Allowance, or SCWA) PROVINCIAL PROGRAM:

Provides supports to the disability related needs of children with physical or intellectual disability living at home (under the age of 18, afterwards, the individual would access adult based services and supports). This program is designed to enable families to purchase items and/or services which are necessary due to the child's disability, as defined by a clinical assessment of the child and a financial assessment of the parents. Supports may include home support, respite care, community inclusion, funding for specialized dietary foods and transportation (includes meals and lodging cost for the child to access a disability related service). This program adheres to provincial guidelines both from a program and financial perspective.

**Special Assistance Program (Provincial Program):**

Provision of medical supplies, orthotics, oxygen, and medical equipment for those who are clinically and financially (families) eligible. Items must be on the provincially approved list. CSP ensures that client clinical needs are met though the program recognizing situations where needs of pediatric clients are outside of standard policy, these cases are reviewed and approved on a case-by-case basis. When items are not on the benefit list exceptions to policy may be granted if clinically indicated by a clinician (eg., seating, specialized learning equipment, etc. )

**Community Behavioral Services Program (CBSP) (Provincial Program):**

Provides behavioral and skill teaching interventions to school-aged children and their families with the goal to train parents and significant others to practice intervention techniques aimed at modifying disruptive behaviors; and to support the child's participation in the community. Please note that any children between the ages of 2 and 5 years of age are serviced through programing at the Janeway. Ages 5 and 18 years are serviced through Community Behavioral Services Program (CBSP) Provincial program. Families receiving services from the Department of Children, Seniors and Social Development (CSSD) may receive these supports from Behavior Management Specialists (BMS) employed with CSSD instead of the regional health authority.

**Speech-Language (SLP) services:**

Screening, assessment, intervention and consultation is offered to pediatric clients with a range of speech and language needs (i.e., articulation, language, fluency, voice, feeding). Children are typically kept on SLP caseloads until speech and language skills are considered age appropriate, or until they transfer to a school based SLP. SLP services are primarily provided through programming at the Janeway Hospital; in select geographical areas there are SLP services offered in community to pediatric clients.

**Occupational Therapy (OT) and Physiotherapy (PT) services:**

There are times where community OT and PT services are needed in collaboration with the Janeway hospital OT/PT for discharge or unique situations (e.g, pediatric palliation).

**Social Work:**

Provides assessment, support, counselling, discharge planning, coordination of community resources and advocacy for children and their families as required.

**Nursing services:**

Provides acute nursing care (i.e., suture removal, wound care management, injections, etc. ) to pediatric clients in community.

**Dietitian:**

Community Dietitian involved on a case-by-case bases when requested by a Janeway clinician.

**Behaviour Management Specialist (BMS) behaviour/skill teaching for caregivers:**

Behaviour Management Specialist (BMS) behaviour/skill teaching for caregivers of their child/adult school age and older that have significant behavioural issues and adaptive functioning.

2. **Information about any policies and procedures related to programs and supports available, including criteria for access.**

**Supportive Service Children's Program SSCP (previously Special Child Welfare allowance (SCWA)**

Policies and procedures for Supportive Services for Children, or SSCP (formerly Special Child Welfare Allowance, or SCWA), a provincial program, remain under review with the Department of Health and Community Services.

Current policies and procedures can be referenced in the Provincial Income  Based Financial Assessment Policy Manual for Long Term Care & Community Support Services.  See link: https://www.gov.nl.ca/hcs/files/publications-policy-manualincome-test.pdf

**Tuckamore Centre**

Please see attached policy re: Referral Criteria for Tuckamore Centre.

**CONNECT**

The CONNECT team serves young people with complex service needs, between the ages of 12 and 18, and their families.

Participation in this program is completely voluntary.

Common reasons for referral:
Individuals and their families may need support to connect with services, or may have services already in place that require further coordination. We work directly with children, youth and their families to address specific needs in the home and in the community.

At this time, the CONNECT team is reviewing its mandate to coincide with the evolution of mental health services since it was initially developed in 2012. This team will continue to service complex youth in the community who are not currently engaged with services they require.

## 3. Information about any policies and procedures related to financial assessments necessary for determination of eligibility for services.

### Tuckamore Centre and CONNECT

There are no financial assessments necessary to determine eligibility for Tuckamore Centre or CONNECT. There are no financial assessments or eligibility requirements for our community based programming.

### Community Supports Programming

With respect to the Community Supports programming, finance assessors use the Provincial Income Based Financial Assessment Policy Manual for Long Term Care & Community Support Services. There are no regional policies in this regard.  See link: https://www.gov.nl.ca/hcs/files/publications-policy-manualincome-test.pdf

## 4. Statistical information in your control or possession on:

- **the number of children with complex needs in Newfoundland and Labrador;**
- **the number of families providing care to a child with complex needs;**
- **the number of children with complex needs who are eligible for services under existing programs;**
- **the number of children with complex needs who are in receipt of services under existing programs.**

Presently there is no consistent definition of complex needs used within the system making the collection and comparison of data difficult.  However, this will change as Eastern Health is working with the Department of Health and Community Services on the introduction of the following new initiatives which are currently working through approval process and/or in various stages of implementation:

- A new provincially standardized assessment tool and software platform;
- A new central intake process for several child and youth community health programs;
- Data collection for the uptake of the new process for coordinating supports for children and youth experiencing complex needs.

For now, Eastern Health cannot offer broad comprehensive statistics related to services for children with complex needs  beyond services that are reflected in active caseloads and waitlists as indicated below.  Several programs reported related data:

**Community Support Program:**

- Eastern Health has 217 SCWA clients regionally, effective August 30,2022:
- 190 of these clients have home support and supplementary benefits; 27 have supplementary benefits only.

**Mental Health & Additions:**

- 3 youth have been referred and deemed eligible for Tuckamore. They are currently awaiting admission.
- 10 youth have been referred and deemed eligible for CONNECT and are on a waitlist for service.
- 12 youth are currently in receipt of services from Tuckamore Centre.
- 24 youth are currently in receipt of service from the CONNECT team (recruitment challenges has limited this team to 2 clinicians).

5. **Information about any partnerships with other public bodies and/or community agencies to provide services and supports to family caregivers.**

**Daybreak Parent Child Centre** (daybreakcentre.com):
Daybreak Parent Child Centre is a non- profit, community based organization governed by a Board of Directors and comprised of four programs. They are the Children's Program, Parenting Program, Community Programs and Family Home Visitation Program.

**Tuckamore and CONNECT:**
Both Tuckamore and CONNECT partner with NLESD to provide services and supports to select schools. This partnership arose from the Child Advocates report on Chronic Absenteeism. The role of the youth outreach worker is to connect and build relationship with students who are experiencing complex mental health issues to support them in engaging in needed services. They work alongside school administration, guidance counsellors, and PASS teachers. These staff also have capacity to liaise with family caregivers to support them in encouraging their child to attend school and connect them to needed mental health/addictions services. Both Youth Outreach Workers from the division of child and adolescent mental health and Child and Youth Care Counsellors from Tuckamore and CONNECT have supported youth in the school setting.

**Sashbear Foundation** https://sashbear.org/en/family-connections/family-connections-2
Sashbear Foundation is a public body we recommend to family caregivers. They have a Family Connections program, an evidence based 12-week group that meets weekly to provide education, skills training, and support to people in a relationship with someone who has emotion dysregulation or related problems. It is free of charge to all participants.

**Youth Outreach Workers**
Youth Outreach Workers, also called 'YOWers', provide brief intervention outreach services to youth within the division of child and adolescent mental health. Some of the goals are to reduce harm associated with substance use, as well as helping youth to stay in school.

Youth outreach workers are available throughout the region to assist in a number of ways, including: acting as a mentor and a positive influence; helping youth find their way through services and treatment available in the community and at Eastern Health; providing information about the things youth can do to stay or get healthy, and supporting them to get the best things out of life; working in partnership schools and community agencies to provide early intervention and outreach services to youth and their friends; and informal counselling.

We see children and youth between the ages of 10 and 17 years old. Admission is determined and coordinated through child and youth intake for St. John's metro. For admission outside the metro area, the numbers below are provided or the client can call the NL Health Line 811 for further information.

- St. John's metro: 709-777-2200
- Holyrood, Whitbourne, St. Mary's Bay, and Placentia Bay: 709-227-6832
- Bay Roberts and Harbour Grace: 709-945-6513
- Bonavista: 709-468-5318
- Clarenville: 709-466-5723
- Grand Bank: 709-832-1640
- Marystown: 709-279-7952

**Department of Children Seniors and Social Development**

**Medical Transportation Program** 1-877-475-2412

**NL Drug Prescription Program**
See link: Drug Cards - Newfoundland and Labrador Prescription Drug Program - SeniorsNL

**NL Housing**
See link: Home - Newfoundland and Labrador Housing Corporation (nlhc.nl.ca)

**Inclusion NL**
Inclusion NL provides support to families in our Newfoundland and Labrador and are advocates for families supporting children with disabilities.

**Newfoundland and Labrador English School District**
Newfoundland and Labrador English school district is part of the ISSP development of care plans for pediatric school aged children.

**Partnerships with various other agencies guided by client needs**
The Community Support Program partners with/refers to agencies like Vision NL, Autism Society and specialized day camps (e.g., Rainbow Riders, Eater Seals) to support client needs.

**Strongest Families Institute**
The Strongest Families Institute offers skills-based educational programs for children, youth, adults and their caregivers. They focus on disruptive behaviours, anxiety & depression concerns, and nighttime bedwetting. See link below:

https://www.google.com/search?q=strongest+families&rlz=1C1GCEB_enCA914CA914&oq=Strongest+Families&aqs=chrome.0.0i512l10.605j0j4&sourceid=chrome&ie=UTF-8

**Bridge the Gapp**
Bridge the Gapp offers to adult and youth online resources designed to support mental wellness.
See link: https://bridgethegapp.ca

6. **Information about any new initiatives that are being considered to support family caregivers.**

   The Community Support Program reports that the model for care as it relates to children and youth with complex needs has been under review by the Department of Health and Community Services and revised provincial standards are pending.

   As referenced previously, the Regional Health Authorities began rollout of The Incredible Years® in the summer of 2022. The Incredible Years® refer to evidence-based programs for parents and children with the goal to prevent and treat young children's behavior problems and to promote their social, emotional, and self-control skills. New groups are offered this fall with plans to offer fall and winter sessions.

7. **Information on any reports, draft reports, consultations, etc. by Eastern Health that address recognition, assistance, support and engagement with family caregivers.**

   Education Action Plan -The way Forward
   https://www.gov.nl.ca/hcs/files/publications-pdf-progress-update-mental-health-way-forward.pdf

   Autism action Plan
   https://www.gov.nl.ca/hcs/files/publications-pdf-autism-action-plan-2019-22.pdf

   Health Accord for NL
   https://healthaccordnl.ca/wp-ontent/uploads/2022/02/HANL_Report_Document_Web_modFeb28-2022.pdf

   The Community Support Program is presently distributing a Client Experience Survey. Caregivers to children may receive a copy of this survey; response from this population is not determined at this time.

8. **Information on the status, process and/or outcome of the review of Newfoundland and Labrador's Model for the Coordination of Services to Children and Youth with Special Needs as per the recommendations of the ISSP/Pathways Commission Report of June 2007.**

   No update on ISSP from Department of Education, although requested. DHSP CMSs ensure ISSP occurs with each active client who receives services from 2 or more service providers.

   Aligning with provincial direction, ongoing training in and the integration of the InterRai ChYMH screening and assessment tools will identify complex children and create collaborative action plans that will replace ISSPs as a collaborative service mechanism.

   A new model “Coordinated Supports for Children and Youth” is being developed for implementation provincially.

The preceding is an overview of the programs, services and supports provided by Eastern Health in relation to the subject matter of your review. Thank you for the opportunity and we look forward to continued collaboration as your review progresses. Mr. Brian Taylor, Senior Manager, Privacy & Access to Information, will be available to coordinate Eastern Health's response to any additional enquiries or clarifications you require.

Sincerely,

Kenneth Baird
President and CEO (Interim)

c.c. Sharon Samson, Assistant Citizens' Representative
Brian Taylor, Regional Manager, Access and Release of Information

Central
Health

ACCREDITED
ACCREDITATION
AGRÉMENT
CANADA

October 21, 2022

Bradley Moss
Office of the Citizens' Representative
4th Floor, Beothuck Building
20 Crosbie Place
P. O. Box 8400
St. John's, NL
A1B 3N7

Dear Bradley:

As a follow up to your letter dated August 11, 2022, please see below the responses to your eight (8) requests.

1. **Information about any existing programs and supports available for family caregivers specific to Central Health.**

<u>Developmental Health Services</u>
Central Health Developmental clinic operated until December 31, 2020. With the new provincial programming / PASS program the developmental Clinic is no longer in place. It has been replaced with Autism Diagnostic Team (PASS) and Developmental issues are referred to pediatrician. Access to Occupational Therapy, Physiotherapy and SLP services are provided through the Janeway Outreach program. Clinicians are in both Gander and GFW.

Children aged 2-9 years who have an identified risk factor for the development of a chronic disease can be referred by any health care professional to be assessed and followed by our team at our next travelling consultation clinic (TCC). TCC takes place in Central Health every 18 months.

Acute Physiotherapy
Outpatient physiotherapy services for specialty areas:

- Brachial Plexus Injuries
- Plagiocephaly/Torticollis
- Congenital lower extremity deformities such as club foot and metatarsus adductus
- Rheumatology
- Cystic Fibrosis or movement disorders
- Childhood obesity
- Infants late meeting physical milestones under age 2, not yet Dx by Janeway
- Ax and management of acute and chronic musculoskeletal conditions
- Scoliosis
- Post-concussion
- Toe walking
- Flat foot
- Growing pains
- posture
- Osgood Schlatter (go under MSK)
- Post amputation rehab

The Janeway Children's Rehabilitation Centre
Access to Occupational Therapy, Physiotherapy and SLP services are provided through the Janeway Outreach program. Clinicians are in both Gander and GFW.

Physiotherapy - Provincially, EH has three regional Physiotherapy positions dedicated to the services of children with both Rehab and developmental needs. Within Central Health, there is a clinic in Grand Falls-Winsor and one in Gander. These positions cover children with rehab and developmental concerns. Additionally, service is provided to: Children with gross motor delay, plagiocephaly/brachycephaly/high risk infants and Virtual care is used regularly as these positions cover a very large geographical area.

Occupational Therapy - Janeway Outreach is accountable for all clients under the age of 18. CH occupational therapists are responsible for those clients over the age of 18.
Psychology - Original role was working with individuals diagnosed with ASD in adjustment to diagnosis, challenges and provide intervention and recommendations Initially 30%-40% of the role was designated to assist with Developmental Clinic and assessments related to Autism.

Present role is predominately diagnostic and assessment - 1 of 2 diagnosticians in the region doing Autism Assessment Clinics.

- provide comprehensive assessments (initial interviews and administer standardized assessments tools) for Autism Assessment- first point of contact for families referred to Autism Intervention Services
- Feedback, education and diagnostics to families, as well as initiate referrals for other services as required. 70-80% of workload

Speech Language Pathology

- Birth –School Entry: Provides outpatient assessment and treatment services that may be in-person at regional referral sites or during travelling clinics to rural sites, virtual or a combination of the two.
- Clinic Assessments: Children of CRC are assessed by Janeway Outreach S-LP through yearly CRC travelling Clinic attendances.
- Technical Aids Team: Janeway Outreach S-LP provides assessment regarding Technical Aids/Assistive technology for communication as a member of the Technical Aids team during travelling clinics.
- Consultative service to School S-LPs regarding Assistive Technology: Janeway Outreach S-LP provides consultative service to school S-LPs regarding Assistive Technology for communication and learning as well as feeding and swallowing issues.
- Swallowing Assessment: Provision of assessment and management services related to evaluation of feeding/ eating/swallowing
- Talk with me Screening Program – Speech and language screening program for children between 24 and 60 months of age in some parts of Central Health region.
- Provides consultative S-LP services to the ABA home therapy programs
- Provides Jasper and Parent Mediated Jasper therapy

<u>Early Child Development</u>

SLP

- Talk with me Screening Program – Speech and language screening program for children between 24 and 60 months of age in some parts of Central Health region.
- Family Resource Center sessions on Normal Speech and Language development and early literacy
- ISSP meetings
- School SLPs provide Resources and sessions for Kinderstart programming
- Provides consultative S-LP services to the ABA home therapy programs
- Provides Jasper and Parent Mediated Jasper therapy

<u>Families Children & Population Health</u>

** the ask above says specific to CH but PH is a provincially driven program and most of our services are not specific to CH

- Healthy Beginnings Program: Goal is to support the optimal development of the child.
  - All new families are contacted by a public health nurse upon discharge from hospital and offered support
  - Assessment is complete and follow up is determined, including immediate needs of family and child, and will be either Short Term Support or Long Term Support based on the identified risk/needs of the child and family

  - Included in this program is a plan for screening and follow-up of priority families

- Special Assistance Program - Provision of medical supplies, orthotics, oxygen and medical equipment for those who are clinically and financially (families) who are eligible. Items must be on the provincially approved list.

- Parenting education sessions
  - Public Health Nurses offer parenting support to families in a variety of programs such as
    - Anticipatory guidance and the provision of health information at Health Check visits
    - Drop in parenting education and support program (known as B.U.R.P.S.) for families with children up to 12 months of age. These sessions provide parents with access to information and education by a public health nurse as well as the opportunity to share experiences and socialize with families in their community with children of the same age.
- Child Health clinics: Goal is to support families in the healthy growth and development of their children, to prevent communicable disease, facilitate access to referral to community supports and services and improve the coordination and integration of supports and services for children and their families.
  - Evidence based screening, early identification of potential health issues, systemized follow up and referral

- Healthy Baby Club services/Family Resource Center sessions
- Preschool Health Check clinics
- ISSP meetings
- Education and assistance with individualized care plan – PHNs have a role in delegation of function with families and caregivers of children with complex needs ie trach care for HSWs, school staff
  - Support to Schools (k-12) - Nurses are assigned to specific schools, and their roles generally include hearing/vision screening, immunizations, and education to students, teachers and school staff.
  - Support to Daycares as requested

Mental Health & Addictions

- Hope Valley Center is a provincial youth addiction treatment center located in Grand Falls-Windsor. The mandate of the program is to provide residential addiction treatment to youth ages 12-18. As a part of Hope Valley's programming, staff engage caregivers in the youth's treatment process. This allows the family to engage in programming specific to the youth's needs and to understand the treatment process undertaken by the youth.
- Complex Youth Case Management is a program meant for youth but this staff member often provides support to the caregiver as a part of the program process.
- Health Promotion (under the Mental Health and Addictions Services division) activities can be targeted to this caregiver population. We have provided this type of group in the past (ie Care for the caregiver).

- There are no other specific programs or supports in place for family caregivers. Family caregivers are able to avail of general services provided by MH&AS such as Doorways, community counselling, and online information and programs provided through bridgethegapp.ca

**Person and Family Centred Care**
At Central Health we recognize the importance of patient and family voices in making a better health care system. Historically health care improvement has often focused on people who work within the health care facility. Evidence and day –to- day experience shows us that in fact everyone's voice needs to be included – not just the people who are care providers. Evidence shows that we can learn a lot from the experiences of patients and families in how to make healthcare safer, improve outcomes and improve both patient and staff experiences.

Patient Experience Advisors have had a health care experience within Central Health themselves or have a family member who has experienced care. This care might be as a resident in a long-term care facility, as an inpatient in an acute care setting, as an outpatient visiting a health center, or as a client of a community service. Patient Experience Advisors use their experiences with health care delivery to bring a patient- and family- focused lens to health care improvement.

**Home First**
Home First is a client-centered philosophy that supports clients to age in place for as long as possible, with community supports. This philosophy supports Central Health's Healthy Aging Strategy and our person-and family-centred care approach. Home First is a system-wide partnership of community supports, acute care, rehabilitative services, long-term care, and primary health care.

**Home Support Services**
Home support services include an array of services which support individuals who require assistance with activities of daily living. Program services allow individuals to remain in their own homes or independent living arrangements. Home supports include personal care, behavioral supports services, household management and respite for caregivers in order to maintain independence.

Paid family Caregiver Option – launching in 2014 under the Provincial Home Support Program. This policy provides clients the option of paying a family member for their home support services based on assessed needs. This option increases client choice and flexibility in how clients manage their support services, maintains existing informal caregiving relationships, maintains accountability for care and mitigates risk of abuse or coercion.

Community Based Residential Options:

- Board and Lodging
- Alternate Family Care Homes
- Individual Living Arrangement/Shared Living Arrangement
- Co-operative Apartment

Eligibility for Alternate Family Care, Individualized Living Arrangement and Cooperative Apartment Programs -18 years of age, and has an intellectual disability; requires supervision, and behavior management; and/or continued residence in the natural home setting or alternate family home is not possible even with the required support services.

Alternate Family Care

- Alternate Family care is a private residence which provides room and board, supervision, personal care, emotional and social support to an adult with intellectual disability.
- Alternate family care homes provide a normal, supportive family environment which will prevent the use of other more restrictive arrangements. The goal of this program is to promote life skills, inclusion and individual potential.
- Currently we are supporting 74 clients in AFCH's in 52 homes in Central Region

Cooperative Apartment Program

- The Co-operative Apartment Program is operated throughout the province by Incorporated Community Residential Services Boards in Central Region the board is names Central residential Services Board
- A coop apartment is a home shared by 2 or 3 individuals with disability who are supported by co-operative apartment workers. The program goals are to encouraging independence and inclusion, supporting development of life and social skills and to enhance a client's quality of life

Individualized Living Arrangement (ILA)

- An Individual Living Arrangement (ILA) is a residential placement suitable for 1 or 2 adults with an intellectual disability.
- Individuals are supported and/or supervised by an Operations Committee that will consist of family and other advocates that will act as the employer and oversees the operations of the home.
- The ILA program is designed to promote client skill development and foster independence. The program is designed to address challenging behaviors and to promote personal potential.
- Currently Central Health supports 27 clients with intellectual disability in ILAs.

2. **Information about any policies and procedures related to programs and supports available, including criteria for access.**

   Please see policies and procedures attached.

   - Healthy Beginnings Program Guide
   - Child Care Subsidy Referral Guidelines
   - Direct Home Services Program Referral
   - Child Health Clinic Practice Guidelines
   - Policy attached for Hope Valley Centre
   - Policy attached for Complex Youth Case Management

3. **Information about any policies and procedures related to financial assessments necessary for determination of eligibility for services.**

Please see attached policies. Client Financial Services has 1 dedicated Financial Assessor to support families and caregivers of children receiving services and supports through Supportive Services for Children and Youth Program (SSCP). There are also 6 Financial Assessors dedicated to disabled adults and seniors. Approximately 60% of those caseloads consist of disabled adults.

Financial assessment is only required for the provision of home support services or board and lodging supplement. These services are provided to clientele of programs with the MH&AS department. There are no financial assessments required for admission to any of the programs provided through MH&AS. All financial assessments are completed by CH's finance department.

4. **Statistical information in your control or possession on:**

**(Long Term Care & Community Services)**
- **the number of children with complex needs in Newfoundland and Labrador;** 32
- **the number of families providing care to a child with complex needs;** 31
- **the number of children with complex needs who are eligible for services under existing programs;** 32
- **the number of children with complex needs who are in receipt of services under existing programs;** 30 (Some children unable to find respite workers or Home Therapists to cover all hours recommended by health professional.)

**(Mental Health & Addictions)**
- **the number of children with complex needs who are in receipt of services under existing programs;**
  - Hope Valley Center currently has 5 youth in the program.
  - Youth Case Management currently has 7 youth in the program. One of those seven receive multiple services from Central Health (ie Community Supports and MH&AS).

**(OBS & Population Health)**
- **# of children with complex needs in NL;** NLCHI
- **# of families providing care to a child with complex needs:** total of 570 children (ages 0 -18) with complex care needs receiving services from PHN's
- **# of children with complex needs who are in receipt of services under existing programs:**
  Special Child Welfare Allowance (ages 0 – 18): total of 162
  Developmental Psychology (ages 0 – 18): total of 11
  Behaviour Management (ages 5 – 18): total of 68
  Child Management (ages 0 – 5): total of 178
- **# of children with complex needs who are eligible for services under existing programs –** not sure how to obtain this number, it would include the numbers who are receiving services; not sure how to determine the numbers that are *eligible* for services but not in receipt of same

5. **Information about any partnerships with other public bodies and/or community agencies to provide services and supports to family caregivers.**

- Home Support Agencies. Agencies are utilized to provide services and supports to children and families requiring home supports for personal care, respite and supportive needs.
- AMAL Youth and Family Centre. This organization provides a range of innovative services responsive to the needs of individuals, families and communities, including educational, social, cultural, outreach, clinical, family-based, alternate care and networking activities. Currently there are children who receive services through AMAL, funded by Central Health's SSCP. AMAL is usually contracted due to challenges with obtaining home supports from local agencies or when a child's needs are very complex and require intensive support.
- Janeway Children's 'Hospital. The Social Work support at the Janeway collaborate with Social Workers to support families for travel and hospitality if travel is required to the Janeway for pediatric appointments.
- Central Residential Services Board. Central Residential Services provides residential and staffing supports for adults with complex care needs. Children have been placed at these residences near families to support families respite needs.
- Jumpstart. Families have been supported in application requirements for Jumpstart to allow children to engage in meaningful and beneficial physical activity when recommended.
- Social Workers. In Central, there are 2 Social workers dedicated solely for Children's Services.
- AMAL – provides family engagement services (currently to one client). This program provides supportive services to the youth and their parents/caregiver.
- Calypso Foundation is a non-profit organization that provides valuable work and learning opportunities for individuals with disability in the Lewisporte area.
- Broadening Horizons is a pre-employment program and is structured with programming Monday to Friday 9:00 am to 3:00 pm for adults with intellectual disability in Gander and the surrounding areas. Calypso and Broadening Horizons offer participants a chance to enhance and develop skills for everyday living. They include household chores such as vacuuming, dishwashing, cleaning, kitchen safety and meal preparation. Community access is facilitated through volunteering with groups in town as well as participating in outside and community activities.

- Exploits Community Employment Corporation. A non-profit agency that provides Supported Employment Services to persons with disabilities in Springdale and surrounding areas.
- Other partners include: Children Seniors and Social Development; Autism Society; Jacob's Principle; Inclusion NL.; MTAP; Schools; NL Drug Prescription Program; NL Housing Corporation

6. **Information about any new initiatives that are being considered to support family caregivers.**

   Realignment of some program responsibilities to ensure one point of contact for Child Youth Community Health support. This will assist with facilitating navigation of the system and further enhance coordinated program responses.

7. **Information on any reports, draft reports, consultations, etc. by Central Health that address recognition, assistance, support and engagement with family caregivers.**

   Optimus SBR completed a review of the capacity of services to Children and Youth to ensure adequate service delivery to children and families in a new provincial child health services model. The vision - partners collaboratively address the needs of children, (particularly with complex needs); seamless info sharing among parents, service providers, resulting in capacity building within families – promote optimal development, well -being and learning.

8. **Information on the status, process and/or outcome of the review of Newfoundland and Labrador's Model for the Coordination of Services to Children and Youth with Special Needs as per the recommendations of the *ISSP/Pathways Commission Report of* June 2007.** Provincial response required.

Sincerely,

J Pelley

(Joanne Pelley for) Andree Robichaud,
President & Chief Executive Officer

Western
Health

October 19, 2022

Mr. Bradley Moss
Citizens' Representative
Office of the Citizens' Representative
4th Floor, Beothuk Building
20 Crosbie Place, P.O. Box 8400
St. John's, NL A1B 3N7

Dear Mr. Moss:

***RE: Citizens' Representative File #526CF22***

Dear Mr. Moss:

Please accept this letter and the attached correspondence as Western Health's response to the "Own Initiative" investigation to examine the current supports, programming and services provided to family caregivers of children with complex needs. Western Health continues to be committed to working with the Office of the Citizens' Representative of Newfoundland Labrador as well as the other Regional Health Authorities and agencies to support the needs of children, as well as adult children with complex needs and their families.

To begin, there are a number of program areas within Western Health that provide services, supports, consultation, and coordination to children, as well as adult children, with complex needs and their families:

a. **Western Health's Developmental Health Programs** include Speech-Language Pathology, Direct Home Services Program, Developmental Psychology, Audiology and Autism Assessment Team. The mandate of Developmental Health services is to provide assessment and intervention services to young children with a wide range of hearing, speech, language, behavioral and developmental issues. The primary aim of these services is to improve child development outcomes and assist families in obtaining information/support and intervention related to the development of their child. These services are based on principles of early intervention, child and family centered care–and collaborative practice. Speech Language and Developmental Health Services and Direct Home Services are available until school entry (Kindergarten), clients receiving autism interventions can continue until grade three (applied behavioural analysis) and age nine for the JASPER program. Autism assessments and audiology services are available to all ages.

b. **Western Health's Public Health Team** offers Maternal, Child and Family Health services that are designed to enable individuals and families to achieve optimal preconception and prenatal health and to prepare for parenthood so that infants and children may attain and sustain the best health and development possible. Maternal/Child and Family Health services include prenatal education and support services, postnatal services, breastfeeding services, healthy beginnings, child health clinics, and comprehensive school health services. Many of these services are universal in nature and are designed to help identify challenges and complexities early, such that appropriate supports can be put in place. Children are followed from birth until school entry.

c. **Western Health's Mental Health and Addictions Programs** service children, youth and adults throughout the Western region and provide services at the following sites: Port aux Basques, Burgeo, Stephenville, Deer Lake, Norris Point, Port Saunders, Blomidon Place and Humberwood Treatment Centre located in Corner Brook. E-mental health and addiction services are available virtually or by phone increasing access to residents throughout the regions. Services are based on the principles of interagency coordination and collaboration with the utilization of an interdisciplinary approach to triage/intake, counseling, assessment and program planning. Services are provided to children and youth until the age of nineteen years while ensuring a collaborative transition into the adult services. Services offered include education and prevention, health promotion, counseling, assessment and case management for youth with complex mental health and/or addictions needs. Assessments are based on a comprehensive biopsychosocial model with intervention focusing on the individual and/or the family/caregivers.

   Western Health's Mental Health and Addictions programs accept referrals for individuals seeking support related to mental health and /or addictions concerns. This also includes services for those impacted by a family or loved one's substance use or mental health concerns. The top three referral sources all program areas include family, physician and the Department of Children, Seniors and Social Development (CSSD) and this has been consistent for several years. Referrals received range from concerns related to parenting, bullying, separation and divorce, anxiety and depression, sexual abuse, and eating disorders, amongst others. Services consist of the following complement of staff throughout the region: triage/intake coordinator/team leader, social workers, youth addictions counsellor, youth case manager, clinical psychologists, and administrative support.

d. **Western Health's Community Support Program** is responsible for the services under the Supportive Services for Children's Program. This program provides case management and financial benefits to support children and their families. Services may include home support, community inclusion support, drug care, developmental rehabilitative services and supports, Special Assistance Program (SAP), support for transportation/meals/lodging, funding for specialized dietary foods, and respite care.

e. **Western Health Pediatrics (Children's Health) Care** provides a wide range of services, including medical, surgical, orthopedics, and palliative care in which fully trained nursing staff, along with general practitioners, surgeons, and pediatricians provide quality care to the pediatric patient population.

In response to your request pursuant to section 31 of the *Citizens' Representative Act*, please see below:

1. **Information about any existing programs and supports available for family caregivers specific to Western Health.**

a. **Western Health's Developmental Health programs** provide individual and/or group assessment and interventions by Speech Language Pathologists, Audiologists, Developmental Psychologists, Child Management Specialists and Social Worker. Some examples of specific services provided include the JASPER program, Intensive Applied Behavioral Analysis, Autism Assessment, Hearing Assessments, Speech Therapy, etc. In addition to providing individual/group assessment and intervention, staff in these programs support families by:

- Referring a child to other developmental health services when other concerns are noted, including the Janeway Outreach program.
- Consulting with other healthcare professionals to gain information and suggestions for parents regarding challenges in a particular area of development.
- Providing information regarding the "Doorways" program with Mental Health Services, see description below.
- Referring clients and families to the Strongest Families Program, see description below.
- Seeking and providing information to families regarding Community Support services, such as respite care.
- Providing information on local Family Resource Centers and their programming.
- Writing letters in support of funding for new/continued daycare placement.
- Visiting daycares, sometimes in conjunction with other service providers, to support the child so that they can continue day care attendance.
- Initiating and participating in Individual Support Service Plans (ISSP) and involving school personnel in the year prior to school entry to ensure needed services are requested to allow a smooth transition to school.
- Referring the child to the Speech-Language Pathologist servicing the child's school for continued intervention as needed once the child starts Kindergarten.
- Providing joint intervention with other service providers to lessen the burden of multiple individual sessions, which may help reduce stress associated with attending multiple appointments.
- Providing virtual care, especially for families who live a significant distance from clinics and for families who prefer this option.
- Providing regular Speech-Language Pathology travelling clinics to two health centers on the Northern Peninsula to service clients in those areas, including children.
- Offering programming designed to strengthen parenting skills and prevent and treat behavior problems in young children. This past year, the Direct Home Services program started a new parenting program for caregivers of children aged 3-6 years called The Incredible Years.
- Providing services to caregivers of children who are referred for autism spectrum disorder (ASD): Caregivers of children who are referred for ASD assessment take part in an intake process with the Autism Assessment Team's Intake Coordinator who is a registered Social Worker. Counselling and support are provided to these families prior to the assessment (during intake) as well as after the assessment is completed, if required.
- Autism Services training is provided to home therapists and caregivers of children receiving services through Autism Services. Topics addressed in the training include information related to the diagnosis of ASD, types of support available to families (e.g., respite, parent

support groups through the Autism Society of Newfoundland and Labrador), Autism Services Interventions, and evidence-based treatments that may be used with the child.
- Providing counseling and support to caregivers. Psychologists in the Developmental Health program meet with caregivers to counsel them on intervention strategies as well as to provide support based on difficulties, they are experiencing in managing their child's concerns.
- Offering counseling services to caregivers of clients who are receiving Developmental Health services. This service is provided by a Social Worker.
- Providing coverage under the Provincial Hearing Aid program to all children diagnosed with hearing loss and who require aids. This program provides hearing aids to children of all ages who have hearing loss at no cost to the family.
- Referring families of hearing-impaired children (who meet the qualifications) to the provincial Cochlear Implant Program. This program provides cochlear implants to children with hearing loss and hearing aids cannot benefit.
- Referring individuals to local Itinerant Teachers for the Deaf and Hard of Hearing who see not only school aged children, but also see preschoolers with hearing loss, and provide supports to the family.

b. **Western Health's Public Health Programs** are universal (provided to all children) but provide increased levels of support for children/families with identified needs. Services that are most relevant for children with complex needs include:

- ***Prenatal Education and Support Services*** are provided to all women and families of childbearing age from pre-conception to delivery by Community Health Nurses (CHN's). Referrals to this prenatal program come from a variety of referral sources such as: self-referrals; the Provincial Mother Baby Nutrition Food Supplement Program; physicians, nurse practitioners; Healthy Baby Clubs; Family Resource Centres; school personnel and others. Services offered through this program include Before Birth and Beyond Information Education and Support (BABIES) program, prenatal classes, and individual nursing support. The assessment completed through the BABIES program determines the level of care and support the mom and family may require in addition to identifying the need for any additional supports or referral(s) that may best meet the mothers and or needs of the family. The BABIES program is based on the Provincial Standards *Education and Support Standards for Pregnancy, Birth and Early Parenting.*

- ***Healthy Beginnings*** is a voluntary service providing support to all families with newborns, infants, and younger children from birth to five years of age. All families with a new baby are contacted and assessed by the community health nurse (CHN) and offered follow-up and support during the postnatal period. All new mothers are expected to be contacted by the Community Health Nurse within 24-48 hours of discharge and offered a home visit. Specific areas to be addressed by the CHN include establishing the service and discussing circle of care, collaborative practice, confidentiality and necessary follow-up to assessing safety concerns, family adjustment issues, infant feeding and breastfeeding support, anticipatory guidance, and any other supportive services that the family will require with the introduction of a child to the home. Children are discharged from Healthy Beginnings when immediate postnatal needs are met and referred to universal services, e.g., breastfeeding support groups, child health clinics and local services available in the community. Based on assessed criteria, children and families who are eligible for long term support are offered Long Term Healthy Beginnings (LTHB) follow-up, and if they agree to participate in the program, are followed at regular intervals until kindergarten entry, or until identified needs have been met.

- ***Child Health Clinics: (including Preschool Health Check)*** provides families the opportunity to have their child's health and development assessed and monitored through the early years of the child's development. Clinics are offered to the child and parent at 2, 4, 6, 12, and 18 months of age. A Preschool Health Check is offered to children between the ages of 3 years and 9 months and 4 years and 2 months. During each clinic, the CHN conducts developmental screening assessments based on the child's age and provides guidance and support in several areas related to the child's development such as infant nutrition, weight, and oral health. The CHN provides the family with parenting support and provides information and/or referrals to other services available to the family through the Regional Health Authority or community partners such as Family Resource Centres and Healthy Baby Clubs in the area. Immunizations are offered to the child during the Child Health Clinic in accordance with the Provincial Immunization Program. All Child Health Clinics are guided by provincial standards, Child Health Clinic Manual, and the Preschool Health Check Manual.

c. **Western Health's Mental Health and Addictions program** offers the following programs and services:

- ***Doorways, Drop-in, Virtual Services and Appointment Based Services*** for individual counselling services are available for caregivers as well as adult children with complex needs. With the release of the all-party report *Towards Recovery*, tremendous work continues to transform the mental health and addictions system in the province. In addition to clinical efficiencies in eliminating a waitlist for services by implementing a drop-in model for services, the offering of (1) DoorWays -walk-in clinic for single session therapy (ages 12 years and older), (2) Therapy Assisted Online (TAO) - e-health technology that pairs online education materials with brief clinician contact by phone, chat or video conferencing and for adults/youth, and (3) the *Strongest Families Institute*, a program that provides a prescribed and customized cognitive behavioral therapy (CBT) program to children ages 3-17 years and their families, continue as part of the provincial Stepped Care Demonstration Project. All these services have had an overall positive impact in terms of client access and reduced wait times. The transition to drop-in services provides more options for children and youth in need of mental health and addiction services, eliminates the waiting time, and mitigates lost clinical time due to no shows, rescheduled, and cancelled appointments – all enhancing client and family centered care. As an example of the services that are offered, services to individuals with Autism Spectrum Disorder as well as their families have been a part of interdisciplinary teams when services are offered. With client consent, family sessions are provided to support the treatment needs of our clients.

- ***Addictions Services*** accepts referrals for youth who are involved in problematic substance use or for parents or caregivers who require support to cope with a youth's substance use. The Youth Case Management program in Corner Brook and Stephenville area accepts referrals for youth with complex mental health and/or addiction concerns, who require intensive intervention and multidisciplinary coordination of services. The youth case manager meets with clients in the community, completing ongoing risk assessment and harm reduction support while providing intervention therapies and linkages with our partners. There are currently 8 active youth case management clients in the Corner Brook and Stephenville region in need of intensive support. The number of youth who are receiving services can vary, but caseload is smaller due to the intensive services required.

- ***Mental Health and Addiction Services*** for children and youth is working closely with other service providers including Newfoundland and Labrador English School District (NLESD), Community Support program, and the Autism Society NL to provide services to clients with neurodevelopmental disabilities. The Team Lead/Intake Coordinator is part of a working group initiated by Provincial Autism Support Services (PASS) to develop an operational manual for the Program for the Education and Enrichment of Relational Skills (PEERS), a program that provides social skills to children and youth with ADHD and ASD. The PEERS program has a strong evidence-base for use with adolescents and young adults with autism spectrum disorder, but is also appropriate for preschoolers, adolescents, and young adults with ADHD, anxiety, depression, and other socioemotional problems. This past year, a PEERS group was piloted using a virtual platform due to the Covid-19 pandemic. The group consisted of 8 teens from the ages of 15-18 years and their caregivers. Group members were from Corner Brook, Stephenville, Deer Lake, and St. John’s. Feedback from caregivers and participants was positive and participants attended a small in-person gathering upon the completion of the group to receive their certificates and prizes earned during their involvement in the group. Mental Health and Addiction Services will continue to be involved with community stakeholders to offer PEERS in the upcoming year.
- ***The Flexible Assertive Community Treatment (FACT) and Early Psychosis Programs*** service the adult population. A board and lodging financial subsidy is available to help support relatives and non-relatives care for individuals with a psychiatric disability. Home Support services are also available to eligible clients to help them live independently at home. FACT and Early Psychosis actively engage family members and caregivers in treatment, with the client’s consent. The majority of FACT and Early Psychosis services occur in the community, in client’s homes, where family members and caregivers are present. With a client’s consent, family members are involved in treatment planning, safety planning and crisis intervention. A primary component of the Early Psychosis program is education to clients and their family members to optimize treatment engagement and outcome. There is a psychiatrist attached to each of the three FACT offices within our region.

- ***MH-BASES*** is a new integrated service delivery model in the process of being planned for child and youth community health services across home, school, and community settings as mandated by the Government of Newfoundland and Labrador in the Towards Recovery Action Plan. Staff have participated in various professional development opportunities and attended working group meetings to support the implementation of this new service delivery model. Staff participated in trainings for two group programs, *Dinosaur Years, Incredible Years (IY)* and *Coping Power* to support the emotional, social, and behavioral needs of children and youth. IY is an evidence-based treatment for young children ages 4-8 years with conduct problems, oppositional behavior, and ADHD. *Coping Power* is an evidence-based program that targets children and youth aged 8-14 years to improve deficits in emotional regulation, problem solving, and social interactions. Staff are currently completing, or have completed, the interRAI Child and Youth Mental Health (ChYMH) on-line training. ChYMH is a comprehensive assessment to intervention for children and youth between 4-18 years of age with mental health needs. The ChYMH assesses psychiatric, social, environmental, and medical issues for children and youth receiving community-based and inpatient/residential services.

- ***A Dialectical Behavior (DBT) group "Skills for Change"*** was implemented for the first time this past year. This is a 24-week group that provides skills for managing emotions, distress tolerance, interpersonal effectiveness, and mindfulness.
- ***The Parenting Difficult Behaviors Group*** is a behavioral intervention program for parents/caregivers of children/youth experiencing behavioral difficulty. This program is offered on an individual and group basis. The Strongest Families behavioral programs for children and youth ages 3-12 years are regularly offered as an option for service-delivery depending on the needs of the client. Parenting Difficult Behaviors, Parenting Information Sessions (Child & Adolescent) and Parenting Your Anxious Child are offered most frequently – all for parents and caregivers of our children and youth connected with services. Staff continue to work closely with agencies who provide care to clients in a group home setting. DBT skills training for caregivers and staff continued over the past year to support staff in areas of distress tolerance, mindfulness, emotional regulation, and interpersonal effectiveness. All groups can be offered in person or by accessing virtual technology. Although groups are not specific to caregivers of adult children with complex needs, they can help provide support and coping skills for anxiety and depression as well as anger management.
- ***Humberwood Treatment Center*** (ages 19 and over) incorporates clients' families into education components and ways to support their loved ones living with addictions.
- ***The Adult Mental Health Unit at Western Memorial Regional Hospital (WMRH)*** with patient consent incorporates and encourages caregiver involvement in treatment of inpatients by inviting them to family meetings and obtaining collateral information on patients to help with assessment and diagnosis. Caregivers are involved in discharge planning and follow-up and family visitors are always supported on the mental health unit when it is in the patient's best interests.
- ***Adolescent Mental Health Unit at Western Memorial Regional Hospital*** which provides a safe, therapeutic, and caring environment for children and adolescents experiencing psychological, physical, behavioral and addictive disorders, through an interdisciplinary team approach. Individual plans of care and treatment are developed for each child and family from a person and family centered care perspective.

**d. Western Health's Community Support (CS) programs** are available to assist individuals to live independently at home, and when no longer possible, to support access to residential community-based care or to facility-based care. Support services, within the program, are available to children and to adults living with intellectual and/or physical disabilities and seniors. Case managers (social workers or nurses) work with individuals, their families and with other health care professionals and team members to support care and ensure quality of care.

The Community Support Program is guided by the principles of collaboration, person centered, and needs based, family involvement and support, accessible, and accountable. Community support has scope of practices established for all clinical staff which include occupational therapists, physiotherapists, community health nurses, licensed practical nurses, nurse practitioners, social workers, behavioral management specialists, and support services which include our social assistance workers (who are responsible for the processing of requests for financial assistance and other benefits), buyers (who are responsible for the implementation of the special assistance program) and administrative staff (who provide a critical role as the first point of contact for our clients and their families).

The Community Support Program provides support to individuals who meet one of the following criteria:

- Are at least 18 years of age and older and have a physical and/or intellectual disability, requiring long term assistance with daily living and/or supplies and equipment.
- Are under age 18 requiring Supportive Services for Children, see below.
- Are at least 65 years of age and over requiring assistance with daily living and/or supplies and equipment which would enable them to remain home
- Require protection under the Adult Protection Act
- Requires short term post-acute care follow up such as non-pressure wound therapy, home infusion program, home chemotherapy program and end of life care.
- Require home nursing care, is home bound and require a home visit from a nurse to a maximum of once per day.
- Have an intellectual disability and require placement in one of the residential options monitored by the Community Support Program including Alternate Family Care, Individual Living Arrangement or Cooperative Living.
- Requires a placement in a long-term care facility or personal care home.

## Children Services:

Supportive Services for Children's Program: This program provides case management and financial benefits to support children and their families. Services may include:

- ***Home Supports*** provides home support and may include assistance in supervision and personal care needs.
- ***Community Inclusion Support*** provides support to link children and their families to ensure inclusion in recreational, social and community activities.
- ***Drug Card*** supports needs as it relates to the child's disability.
- ***Developmental and Rehabilitative Services and Supports*** provides intervention services that are available as needed to support the complex needs of the child. This may include access to behavioral management services for parent training, or intensive therapeutic interventions

with the child. This includes collaboration with other services such as occupational therapy, physiotherapy, etc.

- ***Special Assistance Program (SAP)*** provides basic supportive medical products and may include the following: medical supplies, incontinence and personal health supplies; oxygen and related equipment and supplies; orthotics such as braces and burn garments; and equipment such as wheelchairs, commodes and walkers.
- ***Support for transportation/meals/lodging*** support to access services for medical appointments and social/recreational travel.
- ***Funding for specialized dietary foods*** provides an allowance for diabetic food and dietary supplements for children. The special assistance program (SAP) supports access to these specialized dietary supplements. A listing is enclosed
- ***Respite care*** provides caregiver relief, and/or help with recreational activities.

## Adult Services (Including Adult Children):

There are various supportive services available for adults to support living independently, with family and/or in residential options. These supportive services include:

- ***Home Support*** are intended to supplement, not replace, services provided by the individual's family or support network. The program provides non-professional assistance to help the individual and their family with personal care, household management, respite care and behavioral support as needed.

- ***Residential Services*** are in place to meet the needs of both adults with individual disability and older adults. Care options include support to live in their own homes, board and lodging with relatives, board and lodging with non-relatives, alternate family care, individual living arrangements and co-operative living arrangements.

- ***Alternate Family Care Arrangements*** is a licensed family home that provides room and board, supervision, and personal/social care to an unrelated adult with an intellectual disability. This living arrangement is the first and preferred option should an adult is no longer able to reside with their natural family.

- ***Individual Living Arrangements*** is a 24-hour staffed arrangement for individuals with intellectual disabilities. The responsibility for the operation and continuation of this type of living arrangement rests with the individual and/or their family.

- ***Co-Operative Living Program*** is a flexible program where two or three residents reside in a house with 24-hour support. The program is designed to address individual behaviors and teach life skills that would enable the individual to live in other less restrictive community settings.

- ***Financial Services*** is a service for individuals wishing to avail of home support and other benefits are subject to a financial assessment. The financial assessment is completed by a social worker assistant worker and is income tested.

- ***Special Assistance Program*** is a program to provide medical supplies and equipment to assist with activities of daily living. To quality, the individual must meet financial eligibility and have a clinical assessment completed by a nurse, social worker, occupational therapist, or a physiotherapist depending on the client's needs. Available supplies include medical supplies, oxygen and related equipment and supplies, and orthotics.

- ***Special Assistance Equipment Program*** is a program to provide equipment to assist with activities of daily living for individuals living in the community. To quality, the individual must first meet financial eligibility and have a clinical assessment completed by clinicians as stated above. Available supplies include bathing aids, toilet aids, beds and accessories, transfers assists, ambulation aids and chairs.

- ***Adult Protection Services*** are services for which the Community Support Program has the lead responsibility within Western Health for the implementation, delivery, and evaluation of services to adults in need of protective intervention under the *Adult Protection Act 2011*. Under the *Act*, an adult in need of protective intervention means an adult who lacks capacity and is either incapable of caring for themselves or who refuses, delays or is unable to make provision for adequate care and attention for themselves or is abused or neglected.

- ***Nursing Service*** are services that include acute home nursing services such as home chemotherapy, negative pressure wound therapy, home intravenous therapy, and end of life services; ambulatory clinic services in Deer Lake and Jeffrey's area; continuing care services (clients who have chronic health condition and are not able to access hospitals or clinics and require support to remain living at home). Services offered can include wound care, blood work, IVs, medication administration, management/support of urologic devices, management/support central access devices, and end of life and palliative care services.

- ***Community Behavioral Services*** are services to promote community inclusion, positive programming, and least restrictive principles. The program has three major goals: to support clients living in their community and to participate in their home and community; to support clients and their care-providers/significant others, in the delivery and maintenance of intervention strategies and principles; to promote understanding of lifespan development and the function of behaviors.

- ***Rehab Services*** are services to provide both occupational therapy and physiotherapy resources. Occupational therapists collaborate with clients to enable occupations, the things that people do to look after themselves and others (self-care), enjoy life (leisure) and contribute to their communities (productivity). Examples include cooking, dressing, bathing, reading, volunteering, or going to work. Physiotherapists focus on the following: improving and maintaining functional independence and physical performance; preventing and managing pain, physical impairments, disabilities, and limits to participation; and promoting fitness, health, and wellness.

- ***Home First*** is an approach to care to remove barriers and wrap supports around people in their homes and communities. Home first initiatives may be implemented for a maximum of 8 weeks and are integrated across the health care system with a focus on continuity of care. It facilitates a quick response to provision of home supports, rehabilitation, nursing, counselling and/or spiritual support, medical equipment and supplies and other services depending on need. Palliative/end of life support is provided under Home First. Services will continue until end of life with no financial contribution from the client.

e. **Western Health Pediatrics (Children's Health) Care:**

- Provides a wide range of services, including medical, surgical, and orthopedics in which fully trained nursing staff, along with general practitioners, surgeons, and pediatricians provides quality care to the pediatric patient population. In addition, palliative care for children is also provided on the inpatient unit.

- Western Memorial Regional Hospital has a Women and Children's Health Unit, and five beds on this unit are utilized for the pediatric population aged 28 days up to 18 years in which pediatric services are specifically designed and offered within acute care and children are admitted by a Pediatrician, are medically stabilized during their admission and then discharged home with their families for continued care and support from home/community.

- Typically, pediatric patients are short stay admissions with the goal to return home as soon as possible as evidence has shown that pediatric patients recover quicker at home once stabilized and proper supports in place.

- Acute care social work services are available to pediatric patients and their families to support them to explore any additional supports they may require inclining emotional, financial, equipment for home, respite care hours etc.

- Western Health Pediatric services partner with the Janeway Children’s Hospital for pediatric patients who require tertiary care.

2. **Information about any policies and procedures related to programs and supports available, including criteria for access.**

Western Health has a number of policies and procedures in place to support programming, support and access. These include the following (copies enclosed):

- 6-04-30: Model for Coordination of Services to Children and Youth in Newfoundland and Labrador
- 15-01-05: Baptism or Dedication of Infants and Children
- 15-01-30: Family Presence and Partners in Acute Care
- 15-01-717: Safe Sleep Practices for Newborn Infants
- 15-01-718: Newborn Bottle Feeding
- 15-01-725: Sucrose Oral Solution for Infant Pain
- 15-01-728: Nipple Shield Use for Breastfeeding Newborn Infants in Acute Care
- 15-01-730: Early Heating Detection and Intervention Program
- 15-01-765: Breastfeeding Healthy Term Infants
- 15-01-1195: Lactation Consultant Services
- 17-05-160: Family Presence in Long Term Care and Rural Health
- 18-01-805: Clinical Assessment Community Support Services
- 18-01-1000: Home Financial Assessment and Reassessment
- 18-01-1025: Intake Process and Timelines for Children Program
- 18-01-1030A: Clinical Assessment of Children for Supportive Services Children Program
- 18-01-1030B: Guidelines Support Services for Children
- 18-01-1040A: Finance Assessment Supportive for Children Program
- 18-01-1050: Financial Assessment-Reassessment – Support Services
- 18-01-2610: Referral and Intake Community Support Program
- 18-03-20: ISSP for Children and Youth
- 18-03-425: Prenatal Assessment and Education

- 18-03-430: Health Beginnings Program
- 18-03-435: Child Health Check (0-2 years of age)
- 18-03-440: Child Health Check: Preschool
- 18-03-530: BABIES: (Before Birth and Beyond, Information, Education and Support) Program Screening Assessment
- 18-03-1610: Commencement of Intensive Applied Behavioral Analysis Home Therapy
- 18-03-1805: Eligibility of Referrals for Preschool Children
- 18-03-1807: Processing of Referrals for Preschool Children
- 18-03-1810: Collaborative Practice for Clients Receiving Applied Behavior Analysis
- 18-03-2020: Autism Assessment Team – Intake, Assessment and Follow-up Process
- 12-2643: Form: Community Support Services Financial Application 12-2643
- Manual: Supportive Services for Children Program
- Person and Family Centered Care (PFCC) Strategy
- Provincial Hearing Aid Program
- The Cochlear Implant Program is a provincial program currently operated by Eastern Health.
- The Early Hearing Detection and Intervention document has been submitted to the Department of Health and Community Services (identifies the need for a consistent provincial approach to early hearing detection and intervention).

**Policies Specific to Adults (including Adult Children):**

- 18-01-250 Eligibility Criteria for End-of-Life Services in the Community Setting
- 18-01-560 Referral Process (Community Behavioral Services Program
- 18-01-805 Clinical Assessment – Community Support Services Program
- 18-01-830 Support Plan – Community Support Services Program

- 18-01-1610 Intervention Plans
- 18-01-1620 Home Support Program – Program Components
- 18-01-1650 Home Support Case Management and Monitoring
- 18-01-1670 Home Support – Emergency Response
- 18-01-1700 Home Support – Assessment Process
- 18-01-1710 Home Support Program – Service Delivery Options
- 18-01-1720 Request for Exceptions to Home Support Program
- 18-01-1790 Paid Family Caregiver Option
- 18-01-2000 Cooperative Apartment Program
- 18-01-2045 Cooperative Apartment Referral and Admission
- 18-01-2060 Cooperative Apartment: Monitoring/Annual Review
- 18-01-2110 Individual Living Arrangement – Monitoring/Annual Review
- 18-01-2120 Individual Living Arrangement Program
- 18-01-2140 Individual Living Arrangement Eligibility
- 18-01-2327 Alternate Family Care Home Program
- 18-01-2325 Alternate Family Care Home: Monitoring/Annual Review
- 18-01-2330 Alternate Family Care: Client Eligibility
- 18-01-2410 Client Referral – Screening, Prioritizing and Waitlisting of New Referrals (Occupational Therapy and Physiotherapy)
- 18-01-2610 Referral and Intake – Community Support Program
- 18-01-2620 Service Availability Home First Integrated Network

- Guidelines: Criteria for Prioritization of Referrals and Intervention Occupational Therapy

**<u>Policies Specific to Family Caregivers</u>:** Family caregivers can play an active role in how care and care provision look for their loved ones. Through case management, a client's family will be engaged as requested by the client and/or through the Advance Health Care Directives Act as Substitute Decision Makers. Polices to support include:

- 15-01-30 Family Presence and Partners in Care
- 18-01-2020 Cooperative Apartment Resident Health Care Decisions
- 18-01-2150 Individual Living Arrangement Resident Consent for Health Care Decisions
- 18-01-2329 Alternate Family Care Home Resident Health Care Decisions
- 18-01-2366 Alternate Family Care: Coordination of Health Services for Clients
- 18-02-15 Involvement of Family/Significant Other in Patient Care

**3. Information about any policies and procedures related to financial assessments necessary for determination of eligibility for services.**

The following policies and procedures are in place to support financial assessments for determination of eligibility for services:

**<u>Policies and Procedures Specific to Children:</u>**

- 18-01-1040 Finance Assessment Supportive for Children Program
- Form: Community Support Services Financial Application 12-2643

**<u>Policies and Procedures Specific to Adults (Including Adult Children):</u>**

- 18-01-1000 Home Financial Assessment and Reassessment
- 18-01-1050 Financial Assessments/Reassessments – Adult Services
- 18-01-1060 Alternate Family Care – Financial Assessment/ Reassessment
- 18-01-1070 Financial Hardship Consideration: Financial Reassessment

- 18-01-1075 Financial Services -Special Assistance Program

- 18-01-1080 Individual Living Arrangements – Financial Assessment/ Reassessment

- 18-01-1090 Financial Services – Special Assistance Equipment Program

4. **Statistical information in your control or possession on:**
    - **the number of children with complex needs in Newfoundland and Labrador;**
    - **the number of families providing care to a child with complex needs;**
    - **the number of children with complex needs who are eligible for services under existing programs;**
    - **the number of children with complex needs who are in receipt of services under existing programs:**

Statistical information will be provided by the Department of Health and Community Services.

5. **Information about any partnerships with other public bodies and/or community agencies to provide services and supports to family caregivers.**

Western Health continues to strive to provide quality services to children, youth and families. We know that we cannot do this work without the partnerships of other support services. Staff recognize and value the importance of consultation and collaboration with other service providers in the delivery of support and services to family caregivers of children and adult children with complex needs**.** Western Health partners with various internal and external partners and they include:

- Family Resource Center (FRC): Western Health staff provide information to clients about the FRC. Staff have attended sessions at the FRC to observe clients and have conducted presentations for families there.
- Linkages with the Autism Society of Newfoundland and Labrador: For children receiving a diagnosis of autism spectrum disorder, families are provided with contact information for the Autism Society.
- Strongest Families Institute: Western Health staff refer caregivers to this program based on client needs.
- Children's Friendship Program (in planning phase; scheduled to begin this fall): This program will be offered in conjunction with The Autism Society and the Newfoundland and Labrador English School district). The goal is to give children the skills to have mutually satisfying social interactions with peers. The program involves sessions for both children and their caregivers.
- Canadian Hard of Hearing Association, Newfoundland Chapter (CHHA-NL): The Association has programs to support children of varying ages and their families, as well as adults. Families are made aware of these services when appropriate
- Janeway Outreach Services
- Janeway Psychiatry Department for clients and their caregivers under 16 years for continuation of this service
- Tuckamore Treatment Center

- Hope Valley In-Patient Treatment Center
- Newfoundland and Labrador English School District
- Family Resource Centers
- Child Care Centers and Family Child Care Homes
- Breastfeeding Support Groups
- Other Regional Health Authorities
- Western Regional Wellness Coalition and members
- Local community groups and organizations
- Children, Seniors, and Social Development
- Autism Society
- Jordan's Principle
- Inclusion Newfoundland and Labrador
- Medical Transportation Assistance Program (MTAP)
- Schools
- Newfoundland and Labrador Prescription Drug Program
- Newfoundland and Labrador Housing
- Red Cross (not currently open in Corner Brook)
- CNIB
- Alzheimer's Society
- Home Support Agencies (Tender Loving Care, Caregivers, Maximum, and Compassion)
- Momentum Developmental Support
- Bay St. George Residential Support Board (BSGRSB)
- Humber Valley Cooperative Living Corporation
- Qalipu First Nation
- Patient Advisors
- Strongest Families Program
- Community Mental Health Initiative (CMHI)

**6. Information about any new initiatives that are being considered to support family caregivers.**

- The Speech Language Pathology (SLP) service is in the early process of adding a new collaborative service with Occupational Therapy of the Janeway Outreach program to offer pediatric swallowing services which would help triage children who need further investigation at the Janeway. This would support families by potentially decreasing the need for travel to the larger center and allow more frequent follow-up locally, as needed.

- Western Health continues to work with the Department of Health and Community Services to implement a new provincial Child and Youth Community Services model within the Western Region. This service will encompass four program areas including Developmental Health Services, Mental Health Services (MH Bases), Provincial Autism Services and Supports (PASS) and Supportive Services to Children. The key components of the Child and Youth Community Services will focus on the following:
    - strong evidence-based intervention grounded on developmental practice,

- levels of care based on presentation and complexity of needs,
- professional development, clinical oversight, and core competencies,
- link to primary health care physicians and specialized care,
- parent support and capacity building embedded in all intervention,
- assessment tools and procedures to determine functional need for support and clearly defined exit culture.

A change management plan is being developed to support transition to this new model. Policies and standards have been developed in several of these areas and work is underway to standardize assessment tools and in coordinating an information sharing process to replace the ISSP. Health resource planning is in progress as well as diversification of professional development to support the readiness of staff to deliver these services.
Some examples of new programs which are being introduced to support this new approach include:

- Responsive Interactions for Learning (RIFL) – currently awaiting provincial direction on future implementation. Pilot being completed at present. Responsive Interactions for Learning (RIFL) is a promising training program that targets responsivity as well as stimulation, exploring parents' ability to correctly assess the knowledge and state of mind of his or her child while cooperating to reach a shared goal (Prime, Perlman, Tackett, and Jenkins, 2014). RIFL also emphasizes the caregiver's ability to expand children's ideas and knowledge by asking questions and providing children with appropriate challenge and support through scaffolding of skills. This program has been developed to increase responsivity and engagement and these targets have been linked to improved socio-emotional and language development.

- The Incredible Years Parenting Program for Toddlers. This is a parenting program for caregivers of toddlers aged 1-3 years. The program is designed to strengthen parenting skills and promote children's optimal social, emotional, physical and academic development. Western Health has delivered one program thus far and is planning on offering it again this fall.

- Children's Friendship Program (in planning phase to begin Fall 2022) will be offered in conjunction with The Autism Society of NL and NLESD). The goal of the program is to give children the skills to have mutually satisfying social interactions with peers. The program includes sessions for both children and their caregivers.

There are a number of initiatives that are being considered to support family caregivers and include the following:

- The Department of Health and Community Services is exploring an individualized funding model for home support services, introducing new home support standards, entering into service level agreements with the home care agencies, and development of a new home support solution to improve processes and communication of home support services. This will include a new client and family portal that will enhance communication with the home support agencies.

- A new seamless service provision for adults with developmental disabilities is in development and will fall under the services of the Supporting Abilities Program. Work is going under way with representatives across the RHAs and other community partners working with those with disabilities.

- Deloitte has completed a provincial residential review. This review will help assist in the development of increased residential and other supported living options for individuals with significant complex needs. This residential review included focus groups of care providers, clients, and their family members.

**7. Information on any reports, draft reports, consultations, etc. by Western Health that address recognition assistance, support, and engagement with family caregivers.**

- Western Health recognizes the value of Person and Family Centered Care (PFCC) and acknowledges it is an integral component in the provision of safe, quality care. Western Health understands that families play a critical role in ensuring the health and well-being of clients. We acknowledge the importance of health care providers, leaders, clients, and families working in partnership, when planning, delivering and evaluating health care. As such Western Health has developed and implemented a formal PFCC strategy to expand opportunities to partner with clients and families. Engaging clients and families as partners at all levels within Western Health ensures their voice(s) is integral to programs and services.

- Western Health conducts Client/Patient/Resident Experience Surveys on a regular, rotational basis. This provides clients and their families with the opportunity to provide feedback on their experiences with services. Please see attached a copy of the Infographic of results of the June 2022 Community Support Client Experience Survey.

- A caregiver support pamphlet has been created by the Community Support Program. The pamphlet has been shared with the Patient Family Advisory Group for feedback and in the planning stages for how best to disseminate.

**8. Information on status, process and/or outcome of the review of Newfoundland and Labrador's Model for the Coordination of Services to Children and Youth with Special Needs as per the recommendations of the ISSP/Pathways Commission Reports of June 2007.**

The ISSP and the Model for Coordination of Services has been revised and the new Coordinating Supports for Children and Youth Process has been developed is working through the approval process. This is a streamlined process for coordinating supports for children and youth with complex needs developed. It highlights one comprehensive plan with clearly defined roles and responsibilities for the members of the child/youth team. This process is inclusive of all child servicing departments, agencies and partners and includes an information sharing protocol and shared consent. There are Regional and Provincial committees for oversight embedded into this process. Western Health is working collaboratively with the Department of Health and Community Services on the development of these initiatives.

**9. Any other commentary / questions that may not be addressed in the above questions.**

Western Health offers the following comments in response to this question:

- Currently there are limited community resources available for specific populations within the Western Region to support vulnerable children and their families. Our communities would benefit from other agencies such as daycare to support children with complex needs, home support workers trained to support medically vulnerable children, day programming and residential respite options to provide temporary care for care providers. Similar services are also needed for adult children living with complex needs and their caregivers.

- The Community Support financial services team has identified that gaining access to Revenue Canada (similar to AES/CSSD) for Notice of Assessment will aid in timely completion of financial assessments to clients. This recommendation has been shared with the Department of Health and Community Services.

- Although not all programs offer specific programs solely for family caregivers, Western Health provides support to parents and helps make connections to other services and programs to help them and their child.

- Efforts are made to schedule client appointments at times that are convenient for the caregivers, often in conjunction with other visits; in particular when clients have to travel to access services.

- Audiology and Speech-Language Pathology clinics are held throughout the region to help improve access to services for all ages. There are some limitations with initial Audiology assessments at these clinic sites due to age of client and availability of equipment at the site.

- Infant hearing screenings are completed on all children at birth to identify hearing loss as soon as possible and to have children with hearing loss fitted with hearing aids prior to six months of age (unless other medical needs have greater priority at the time).

- Children are given priority on Audiology waitlists.

- Women experiencing postpartum depression receive immediate mental health and addiction services.

Western Health wishes to express appreciation for the opportunity to provide a response to this important issue. We are committed to working with the Office of the Citizens' Representative to implement any recommendations you may provide in response to this investigation. If you have any questions or concerns, please contact Ms. Sherri Tiller-Park via email at sherritiller@westernhealth.nl.ca or by telephone at (709) 784-5248.

Sincerely,

MHouse

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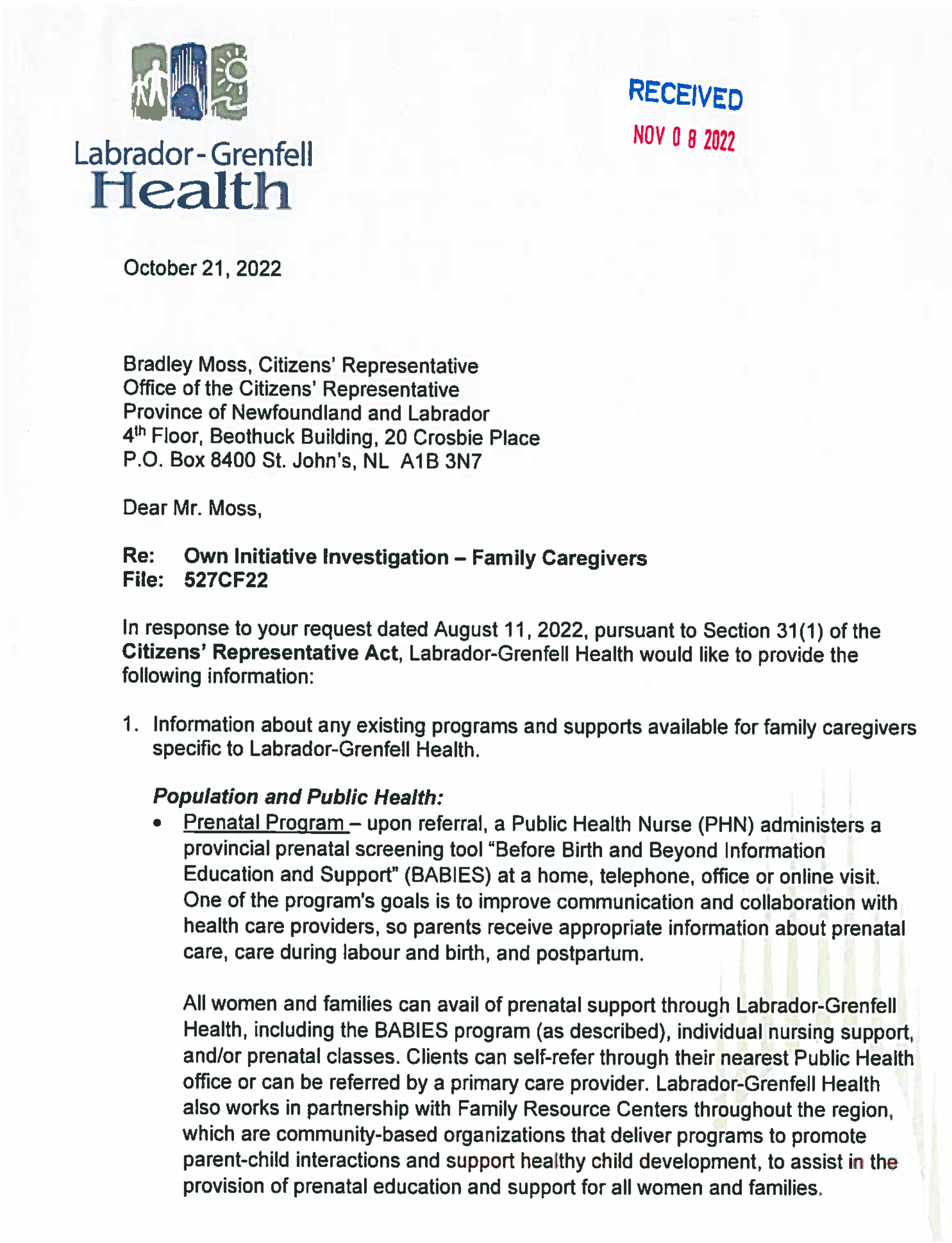
Ms. Michelle House
Interim Chief Executive Officer
Western Health

c.c. Ms. Sharon Samson, Assistant Citizens' Representative
Sherri Tiller-Park, Regional Manager Information Access & Privacy

Enclosures



Labrador-Grenfell
Health

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October 21, 2022

Bradley Moss, Citizens' Representative
Office of the Citizens' Representative
Province of Newfoundland and Labrador
4th Floor, Beothuck Building, 20 Crosbie Place
P.O. Box 8400 St. John's, NL  A1B 3N7

Dear Mr. Moss,

**Re: Own Initiative Investigation – Family Caregivers**
**File: 527CF22**

In response to your request dated August 11, 2022, pursuant to Section 31(1) of the **Citizens' Representative Act**, Labrador-Grenfell Health would like to provide the following information:

1. Information about any existing programs and supports available for family caregivers specific to Labrador-Grenfell Health.

***Population and Public Health:***

- Prenatal Program – upon referral, a Public Health Nurse (PHN) administers a provincial prenatal screening tool "Before Birth and Beyond Information Education and Support" (BABIES) at a home, telephone, office or online visit. One of the program's goals is to improve communication and collaboration with health care providers, so parents receive appropriate information about prenatal care, care during labour and birth, and postpartum.

  All women and families can avail of prenatal support through Labrador-Grenfell Health, including the BABIES program (as described), individual nursing support, and/or prenatal classes. Clients can self-refer through their nearest Public Health office or can be referred by a primary care provider. Labrador-Grenfell Health also works in partnership with Family Resource Centers throughout the region, which are community-based organizations that deliver programs to promote parent-child interactions and support healthy child development, to assist in the provision of prenatal education and support for all women and families.

- Healthy Beginnings Program - this early childhood intervention program from birth to age 5, is universally offered by PHNs to all families following the birth of a new baby. The program is designed to develop and maintain a network of health and community services to ensure that all families with young children have access or links to a range of health education, prevention, and early intervention services. Services include assessment, consultation and a variety of interventions as needed. Information about various topics such as parenting, safety, nutrition and growth and development are available to parents. PHNs use the Helen Parkyn Priority Assessment tool, information provided from the Live Birth Notification form (received from the hospital), Edinburgh Postnatal Depression Scale (EPDS) and professional judgment to determine whether the child is at risk and should be referred to other community services and supports and the duration of the Healthy Beginnings program. Short Term Healthy Beginnings (STHB) is maintained until the child's first well-baby clinic visit.

  Children engaged in the Long Term Healthy Beginnings (LTHB) program receive prescribed home, clinic, or telephone visits where a PHN may provide counselling, parenting education, support, reinforcement of medical and other professionals' recommendations, organize team meetings and provide referrals to medical/ community/ government resources or services to help the child reach developmental milestones. Children remain in the LTHB program until they enter kindergarten, voluntarily leave, or when the developmental concern resolves. A PHN reflects on their practice to ensure that individual service informs population service at the community level, e.g., the PHN notes that several individual children in their community have no place to play with other children; this is an opportunity to create a community childhood playgroup.

- Child Health Checks – this program provides screening, support, interventions (i.e. immunizations), and risk assessments. It also provides opportunities for assessment of growth and development and anticipatory guidance as needed. Referrals are made to various services as appropriate. These clinics are offered to the child and parent at 2, 4, 6, 12, and 18 months of age. A Preschool Health Check is also offered to children 4 years of age.

- Health Check 2 ½ program – prior to the initiation of this program, it was found that children with a wide variety of health issues and concerns were not being identified in a timely manner, further compounded by the fact that children were often required to be placed on waitlists for service provision once an issue was identified.

  As a result, the Health Check 2 ½ program was developed. Established as a regular part of public health programming in some areas within the current Labrador-Grenfell Health region in 2002, with expansion throughout the entire

Labrador-Grenfell Health region in January 2011, the overall goals of the program include the following:

- Prevent or limit the onset, duration, and effect of specific health problems for young children and their families
- Foster and reinforce the achievement of healthy lifestyles, sound health practices and behaviors, and positive adjustments to developmental changes of young children
- Facilitate access and/or refer to community supports and services for young children and their families
- Improve the coordination and integration of health services

To accomplish these goals, the Health Check 2 ½ program provides health screening using the Ages and Stages Questionnaire, which is a validated, parent-led screening tool used to measure a child's development related to communication, fine and gross motor skills, personal-social skills, and problem solving. This program also provides families with anticipatory guidance, referral for services, follow-up when concerns are identified, recommendations for available community supports and services, as well as verification of immunization status and provision of immunizations when appropriate.

An evaluation of this program in 2017 revealed that the Health Check 2 ½ is supported and valued by community health nurses, service providers, parents, and the manager and coordinator of the program, and that this program provides a consistent opportunity for early identification of any concerns related to a child's health and development. Labrador-Grenfell Health is currently the only Regional Health Authority within Newfoundland and Labrador that has incorporated the Health Check 2 ½ program.

- <u>School Health</u> – the Population Health department collaborates with and provides services for children and staff with both the Newfoundland and Labrador English School District as well as Conseil Scolaire Francophone. All services that are provided support the four health pillars of the *Joint Consortium on School Health*, which was established in 2005 as a partnership between federal, provincial, and territorial governments across Canada to support optimal health, well-being and learning of youth in school communities. The four pillars include teaching and learning, social and physical environments, healthy school policy, and partnerships and services.

  To achieve these goals, Public Health Nurses, School Health Liaison Consultants, Regional Nutritionists and Health Promotion Educators within Labrador-Grenfell Health partner with the school to provide individual client services as well as health promotion initiatives to the school aged population. On an individual client level, PHNs provide allergy management sessions (for example education for staff on allergies, how to recognize anaphylaxis and assist the child with administration of their Epi-Pen), hearing and vision screening, immunizations per the NL immunization schedule including routine vaccinations as well as targeted vaccines (for example COVID-19 vaccine clinics in schools), Communicable Disease Control when required, supporting parents and caregivers with respect to educating school staff for the delegation of nursing asks (for example administering feeds via feeding tubes), and supporting the development of Individual Support Services Plans (ISSP). ISSP is a collaborative, integrated, and preventative approach to the planning and delivery of services to children/youth at risk or in need including, but not limited to, children with an identified health challenge (congenital or acquired), children in families with interaction or social problems, or children at risk for developmental delay. It consists of a working plan involving the multidisciplinary team which identifies strengths, needs, child-specific goals, context-specific interventions, accountability, and time frames for completion of objectives.

Population health promotion initiatives include, but are not limited to, the following:

- Provision of health education and information to students, including puberty education, healthy sexuality, and Sexually Transmitted Blood Borne Infection (STBBI) education
- Provision of health information and resources to teachers as needed
- Collaboration with schools regarding issues impacting health and education, such as head lice management
- Development and implementation of health promotion programs and activities in collaboration with the LGH School Health Liaison Consultant
- Provision of education to Kinderstart classes upon request

Within the high school system, the Wellness Café is offered to youth on a drop-in basis to provide integrated health and wellness services in a safe and supportive environment. The Café is held within the school and is a place where students can discuss issues related to their growth and development. The School Health Liaison Consultant supports this program in collaboration with PHNs and youth outreach workers. The Wellness Café model was first piloted with the LGH region in Happy Valley-Goose Bay in 2017 with plans to expand the program to other areas within the region and has been modelled after a similar initiative in Eastern Health.

- <u>Janeway Lifestyles Clinic</u> – as a unique pediatric chronic disease prevention service for children and families, this clinic offers multidisciplinary assessment, written summary and feedback to families and referring health care professionals, follow up consultation including telehealth, and specific resources to help in the child's continued care. The clinic members include a team that travels to Happy Valley-Goose Bay and Sheshatshiu and consists of six health care professionals (pediatric endocrinologist, physiotherapist, dietitian, therapeutic recreation specialist, social worker, and psychologist). Clients avail of all or as many of these services as identified by the team to be beneficial. Clients can be referred if they are between 2-18 years old and are either at risk of acquiring or currently has a chronic health condition and would benefit from Janeway's multidisciplinary team. Any health care provider can refer a child to this program. Historically, the team traveled once a year, but additional funding has recently been secured and the team will now be traveling for these clinics twice per year.

***Mental Health & Addictions:***

- Doorways: this walk-in counselling service provides rapid access to mental health and addictions counselling services 'one session at a time'.
    - Available to children, youth and adults without an appointment or referral.
    - It is primarily a walk-in service, but some locations provide same-day, next-day or appointment-by-phone.
    - If further counselling is required, staff will work with you to provide access to additional services and supports.
    - Doorways provides information and support focused on your need.
    - Some examples of what you may want to discuss are: family, health, grief, work, relationships, stress, anxiety, depression, drinking or drug use.

  Doorways is NOT an emergency service. In an emergency, call 9-1-1- or the Mental Health Crisis Line at 1-888-737-4668, or proceed to the nearest emergency room department.

- Bridge The Gapp: is an online mental health resource available in Newfoundland and Labrador connecting you to local services, information, and tools to support wellness. The best thing about it is its accessibility. From a computer, tablet, or a phone in your pocket, you can instantly access content that can provide advice, inspiration, assurance, or direction for finding additional supports when you need it the most.

- Strongest Families: this province-wide program includes *Parents Empowering Kids, Chase the Worries Away, Defeat Anxiety, Dry Nights Ahead, ICAN Adult Anxiety & Depression, Parents Empowering Kids – The Early Years.* Clients can enroll directly for our ICAN Adult (18+) Anxiety & Depression program. Clients can enroll directly for our Parents Empowering Kids (7-12 years old), Parents Empowering Kids – The Early Years Program (3-6 years old at time of referral), Defeat Anxiety (12-17 years old), or Chase Worries Away program (6-11 years old).

- FACTT (18 +): is an interdisciplinary team that provides treatment of serious mental illness and symptoms, hands-on assistance with daily living activities and recovery support for individuals. Often referred to as a "hospital without walls", FACTT teams strive to ensure continuity of care and prevent admission to hospital by providing intensive services for individuals in the community through assertive community outreach. FACTT provides services to individuals usually over the age of 18, with serious mental illness who might otherwise require hospital admission, particularly during episodes of acute mental illness. FACTT serves people in the community living with serious mental illness and focuses more on the person's needs rather than a specific diagnosis.

- Board & Lodging (relative/non-relative): the Board and Lodging Supplement is a financial service that is available to an adult with psychiatric, physical and/or intellectual disabilities, 18 years of age and older, who resides with relatives or non-relatives. These adults must be identified as having needs and must require a higher board and lodging rate to live in these arrangements. The basic rate of board and lodging is available through the Department of Advanced Education, Skills and Labour (AESL) and the supplement is available through Labrador-Grenfell Health.

- Community Inclusion Fund: this fund is intended to assist clients to be integrated into the community, thus improving their mental health. The fund may also be used to assist clients in emergency situations, with intent to prevent a breakdown in a service or the client's level of functioning. Clients requesting funding assistance under the Community Inclusion Fund must have first explored all other sources (e.g., Human Resources, Labour and Employment [HRLE], Food Banks, Community Centres). It is the Case Manager's responsibility to explore all funding sources with the client, and the Community Inclusion Fund is to be used only when no other funding sources are identified. There are limitations to what the fund can be utilized for.

- Home Supports (specific to MH& A clients who qualify): clients accepted to this program should:
  - Be between the ages of 18-64
  - Be willing to work with a Case Manager/FACTT
  - Have a psychiatrist or family physician providing care
  - Have a primary psychiatric diagnosis; specifically schizophrenia, schizoaffective disorder or bipolar/manic depression and unexplained psychosis without primary diagnosis
  - Have needs that cannot be adequately met by referral to existing community-based services alone
  - Not already be receiving similar services from another source

  *Clients must also require assistance with some of the following areas*: Management of Mental Illness; Living Skills (Personal Care, Communication, Money Management, Home Management, Interpersonal Skills, Use of Transportation); Locating and/or Maintaining Housing; Locating and/or

Maintaining Occupational or Educational Programming or Productive, Meaningful Daily Activities; Establishing and/or Maintaining a Support Network; Coordination of Community-based services.

*Assessment:*
The *Adult Needs Assessment* and Home *Supports Assessment/ Reassessment Guidelines* are used to determine the number of hours the client is eligible for. Once approved by your manager and regional director, consult with the finance department to complete the *Request for Special Needs Using Enriched Needs* form. This will determine, based on the client's income and expenses, how much they will need to co-pay for the community supports program. If the client is a recipient of Income Support through the Department of Advanced Skills, Education and Labour (AESL), then the enriched needs assessment does not need to be completed. You will just need a confirmation from the client and AESL that the client is in receipt of income support. This means that the client would not have any co-pay and they are automatically covered for the full cost of their approved home supports. The *Home Support Financial Breakdown* also needs to be completed.

- Clinical Counselling: counsellors are available to support individuals who have mental health or substance use concerns as well as family/friends who are affected by the following: Alcohol and Drugs; Grief and Loss; Anxiety and Stress; Depression; Mental Illness; Parenting; Relationships; Sexual, Physical and Emotional Abuse; Smoking; Suicide; Gender and Identity; Anger; Eating Disorders; Family Issues; Fears and Phobias; Gambling; or any other concern that is affecting your mental health and wellbeing.

- Managers on-call after hours and on weekends: Mental Health & Additions managers are providing on-call on a weekly rotational basis. They are available on weekdays from 4:00 pm – 8:00 am and on weekends from 4:00 pm on Friday until 8:00 am on Monday. This provides physicians and clinical nurse managers the option to consult with the manager who is on-call regarding any urgent clinical issues such as critical incidents, crisis response and other clinical issues that cannot wait until Mental Health & Addictions' regular department hours.

- Mobile Crisis Response Team: the Mobile Crisis Response Team (MCR) travels as a team to assist/intervene with a mental health-related crisis, in a person's home or community. The team has significant experience in mental health. In addition, Mobile Crisis Response can accompany other health care providers in client/patient community visits. The service is currently available in Labrador West and Happy Valley-Goose Bay, seven days a week from 10:00 am to 10:00 pm.

***Community Supports:***

- Guided by the principles of collaboration, person centered, and needs based, family involvement and support, accessible, and accountable. Community support has scope of practice established for all clinical staff which include occupational therapists, physiotherapists, community health nurses, licensed practical nurses, nurse practitioners, social workers, behavioral management specialists, and support services which include our social assistance workers (who are responsible for the processing of requests for financial assistance and other benefits), buyers (who are responsible for the implementation of the special assistance program) and administrative staff (who provide a critical role as the first point of contact for our clients and their families).
- Provides support to the disability related unmet needs of children and adults with physical and intellectual disabilities, as well as seniors. This program adheres to provincial guidelines both from a program and financial perspective and are available to assist individuals to live independently at home, and when no longer possible, to support access to residential community-based care or to facility-based care. Support services within the program, are available to children and to adults living with intellectual and/or physical disabilities and seniors. Case managers (social workers or nurses) work with individuals, their families and with other health care professionals and team members to support care and ensure quality of care.
- The Community Support Program provides support to individuals who meet one of the following criteria:
    - Are at least 18 years of age and older and have a physical and/or intellectual disability, requiring long term assistance with daily living and/or supplies and equipment
    - Are under age 18 requiring Supportive Services for Children (see below)
    - Are at least 65 years of age and over requiring assistance with daily living and/or supplies and equipment which would enable them to remain home
    - Require protection under the Adult Protection Act
    - Requires short term post-acute care follow up such as non-pressure wound therapy, home infusion program, home chemotherapy program and end of life care
    - Require home nursing care, is home bound and require a home visit from a nurse to a maximum of once per day
    - Have an intellectual disability and require placement in one of the residential options monitored by the Community Support Program including Alternate Family Care, Individual Living Arrangement or other residential service options
    - Requires a placement in a long-term care facility or personal care home

- Supportive Services for Children, or SSCP (formerly Special Child Welfare Allowance, or SCWA) PROVINCIAL PROGRAM: Provides supports to the disability related needs of children with physical or intellectual disability living at home (under the age of 18 as afterwards, the individual would access adult-based services and supports). This program is designed to enable families to purchase items and/or services which are necessary due to the child's disability, as defined by a clinical assessment of the child and a financial assessment of the parents. This program adheres to provincial guidelines both from a program and financial perspective. Supports may include:

- ***Home Supports*** provides home support and may include assistance in supervision and personal care needs
- ***Community Inclusion Support*** provides support to link children and their families to ensure inclusion in recreational, social and community activities
- ***Drug Card*** supports needs as it relates to the child's disability
- ***Developmental and Rehabilitative Services and Supports*** provides intervention services that are available as needed to support the complex needs of the child. This may include access to behavioral management services for parent training, or intensive therapeutic interventions with the child. This includes collaboration with other services such as occupational therapy, physiotherapy, etc.
- ***Special Assistance Program (SAP)*** provides basic supportive medical products and may include the following: medical supplies, incontinence and personal health supplies; oxygen and related equipment and supplies; orthotics such as braces and burn garments; and equipment such as wheelchairs, commodes and walkers
- ***Support for transportation/meals/lodging*** support to access services for medical appointments and social/recreational travel
- ***Funding for specialized dietary foods*** provides an allowance for diabetic food and dietary supplements for children. The special assistance program (SAP) supports access to these specialized dietary supplements
- ***Respite care*** provides caregiver relief, and/or help with recreational activities

- Adult Services (Including Adult Children): There are various supportive services available for adults to support living independently, with family and/or in residential options. These supportive services include:

  - ***Home Supports*** are intended to supplement, not replace, services provided by the individual's family or support network. The program provides non-professional assistance to help the individual and their family with personal care, household management, respite care and behavioral support as needed. In addition to the regular home support program, there are also service options under enhanced care and short term acute, all operating under a home first philosophy. Clients/families can choose self-managed care or agency provided services as applicable.

  - ***Residential Services*** are in place to meet the needs of both adults with individual disability and older adults. Care options include:
    - Support to live in own home
    - Board and Lodging (Relatives)
    - Board and Lodging (Non-Relatives)

- Alternate Family Care Homes is a licensed family home that provides room and board, supervision, and personal/social care to an unrelated adult with an intellectual disability. This living arrangement is the first and preferred option should an adult is no longer able to reside with their natural family.
- Individualized Living Arrangements is a 24-hour staffed arrangement for individuals with intellectual disabilities.
- Shared Living Arrangements is a 24-hour staffed arrangement for individuals with intellectual disabilities where more thanone client may live in the home.

- ***Financial Services*** is a service for individuals wishing to avail of home support and other benefits are subject to a financial assessment. The financial assessment is completed by a social worker assistant worker and is income tested.

- ***Special Assistance Program*** is a program to provide medical supplies and equipment to assist with activities of daily living. To qualify, the individual must meet financial eligibility and have a clinical assessment completed by a nurse, social worker, occupational therapist, or a physiotherapist depending on the client's needs. Available supplies include medical supplies, oxygen and related equipment and supplies, and orthotics.

- ***Special Assistance Equipment Program*** is a program to provide equipment to assist with activities of daily living for individuals living in the community. To quality, the individual must first meet financial eligibility and have a clinical assessment completed by clinicians as stated above. Available supplies include bathing aids, toilet aids, beds and accessories, transfers assists, ambulation aids and chairs.

- ***Adult Protection Services*** are services for which the Community Support Program has the lead responsibility within Labrador-Grenfell Health for the implementation, delivery, and evaluation of services to adults in need of protective intervention under the *Adult Protection Act 2011*. Under the *Act*, an adult in need of protective intervention means an adult who lacks capacity and is either incapable of caring for themselves or who refuses, delays or is unable to make provision for adequate care and attention for themselves or is abused or neglected.

- ***Nursing Services*** are provided through ambulatory care clinics and in-home services for homebound clients. Services can include wound care, blood work, IVs, medication administration, end of life, palliative care services, etc.

- ***Community Behavioral Services*** are services to promote community inclusion, positive programming, and least restrictive principles. The program has three major goals: to support clients living in their community and to participate in their home and community; to support clients and their care-providers/significant others, in the delivery and maintenance of intervention strategies and principles; to promote understanding of lifespan development and the function of behaviors.

- ***Rehab Services*** including occupational therapy, physiotherapy, speech language and audiology services. Referrals are made to these service providers where the need is indicated.

- ***Home First*** is an approach to care to remove barriers and wrap supports around people in their homes and communities. Home first initiatives may be implemented for a maximum of 8 weeks and are integrated across the health care system with a focus on continuity of care. It facilitates a quick response to provision of home supports, rehabilitation, nursing, counselling and/or spiritual support, medical equipment and supplies and other services depending on need. Palliative/end of life support is provided under Home First. Services will continue until end of life with no financial contribution from the client.

It is acknowledged that availability of home care workers is a significant challenge for some clients and their families. Particularly for those with complex needs and with aging caregivers. Reviews of both the home support program and residential service options have been completed and conversations are ongoing between Regional Health Authorities and the Department of Health and Community Services around how these provincial programs may be strengthened.

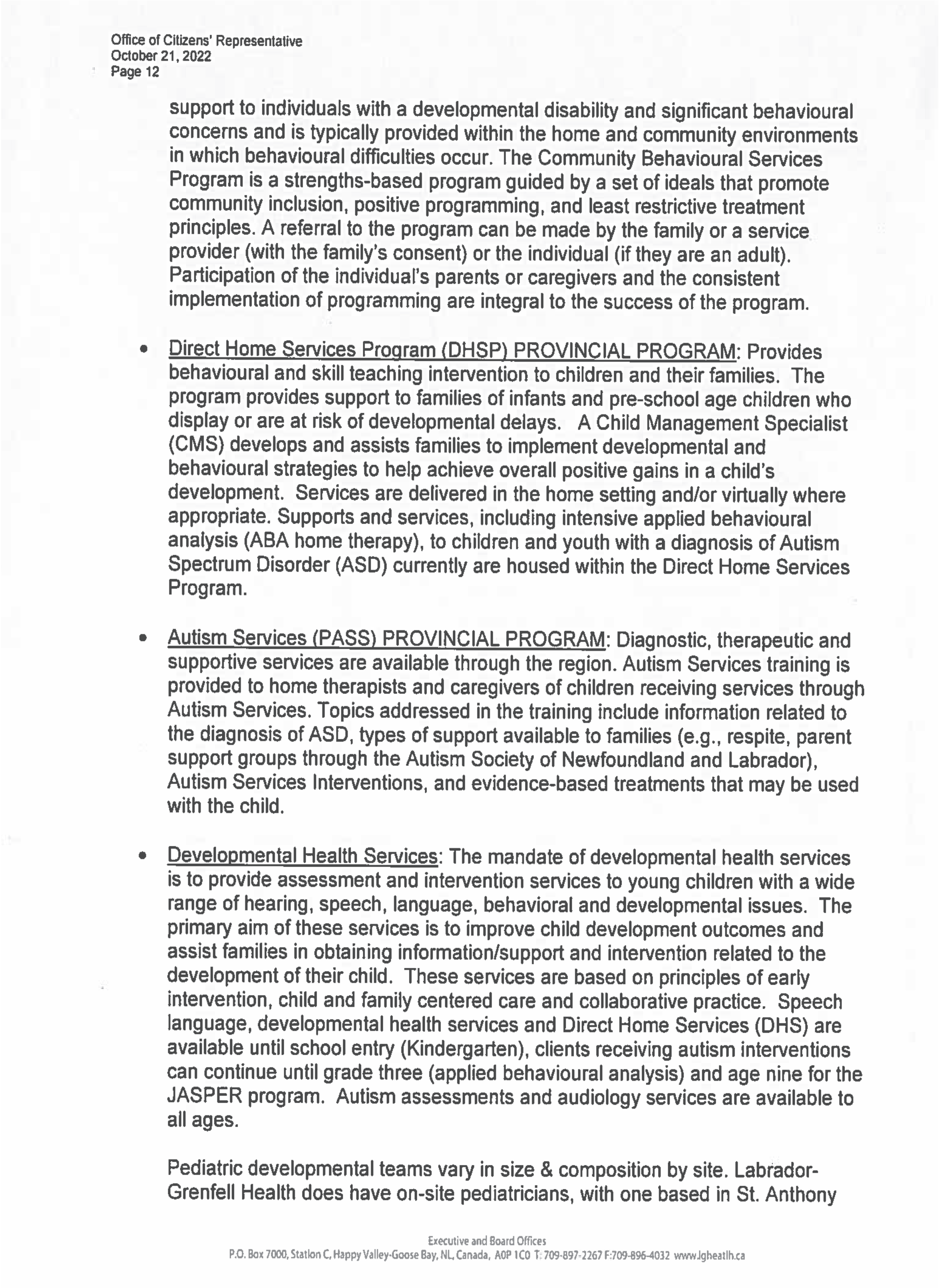
- Special Assistance Program PROVINCIAL PROGRAM:

  Provision of the following where there is clinical and financial eligibility as per the provincially approved list:
  - Medical supplies (such as dressings, catheters and incontinent supplies),
  - Oxygen and related equipment and supplies,
  - Orthotics such as braces and burn garments, and
  - Equipment such as wheelchairs, commodes or walkers.

- Community Behavioral Services Program (CBSP) PROVINCIAL PROGRAM:

  Provides behavioral and skill teaching interventions to school-aged children and their families with the goal to train parents and significant others to practice intervention techniques aimed at modifying disruptive behaviors; and to support the child's participation in the community. Please note that any children between the ages of 2 and 18 years, and families receiving services from the Department of Children, Seniors and Social Development (CSSD) may receive these supports from Behaviour Management Specialists (BMS) employed with CSSD instead of the Regional Health Authority.

  A voluntary, community-based behavioural support program that is available for individuals school-aged and older. The program provides intervention and



support to individuals with a developmental disability and significant behavioural concerns and is typically provided within the home and community environments in which behavioural difficulties occur. The Community Behavioural Services Program is a strengths-based program guided by a set of ideals that promote community inclusion, positive programming, and least restrictive treatment principles. A referral to the program can be made by the family or a service provider (with the family's consent) or the individual (if they are an adult). Participation of the individual's parents or caregivers and the consistent implementation of programming are integral to the success of the program.

- Direct Home Services Program (DHSP) PROVINCIAL PROGRAM: Provides behavioural and skill teaching intervention to children and their families. The program provides support to families of infants and pre-school age children who display or are at risk of developmental delays. A Child Management Specialist (CMS) develops and assists families to implement developmental and behavioural strategies to help achieve overall positive gains in a child's development. Services are delivered in the home setting and/or virtually where appropriate. Supports and services, including intensive applied behavioural analysis (ABA home therapy), to children and youth with a diagnosis of Autism Spectrum Disorder (ASD) currently are housed within the Direct Home Services Program.

- Autism Services (PASS) PROVINCIAL PROGRAM: Diagnostic, therapeutic and supportive services are available through the region. Autism Services training is provided to home therapists and caregivers of children receiving services through Autism Services. Topics addressed in the training include information related to the diagnosis of ASD, types of support available to families (e.g., respite, parent support groups through the Autism Society of Newfoundland and Labrador), Autism Services Interventions, and evidence-based treatments that may be used with the child.

- Developmental Health Services: The mandate of developmental health services is to provide assessment and intervention services to young children with a wide range of hearing, speech, language, behavioral and developmental issues. The primary aim of these services is to improve child development outcomes and assist families in obtaining information/support and intervention related to the development of their child. These services are based on principles of early intervention, child and family centered care and collaborative practice. Speech language, developmental health services and Direct Home Services (DHS) are available until school entry (Kindergarten), clients receiving autism interventions can continue until grade three (applied behavioural analysis) and age nine for the JASPER program. Autism assessments and audiology services are available to all ages.

Pediatric developmental teams vary in size & composition by site. Labrador-Grenfell Health does have on-site pediatricians, with one based in St. Anthony and the other in Happy Valley-Goose Bay. Pediatricians offering in-person and/or virtual care where appropriate to Labrador City and Coastal Labrador. Referrals from allied health professionals, outside agencies and self-referrals are accepted for all children. Services are delivered primarily in a clinic setting or virtually where appropriate.

Pediatric rounds are completed by the pediatrician with available service providers / team members in St. Anthony and Happy Valley-Goose Bay team on a weekly / biweekly basis.

- Rainbow Clinic in St. Anthony
- Northern Lights Clinic in Happy Valley-Goose Bay
  - Provides a team approach to coordinated assessment, therapy and follow-up services for pediatric clients who are birth to 16 years of age with multiple needs, requiring services from at least three team members. This may include rehabilitative, behavioral, developmental and social needs. The appropriate team members work with the child and family to develop a plan of care.
- Labrador West Child Health Services Team.
  - In Labrador City, the Labrador West Child Health Services Team does meet for monthly rounds, but the team does not include the involvement of a pediatrician.

- Speech-Language (SLP) services: Screening, assessment, intervention and consultation is offered to pediatric clients with a range of speech and language needs (ex. articulation, language, fluency, voice, feeding). Children are typically kept on SLP caseloads until speech and language skills are considered age appropriate, or until they transfer to a school based SLP.

- Occupational Therapy (OT) and Physiotherapy (PT) services: Available to all pediatric clients. Self-referrals are accepted for all children. Children are typically kept on caseloads until their goals are completed. There is consultation with the Janeway team for children with complex conditions.

- Audiology: Early Detection and Hearing Intervention Program offered at the three main sites in the LGH region. based on locum staff availability.
  - Providing coverage under the Provincial Hearing Aid program to all children diagnosed with hearing loss and who require aids. This program provides hearing aids to children of all ages who have hearing loss at no cost to the family.
  - Referring families of hearing-impaired children (who meet the qualifications) to the provincial Cochlear Implant Program. This program provides cochlear implants to children with hearing loss and hearing aids cannot benefit.

  - Referring individuals to local Itinerant Teachers for the Deaf and Hard of Hearing who see not only school aged children, but also see preschoolers with hearing loss, and provide supports to the family.

- Feeding Therapy: A program offered by the OT, SLP and Dietician to children residing in the upper Lake Melville area, the North Coast of Labrador and St. Anthony. Feeding Therapy is a program designed for restrictive eaters that follows very specific criteria for eligibility. The goal of the program is to increase feeding behaviours of infants and children in the LGH region over the course of 10 weekly / biweekly group sessions co-facilitated by OT, SLP and Dietician. In Labrador West, this service is provided on an individualized basis by the OT, rather than in a group situation.

- Social Work: Provides assessment, support, counselling, discharge planning, coordination of community resources and advocacy for children and their families as required.

***Acute Care:***

- Antenatal Clinic: Interdisciplinary antenatal clinic for patients in their third trimester. Physician and obstetrical (OBS) Registered Nurses are present for antenatal assessments. Provides assessment, screening, support, interventions, and risk assessments. Also provides opportunities for assessment of growth and development; anticipatory guidance is provided as needed. Referrals sent to services as appropriate.

- Pre- and Post-Natal Care: Inpatient staff, inclusive of OBS trained nurses provide pre and post natal care to families while admitted on the unit. The multidisciplinary team works collaboratively to ensure supports are in place for transition to home, i.e., referral to Public Health, Lactation Consultant, etc.

- Infant Hearing Screening: newborn screening test completed before discharge. Referral sent to Public Health and/or Audiology as necessary.

- Multidisciplinary Rounds: biweekly rounds with all disciplines to ensure appropriate supports and services are in place for discharge. Social Worker in collaboration with the multidisciplinary team provides assessment, support, counselling, discharge planning, coordination of community resources and advocacy for children and their families as required.

- Managers on-call after hours and on weekends: Acute Care managers are providing on-call on a weekly rotational basis. They are available on weekdays from 4:00 pm – 8:00 am and on weekends from 4:00 pm on Friday until 8:00 am on Monday. This provides physicians and clinical personnel the option to consult with the manager who is on-call regarding any urgent clinical issues that cannot wait until the next day.

2. Information about any policies and procedures related to programs and supports available, including criteria for access.

***Population and Public Health:***

Organizational policies are in place for BABIES program, Healthy Beginnings, and Child Health Clinics. Public Health programming is available to all children. Please refer to response in question one for criteria for referral to Janeway Lifestyles Clinic and Long-Term Healthy Beginnings Program.

**LGH Policies/Procedures to supplement Question 2 (Information about any policies and procedures related to programs and supports available, including criteria for access):**

E-10 – Coordination of Services to Children and Youth
E-110 – BABIES program
E-130 – Postnatal – Healthy Beginnings
E-180 – Child Health Clinics
E-190 – 2 ½ Year Health Check
E-200 - Pre-School Health Check
E-210 – Postpartum Depression Screening
E-220 – Family Resource Centers
E-230 – School Health Promotion/Disease Prevention
E-250 - Role of the Community Health Nurse: Education Guidelines for Management of Children with Allergies and Anaphylaxis in the School and Child Care Setting

***Mental Health & Addictions:***

- Advertised on Bridge the Gapp
- Advertised through Community Partners
- Advertised on LGH internet site
- FACTT – complex mental health or addictions needs; 18 +
- Doorways- no appointment necessary; Monday – Friday 8:00 – 4:00 in most locations; Tuesdays 8:00 – 10:00 pm
- Access to Mental Health & Addictions Counsellors 7 days a week until 10:00 pm in Emergency Room and for clients admitted to Acute Care

***Community Supports:***
Policies and procedures for Child and Youth Community Health (CYCH) program remain under review with the Department of Health and Community Services.

***Acute Care:***
CSSD/LGH Guidelines for Supervision of Children and Youth in Care in Health Care Settings.

3. Information about any policies and procedures related to financial assessments necessary for determination of eligibility for services.

   ***Population and Public Health:***
   Not Applicable

   ***Mental Health & Addictions:***
   - Financial assessments are completed for Board & Lodging and includes the level of need – low, moderate or high.
   - ANA is completed for home supports.
   - Community Inclusion fund is approved based on financial need and meeting criteria to be a FACT client.

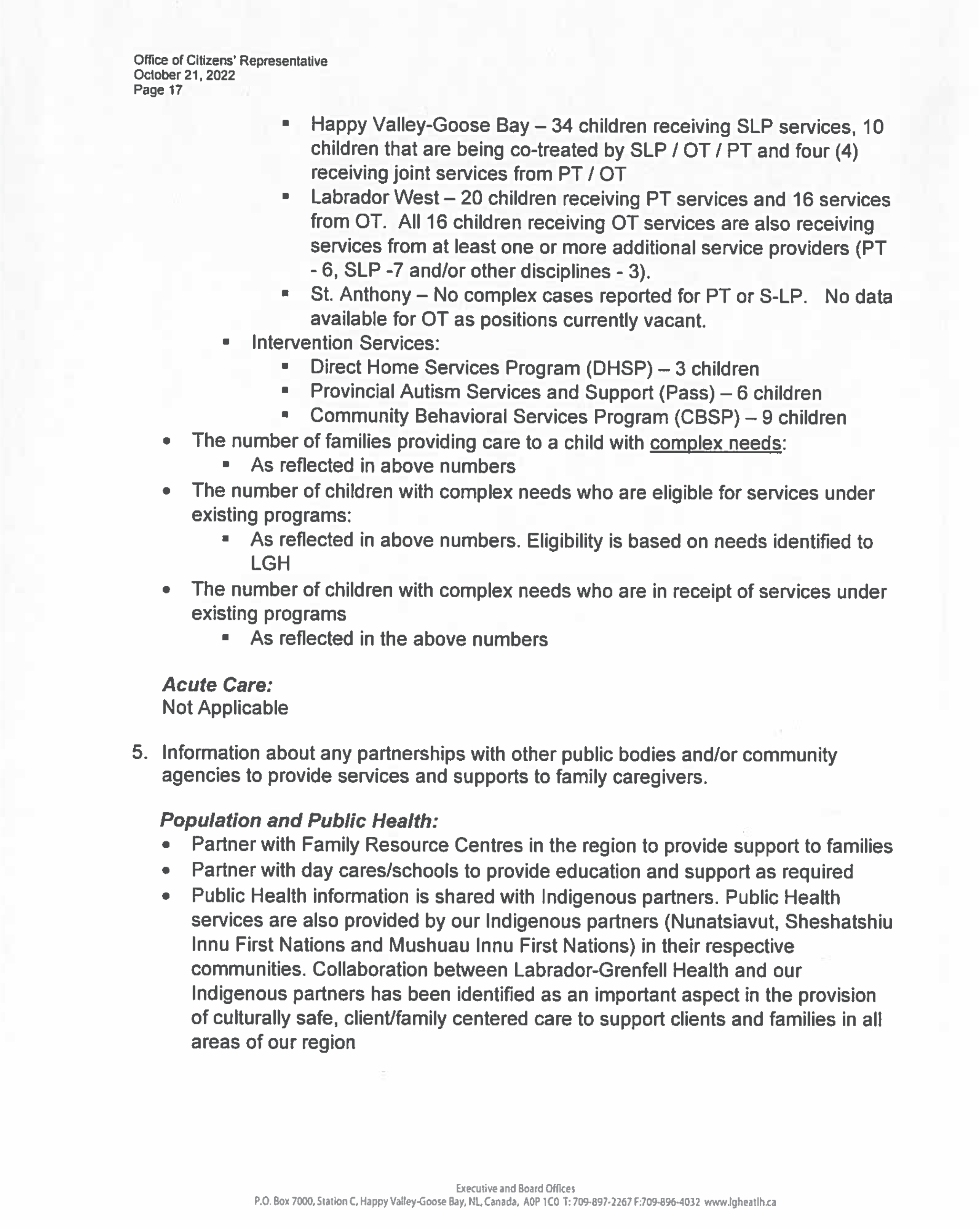
   ***Community Supports:***
   Finance assessors use the Provincial Income Based Financial Assessment Policy Manual for Long Term Care & Community Support Services. There are no regional policies in this regard.

4. Statistical information in your control or possession on:
   - the number of children with complex needs in Newfoundland and Labrador;
   - the number of families providing care to a child with complex needs;
   - the number of children with complex needs who are eligible for services under existing programs;
   - the number of children with complex needs who are in receipt of services under existing programs.

   ***Population and Public Health:***
   - Janeway Lifestyle Clinics normally see approximately 50-60 clients per clinic (10-12 visits daily), which are a combination of follow-up appointments and new referrals.
   - Public Health programming is available to all families in the LGH region.

   ***Mental Health & Addictions:***
   Mental Health & Addictions does not currently record these stats but only include the number of referrals for children overall.

   ***Community Supports:***
   - LGH would not have statistics regarding the number of children with complex needs in Newfoundland and Labrador, or within the region beyond services that are reflected on our active caseload and waitlist as indicated below:
     - Five children receiving services from SSCP
     - Rainbow Pediatric Program (St. Anthony) – 30 children
     - Rehabilitation Services:



        - Happy Valley-Goose Bay – 34 children receiving SLP services, 10 children that are being co-treated by SLP / OT / PT and four (4) receiving joint services from PT / OT
        - Labrador West – 20 children receiving PT services and 16 services from OT. All 16 children receiving OT services are also receiving services from at least one or more additional service providers (PT - 6, SLP -7 and/or other disciplines - 3).
        - St. Anthony – No complex cases reported for PT or S-LP. No data available for OT as positions currently vacant.
    - Intervention Services:
        - Direct Home Services Program (DHSP) – 3 children
        - Provincial Autism Services and Support (Pass) – 6 children
        - Community Behavioral Services Program (CBSP) – 9 children
- The number of families providing care to a child with <u>complex needs</u>:
    - As reflected in above numbers
- The number of children with complex needs who are eligible for services under existing programs:
    - As reflected in above numbers. Eligibility is based on needs identified to LGH
- The number of children with complex needs who are in receipt of services under existing programs
    - As reflected in the above numbers

***Acute Care:***
Not Applicable

5. Information about any partnerships with other public bodies and/or community agencies to provide services and supports to family caregivers.

***Population and Public Health:***

- Partner with Family Resource Centres in the region to provide support to families
- Partner with day cares/schools to provide education and support as required
- Public Health information is shared with Indigenous partners. Public Health services are also provided by our Indigenous partners (Nunatsiavut, Sheshatshiu Innu First Nations and Mushuau Innu First Nations) in their respective communities. Collaboration between Labrador-Grenfell Health and our Indigenous partners has been identified as an important aspect in the provision of culturally safe, client/family centered care to support clients and families in all areas of our region

***Mental Health & Addictions:***

- Work in collaboration with Nunatsiavut Government, Innu Round Table, Mushua Innu First Nation, Sheshatshui Innu First Nation, NunatuKavut Community Council
- CSSD through informed consent
- Lifewise
- Community Supports & Interventions
- Treatment Centers, Crisis Shelters and Centers
- Housing and Homelessness hubs/committees
- Community coalitions
- Ministerial Associations

***Community Supports:***

- Inclusion NL provides support to families in our Province and are strong advocates for families supporting children with disabilities.
- Nunatsiavut Government:
  - OT (Happy Valley-Goose Bay) partners with the Nunatsiavut Government to facilitate ordering and covering adaptive equipment for Nunatsiavut beneficiaries; making it easier on caregivers in the home setting.
- Sheshatshiu Innu First Nation (SIFN):
  - Yearly health fair in the spring with service providers from LGH Rehab Services and Intervention Services departments along with SIFN and IRT to promote services available to children and families in Sheshatshiu.
  - Partner with SIFN to make home modifications to allow clients and their caregivers to transition from hospital to living at home.
- Mushuau Innu First Nations (MIFN)
  - Partner with MIFN staff when completing home visits in Natuashish to establish rapport with elders and caregivers, offering translation services as needed.
- CSSD – Day care

***Acute Care:***

- CSSD through informed consent
- Community Supports & Interventions
- Indigenous Partners: collaboration between Labrador-Grenfell Health and our Indigenous partners is an important aspect in the provision of culturally safe, client/family centered care.

6. Information about any new initiatives that are being considered to support family caregivers.

   ***Population and Public Health:***
   - Ages and Stages Questionnaire: Social Emotional (ASQ-SE) – potential for social emotional developmental screening of children to existing child health clinics being explored
   - Provincial health information website to be developed to support families and caregivers
   - New Child Youth Community Health (CYCH) services model to coordinate services through the utilization of a centralized intake for children and youth requiring specialized services

   ***Mental Health & Addictions:***
   Incredible Years & Small Group Dino – for children with behavior issues and their caregivers.

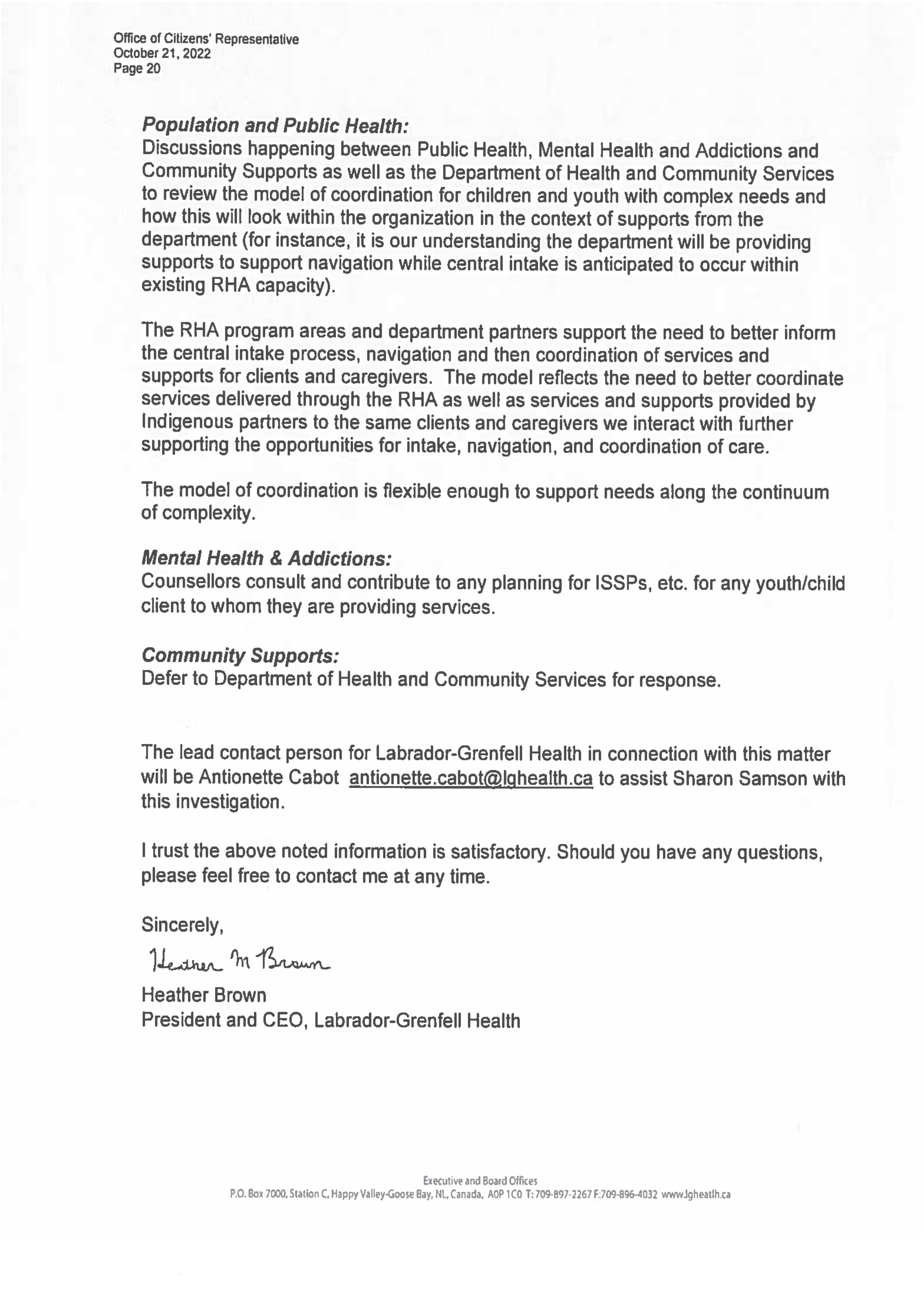
   ***Community Supports:***
   The model for care as it relates to children and youth with complex needs has been under review by the Department of Health and Community Services and revised provincial standards are pending.

7. Information on any reports, draft reports, consultations, etc. by Labrador-Grenfell Health that address recognition, assistance, support and engagement with family caregivers.

   ***Population and Public Health:***
   - Health Check 2 ½ (part of Child Health Check program) evaluation in 2017 engaged families through surveys and supported the benefits of this program for early intervention
   - Provincial Healthy Beginnings/Preschool Health Check evaluation completed in 2019 and engaged families through surveys

   ***Mental Health & Addictions:***
   Monthly Stakeholder meetings for consultations on the new Mental Health Unit located in Happy Valley-Goose Bay.

8. Information on the status, process and/or outcome of the review of Newfoundland and Labrador's Model for the Coordination of Services to Children and Youth with Special Needs as per the recommendations of the *ISSP/Pathways Commission Report* of 2007.



***Population and Public Health:***
Discussions happening between Public Health, Mental Health and Addictions and Community Supports as well as the Department of Health and Community Services to review the model of coordination for children and youth with complex needs and how this will look within the organization in the context of supports from the department (for instance, it is our understanding the department will be providing supports to support navigation while central intake is anticipated to occur within existing RHA capacity).

The RHA program areas and department partners support the need to better inform the central intake process, navigation and then coordination of services and supports for clients and caregivers. The model reflects the need to better coordinate services delivered through the RHA as well as services and supports provided by Indigenous partners to the same clients and caregivers we interact with further supporting the opportunities for intake, navigation, and coordination of care.

The model of coordination is flexible enough to support needs along the continuum of complexity.

***Mental Health & Addictions:***
Counsellors consult and contribute to any planning for ISSPs, etc. for any youth/child client to whom they are providing services.

***Community Supports:***
Defer to Department of Health and Community Services for response.

The lead contact person for Labrador-Grenfell Health in connection with this matter will be Antionette Cabot antionette.cabot@lghealth.ca to assist Sharon Samson with this investigation.

I trust the above noted information is satisfactory. Should you have any questions, please feel free to contact me at any time.

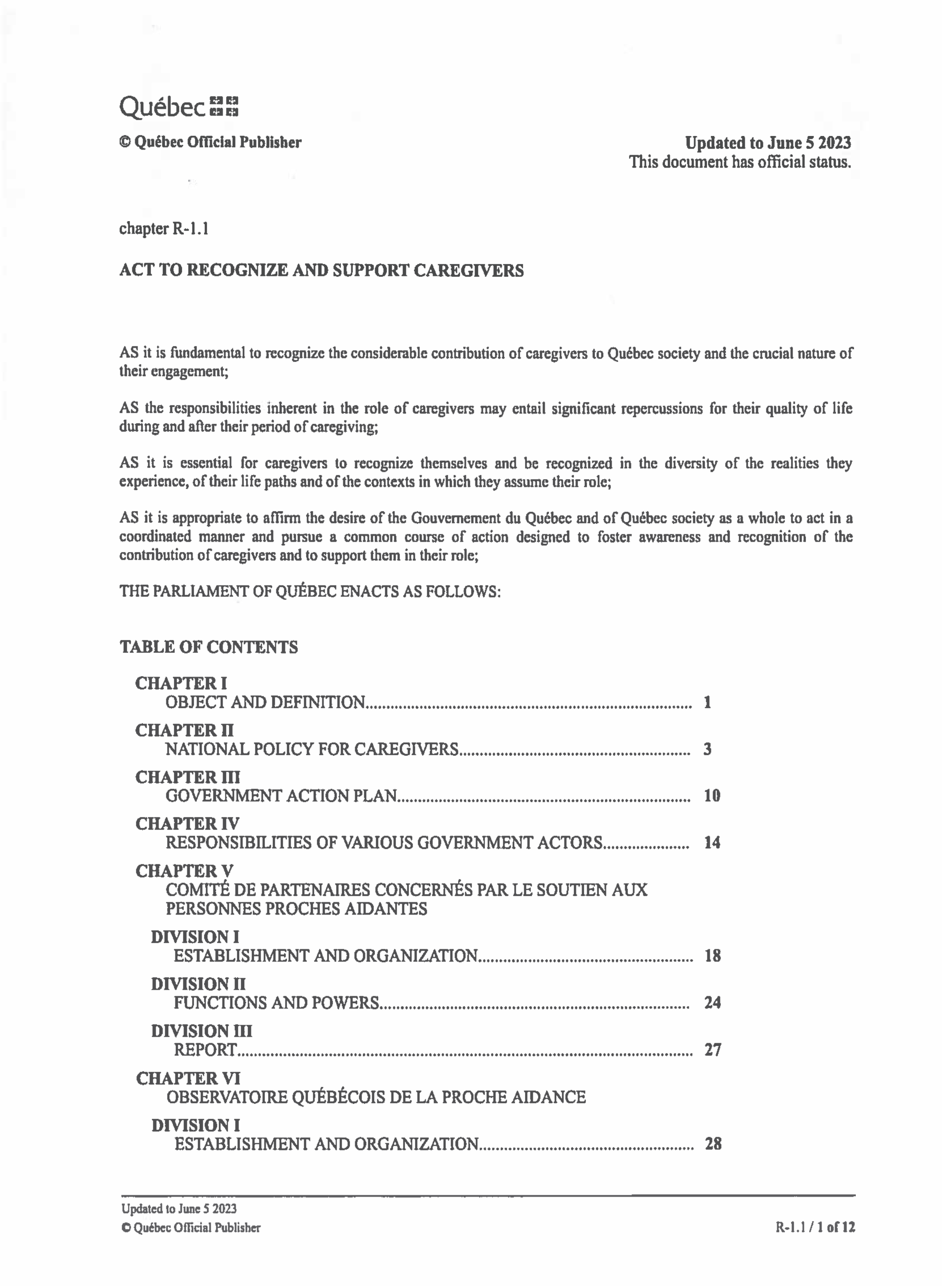
Sincerely,

Heather M Brown

Heather Brown
President and CEO, Labrador-Grenfell Health

# Appendix 2

## Act to Recognize and Support Caregivers - Quebec



Québec

**Updated to June 5 2023**
This document has official status.

chapter R-1.1

# ACT TO RECOGNIZE AND SUPPORT CAREGIVERS

AS it is fundamental to recognize the considerable contribution of caregivers to Québec society and the crucial nature of their engagement;

AS the responsibilities inherent in the role of caregivers may entail significant repercussions for their quality of life during and after their period of caregiving;

AS it is essential for caregivers to recognize themselves and be recognized in the diversity of the realities they experience, of their life paths and of the contexts in which they assume their role;

AS it is appropriate to affirm the desire of the Gouvernement du Québec and of Québec society as a whole to act in a coordinated manner and pursue a common course of action designed to foster awareness and recognition of the contribution of caregivers and to support them in their role;

THE PARLIAMENT OF QUÉBEC ENACTS AS FOLLOWS:

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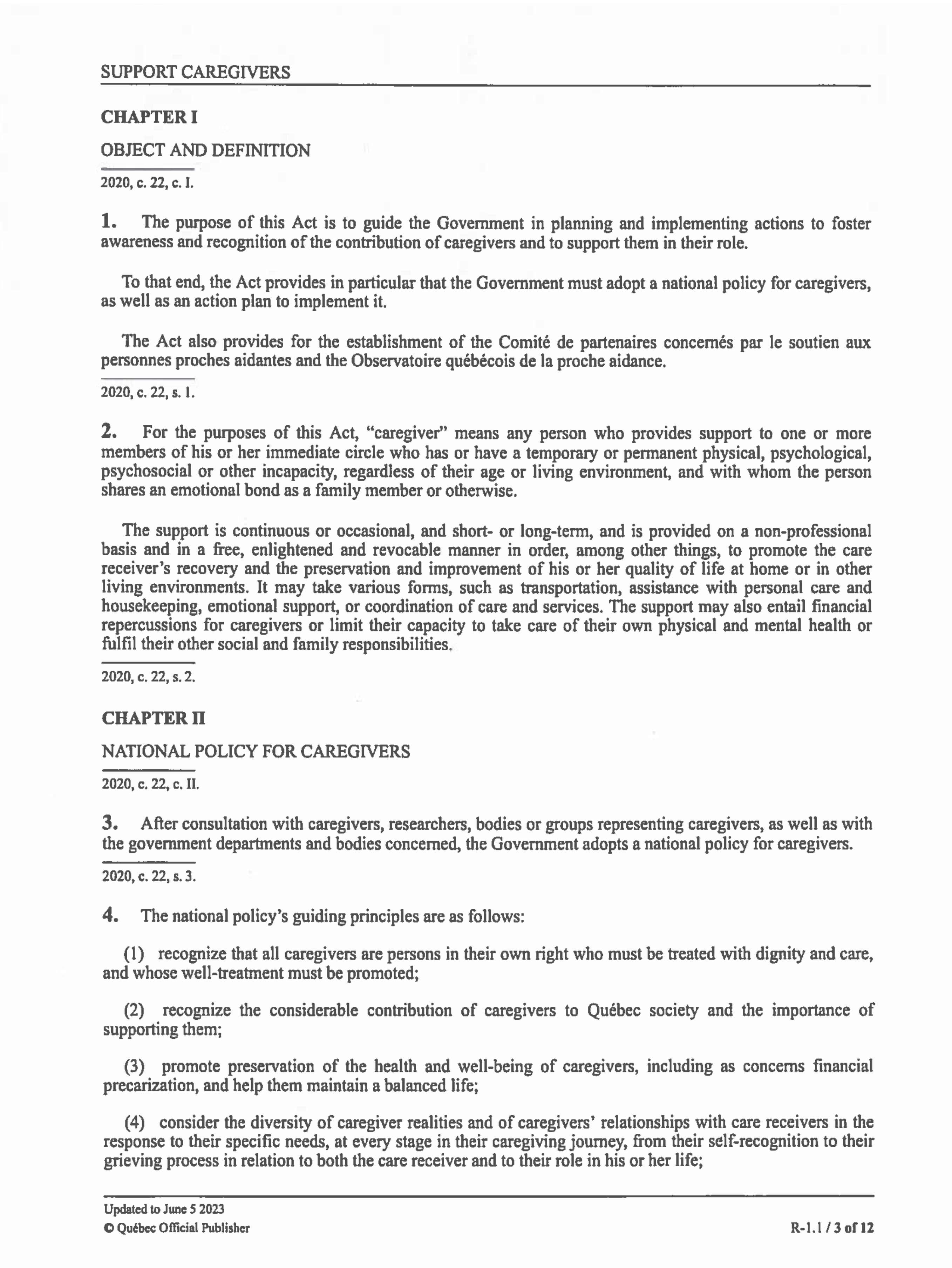


SUPPORT CAREGIVERS

## CHAPTER I

## OBJECT AND DEFINITION

2020, c. 22, c. I.

**1.** The purpose of this Act is to guide the Government in planning and implementing actions to foster awareness and recognition of the contribution of caregivers and to support them in their role.

To that end, the Act provides in particular that the Government must adopt a national policy for caregivers, as well as an action plan to implement it.

The Act also provides for the establishment of the Comité de partenaires concernés par le soutien aux personnes proches aidantes and the Observatoire québécois de la proche aidance.

2020, c. 22, s. 1.

**2.** For the purposes of this Act, "caregiver" means any person who provides support to one or more members of his or her immediate circle who has or have a temporary or permanent physical, psychological, psychosocial or other incapacity, regardless of their age or living environment, and with whom the person shares an emotional bond as a family member or otherwise.

The support is continuous or occasional, and short- or long-term, and is provided on a non-professional basis and in a free, enlightened and revocable manner in order, among other things, to promote the care receiver's recovery and the preservation and improvement of his or her quality of life at home or in other living environments. It may take various forms, such as transportation, assistance with personal care and housekeeping, emotional support, or coordination of care and services. The support may also entail financial repercussions for caregivers or limit their capacity to take care of their own physical and mental health or fulfil their other social and family responsibilities.

2020, c. 22, s. 2.

## CHAPTER II

## NATIONAL POLICY FOR CAREGIVERS

2020, c. 22, c. II.

**3.** After consultation with caregivers, researchers, bodies or groups representing caregivers, as well as with the government departments and bodies concerned, the Government adopts a national policy for caregivers.

2020, c. 22, s. 3.

**4.** The national policy's guiding principles are as follows:

(1) recognize that all caregivers are persons in their own right who must be treated with dignity and care, and whose well-treatment must be promoted;

(2) recognize the considerable contribution of caregivers to Québec society and the importance of supporting them;

(3) promote preservation of the health and well-being of caregivers, including as concerns financial precarization, and help them maintain a balanced life;

(4) consider the diversity of caregiver realities and of caregivers' relationships with care receivers in the response to their specific needs, at every stage in their caregiving journey, from their self-recognition to their grieving process in relation to both the care receiver and to their role in his or her life;

(5) recognize the experience and knowledge of caregivers and of the care receiver, and consider such experience and knowledge in a partnership-based approach;

(6) respect the wishes and capacities of caregivers as to the nature and scope of their engagement; and

(7) facilitate and consolidate partnerships between government departments and bodies and non-government bodies at the national, regional and local levels, and involve caregivers so as to promote responses adapted to their specific needs.

2020, c. 22, s. 4.

**5.** The policy directions set out in the national policy focus on the following key areas:

(1) recognition and self-recognition of caregivers, as well as mobilization of the Québec society stakeholders concerned by caregiving;

(2) information sharing, the promotion of resources made available to caregivers and the development of knowledge and skills;

(3) the development of health and social services intended for caregivers, in a partnership-based approach; and

(4) the development of accommodating environments that support and promote the preservation and improvement of caregivers' living conditions, including to prevent their financial precarization.

2020, c. 22, s. 5.

**6.** The policy directions related to recognition and self-recognition of caregivers and to mobilization of the stakeholders concerned must, in particular, be aimed at raising awareness within Québec society of the role and undeniable contribution of caregivers, of the diversity of their realities and of the importance of supporting them through coordinated actions relating to various spheres of their life.

2020, c. 22, s. 6.

**7.** The policy directions related to information sharing, the promotion of resources and the development of knowledge and skills must, in particular, be aimed at meeting the information and training needs of caregivers and of the various stakeholders concerned, and at supporting research and the transfer of knowledge regarding caregivers.

2020, c. 22, s. 7.

**8.** The policy directions related to the development of health and social services must aim to support the health and well-being of caregivers as users, taking into account their knowledge, wishes and engagement capacity and promoting a partnership-based approach.

2020, c. 22, s. 8.

**9.** The policy directions related to the development of accommodating environments that support and promote the preservation and improvement of caregivers' living conditions must, in particular, be aimed at promoting balance between the caregiver role and the other spheres of caregivers' lives.

2020, c. 22, s. 9.

## CHAPTER III

## GOVERNMENT ACTION PLAN

2020, c. 22, c. III.

**10.** Every five years, the Government adopts and makes public a government action plan setting out measures and actions to implement the national policy for caregivers.

The action plan describes the objectives to be attained, the means to be used to attain them and the available resources. It also determines the conditions, terms and schedule for implementing the actions set out in the plan, which involves identifying the stakeholders concerned and their responsibilities.

2020, c. 22, s. 10.

**11.** The Comité de suivi de l'action gouvernementale pour le soutien aux personnes proches aidantes, the Comité de partenaires concernés par le soutien aux personnes proches aidantes, the Observatoire québécois de la proche aidance and caregivers are consulted in the development and follow-up stages of the action plan.

Those committees and the observatory must meet at least twice a year to discuss the follow-up to the action plan.

2020, c. 22, s. 11.

**12.** As an incentive for collective mobilization, the action plan must provide for the making of agreements between the ministers concerned and the national, regional and local partners, and for mechanisms for coordinating and periodically following up on the actions carried out within the scope of those agreements.

2020, c. 22, s. 12.

**13.** The Minister is responsible for the implementation of the action plan and coordinates its application.

The Minister submits an annual report to the Government on the activities carried out within the scope of the action plan for the preceding fiscal year. The Minister may, for that purpose, request from the other ministers concerned specific reports concerning the activities carried out in their fields of jurisdiction.

The Minister makes the report public within 60 days after it is submitted to the Government.

2020, c. 22, s. 13.

## CHAPTER IV

## RESPONSIBILITIES OF VARIOUS GOVERNMENT ACTORS

2020, c. 22, c. IV.

**14.** The Minister is, by virtue of office, the Government's adviser on all issues relating to caregivers, in particular in the development of the national policy for caregivers and the related government action plan. In that capacity, the Minister gives other ministers any opinion the Minister considers advisable to ensure implementation of the policy and the action plan, and takes part in the development of measures, policy directions and actions that could have a significant impact on caregivers. The Minister also monitors implementation of the national policy and the action plan.

It is incumbent on government departments and bodies to communicate to the Minister any information necessary for the carrying out of those responsibilities.

2020, c. 22, s. 14.

**15.** The Minister establishes a committee to monitor government action for caregiver support, called the "Comité de suivi de l'action gouvernementale pour le soutien aux personnes proches aidantes" (monitoring committee), to support the Minister in the exercise of his or her responsibilities.

The Minister designates the committee members from among the representatives of the departments, government bodies or persons appointed by the Government to hold office that are concerned by caregiver support.

2020, c. 22, s. 15.

**16.** Ministers and government bodies must, in keeping with their respective missions and the Government's budgetary and fiscal policies, take into account the guiding principles of the national policy for caregivers and its policy directions when developing, implementing and evaluating any program or any other service or measure concerning caregivers.

2020, c. 22, s. 16.

**17.** If a minister considers that proposals of a legislative or regulatory nature could have direct and significant impacts on caregivers, the minister must report on the impacts he or she anticipates when presenting the proposals to the Government.

2020, c. 22, s. 17.

## CHAPTER V

## COMITÉ DE PARTENAIRES CONCERNÉS PAR LE SOUTIEN AUX PERSONNES PROCHES AIDANTES

2020, c. 22, c. V.

### DIVISION I

### ESTABLISHMENT AND ORGANIZATION

2020, c. 22, Div. I.

**18.** A committee of partners concerned by caregiver support, called the "Comité de partenaires concernés par le soutien aux personnes proches aidantes" (partners committee), is established.

2020, c. 22, s. 18.

**19.** The partners committee is composed of at least 11 and not more than 17 members appointed by the Minister, as follows:

(1) at least three persons from non-government bodies concerned by caregiver support, appointed after a public call for applications;

(2) at least four caregivers providing support to care receivers who have different profiles, appointed after a public call for applications;

(3) at least two researchers appointed after consultation with the integrated university health network coordination panel established under section 436.8 of the Act respecting health services and social services (chapter S-4.2); and

(4) one member from the Observatoire québécois de la proche aidance, appointed after consultation with the latter.

The partners committee must be composed of an equal number of women and men. An equal number is presumed if the difference is not more than two.

The partners committee must include at least one member from a rural area and at least one member from an Aboriginal community or organization.

The Minister designates a member of the monitoring committee as an observer within the partners committee. The observer participates in committee meetings, but is not entitled to vote.

2020, c. 22, s. 19.

**20.** The members are appointed for a term of not more than five years, which may not be renewed consecutively more than once.

On the expiry of their terms, the members remain in office until reappointed or replaced.

2020, c. 22, s. 20.

**21.** Any vacancy among the members of the partners committee is filled in accordance with the rules of appointment to the committee.

2020, c. 22, s. 21.

**22.** The members of the partners committee receive no remuneration, except in the cases, on the conditions and to the extent that may be determined by the Government. They are, however, entitled to the reimbursement of expenses incurred in the exercise of their functions, on the conditions and to the extent determined by the Government.

2020, c. 22, s. 22.

**23.** The Minister designates the chair and the vice-chair from among the members of the partners committee.

2020, c. 22, s. 23.

## DIVISION II

## FUNCTIONS AND POWERS

2020, c. 22, Div. II.

**24.** The partners committee's functions are

(1) to make any recommendation or give any opinion to the Minister that it considers necessary regarding the national policy for caregivers, the government action plan or any other matter relating to caregivers;

(2) to support the Minister and the monitoring committee in implementing the national policy for caregivers and the government action plan; and

(3) to give the Minister its opinion on any matter referred to it by the Minister regarding caregiving.

2020, c. 22, s. 24.

**25.** The partners committee must make its recommendations and opinions public within 30 days after sending them to the Minister.

2020, c. 22, s. 25.

**26.** In the exercise of its functions, the partners committee may recommend to the Minister to consult with, solicit opinions from, or receive or hear requests and suggestions from persons, bodies or associations regarding caregiving. The partners committee may also seek the contribution of the Observatoire québécois de la proche aidance.

2020, c. 22, s. 26.

### DIVISION III

### REPORT

2020, c. 22, Div. III.

**27.** The partners committee must, within six months after the end of the fiscal year, send the Minister a report on its activities for that year.

The Minister must table the report in the National Assembly within 30 days of receiving it or, if the Assembly is not sitting, within 30 days of resumption.

2020, c. 22, s. 27.

## CHAPTER VI

## OBSERVATOIRE QUÉBÉCOIS DE LA PROCHE AIDANCE

2020, c. 22, c. VI.

### DIVISION I

### ESTABLISHMENT AND ORGANIZATION

2020, c. 22, Div. I.

**28.** An observatory on caregiving, called the “Observatoire québécois de la proche aidance” (observatory), is established.

2020, c. 22, s. 28.

**29.** The observatory is managed by a managing committee composed of the following 13 members, appointed by the Minister:

(1) two members representing the departments concerned by caregiver support, including one member representing the Ministère de la Santé et des Services sociaux, appointed after consultation with the ministers concerned;

(2) the observatory’s scientific director;

(3) one member representing the institution or body responsible for the observatory’s organization and administrative support;

(4) four researchers appointed after consultation with the integrated university health network coordination panel;

(5) three members from non-government bodies concerned by caregiver support, appointed after a public call for applications; and

(6) two caregivers providing support to care receivers who have different profiles, appointed after a public call for applications.

The Minister designates the chair and the vice-chair from among the members of the managing committee.

The managing committee must be composed of an equal number of women and men. An equal number is presumed if the difference is not more than two.

The managing committee must include at least one member from a rural area and at least one member from an Aboriginal community or organization.

2020, c. 22, s. 29.

**30.** The observatory's managing committee determines the observatory's scientific directions, general objectives and policies, as well as the annual activities it intends to carry out, and sends that information to the Minister.

It also evaluates the relevance, priority status and scientific quality of the observatory's programs and activities.

2020, c. 22, s. 30.

**31.** The members of the observatory's managing committee are appointed for a term of not more than five years, which may not be renewed consecutively more than once.

On the expiry of their terms, the members remain in office until reappointed or replaced.

2020, c. 22, s. 31.

**32.** Any vacancy among the members of the managing committee is filled in accordance with the rules of appointment to the committee.

2020, c. 22, s. 32.

**33.** The members of the observatory's managing committee receive no remuneration, except in the cases, on the conditions and to the extent that may be determined by the Government. They are, however, entitled to the reimbursement of expenses incurred in the exercise of their functions, on the conditions and to the extent determined by the Government.

2020, c. 22, s. 33.

**34.** The Minister entrusts, by agreement, the observatory's organization and administrative support to an institution within the meaning of the Act respecting health services and social services or to any other body.

2020, c. 22, s. 34.

## DIVISION II

## FUNCTIONS AND POWERS

2020, c. 22, Div. II.

**35.** The purpose of the observatory is to provide reliable and objective information regarding caregiving through observation, monitoring, analysis and knowledge sharing.

More specifically, the observatory's functions are

(1) to collect, integrate, compile, analyze and disseminate information, in particular of a statistical nature, on caregiving;

(2) to monitor the evolution of caregivers' needs as well as effective and innovative practices, measures and actions, at the national and international levels, to support caregivers;

(3) to facilitate the transfer of knowledge for the benefit of the various actors involved in caregiving; and

(4) to facilitate collaborations regarding caregiving, in particular with university institutions, research centres, other observatories or the government bodies participating in research activities or activities to promote clinical excellence and efficient use of resources in health and social services.

In the exercise of its functions, the observatory may consult experts or other actors from the caregiving sector and entrust them with any mandate it deems necessary.

2020, c. 22, s. 35.

**36.** The observatory enlightens the Minister by finding and reporting on current knowledge and trends, or those to be developed, concerning evaluation approaches and indicators to measure the quality of life, health and well-being of caregivers, and to measure the impact of the policy directions, measures and actions set out in the national policy for caregivers and the government action plan. To that end, the observatory enhances the value of existing information and data and promotes knowledge transfer and sharing.

2020, c. 22, s. 36.

**37.** Within the scope of its work, the observatory must cooperate with the monitoring committee and the partners committee.

2020, c. 22, s. 37.

## DIVISION III

## REPORT

2020, c. 22, Div. III.

**38.** The observatory's managing committee must, within six months after the end of the fiscal year, send the Minister a report on its activities for that year.

2020, c. 22, s. 38.

## CHAPTER VII

## NATIONAL CAREGIVERS WEEK

2020, c. 22, c. VII.

**39.** The first week of November is proclaimed National Caregivers Week.

2020, c. 22, s. 39.

## CHAPTER VIII

## REPORT

2020, c. 22, c. VIII.

**40.** The Minister must, not later than 28 October 2025, report to the Government on the implementation of this Act.

After that, the Minister must report to the Government on the carrying out of this Act every five years. The report is prepared in coordination with the other ministers concerned. It must take into account the opinions received from the partners committee as well as the evaluation approaches and indicators proposed by the observatory that have been selected by the Minister. The report must also state the results obtained in implementing the national policy for caregivers and include a status report on the progress of Québec society toward achieving the goals pursued by the policy.

Any report referred to in this section is tabled by the Minister in the National Assembly within 30 days after it is presented to the Government or, if the Assembly is not sitting, within 30 days of resumption.

2020, c. 22, s. 40.

## CHAPTER IX

## AMENDING PROVISIONS

2020, c. 22, c. IX.

### ACT RESPECTING HEALTH SERVICES AND SOCIAL SERVICES

**41.** *(Amendment integrated into c. S-4.2, s. 438).*

2020, c. 22, s. 41.

**42.** *(Amendment integrated into c. S-4.2, s. 489.0.1).*

2020, c. 22, s. 42.

## CHAPTER X

## TRANSITIONAL AND FINAL PROVISIONS

2020, c. 22, c. X.

**43.** The Government must adopt a national policy for caregivers not later than 28 April 2021.

The Government must adopt and make public the first government action plan not later than six months after the adoption of the national policy.

2020, c. 22, s. 43.

**44.** The first government action plan must, in particular, contain measures and actions concerning:

(1) the conduct, by the health and social services institutions, of an assessment of caregivers' needs and the preparation of a support plan for the planning and delivery of services provided to caregivers, in keeping with the objectives of the policy directions of the national policy for caregivers referred to in section 8;

(2) the assessment of the pertinence and feasibility of recognizing certain rights of caregivers and the related obligations;

(3) a review of the components of the mission of L'Appui national, a non-profit legal person constituted under Part III of the Companies Act (chapter C-38), and the continuation of its financing, in keeping with the national policy for caregivers; and

(4) the assessment of the pertinence and feasibility of establishing and maintaining a public register of caregivers intended, in particular, to promote the recognition of their role.

2020, c. 22, s. 44.

**45.** The Minister must, before 28 April 2021, appoint the members of the observatory's managing committee.

2020, c. 22, s. 45.

**46.** Section 438 of the Act respecting health services and social services (chapter S-4.2), as amended by section 41, does not prevent persons or partnerships that, on 11 June 2020, carry on their activities under a name that includes the words "seniors home" or "alternative home" and appears in the registration declaration filed under the Act respecting the legal publicity of enterprises (chapter P-44.1) from continuing to use those words in their name.

2020, c. 22, s. 46.

**47.** The Minister Responsible for Seniors is responsible for the administration of this Act.

2020, c. 22, s. 47.

Note *See Order in Council 785-2023 dated 10 May 2023, (2023) 155 G.O. 2 (French), 1955.*

**48.** *(Omitted).*

2020, c. 22, s. 48.

# Appendix 3

## The Caregiver Recognition Act - Manitoba

MANITOBA

# THE CAREGIVER RECOGNITION ACT

C.C.S.M. c. C24

# LOI SUR LA RECONNAISSANCE DE L'APPORT DES AIDANTS NATURELS

c. C24 de la *C.P.L.M.*

Archived version

This version was current for the period set out in the footer below. Any amendment enacted after May 31, 2022 with retroactive effect is not included.

Version archivée

La présente version était à jour pendant la période indiquée en bas de page. Les modifications rétroactives édictées après le 31 mai 2022 n'y figurent pas.

## LEGISLATIVE HISTORY

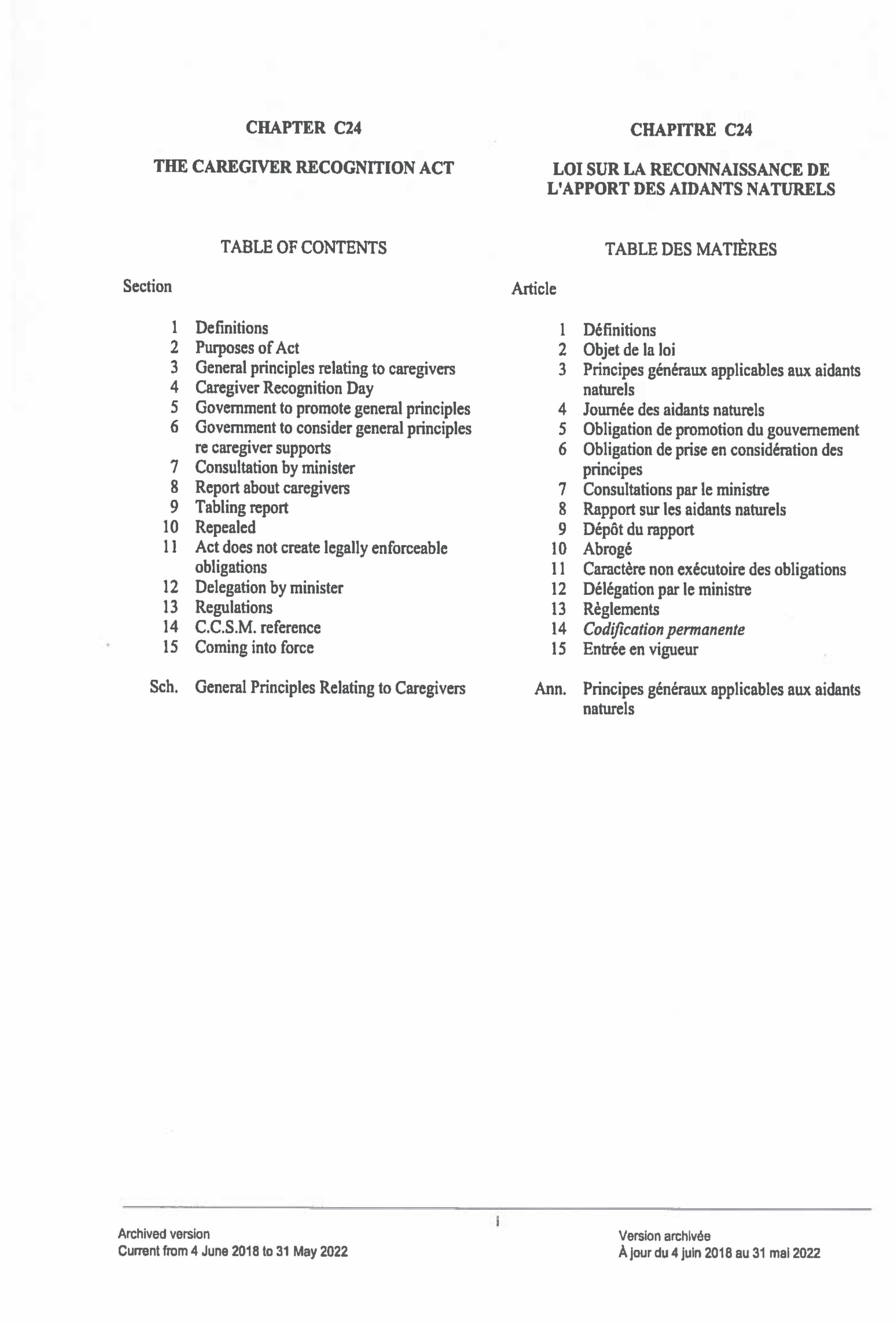
*The Caregiver Recognition Act*, C.C.S.M. c. C24

| **Enacted by** | **Proclamation status (for provisions in force by proclamation)** |
|---|---|
| SM 2011, c. 32 | |
| **Amended by** | |
| SM 2013, c. 54, s. 9 | |
| SM 2018, c. 8, s. 17 | |

## HISTORIQUE

*Loi sur la reconnaissance de l'apport des aidants naturels*, c. C24 de la C.P.L.M.

| **Édictée par** | **État des dispositions qui entrent en vigueur par proclamation** |
|---|---|
| L.M. 2011, c. 32 | |
| **Modifiée par** | |
| L.M. 2013, c. 54, art. 9 | |
| L.M. 2018, c. 8, art. 17 | |



## CHAPTER C24

## THE CAREGIVER RECOGNITION ACT

## CHAPITRE C24

## LOI SUR LA RECONNAISSANCE DE L'APPORT DES AIDANTS NATURELS

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## CHAPTER C24

# THE CAREGIVER RECOGNITION ACT

(Assented to June 16, 2011)

WHEREAS caregivers are important to the well-being of Manitobans and Manitoba communities;

AND WHEREAS recognition and awareness of caregivers should be increased and their valuable social and economic contribution to society should be acknowledged;

AND WHEREAS it is desirable to set out principles for evaluating and improving caregiver supports;

THEREFORE HER MAJESTY, by and with the advice and consent of the Legislative Assembly of Manitoba, enacts as follows:

### Definitions

1 The following definitions apply in this Act.

**"caregiver"** means a person who provides informal and unpaid personal care, support or assistance to another person because that other person lives with challenges due to

(a) a disability;

## CHAPITRE C24

# LOI SUR LA RECONNAISSANCE DE L'APPORT DES AIDANTS NATURELS

(Date de sanction : 16 juin 2011)

Attendu :

que les aidants naturels sont importants pour le bien-être des Manitobains et des collectivités manitobaines;

que l'apport des aidants naturels devrait être mieux connu et reconnu en raison de la contribution économique et sociale de grande valeur qu'ils apportent à la société;

qu'il est souhaitable d'énoncer les principes nécessaires à l'évaluation et à l'amélioration des mesures de soutien aux aidants naturels,

SA MAJESTÉ, sur l'avis et avec le consentement de l'Assemblée législative du Manitoba édicte :

### Définitions

1 Les définitions qui suivent s'appliquent à la présente loi.

« **aidant naturel** » Personne qui, sans rémunération et d'une façon informelle, donne des soins personnels, apporte un appui ou fournit de l'aide à une autre personne dont la vie est difficile en raison :

(b) an illness;

(c) an injury; or

(d) aging. (« aidant naturel »)

**"caregiver supports"** means policies, programs or services directed to caregivers. (« mesures de soutien aux aidants naturels »)

**"department"** means a department, branch or office of the executive government of the province. (« ministère »)

**"general principles"** means the general principles relating to caregivers as set out in the Schedule. (« principes généraux »)

**"government agency"** means

(a) any board, commission, association, agency, or similar body, whether incorporated or unincorporated, all the members of which, or all the members of the board of management or board of directors or governing board of which, are appointed by an Act of the Legislature or by the Lieutenant Governor in Council; and

(b) any other body designated as a government agency in the regulations. (« organisme gouvernemental »)

**"minister"** means the minister appointed by the Lieutenant Governor in Council to administer this Act. (« ministre »)

S.M. 2018, c. 8, s. 17.

**Purposes of Act**

2 The purposes of this Act are

(a) to increase recognition and awareness of caregivers;

(b) to acknowledge the valuable contribution they make to society; and

a) d'un handicap;

b) d'une maladie;

c) d'une blessure;

d) de l'âge. ("caregiver")

**« mesures de soutien aux aidants naturels »** Les politiques, les programmes et les services conçus pour les aidants naturels. ("caregiver supports")

**« ministère »** Ministère, direction ou bureau du gouvernement provincial. ("department")

**« ministre »** Le ministre que le lieutenant-gouverneur en conseil charge de l'application de la présente loi. ("minister")

**« organisme gouvernemental »**

a) Conseil, commission, association, bureau ou autre entité semblable, constitué ou non en personne morale, dont tous les membres ou tous ceux du conseil de direction ou d'administration sont nommés par une loi de l'Assemblée législative ou par le lieutenant-gouverneur en conseil;

b) tout autre organisme que les règlements désignent comme tel. ("government agency")

**« principes généraux »** Les principes généraux applicables aux aidants naturels énumérés à l'annexe. ("general principles")

L.M. 2018, c. 8, art. 17.

**Objet de la présente loi**

2 La présente loi a pour objet :

a) de promouvoir la prise de conscience et la reconnaissance de l'apport des aidants naturels;

b) de reconnaître la valeur de la contribution qu'ils apportent à la société;

(c) to help guide the development of a framework for caregiver recognition and caregiver supports.

### General principles relating to caregivers

**3** The general principles relating to caregivers are set out in the Schedule.

### Caregiver Recognition Day

**4** The first Tuesday of April in each year is proclaimed as Caregiver Recognition Day.

### Government to promote general principles

**5** Each department and government agency must take practicable measures to promote amongst its employees and others an awareness and understanding of the general principles.

### Government to consider general principles re caregiver supports

**6** Each department or government agency that is responsible for the development, implementation, provision or evaluation of caregiver supports is to give due consideration to the general principles in developing, implementing, providing or evaluating caregiver supports.

### Consultation by minister

**7** In furthering the purposes of this Act, the minister is to consult with

(a) caregivers;

(b) organizations or bodies that serve caregivers;

(c) departments and government agencies; and

(d) [repealed] S.M. 2018, c. 8, s. 17;

(e) any other persons or bodies, as determined by the minister.

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S.M. 2018, c. 8, s. 17.

c) d'aider au développement d'un cadre visant à reconnaître leur apport et à leur fournir des mesures de soutien.

### Principes généraux applicables aux aidants naturels

**3** Les principes généraux applicables aux aidants naturels sont énumérés à l'annexe.

### Journée des aidants naturels

**4** Il est proclamé que le premier mardi d'avril est la Journée des aidants naturels.

### Obligation de promotion du gouvernement

**5** Les ministères et les organismes gouvernementaux sont tenus de prendre des mesures pratiques pour promouvoir la connaissance et la compréhension des principes généraux, auprès de tous, notamment leurs employés.

### Obligation de prise en considération des principes généraux

**6** Tous les ministères et tous les organismes gouvernementaux qui sont chargés de l'élaboration, de la mise en œuvre, de la fourniture et de l'évaluation des mesures de soutien aux aidants naturels sont tenus, dans l'exercice de ces responsabilités, de prendre en compte les principes généraux.

### Consultation par le ministre

**7** Dans la poursuite des objectifs de la présente loi, le ministre consulte :

a) les aidants naturels;

b) les organismes qui fournissent des services aux aidants naturels;

c) les ministères et organismes gouvernementaux;

d) [abrogé] L.M. 2018, c. 8, art. 17;

e) les autres personnes et organismes qu'il juge indiqués.

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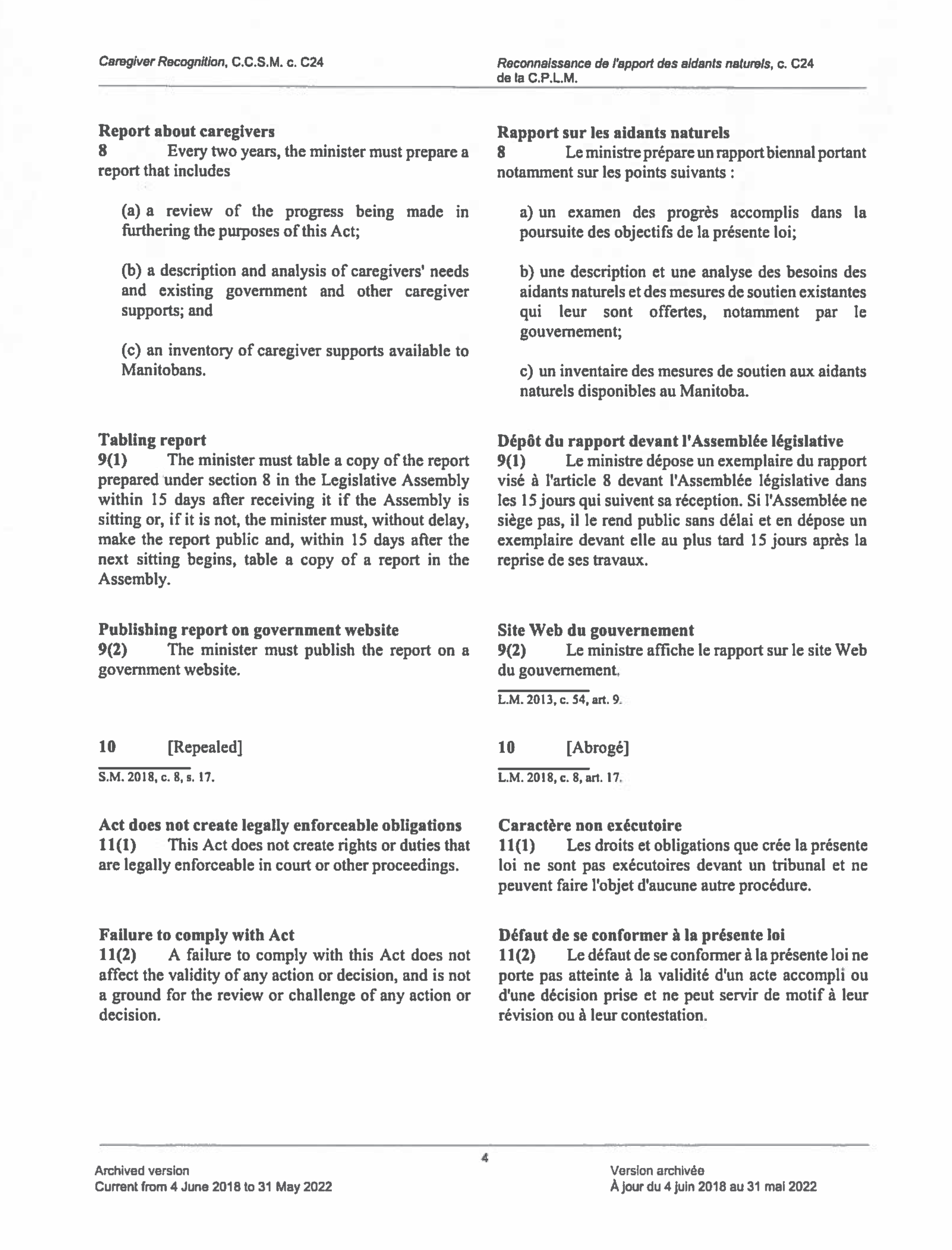
L.M. 2018, c. 8, art. 17.



**Report about caregivers**

**8** Every two years, the minister must prepare a report that includes

(a) a review of the progress being made in furthering the purposes of this Act;

(b) a description and analysis of caregivers' needs and existing government and other caregiver supports; and

(c) an inventory of caregiver supports available to Manitobans.

**Tabling report**

**9(1)** The minister must table a copy of the report prepared under section 8 in the Legislative Assembly within 15 days after receiving it if the Assembly is sitting or, if it is not, the minister must, without delay, make the report public and, within 15 days after the next sitting begins, table a copy of a report in the Assembly.

**Publishing report on government website**

**9(2)** The minister must publish the report on a government website.

**10** [Repealed]

S.M. 2018, c. 8, s. 17.

**Act does not create legally enforceable obligations**

**11(1)** This Act does not create rights or duties that are legally enforceable in court or other proceedings.

**Failure to comply with Act**

**11(2)** A failure to comply with this Act does not affect the validity of any action or decision, and is not a ground for the review or challenge of any action or decision.

**Rapport sur les aidants naturels**

**8** Le ministre prépare un rapport biennal portant notamment sur les points suivants :

a) un examen des progrès accomplis dans la poursuite des objectifs de la présente loi;

b) une description et une analyse des besoins des aidants naturels et des mesures de soutien existantes qui leur sont offertes, notamment par le gouvernement;

c) un inventaire des mesures de soutien aux aidants naturels disponibles au Manitoba.

**Dépôt du rapport devant l'Assemblée législative**

**9(1)** Le ministre dépose un exemplaire du rapport visé à l'article 8 devant l'Assemblée législative dans les 15 jours qui suivent sa réception. Si l'Assemblée ne siège pas, il le rend public sans délai et en dépose un exemplaire devant elle au plus tard 15 jours après la reprise de ses travaux.

**Site Web du gouvernement**

**9(2)** Le ministre affiche le rapport sur le site Web du gouvernement.

L.M. 2013, c. 54, art. 9.

**10** [Abrogé]

L.M. 2018, c. 8, art. 17.

**Caractère non exécutoire**

**11(1)** Les droits et obligations que crée la présente loi ne sont pas exécutoires devant un tribunal et ne peuvent faire l'objet d'aucune autre procédure.

**Défaut de se conformer à la présente loi**

**11(2)** Le défaut de se conformer à la présente loi ne porte pas atteinte à la validité d'un acte accompli ou d'une décision prise et ne peut servir de motif à leur révision ou à leur contestation.

### Conflict with another enactment

**11(3)** If a department or government agency is required by an enactment to consider particular matters in the exercise of its duties or powers, nothing in this Act is to be taken to require it to act inconsistently with that enactment.

### Delegation by minister

**12** The minister may, in writing, delegate to an employee who is in the minister's department, any power or duty conferred or imposed on the minister under this Act.

### Regulations

**13** The Lieutenant Governor in Council may make regulations

(a) designating bodies as government agencies, for the purpose of the definition "government agency";

(b) defining any word or expression used in this Act but not defined in this Act;

(c) respecting any other matter necessary or advisable to carry out the purposes of this Act.

### C.C.S.M. reference

**14** This Act may be referred to as chapter C24 of the *Continuing Consolidation of the Statutes of Manitoba*.

### Coming into force

**15** This Act comes into force on the day it receives royal assent.

### Incompatibilité

**11(3)** Dans le cas où un texte législatif oblige un ministère ou un organisme gouvernemental à prendre en considération des questions particulières dans l'exercice de ses attributions, la présente loi ne peut servir de motif pour l'obliger à déroger à ce texte législatif.

### Délégation par le ministre

**12** Le ministre peut, par écrit, déléguer à un fonctionnaire de son ministère les attributions que la présente loi lui confère et les responsabilités dont elle le charge.

### Règlements

**13** Le lieutenant-gouverneur en conseil peut, par règlement :

a) désigner des organismes à titre d'organismes gouvernementaux pour l'application de la définition de « organisme gouvernemental »;

b) définir les termes qui sont utilisés dans la présente loi sans y être déjà définis;

c) prendre toute autre mesure nécessaire ou souhaitable à la poursuite des objectifs de la présente loi.

### *Codification permanente*

**14** La présente loi constitue le chapitre C24 de la *Codification permanente des lois du Manitoba*.

### Entrée en vigueur

**15** La présente loi entre en vigueur le jour de sa sanction.

## SCHEDULE

### General Principles Relating to Caregivers

1. The relationship between caregivers and the persons for whom they care should be recognized and respected.
2. The valuable social and economic contribution that caregivers make to society should be recognized and supported.
3. Caregivers should be acknowledged as individuals with their own needs within and beyond the caring role.
4. Caregivers should be supported to enjoy optimum health and social well-being and to participate in family, social and community life.
5. Caregivers should be considered as important contributors with other care providers in the provision of care, support or assistance, acknowledging the unique knowledge and experience of caregivers.
6. Caregivers should be treated with dignity and respect.
7. Caregivers should be supported to achieve greater economic well-being and sustainability and, where appropriate, should have opportunities to participate in employment and education.
8. Support for caregivers should be timely, responsive, appropriate and accessible.

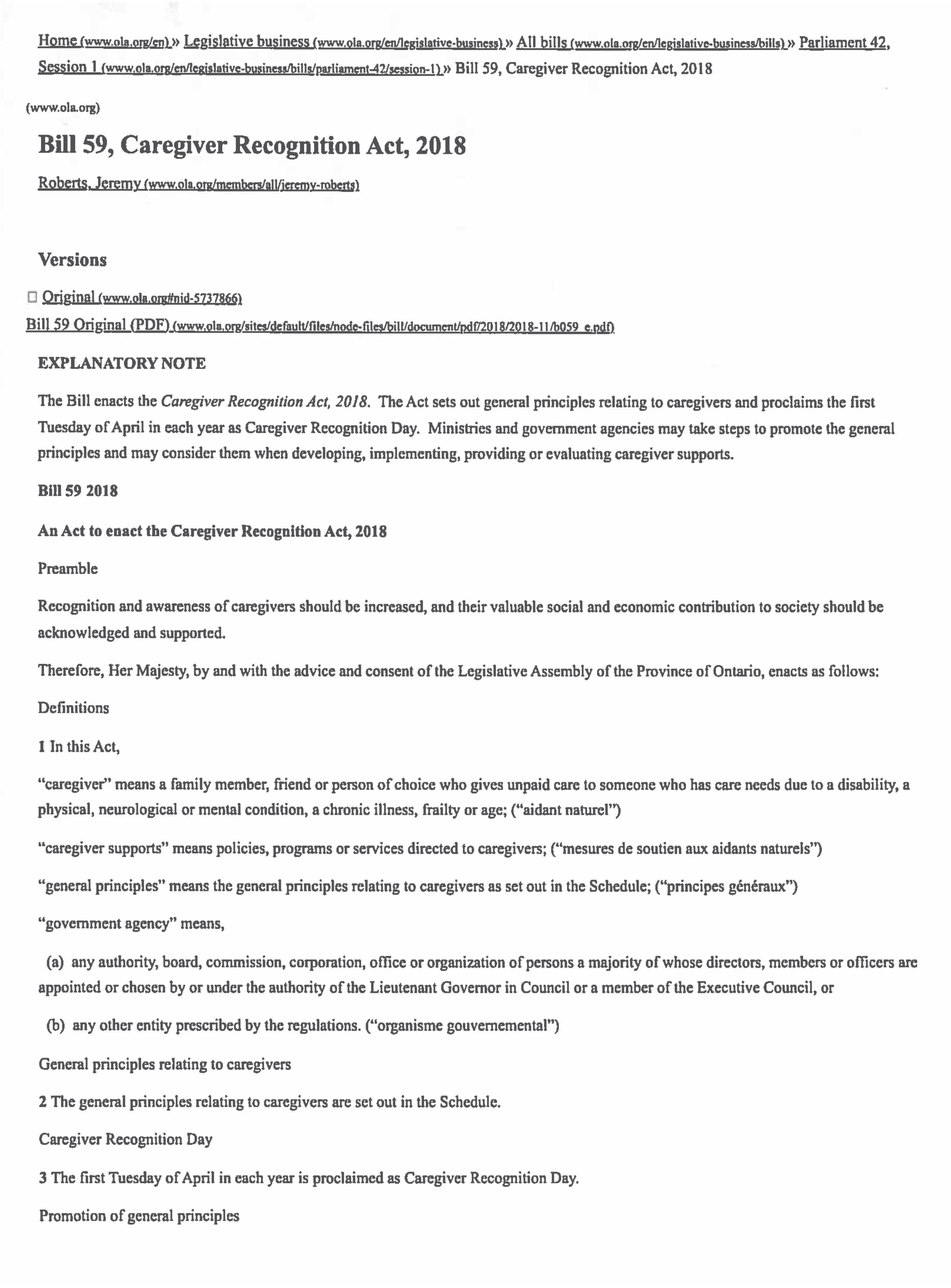
## ANNEXE

### Principes généraux applicables aux aidants naturels

1. Le lien entre les aidants naturels et les personnes qu'ils aident doit être reconnu et respecté.
2. La valeur de la contribution économique et sociale que les aidants naturels apportent à la société doit être reconnue et soutenue.
3. Les aidants naturels doivent être reconnus comme des individus ayant des besoins propres qui vont au-delà de leur rôle d'aidant.
4. Il faut appuyer les aidants naturels pour favoriser leur bien-être physique et social et leur permettre de prendre part à la vie en famille, dans la collectivité et dans la société.
5. L'importance des aidants naturels à titre de collaborateurs importants des autres fournisseurs de soins, d'aide et d'assistance doit être reconnue, compte tenu de leurs connaissances uniques et de leur expérience.
6. Les aidants naturels doivent être traités avec dignité et respect.
7. Il faut appuyer les aidants naturels pour leur permettre d'accéder à un meilleur bien-être économique et une plus grande indépendance; dans la mesure du possible, les aidants naturels devraient bénéficier de la possibilité de prendre part à des activités d'emploi et de formation.
8. Les mesures de soutien aux aidants naturels devraient être opportunes, pertinentes, indiquées et accessibles.

# Appendix 4

## Caregiver Recognition Act, 2018 -Ontario



Home (www.ola.org/en) » Legislative business (www.ola.org/en/legislative-business) » All bills (www.ola.org/en/legislative-business/bills) » Parliament 42, Session 1 (www.ola.org/en/legislative-business/bills/parliament-42/session-1) » Bill 59, Caregiver Recognition Act, 2018

(www.ola.org)

# Bill 59, Caregiver Recognition Act, 2018

Roberts, Jeremy (www.ola.org/members/all/jeremy-roberts)

## Versions

☐ Original (www.ola.org#nid-5737866)

Bill 59 Original (PDF) (www.ola.org/sites/default/files/node-files/bill/document/pdf/2018/2018-11/b059_e.pdf)

**EXPLANATORY NOTE**

The Bill enacts the *Caregiver Recognition Act, 2018*. The Act sets out general principles relating to caregivers and proclaims the first Tuesday of April in each year as Caregiver Recognition Day. Ministries and government agencies may take steps to promote the general principles and may consider them when developing, implementing, providing or evaluating caregiver supports.

**Bill 59 2018**

**An Act to enact the Caregiver Recognition Act, 2018**

Preamble

Recognition and awareness of caregivers should be increased, and their valuable social and economic contribution to society should be acknowledged and supported.

Therefore, Her Majesty, by and with the advice and consent of the Legislative Assembly of the Province of Ontario, enacts as follows:

Definitions

**1** In this Act,

"caregiver" means a family member, friend or person of choice who gives unpaid care to someone who has care needs due to a disability, a physical, neurological or mental condition, a chronic illness, frailty or age; ("aidant naturel")

"caregiver supports" means policies, programs or services directed to caregivers; ("mesures de soutien aux aidants naturels")

"general principles" means the general principles relating to caregivers as set out in the Schedule; ("principes généraux")

"government agency" means,

(a) any authority, board, commission, corporation, office or organization of persons a majority of whose directors, members or officers are appointed or chosen by or under the authority of the Lieutenant Governor in Council or a member of the Executive Council, or

(b) any other entity prescribed by the regulations. ("organisme gouvernemental")

General principles relating to caregivers

**2** The general principles relating to caregivers are set out in the Schedule.

Caregiver Recognition Day

**3** The first Tuesday of April in each year is proclaimed as Caregiver Recognition Day.

Promotion of general principles

4. Ministries and government agencies may take such practicable measures as they consider advisable to promote amongst their employees and others an awareness and understanding of the general principles.

Government to consider general principles re caregiver supports

5 Each ministry or government agency that is responsible for the development, implementation, provision or evaluation of caregiver supports may consider the general principles in developing, implementing, providing or evaluating caregiver supports.

Act does not create legally enforceable obligations

6 (1) This Act does not create rights or duties that are legally enforceable in court or other proceedings.

Failure to comply with Act

(2) A failure to comply with this Act does not affect the validity of any action or decision, and is not a ground for the review or challenge of any action or decision.

Conflict

(3) If a ministry or government agency is required by an Act to consider particular matters in the exercise of its duties or powers, nothing in this Act is to be taken to require it to act inconsistently with the other Act.

Regulations

7 The Lieutenant Governor in Council may make regulations,

(a) prescribing entities for the purpose of the definition "government agency" in section 1;

(b) defining any word or expression used in this Act that is not already defined in this Act;

(c) respecting any other matter necessary or advisable to carry out the purposes of this Act.

Commencement

8 This Act comes into force on the day it receives Royal Assent.

Short title

9 The short title of this Act is the *Caregiver Recognition Act, 2018.*

## SCHEDULE
## General Principles Relating to Caregivers

1 The relationship between caregivers and the persons for whom they care should be recognized and respected.

2 The valuable social and economic contribution that caregivers make to society should be recognized and supported.

3 Caregivers should be acknowledged as individuals with their own needs within and beyond the caring role.

4 Caregivers should be supported to enjoy optimum health and social well-being and to participate in family, social and community life.

5 Caregivers should be considered as important contributors with other care providers in the provision of care, support or assistance, acknowledging the unique knowledge and experience of caregivers.

6 Caregivers should be treated with dignity and respect.

7 Caregivers should be supported to achieve greater economic well-being and sustainability and, where appropriate, should have opportunities to participate in employment and education.

8 Support for caregivers should be timely, responsive, appropriate and accessible.

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**(Photos: istockphoto.com)**

# Welcome To Holland

by Emily Perl Kingsley

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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this……

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland." "Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.