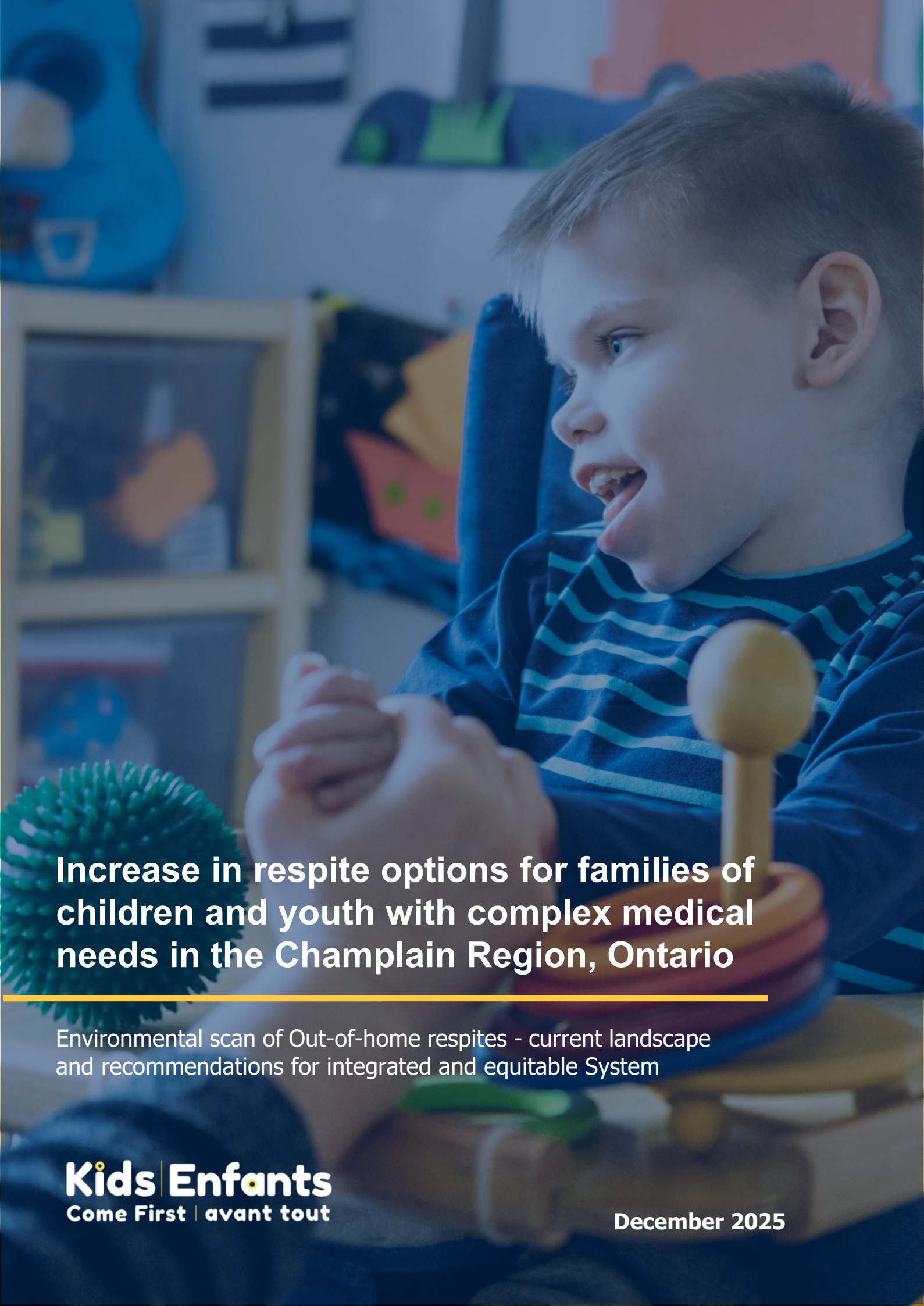


Increase in respite options for families of children and youth with complex medical needs in the Champlain Region, Ontario

Environmental scan of Out-of-home respites - current landscape and recommendations for integrated and equitable System

Kids | Enfants
Come First | avant tout

December 2025

Project Contributors

Kids Come First	Kids Come First is a network that includes over 70 hospitals and community-based organizations, healthcare providers, and Youth and Family/Caregiver Partners with lived and living expertise.
CHEO	CHEO is a leading pediatric healthcare institution located in Ottawa, Ontario, that provides specialized medical care to children and youth across eastern and northern Ontario, western Quebec, and Nunavut.
Ottawa Rotary Home (ORH)	ORH provides respite, recreation, and residential supports for children, youth, and adults with disabilities, helping families access short-term relief and community participation opportunities.
Roger Neilson Children's Hospice (RNCH)	RNCH provides pediatric hospice care and family supports for children and youth living with life-limiting illnesses, from diagnosis through end-of-life care and grief support.
Ottawa Catholic District School Board (OCDSB)	OCDSB is a publicly funded school board serving Eastern Ontario and supporting student learning, well-being, and inclusion.
Service Coordination Support (SCS)	SCS helps individuals and families access developmental services and community supports available throughout Eastern Ontario.
Ministry of Children, Community and Social Services (MCCSS)	The Ministry of Children, Community and Social Services (MCCSS) funds and supports programs and services for children, youth, families, and individuals with developmental and community support needs.
Bayshore Healthcare	Bayshore HealthCare is a Canadian provider of home and community care services, delivering nursing, personal support, and specialized care across the country.
Safe Haven	Safe Haven provides residential, respite, and transitional care services for children and adults with complex medical needs.

Increase in Respite Options for Families of Children and Youth with Complex Medical Needs in the Champlain Region, Ontario

Environmental Scan of Out-of-Home Respites - Current Landscape and Recommendations for Integrated and Equitable System

Executive Summary

This environmental scan, conducted under the Kids Come First (KCF) Home and Community Care (HCC) initiative, explores the current landscape of out-of-home respite care for children and youth with medical complexities (CMCs) in the Champlain region of Ontario. Drawing on population data, family and provider surveys, provider reports, and literature reviews, the scan identifies systemic gaps, access barriers, and opportunities for improving the delivery of equitable, coordinated, and culturally responsive respite care. Its purpose is to inform community partners and decision-makers as they work to expand effective out-of-home respite options across the region.

Families of CMCs, often requiring 24/7 care, manage high-intensity caregiving responsibilities with little or no formal support. Out-of-home respite care provides these families with essential temporary relief - improving caregiver well-being, reducing burnout, and promoting family stability. However, the scan reveals that, beyond Roger Neilson Children's Hospice (RNCH) and Ottawa Rotary Home (ORH), there are limited options for out-of-home respite services in the region for CMCs, especially for families living in rural areas or from marginalized communities. Barriers include financial constraints and a lack of culturally and linguistically appropriate services, especially for Francophone and newcomer families. These gaps underscore persistent challenges in both the availability and equitable access to respite care across the region.

The consequences of unmet respite needs are significant. Families report high levels of stress and burnout, with impacts on physical and mental health, increased emergency department visits, and, in rare cases, relinquishment of care due to exhaustion and lack of support.

Population trends underscore the urgency of action. CHEO's Complex Care Program grew by nearly 50% over the past five years, from 167 active patients in 2019/20 to 245 in 2024/25, with mid-year 2025/26 volumes remaining high at 235 patients. The program is funded for 200 patients and has operated above capacity for multiple years. For contextual comparison, this growth far outpaces the 7.5% increase in the general child and youth population in the region, highlighting the disproportionate rise in medically complex care needs.

In addition, postal-code patterns and qualitative evidence from surveys, partner feedback, and literature confirm that families live across both urban and rural communities, with rural families facing significantly greater barriers to accessing respite.

Despite recent progress, such as increased bed capacity at RNCH, families and providers consistently describe a system under strain. They express gratitude for existing services but frustration with persistent limitations in availability, geographic reach, and continuity of care.

Major challenges identified include:

- Capacity Constraints and Workforce Shortages
- Facility Capacity and Service Cancellations
- Regulatory and Licensing Barriers
- Service Utilization and Unmet Needs
- Access Barriers: Geographic and Socioeconomic Disparities
- Gaps for High-Care and Behavioral Needs
- Cultural and Language Accessibility
- Caregiver Burnout and System Navigation
- Transition to Adulthood: lack of respite continuity beyond age 18

In response, the scan offers a series of strategic recommendations, summarized under the following key themes:

1. **Geographic Equity**
   1.1. Advocate for funding to establish two out-of-home respite beds in rural regions, or
   1.2. Expand existing direct funding programs with a rural top-up to ensure a more equitable access for geographically underserved families.
   1.3. If infrastructure development is not feasible, implement a stipend model to help rural families secure in-home respite locally.

2. Transition to Adult Services
   2.1. Advocate for extending pediatric respite services to age 21 to bridge the gap while adult systems are developed.
   2.2. Launch a pilot program offering weekend respite (with 24-hour nursing support) through an adult respite provider for older youth patients.
   2.3. Engage partners such as the Provincial Network Health Engagement Strategy and Development Service Ontario East Region to build a continuum of care.
   2.4. Collaborate with the Transition Age Project to ensure alignment with broader transition planning efforts.

3. Navigation and Access
   3.1 Standardize a single referral and application package across KCF partners to reduce the administrative burden.
   3.2 Create a centralized navigation hub with multilingual resources, education, and outreach capabilities.
   3.3 Partner with school boards and existing CHEO and partner programs to identify families in need and coordinate referral pathways.
   3.4 Design a visual flow chart of programs and services to clarify connections and responsibilities across providers.

4. Service Capacity Expansion
   4.1. Advocate for cross-ministerial funding to expand both in-home and out-of-home respite options using a range of trained professionals (PSWs, DSWs, RPNs, RNs).
   4.2. Develop a Transitional Care Program modeled after Safehaven to facilitate hospital discharges and community reintegration.

4.3. Build partnerships with willing community and adult agencies—particularly in rural areas—and explore opportunities with local hospitals or clinics.
4.4. Pilot innovative ideas like sibling weekend respite and investigate future opportunities at the new 1Door4Care site.

5. Cultural Competency

5.1. Standardize training using an existing CHEO-developed cultural competency module, shared via the Centre of Excellence and other training platforms for all healthcare providers in our region.
5.2. Partner with “Winning Strategies for serving Francophone Clients” initiative through KCF Health Team to deliver multilingual workshops and embed FLS principles in new respite initiatives.

6. System Integration and Collaboration

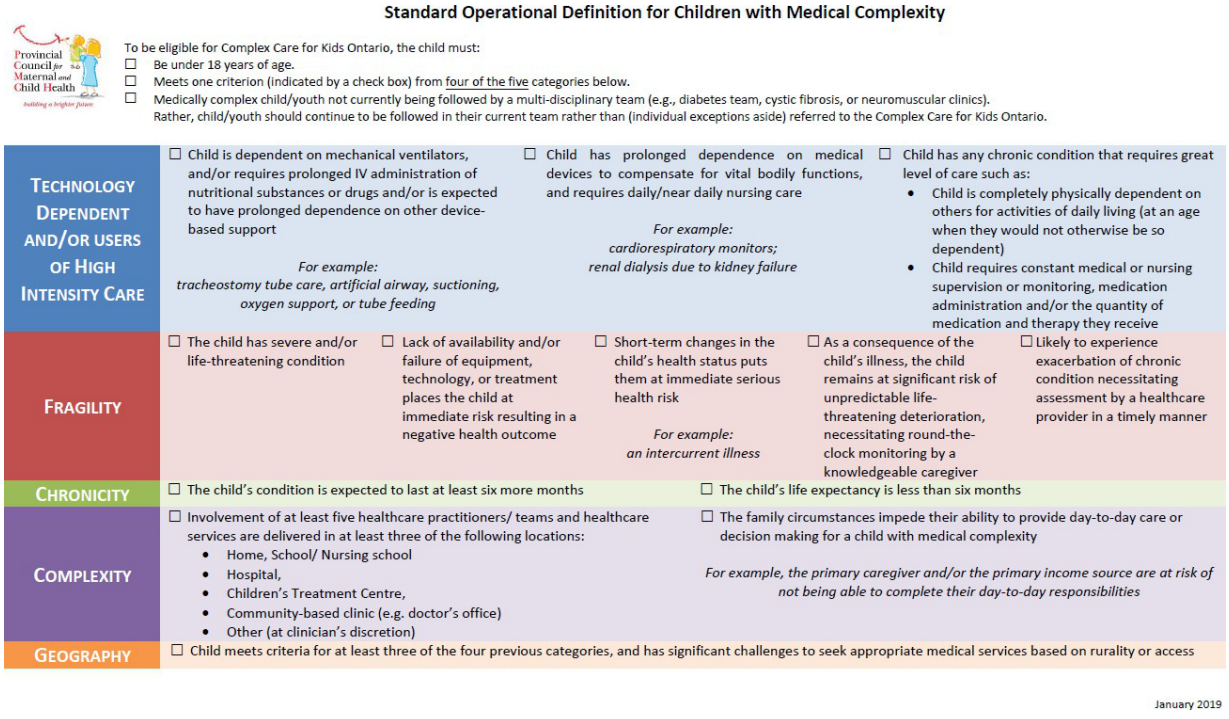
6.1. Strengthen relationships among pediatric service providers (health and community) to ensure consistent messaging, coordinated referrals, and equitable access to respite.
6.2. Clarify the roles of Case Managers, Parent Navigators, Respite Providers, Complex Care, and Coordinated Service Planning in respite planning.
6.3. Co-design solutions in partnership with Family Advisory Groups and incorporate real-time feedback from projects like FACT and Transition to Adulthood initiatives.

Contents

Introduction

Context: Who Are Children with Medical Complexity?

Children and youth with medical complexities (CMCs) represent a growing yet underserved population in the Champlain region. According to the 2019 standard operational definition of CMC by Provincial Council for Maternal and Child Health (PCMCH), these individuals often have chronic health conditions, requiring intensive and highly specialized care. They frequently rely on life-sustaining technologies and complex care coordination, placing a high burden on families. While many depend primarily on informal caregiving from parents and other family members – an average of 38 hours per week according to a 2020 Canadian Institute for Health Information (CIHI) report - these informal support systems alone are often not enough. In such cases, access to supplementary services, particularly home care and out-of-home respite, is essential to maintaining the health and well-being of both child and their caregivers (CIHI, 2020).



Standard Operational Definition for Children with Medical Complexity

Provincial Council for Maternal and Child Health

To be eligible for Complex Care for Kids Ontario, the child must:
- ☐ Be under 18 years of age.
- ☐ Meets one criterion (indicated by a check box) from four of the five categories below.
- ☐ Medically complex child/youth not currently being followed by a multi-disciplinary team (e.g., diabetes team, cystic fibrosis, or neuromuscular clinics). Rather, child/youth should continue to be followed in their current team rather than (individual exceptions aside) referred to the Complex Care for Kids Ontario.

TECHNOLOGY DEPENDENT AND/OR USERS OF HIGH INTENSITY CARE	☐ Child is dependent on mechanical ventilators, and/or requires prolonged IV administration of nutritional substances or drugs and/or is expected to have prolonged dependence on other device-based support *For example: tracheostomy tube care, artificial airway, suctioning, oxygen support, or tube feeding*	☐ Child has prolonged dependence on medical devices to compensate for vital bodily functions, and requires daily/near daily nursing care *For example: cardiorespiratory monitors; renal dialysis due to kidney failure*	☐ Child has any chronic condition that requires great level of care such as: • Child is completely physically dependent on others for activities of daily living (at an age when they would not otherwise be so dependent) • Child requires constant medical or nursing supervision or monitoring, medication administration and/or the quantity of medication and therapy they receive
FRAGILITY	☐ The child has severe and/or life-threatening condition ☐ Lack of availability and/or failure of equipment, technology, or treatment places the child at immediate risk resulting in a negative health outcome	☐ Short-term changes in the child's health status puts them at immediate serious health risk *For example: an intercurrent illness*	☐ As a consequence of the child's illness, the child remains at significant risk of unpredictable life-threatening deterioration, necessitating round-the-clock monitoring by a knowledgeable caregiver ☐ Likely to experience exacerbation of chronic condition necessitating assessment by a healthcare provider in a timely manner
CHRONICITY	☐ The child's condition is expected to last at least six more months	☐ The child's life expectancy is less than six months	
COMPLEXITY	☐ Involvement of at least five healthcare practitioners/ teams and healthcare services are delivered in at least three of the following locations: • Home, School/ Nursing school • Hospital, • Children's Treatment Centre, • Community-based clinic (e.g. doctor's office) • Other (at clinician's discretion)	☐ The family circumstances impede their ability to provide day-to-day care or decision making for a child with medical complexity *For example, the primary caregiver and/or the primary income source are at risk of not being able to complete their day-to-day responsibilities*	
GEOGRAPHY	☐ Child meets criteria for at least three of the four previous categories, and has significant challenges to seek appropriate medical services based on rurality or access		

January 2019

Figure 1: standard operational definition of CMC *by PCMCH*

Why Respite Care Matters

Respite care is a vital support for families caring for CMC, offering them a rare and much-needed temporary opportunity to rest, recharge, and attend to other responsibilities. These families often provide around-the-clock care, balancing complex medical tasks with emotional, physical and financial demands, while also maintaining employment and supporting other family members. In addition to daily care, families also face multiple medical and therapeutic appointments, and at times, lengthy admissions and prolonged hospital stays and the cumulative effects of pediatric medical traumatic stress, all of which can further impact their capacity to cope (Dewan, and al., 2022).

This strain often leads to caregiver burnout, chronic stress, and isolation. A Canadian study by Rosenbaum et al. (2020) found that 68% of caregivers for CMCs experienced high levels of stress, with over 50% expressed unmet needs for respite services. Another report by Krantz et al. (2021), highlighted the total financial toll on Canadian families of children with disabilities, ranging from $20,000 to $60,000 per year, with an average of $30,500 out-of-pocket. The 2025 Canadian Centre for Caregiving Excellence (CCCE) survey further shows compounding caregiver challenges, particularly for older parents or those managing employment constraints alongside caregiving duties.

Out-of-home respite care provides caregivers with a protected window to tend to their own health, relationships, and other children while ensuring their child is cared for in a safe, medically supported environment. These services not only sustain the capacity of families to continue caregiving but also contribute to overall family resilience and quality of life.

Consequences of Unmet Respite Needs

The absence of out-of-home respite care has significant negative consequences for families of CMCs. A 2018 study by the Canadian Partnership for Children with Complex Care and the Pediatric Complex Care Coordination Centre found that over 60% of families reported moderate to severe caregiver strain, with 40% reporting deteriorating physical or mental health due to lack of support. Additionally, research by Cohen et al. (2012) showed that families without respite options had higher rates of hospital readmissions of their CMC and emergency visits, often due to caregiver fatigue impacting care at home.

Moreover, according to feedback from providers and family partners, lack of respite has been associated with increased marital strain, financial instability, and even decisions to relinquish care of their medically complex child to institutional care due to being overwhelmed.

Purpose and Project Background

Strategic Alignment and Goals

This environmental scan was commissioned under the Kids Come First (KCF) Home and Community Care (HCC) initiative, hosted by the Children's Hospital of Eastern Ontario (CHEO). As part of KCF's 2023–2026 strategic goals to improve pediatric care integration, the HCC Working Group took up the initiative to increase respite options for families of CMC through assessing the current state of out-of-home respite services, identify systemic gaps, and recommend actionable strategies. The initiative supports the Quadruple Aim: enhancing health outcomes, caregiver and provider experiences, and system value.

How the Project Evolved

To guide this work, a focus session was held with representatives from CHEO leadership, service providers, community agencies, and family partners, with the following outcomes below:

Identified Gaps:

- **Limited availability:** Outside of Rotary Home and Roger Neilson Children's Hospice (RNCH), there are limited additional options.
- **Financial barriers**: Even when additional respite services are available, the cost of service can be unaffordable for families.

- **Accessibility and awareness barriers:** Many families are unaware of available respite services, and increased demand has made access more difficult.
- **Regional inequities:** Families in the rural and western Champlain face more barriers compared to those in urban centers like Ottawa.
- **Information gaps for families willing to pay for services:** Some families would consider private-pay options but lack information on what exists.

Identified Priorities:

- Form a dedicated action team to improve respite options.
- Conduct a regional environmental scan.
- Develop evidence-based recommendations to inform community partners and funders.

Project Objectives and Scope

Aim of the Environmental Scan

The aim of this environmental scan is to provide a comprehensive overview of the current landscape of out-of-home respite care in the Champlain region, with the following objectives:

- Assess existing respite services and utilization
- Identify population trends and unmet needs
- Examine barriers to access, and
- Propose evidence-informed recommendations to guide future system improvements.

Scope and Focus Areas:

- **Geographic Scope**: The environmental scan focused on the Champlain Region, including both urban areas and surrounding rural areas.
- **Population Focus**: Children and youth with complex medical needs, based on the PCMCH standard operational definition of CMC. Population growth trends are also analyzed to forecast future demand.
- **Respite Service Type**: Emphasis is placed ***on out-of-home*** respite care, as other KCF Home and Care initiatives are addressing in-home respite support. The assessment includes availability, accessibility, and any existing gaps in services.
- **Intended Outcomes**: The scan aims to support the development of a recommendation report with evidence-based strategies for community organizations and funders. These insights will identify critical areas for improvement and opportunities to expand respite options.

Out of Scope:

- Develop a new respite program, though hoping the outcome would guide any future work by KCF.
- Implement recommendations generated from this project (future work by KCF Health team may take this on).
- Families/caregivers with adult dependents. Focus will be on children while recognizing transition to adult care is important.

Work Plan and Contributors

Action Team Members:

Valerie Holmes (CHEO) – Project Sponsor	Stephanie King (OCDSB)
Sylvia Graham (CHEO)	Cathy Lonergan (Service Coordination Support)
Gina St. Amour (Ottawa Rotary Home) - Project Lead	Natalie Kent (MCCSS)
Madelaine Mcfadden (CHEO) – Project Lead	Casandra Richard (MCCSS)
Amarachi Iheonunekwu (CHEO) – Project Manager	Stephanie Toll (RNCH)
Chinyere Opia (KCF Family Partner)	Diane Paradis (CHEO)
Jodi Courchaine (KCF Family Partner)	Jennifer Dewaard (Bayshore HealthCare)
Meaghan Hysert (MCCSS)	
David Bell (KCF Family Partner)	
Susan Bisaillon (Safe Haven)	

Table 1: List of Action team members involved in this work

Workplan and Timeline:

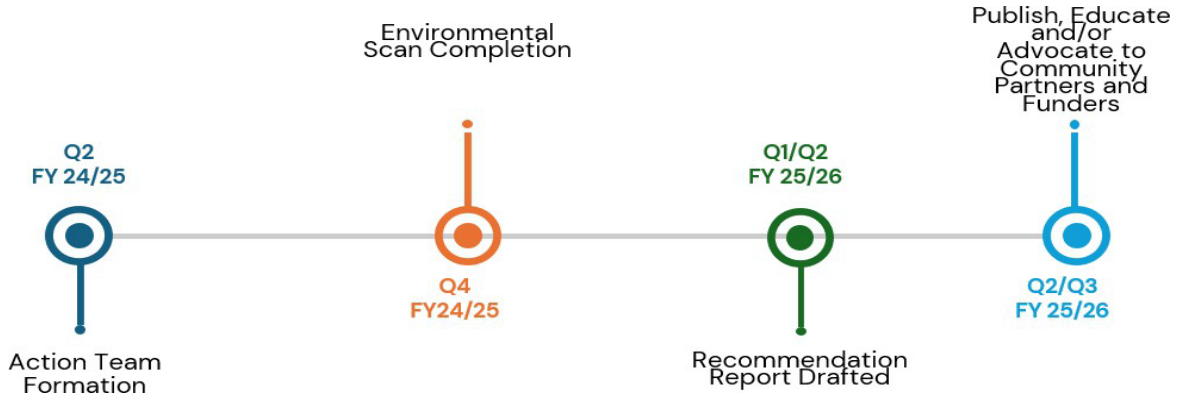


Figure 2: Workplan with key deliverables

Data Collection Methodology

This environmental scan utilized a mixed-method approach combining quantitative data from the CHEO EPIC system, StatCan databases and provider submissions from organizations like ORH and RNCH, and qualitative data from surveys from 23 families, 10 case managers, and 4 providers (see Appendix B for overview of survey responses and providers data), inputs from action team discussions and literature reviews.

Key Findings and Analysis:

Population Trends, Context, and Implications

CHEO's Complex Care Program is one of four provincial sites under the Complex Care for Kids Ontario (CCKO), an initiative by the Provincial Council for Maternal and Child Health (PCMCH), which aims to strengthen coordinated, family-centred care across Ontario. Since its implementation, the CHEO Complex Care program has continued to experience significant growth. Using validated CCKO program data, active enrollment increased from 167 patients in 2019/20 to 245 in 2024/25 - representing nearly 46.7% overall growth over five years. In fiscal year 2025/26, the program was supporting 235 active patients at the midpoint of the year, indicating continued high utilization and suggesting that overall volumes are stabilizing at an elevated level following several years of rapid growth.

The program is funded to support 200 patients, meaning demand has exceeded capacity for multiple consecutive years. Although the CCKO dataset does not capture all children in the region with medical complexity, it provides a clearer and more reliable indication of the scale and pace of rising needs. For contextual reference, the general child and youth population (0 - 21 years) in the Champlain region grew by 7.5% between 2019 and 2024 (Statistics Canada, 2025. While this is not a direct comparison - given the differences in definitions and tracking mechanisms - it illustrates the disproportionately rapid increase in medically complex care needs relative to overall population growth.

Reference Date	Children and Youth Age 0-21 in the Champlain Region
2019	652,534
2020	661,404
2021	661,426
2022	669,712
2023	684,588
2024	701,332

2020-2024 Population Estimates *Table 2: 2019-2024 Population estimate – Champlain, Ontario and Canada for children aged 0-21. Source: StatCan population data (Release date: 2025-01-16)*

Group	2019	2024	Growth
Children & Youth (0–21)	652,534	701,332	7.5%
Children w/ Complex Needs	182	325	78.6%

Table 3: Comparison of children with medical complexities (CMC) and general children and youth (0-21) population

Within the Champlain region, rural families remain significantly impacted as demonstrated by the geographical distribution data below.

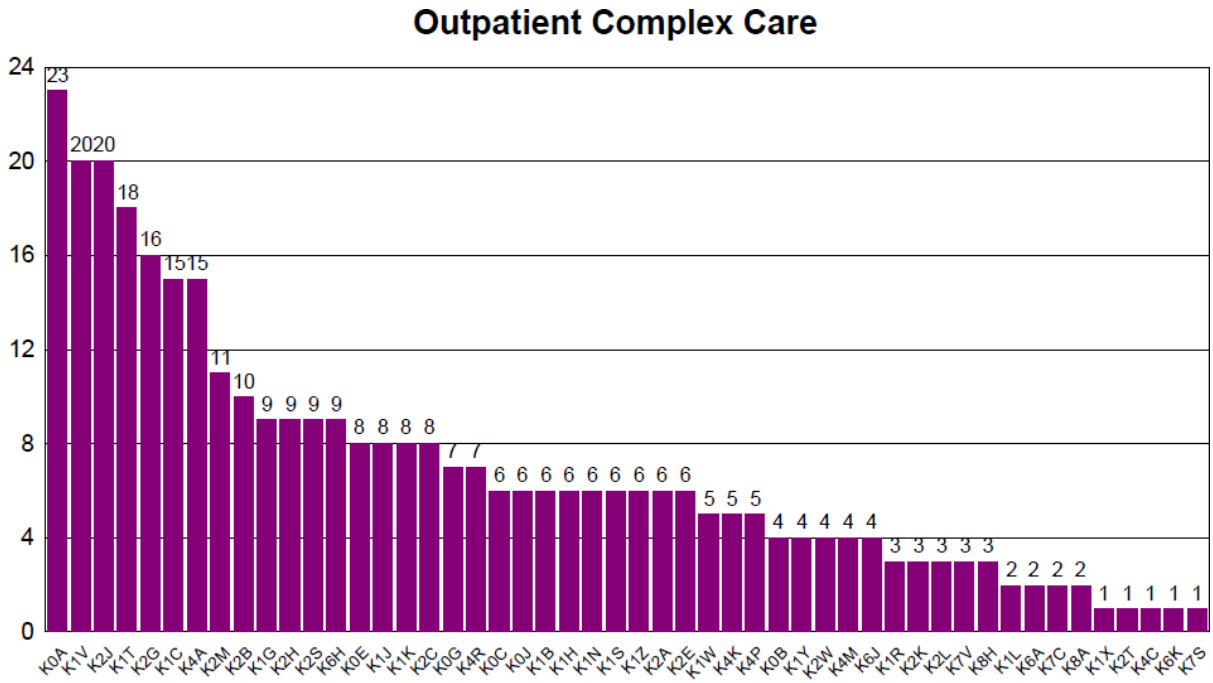


Figure 4: CHEO outpatient complex care with active Single Plan of Care (SPOC) in the Champlain region in 2025 by Post Codes. Source: CHEO EPIC System. (EPIC postal-code counts may be inflated due to historical SPOC closure practices. While numerical totals cannot be interpreted literally, the geographic distribution pattern (urban vs. rural postal codes) remains directionally accurate and aligns with qualitative and provincial evidence of rural service inequities.)

Although historical rural trend data cannot be reconstructed due to pre-2025 EPIC data limitations – particularly Episodes of Care not being consistently closed when patients left the program - postal-code distribution remains directionally accurate. It shows that children and youth in the program reside across both urban and rural communities, a pattern that aligns strongly with qualitative evidence and literature review of rural inequities shared by families, case managers, providers.

The contrast between 7.5% regional child population growth and the much faster rise in medically complex care needs highlights an urgent system-level challenge. CMCs remain a relatively small proportion of the pediatric population, yet they account for a disproportionate share of healthcare utilization and cost - consistent with literature review. For example, CIHI (2020) reported that, in 2015 - 2016 alone, 948 out of every 100,000 children and youth in Ontario lived with medical complexities. Similarly, a 2011 PCMCH action plan notes that children with medical complexity represent roughly 32% of total pediatric health-care spending, and the 2017 THRIVE report found that in the Champlain region they accounted for 25.4% of emergency department visits, 64% of hospital admissions, 64% of home-care costs, and 73% of services at the Ottawa Children's Treatment Centre.

Overall, these trends point to an expanding and increasingly complex patient population whose needs are outpacing current regional capacity, and whose access to respite and community supports varies significantly by geography. According to PCMCH, advances in neonatal and pediatric medicine have improved survival for medically fragile children; however, these gains are accompanied by increasingly complex care trajectories that require sustained, family-centred support across hospital, home, and community settings.

Respite Landscape in the Champlain Region

Out-of-home respite care for CMCs in the Champlain region is primarily provided by a small number of organizations (link to Respite Care for Children with Disabilities - Champlain - champlainhealthline.ca), including the most sought-after providers - Ottawa Rotary Home (ORH) and Roger Neilson Children's Hospice (RNCH), both located in Ottawa. While these providers offer invaluable support to families, demand for respite services significantly exceeds their current capacity. Families consistently report challenges accessing care due to service limitations, financial constraints, staffing shortages, waitlists, and geographic inequities - particularly for those living in rural areas where options are nearly nonexistent.

It is also important to note that RNCH, whose primary mandates include end-of-life care and pain and symptom management, offers respite care only to patients who meet specific eligibility criteria, including having a life-limiting condition and being followed by CHEO's Palliative Care Team. As such, many children with complex medical needs in the community do not qualify for RNCH respite services. Thus, respite capacity may be further constrained during periods of high demand for these primary services, reducing availability for families seeking routine or preventative respite.

Progress and Systemic Limitations

While challenges remain, recent developments show meaningful progress in supporting families of children with medical complexity in the Champlain region.

The 2017 *THRIVE* report - *The Future of Integrated Health Service Planning for Children and Youth in the Champlain Region* - recommended establishing a distinct child and youth HCC program to ensure specialized expertise and high-quality service delivery. Building on that vision, pediatric home care services were transferred from former Home & Community Care Support Services (now Ontario Health at Home) to CHEO in 2021 to strengthen collaboration and improve service delivery. More recently, in fall 2023, the Complex Care and Coordinated Service Planning (CSP) teams were re-aligned from the Development & Rehabilitation department to HCC, further integrating and coordinating support for families.

In 2024, RNCH received provincial funding to expand bed capacity, boosting its ability to deliver both hospice and respite services. While this is a positive step forward, demand for respite continues to far outpace the available resources.

Other regional initiatives also signal a growing commitment to more integrated and accessible pediatric care. The planned expansion of Manoirs Ronald McDonald House in Ottawa will provide more support for families traveling for care, and CHEO's upcoming Integrated Treatment Centre (formerly 1Door4Care) will bring multiple pediatric services together under one roof on the main campus. Although not exclusively focused on respite, these investments contribute to a stronger system of family support.

Despite these advances, access to out-of-home respite, especially for families in rural areas caring for children with complex medical needs, remains limited. Continued, targeted investment is needed to close the gap between service availability and growing demand.

Key Barriers and Service Gaps

Capacity Constraints and Workforce Shortages

Survey feedback from families, providers, and case managers highlighted consistent barriers rooted in physical space limitations, insufficient staffing, and increased demand for complex

care. Families often cannot access respite care as frequently as needed. Providers emphasized staffing as a major concern:

> "*The sector is experiencing staffing challenges and we would like to see a better response from colleges who provide the Developmental Service Worker program. We would like to see it funded by the government in the same way the Personal Support Worker program is, to attract individuals into the sector*." — Provider

The COVID-19 pandemic exacerbated these challenges, further straining respite capacity through staffing losses and health-related restrictions (ORH Annual Report, 2023).

Facility Capacity and Service Cancellations

Both ORH and RNCH continue to operate at near or full capacity, and many families experience last-minute cancellations. As a result, many families report frequent last-minute cancellations of scheduled respite care. These cancellations may be due to staffing shortages, emergency admissions, or priority cases. In 2023 - 24, RNCH reported 260 respite admissions, totaling 1,324 respite care days. However, 20 scheduled respite admissions were cancelled by care coordinators due to high-acuity cases or end-of-life care transitions. In addition, both ORH and RNCH are unable to support children requiring 1:1 staffing due to behavioral or medical complexity.

> *"I was told my child couldn't be accommodated because of behavior-related complexity."* – Parent

Currently, ORH offers 10 beds for children's overnight respite, with 2 of those designated for medically complex clients. Although ORH does not maintain a formal waitlist, many families are unable to book their preferred dates due to limited availability.

At RNCH, 10 beds are available for pediatric hospice palliative care patients who may access respite among other admission types. However, bed allocation is prioritized for end-of-life care, followed by symptom management, and lastly, respite stays. Because there is no standardized process or benchmark for tracking waitlists, most families seeking respite are often waiting for specific days to open up based on their needs, resulting in some families missing out on respite altogether.

These capacity constraints are not limited to ORH and RNCH. For example, the City of Ottawa's Spirit Program, once able to offer children weekly or biweekly access to respite activities, has seen a notable decline in availability and over a year-long waitlist according to family partners and providers. Access is now typically limited to once per month, with a one-week summer program as the only consistent extended offering. While this reduction may be attributed to factors such as static funding or operational limitations, stakeholder feedback indicates it is not due to declining interest. Rather, it reflects a growing demand from families seeking access to the program. Although families deeply value the program, this rising pressure highlights the urgent need for increased community-based respite capacity and investment to prevent further access delays or service denial.

This issue is not unique to the Champlain region. National literature reflects similar concerns across Canada. An environmental scan by Dunbrack (2003) of publicly funded programs providing respite for families and caregivers across Canada found that respite providers consistently rate demand as high, citing a lack of trained caregivers - especially for children with disabilities - as a significant barrier. Similarly, Woodgate et al. (2023) highlighted long waits and systemic delays as a recurring theme across provinces such as waiting to get a diagnosis, waiting to be assigned a case worker, waiting for an available respite slot, etc. According to

experiences shared by parents in this report, these multiple steps and waiting often resulted in families reaching breaking points and exhaustion.

Regulatory and Licensing Barriers

Beyond capacity limitations, the expansion of pediatric respite care, particularly for children with medical complexity, is often hindered by stringent regulatory and licensing frameworks. In Ontario, all out-of-home respite programs for children must comply with licensing standards under the Child, Youth and Family Services Act (CYFSA), which governs children's group homes (Ministry of Children, Community and Social Services, 2020). These regulations, while grounded in child protection, include rigorous requirements around individualized care plans, facility design, safety protocols, staff qualifications, and regular inspections - standards that far exceed those applied to adult respite programs.

While these safeguards are well-intentioned and designed to protect vulnerable children, many service providers and stakeholders report that they create both philosophical and operational misalignments with the core purpose of respite care. Respite, by design, is meant to be short-term, flexible, and family-centered. Yet, the increasingly demanding and prescriptive legislation is oriented toward long-term care or protective oversight, which does not always fit the respite model. This fundamental mismatch can contribute to delays, confusion, and program ineligibility.

Administratively, pediatric respite providers face substantial compliance burdens, including costly facility upgrades, enhanced insurance coverage, staffing ratios, and mandatory training, all without consistent operational or startup funding. In Ontario, there is no dedicated provincial funding stream for pediatric respite infrastructure or sustainability, forcing agencies to rely on grants or philanthropy (Service Coordination Support, 2025).

Partner feedback also revealed that several out-of-home respite and foster placements that closed during the pandemic have yet to reopen. Additionally, partners reported that agencies that initially expressed interest in offering pediatric respite ultimately withdrew, citing the burdensome regulatory requirements and lack of financial support as key deterrents.

Service Utilization and Unmet Needs

Despite the above noted barriers, service utilization remains extremely high. Both RNCH and ORH report that whenever respite slots become available, they are quickly filled - indicating a near 100% utilization rate for available beds. Yet high utilization masks the unmet needs that persist for families who cannot access services due to eligibility restrictions, behavioral complexity, need for 1:1 care or lack of flexibility in scheduling.

In Ontario, only 46% of caregivers of children with cerebral palsy and 49.5% of families with children and youth with special healthcare needs (CYSHCN) had received any respite care in the past year (Woodgate et al., 2023). Even when families are eligible and approved, systemic issues persist. In Manitoba, for example, only 30.8% of the 2,049 families approved for publicly funded respite in 2019 - 2020 received services, largely due to the unavailability of workers or lack of awareness of options (Woodgate et al, 2023).

A 2023 white paper by the BC Complex Kids Society notes that despite funding improvements, service gaps remain, particularly for children dependent on medical technologies like ventilators or tracheostomies. These findings highlight that Champlain's challenges are not unique, but rather part of a broader national shortfall in comprehensive respite care delivery.

Access Barriers: Geographic and Socioeconomic Disparities

Geographic challenges emerged as one of the most consistent themes across family surveys, provider interviews, and case manager feedback. Directional postal code patterns from CHEO's EPIC data confirm that families in the Complex Care Program live in both urban and rural areas, while qualitative feedback highlights that rural families face significantly greater challenges accessing out-of-home respite.

Families living outside Ottawa reported limited availability of formal respite beds in their communities, limited local programming, long waitlists (sometimes up to two years) for the nearest respite home, long travel distances to reach Ottawa-based services and missed work. Transportation barriers, especially for families with only one vehicle or no driver's license, further limit their ability to use respite even when eligible:

> "*Most respite homes are located in Ottawa (ex: Rotary Home or Roger Neilson). Most of my families would need to drive about 1hr each way to access. Lots of my families only have 1 vehicle (limits when they can go) and a few of my moms don't have a driver's license"* – Case Manager

> "*I miss work a lot because of her medical needs, appointments, sickness etc. There is no public transportation in Stormont, Dundas and Glengarry (SDG). I will have to miss work next year because day programs don't have transportation, and someone has to drive my daughter to program*" - Parent

Provincially, northern and rural communities often report a medium to high demand but low availability of facility-based respite. A national scan also found that remote areas often have no dedicated respite facilities, leaving families to use general home care programs or travel long distances. (Dunbrack, A., 2003).

The 2017 THRIVE report also highlighted significant regional disparities in access to pediatric health services, including out-of-home respite care, across Eastern Ontario. Children and youth in Western Champlain received only 51% of the former LHIN average visits per child for developmental and rehabilitation services. They also had 2.37 times the emergency department visits expected at the provincial average, indicating gaps in community-based care. Overall, children and youth across the former LHIN received 19% fewer home and community services than the provincial average, with Western Champlain showing the lowest access.

Financial barriers compound these challenges. Families living both in rural and urban areas reported often paying out-of-pocket due to inadequate funding, leading to exhausting respite subsidies well before year-end. About 45% of families in the survey cited out-of-pocket costs and insufficient government funding.

> *"I have a family who is only able to use the Smith Falls respite home because they have funding – this is in the territory of Connectwell. Without the funding it would be unaffordable. Rotary remains the only affordable option, outside of RNCH which is covered."* – Social Worker

> "*We are spending a big amount of money on the accessibility of the home and paying for the care. We are either ineligible for the government funding or our expenses on the care and accessibility exceed amount of funding*" - Parent.

Case managers emphasized that low-income families struggle to afford respite. Some government respite programs offering direct funding to families such as Ontario's Special Services at Home - Special Services at Home | ontario.ca (SSAH), Enhanced Respite for Medically Fragile Children - Family support and respite for children and youth with special needs | ontario.ca, and Assistance for Children with Severe Disabilities (ACSD) - Family support and

respite for children and youth with special needs | ontario.ca - provide modest annual funds. These funding programs often cover only a fraction of actual needs according to families.

> "*SSAH and Enhanced respite barely last until Sept for most families"* – Social Worker

In addition, families are obliged to initially pay respite out-of-pocket and submit the invoice to be reimbursed for SSAH and Enhanced Respite (which can take 2 to 3 months), creating further barriers:

> *"We have many families for whom this makes using their funding challenging and at times impossible."* – Social Worker

These disparities underscore the urgent need for equitable distribution of pediatric health services, including respite care, to ensure that all families, regardless of their geographic location and socioeconomic status, have access to the support necessary to care for children with medical complexities.

Gaps for High-Care and Behavioral Needs

Surveys data and stakeholder feedback underscore significant gaps in respite options for children with higher care needs, especially those requiring 1:1 care, behavioral complexities medical technology, or too young (0 - 6 years) - who are frequently denied services due to staffing limitations and facility readiness.

> "*There are no facilities for medically complex youth requiring 1:1 care".* Another noted*.*
>
> *"Tube Feeding, 1:1 assistance required, Toileting/changing, Unqualified/not trained staffing" "Also if additional 1-1 support is needed there is either an additional cost or families need to find their own 1-1 worker to attend with the child"* – Case Manager

These limitations are mirrored in ORH and RNCH service data*:*

- ORH reserves only 2 beds for medically complex youth.
- RNCH cannot accommodate clients who are too physically active or require intensive 1:1 support due to existing care team ratios and eligibility criteria.

Cultural and Language Accessibility

Francophone and newcomer families face difficulties due to limited translation and multilingual service access. Case managers report families struggling to navigate services without support in their preferred language.

> *"A few of my families are also impacted by language barriers (they have a hard time contacting the respite homes on their own)*". – Case Manager
>
> *"If families have specific cultural considerations and needs, they're limited with what respite they can access" – Case Manager.*

The literature reinforces this gap. In a 2021 regional consultation, Francophone parents of CMC praised the care at RNCH and ORH but expressed that "*the challenge is the English*" during respite stays (Children's Health Coalition, 2021). The following responses from parents were also noted:

> *"Respite – particularly at RNCH – no services at home. It works well but not in French. When I call to inquire about my child, An Anglophone nurse often answers. I accept that some services are more in English. For 10 years, it has been hard. The complex care program makes a difference. Well supported and good resources. Services, mostly in*

> *English, except Dr. Major. School is going very well. Special class for French service. Good services in general. RNCH changed a lot of things for us in terms of respite and overall support for parents". "Complex care program managed by a Francophone. It makes a big difference. Dr. Major. It works really well. We spent a few days at CHEO and she is taking over. There is continuity. We can ask her questions in French. The nurses are not necessarily French but my daughter can have services in French. Afraid about when Dr. Major retires".* - Children's Health Coalition. (2021). pg. 93-95

The 2017 THRIVE report and the 2025 National Caregiving Survey by Canadian Center for Caregiving Excellence (CCCE) also highlighted that caregivers from the francophone and Indigenous populations have unmet service needs.

Caregiver Burnout and Ambiguous System Navigation

The environmental scan reveals that parents and caregivers of CMC face not only limited access to respite but also overwhelming administrative and logistical burdens in navigating a fragmented support system. Evidence from various sources shows that parents and caregivers are missing work, reducing hours or have to entirely leave their jobs to meet their child's intensive needs, often at great personal and financial cost.

Stakeholder feedback and survey results consistently identified key barriers such as heavy administrative burden, inconsistent eligibility requirements, and unclear referral pathways.

> *"It's not just the paperwork - it's that we don't know who to talk to. Every service has a different form."* - Parent

> "*Families are burned out. Asking them to coordinate their own services is unrealistic*." - Provider

This is not unique to the Champlain region. A 2023 environmental scan by Woodgate et al. highlighted that across jurisdictions, families and service providers alike find the system confusing and difficult to navigate due to inconsistent information, bureaucracy, and siloed services.

> *It's just so complex …I've been doing it for a little while, but it is a mysterious web of systems and that is for me as a service provider and never mind being a lay person, never mind being a newcomer family, never mind having a language barrier and if you aren't attached to [organization], how are you supposed to know?* – Stakeholder (Woodgate et al., 2023, p. 5))

As highlighted earlier in this report, The consequences of this complexity and lack of coordinated support are profound. High stress and prolonged burnout are having a direct impact on caregivers' mental and physical health. Woodgate et al. (2023) found that nearly half (48.8%) of mothers of children with special healthcare needs who did not receive respite services reported significant mental health concerns, while 60.8% experienced physical health conditions, as compared to those who did receive support. Similarly, the 2025 CCCE report on National Caregiving Strategy emphasized that many caregivers are bearing the burden alone, without any days off. This deepens mental health challenges and burnout, with long-term consequences for families and the system.

> *"We are beyond burnt out but we have no choice but to keep going 24/7."* - Panel survey participant (Canadian Centre for Caregiving Excellence (CCCE), 2024)"

In the most extreme cases, prolonged burnout, combined with lack of support and limited options, has led some families to consider, or even follow through with, the relinquishment of

care. One provider cited three cases of care relinquishment within 18 months - all involving single parents. A family partner added:

> *“I know parents who would relinquish care if they weren’t afraid of the consequences.”* – Family Partner

> *There's been lots of situations where people have had to sign their children over to Child and Family Services (CFS). Because they don't know what else to do, and they're not being given the support that they need in their home to be able to keep their child at home. And like what an awful and horrible thing to have to do simply because you don't have the support that you need.* – Respite Stakeholder (Woodgate et al., 2023, p. 6)

This is not just a tragedy at the family level, it also carries broader system impacts. As one provider noted in the Woodgate et al report, the lack of investment in direct respite services results in even greater public costs later.

> *I think it's absolutely ridiculous that, you know, where families with children who have severe disabilities that require 24/7, seven days a week care and the government or whoever is willing to pay thousands and thousands of dollars to have that child come into CFS care and be placed in a foster home and receive like high level funding, when they're not willing to put the services in that home so that that parent can stay home and take care of their child* – Service Provider (Woodgate et al., 2023, p. 6)

These findings point to an urgent need for more accessible, coordinated support systems, including case management and proactive outreach, before families reach a point of crisis. Improving navigation and reducing red tape can not only help families maintain stability but also prevent costly downstream consequences for the broader health and social service systems.

Transition to Adulthood: The Gap Beyond 18

In Ontario, eligibility for pediatric respite services typically ends at age 18, requiring youth to transition into adult care system. While this is a structural reality, it creates a critical service gap for medically complex youth whose care needs remain unchanged. Many family partners and providers alike describe this abrupt shift as deeply destabilizing.

> *“It simply does not exist for those who are medically complex.*” – Parent

> *“Falling off a cliff at 18 years and one day is not a system.”* - Family Partner.

> *“Respite ends, but the needs don’t.”* – Provider

At CHEO, the Complex Care Program follows transition protocols informed by guidelines developed by Complex Care for Kids Ontario (CCKO) and PCMCH (2022). This includes starting transition planning as early as age 12 and offering families structured tools, timelines, and support. Still, families often face high levels of emotional stress, anxiety, and uncertainty. This is compounded by the reality that many adult programs are not designed or equipped to serve the same level of complexity. According to providers, the gap in services, shortage of adult Primary Care Providers in the community available to take on complex care patients, and the change in loss of long-standing and trusted care teams also create a profound sense of grief and anxiety for families who have relied on consistent relationships for years.

The experience at Roger Neilson Children’s Hospice (RNCH) reinforces this concern. Each year, 2 to 6 clients age out of pediatric respite and move into adult services, often without formal referrals, handoffs, or access to comparable care. While families are directed to adult options

like ORH, these programs are few and often not suited to the needs of CMC population. ORH, for example, also ends respite services for CMC at age 18.

This transition gap is well documented in the literature. Porepa et al. (2017) describe it as a persistent system-wide challenge:

> "*There is a general deficiency of equivalent respite care services once children transition into the adult system*." (p. 369 - 371).

The broader implications are significant. According to CIHI (2020), more than 1 in 3 unpaid caregivers across the Canadian health system experience distress, including depression, anger, and burnout. Without a coordinated, appropriate transition plan for youth requiring 24/7 care, these pressures are only expected to grow, placing further strain on families and the health system

Despite the proactive efforts of pediatric teams, the absence of accessible and appropriate adult services leaves families navigating this vulnerable period with insufficient support, at a time when continuity and stability are needed most.

Stakeholder-Driven Improvement Suggestions:

Throughout this environmental scan, extensive input was gathered from families, case managers, and service providers through surveys and consultations. Their firsthand experiences shed light not only on existing barriers but also on potential solutions. This section synthesizes their key suggestions - offered from lived experience and professional insight - which informed the forthcoming recommendations.

These improvement ideas highlight urgent system gaps and suggest practical enhancements in service models, capacity, accessibility, staffing, and cultural responsiveness. Importantly, the suggestions emphasize that respite services must be flexible, equitable, and tailored to the complex needs of children, families, and the providers supporting them.

Feedback from Families:
Families who participated in the survey expressed the need for:

- Longer respite stays and greater flexibility in scheduling (e.g., drop-off/pick-up flexibility).
- More geographically distributed options, particularly in rural and underserved areas.
- Affordable, extended stays (e.g., month-long or seasonal relief programs):
  "I wish there could be a month-long stay so our family can go overseas."
- Structured, high-quality programs modeled after RNCH, including trained volunteers and therapeutic supports.
- Staff trained specifically in complex care, especially where 1:1 support or medical technology is involved.

Feedback from Case Managers:
Case managers underscored the following needs:

- Increased number of service providers and physical respite sites across the region.
- Enhanced government subsidies to help families access respite services.
- Availability of recreational and camp-style respite programs, especially in summer months.
- Workforce development, including training staff in complex care and behavioral management.
- Culturally and linguistically appropriate services that reflect the region's diversity.
- Affordable respite options that reduce caregiver burnout and promote long-term family resilience.

Feedback from Service Providers:
Providers identified system-level changes and infrastructure improvements, including:

- Increased government funding to expand physical bed capacity.
- Investments in staffing pipelines through training programs and sector recruitment strategies.
- Flexible service delivery models, including short-term, emergency, and long-term respite stays.
- Integration of mental health and behavioral supports into respite offerings.
- Strengthened transition planning, with a clearer continuum from pediatric to adult respite care.

Innovative Respite Models and National Best Practices

While the Champlain region continues to face major gaps in out-of-home respite for children with medical complexity (CMC), several jurisdictions across Canada offer promising models worth adapting. These programs demonstrate the value of innovation, cross-sector collaboration, and a family-centered approach to respite care.

Toronto Ontario Innovative Models:
Safehaven model: Key features include staffed facilities with nurses and personal support workers; accommodation for stays ranging from a few hours to a couple of weeks; a family-centered approach that creates a fun, home-like environment; and the ability to care for children with tracheostomies, feeding tubes, seizures, and other high needs. Innovative programs include:

- **Chronic Vent Program**: Unique in Ontario, this program serves eight clients with complex medical needs, setting a provincial benchmark for medically intensive community care.
- **Transitional Care for Medically Complex Children (TCMCC)** program (launched in 2022 with Holland Bloorview): Helps medically complex children transition from prolonged hospital stays to home and community life—alleviating hospital pressures and improving family preparedness.

The City of Toronto's "**Rest, Relax and Restore**" respite initiative is another innovative model that provides children with respite care while parents enjoy a night away, complete with limo transportation and accommodations in the city. This holistic approach supports both the child and caregiver wellbeing.

British Columbia - Systems Change through Innovations, Collaborations and Expansion:

BC's Centre for Health Complexity: is constructing a Centre for Health Complexity—the first of its kind in Canada—set to open in 2028 in Vancouver. This future hub will provide integrated care, specialized training, and family support under one roof. While not yet operational, this initiative is viewed as a leading-edge model for comprehensive care.

In its **2025 white paper**, the BC Complex Kids Society outlines five principles to transform systems for CMC:

- **Cross-Ministry Collaboration**: A unified, cross-ministerial and outcomes-based care strategy co-designed with families.
- **Community-Based Care**: Localized coordinated support, extending up to age 25 for CMC.
- **Rights & Needs-Based Funding**: Fair, flexible, inflation-adjusted funding that values family caregiving.
- **Equitable Access**: Rural and remote community-based service expansion to reduce reliance on urban-centric care.

- **Trauma-Informed, Culturally Safe Practices**: Empower families to choose care aligned with their unique circumstances and backgrounds.

Manitoba - Centralized Systems and Family-Centered Design:
Qualitative studies by Woodgate et al. (2023, 2024) highlight recurring themes from **Manitoba families** of CMC:

- A **centralized navigation system** with a single-entry point and real-time access to service directories.
- More respite hours, **shorter wait times**, and improved emergency options
- **A professionalized respite workforce,** with standardized training and funding for family caregivers.
- Strong emphasis on **equity**, cultural safety, and a **human-rights-based** model of care.

National Recommendations: 2025 Canadian Centre for Caregiving Excellence (CCCE) Caregiver Strategy:
The **CCCE** outlines priority actions to support caregivers of children with high medical needs:

- **Expand and fund respite services**, with targeted programs for underserved populations
- Ensure **cultural and identity-based care**, acknowledging the needs of Indigenous, racialized, LGBTQ2S+, and youth caregivers
- **Stabilize the workforce** through fair pay, training, and better working conditions
- Advance **caregiver-friendly policies**, such as job flexibility and paid leave to facilitate respite access.

Toward an Integrated, Equitable Respite System: Key Recommendations for Increasing and Strengthening Out-of-Home Respite Services for Families of CMC in the Champlain Region

1. Geographic Equity:

Statement: Rural CMC population in the Champlain region is increasing at a disproportionate rate and presently offers minimal to zero out of home options**.** There is strong evidence that rural families have significant out of pocket expenses, including travel costs, that are a barrier to paying for respite supports. Current funding mechanisms, such as the Special Services at Home (SSAH) and Enhanced Respite programs, offer some support but are often insufficient and quickly depleted. Rural families face unique and added challenges that are not currently addressed in these funding models.

Recommendations 1.:

1.1. **Funding for Rural Respite Beds**: KCF to advocate for funding for 2 out-of-home respite beds in the rural region to support children with complex medical needs
1.2. **Expand Direct Funding Programs with a Rural Top-Up**: KCF should recommend expanding existing direct funding programs such as SSAH, Enhanced Respite, or ACSD, to include an additional rural allotment. This "rural top-up" would help towards offsetting travel and caregiver costs and ensure more equitable access for geographically underserved families

1.3. **Introduce a Respite Stipend Model**: If sufficient funding cannot be allocated for an equivalent out of home program in the rural areas, then offer a stipend so families can secure some in-home respite in their area.

2. Transition to Adult Services:

Statement: There are minimal equivalent respite services for children with complex needs in the adult health or developmental services system. Given that the services do not exist, the transition for the youth and family is not well supported and has negative consequences for both.

Recommendations 2.:

2.1. **Extend Pediatric Support into Early Adulthood**: KCF to advocate for health and social services to extend supports to age 21 to ease transitions while the adult services develop appropriate transition systems. This would include youth still in school or not in school until the age of 21.
2.2. **Fund Pilot Weekend Respite for Adults**: Advocate for funding for 24-hour nursing support dollars to be allocated to one out-of-home adult respite provider who can begin services immediately for transitional aged youths. A pilot project could be initiated for 6 – 9 months for weekend respite (most requested respite need from families within the survey).
2.3. **Leverage Cross-Sector Partnerships**: KCF to utilize existing groups such as the Provincial Network Health Engagement Strategy, Developmental Services Ontario (East Region) and our regional OHT's to promote the benefit of a full continuum of service delivery through childhood to adulthood for this population.
2.4. **Link to KCF Existing Initiatives**: Align with the "Supporting Transitional Aged Youth Initiative," recently launched by KCF in partnership with youth partners, to streamline and improve care during transitions. Findings from this environmental scan can be used to advocate for prioritizing improved access to respite services for transitional-aged youth and their families.

3. Navigation and Access:

Statement: Historically, Ottawa Children Treatment Centre (OCTC), RNCH and ORH have a streamlined referral process. Families would tell their stories once and the package can be used between providers.

Recommendations 3:

3.1. **Promote Standardize A Single Referral Process Across Providers**: Advocate KCF partners to utilize one package for respite applications and expand to other respite providers to reduce the administrative burden on families.
3.2. **Develop a Centralized Navigation Hub**: Create a navigation hub for respite care which includes written material and the ability to educate and create awareness about all respite services available to this group. This hub would have the ability to support navigation and advocacy (including outreach).
3.3. **Partner with School Boards for Family Identification**: KCF to create an initiative with the school boards and existing CHEO and partner programs to locate all families with children with complex care needs that are in need of respite, and share information on out of home respite options (including referral process and marketing material).
3.4. **Map Regional Referral Pathways**: Design Flow chart for all programs that can connect with this target population. Utilize the existing service programs within CHEO (Neuro Developmental Health, Coordinated Services Planning, Extensive Special Needs,

Complex Care Program, Urgent Response, etc.), Service Coordination Supports and regional respite providers to ensure no child is missed and that all providers are aware of each other and the referral process.

4. Service Capacity Expansion:

Statement: Evidence shows that the current respite care capacity is insufficient to meet the needs of children and youth with medical complexity. Service capacity for this group of children must be expanded. Services need to consider the full continuum from in-home to out of home supports.

Recommendations 4:

4.1. Funding for Cross Ministerial Workforce: Advocate for cross ministerial funding for services that leverage the strengths of trained professionals from Personal Support Workers, Developmental Services Workers, RPN's, RN's.

4.2. Develop a Transitional Care Program: Advocate for a Transitional Care Program funded by Health to discharge children from hospital sooner and support transition back into full community setting. (for example, the SafeHaven model).

4.3. Build Partnerships with Willing Community Respite Providers: Develop relationships with agencies (children and adult) that are interested and willing to provide out-of-home respite to this target group (particularly in rural regions) and explore opportunities with local hospitals or clinics.

4.4. Explore Rural Respite Spaces: Pursue partnerships with rural hospital partners/ health clinics to determine if there is a feasibility for space for a respite service.

4.5. Explore Opportunity within CHEO's Future Integrated Treatment Centre for Respite Integration: Determine with KCF if the new 1Door4Care site could create a space for the respite hub.

5. Cultural Competency:

Statement: There is strong evidence that a focus needs to be placed on culturally competent care and multilingual staff.

Recommendations 5:

5.1. Leverage CHEO Cultural Competency Training: KCF to advocate to CHEO to make existing training module to respite providers through the Center of Excellence expansion and Community Support Training Solutions. CHEO has robust training and resources for French language services, LGBTQ+, Indigeneity, and newcomers. Streamline access and standardize training for respite providers in the region.

5.2. Link to Existing Initiatives: Partner with the KCF Francophone Working Group on their Winning Strategy initiative to create a workshop (with lessons learned) that they can now share. All services expanded or developed moving forward should be implemented with FLS consideration.

6. Overall System Integration and Collaboration:

6.1. Strengthen relationships among pediatric service providers: In anticipation of the advocacy efforts for funding and resources, a structured approach should begin to build relationships amongst pediatric service providers (health and community) with the goal of equal understanding of respite offerings in our region to ensure families are being referred to the right pathways. There continues to be multiple doors through which

families enter, and a consistent respite message should be developed so that all families are informed and supported in the path they choose

6.2. **Existing Roles and Scopes Clarification:** Clarify the roles of Case Managers, Parent Navigators, Respite Providers, Complex Care, and Coordinated Service Planning in respite planning.

6.3. **Explore Partnerships with Families**: Co-design solutions in partnership with Family Advisory Groups and incorporate real-time feedback from projects like FACT and Transition to Adulthood initiatives.

Conclusion

This environmental scan highlights a growing and underserved population of CMCs in the Champlain region and the urgent need to expand equitable out-of-home respite services. Despite the dedication of families, care providers, and community partners, the current system faces major limitations in capacity, accessibility, and continuity, particularly for rural, Francophone, newcomer, and high-needs families.

The scan reveals not only where gaps exist, but also where opportunities lie - from rural respite expansion, navigation supports and culturally responsive care to exploring avenues to strengthen the overall system integration and collaboration. Promising practices across Canada offer models that could be adapted locally. Stakeholder-driven insights underscore the need for cross-sector collaboration and sustained investment to build a coordinated, inclusive, and resilient respite care system.

Moving forward, considerations for implementing the proposed recommendations will be key to ensuring that all families, regardless of geography or background, have access to the respite support they need to sustain their caregiving role and family well-being.

Limitations

While this environmental scan provides valuable insights, several limitations should be acknowledged.

- **Data Scarcity**: Limited disaggregated data on children with complex needs in the Champlain region.
- **Provider Reporting Gaps**: providers do not track data on declined requests or early discharge.
- **Survey Representation**: Survey responses may not fully capture the experiences of all families, and may not represent all community voices, especially marginalized groups.
- **Incomplete Program Data**: the outpatient Complex Care data provided by CHEO Complex Care Program likely underrepresents the broader population of children with medical complexity, as it excludes those not enrolled in the program - such as those with evolving or undocumented needs - or those followed outside the Champlain region.

These limitations highlight the need for improved data collection, better tracking of service gaps, and more inclusive stakeholder engagement to ensure a comprehensive understanding of system needs.

Appendix A

Summary Table of Key Findings:

Key Area	Key Findings
Population Trend	Outpatient CMC population grew from 182 (2019) to 325 (2024), with 33.8% of active cases in rural areas; growth reflects increased needs and program capacity.
Capacity Constraints and Workforce Shortages	Physical space limitations, insufficient staffing, and increased demand for complex care as major challenges.
Facility Capacity and Service Cancellations	Frequent service cancellations due to staff shortages, emergency admissions and priority cases; limited bed space results in missed opportunities for care.
Regulatory and Licensing Barriers	A more stringent regulatory and licensing framework than the adult world based on partners feedback; high compliance costs deter new entrants.
Service Utilization and Unmet Needs	Utilization is near 100% where beds exist, but many eligible families unable to access due to capacity and system navigation barriers.
Access Barriers: Geographic and Socioeconomic Disparities	Rural families face longer wait times, fewer providers, and higher travel costs; lack of equitable service distribution.
Gaps for High-Care and Behavioral Needs	Existing services often lack the ability to support children needing 1:1 care or with behavioral complexity.
Cultural and Language Accessibility	Language barriers and limited cultural competency training among providers limit accessibility for diverse populations.
Caregiver Burnout and System Navigation	High administrative burden and fragmented systems increase caregiver stress; associated with mental and physical health decline, including reported family disintegration.

Transition to Adulthood: Lack of Respite Continuity Beyond Age 18	Minimal adult respite options - families face abrupt cutoffs at 18, with no continuity plan for complex care youth transitioning to adulthood.

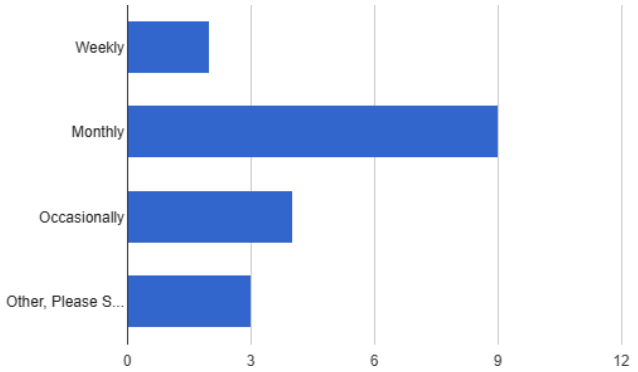
Appendix B

Surveys and Provider Data Overview

- **Number of Responses**: 23 from families (22 parents & 1 foster parent); 10 from case managers; 4 from providers.
- **Respondents Regions**:
  - Ottawa: 19 families, 8 case managers
  - Renfrew: 2 Families
  - Prescott & Russell: 2 families
  - Stormont / Dundas / Glengarry: 2 families, 1 case managers
  - North Lanark: 5 Case managers
- **Travel Preference:** Majority of the families are not willing to travel more than 50km to access out of home respite. Though some families who live outside of Ottawa are willing to travel up to 100kms.
- **Age Group**: Table 2 –
-

Age Group	Families (Caring For)	Case Managers and Social Workers (follow)	Providers (Serve)
0–5	3	5	2
6–12	6	6	3
13–17	9	6	3
18+	5	5	4

- **Frequency of Use From families currently using out-of-home respite**:

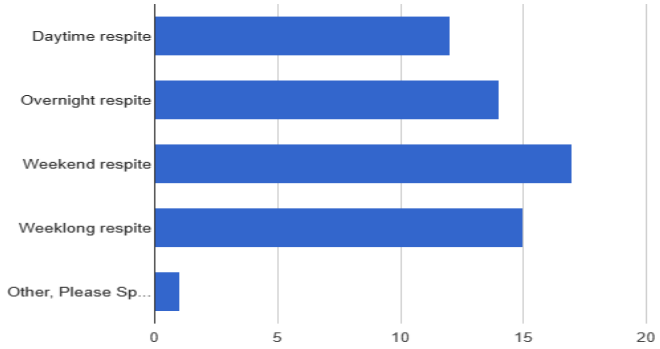


- Other (e.g., seasonal, irregular)
- Some (4 responses) did not specify frequency

- **Annual Out-of-Home Respite Days Used by Families**

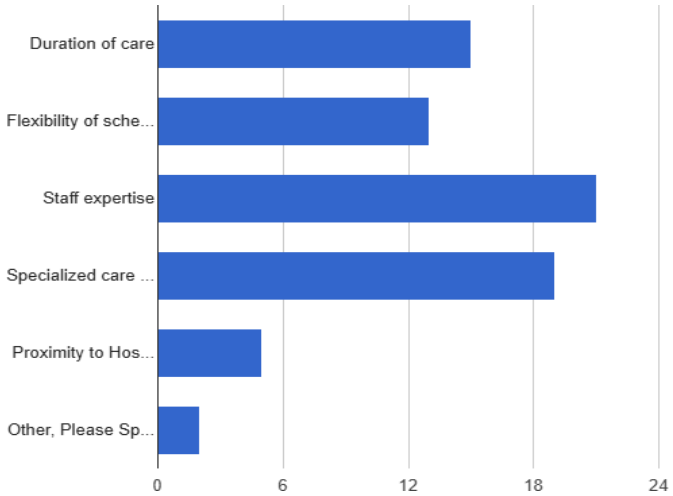
Language Group	Respondent Count	Average (Mean) Days/Year	Median Days/Year
English Respondents	18	53.7 days	24.5 days
French Respondents	1	30.0 days	30.0 days

- **Best-Fit Out-of-Home Respite Options identified by Families to meet their needs**:



Other – 1 family (extended/seasonal)

- **Most Valuable Aspects of Respite Services identified by Families in out-of-home care**:



- *Staff expertise – 21*
- *Specialized care for CMC – 19*
- *Duration of care – 15*
- *Flexibility in scheduling – 13*
- *Proximity to hospital – 5*
- *Other - stimulating engagement for my child*

- **Declined Request**: Most providers and case managers do not track data on declined requests or early discharge.
- **ORH** and **RNCH** were the most cited out-of-home respite providers used by families and appear to be the most used providers of out-of-home respite care in the Champlain region with few families citing IHealth, Evolving Youth Tender Tots and Spirit Program.

ORH respite profile and statistics

The Ottawa Rotary Home Respite Program Profiles

	# Beds/Spots	Eligible Age Group	Operating Times	# days/ year clients entitled to	Entitlement Notes	Cost	# Active Clients	# Clients Supported in 2024-25	Staffing
Children's Regular Overnight Respite	8	0-21	356 days/year	35	we allow clients to access more if needed	$10.00/day	52	45	DSW & Equivalent
Multipel Special Needs (Medically Complex)	2	0-18	356 days/year	35	we allow clients to access more if needed	$10.00/day	18	17	RPNs and RN Supervisor
Adult Respite - Funded	2	16-50	356 days/year	19	we allow clients to access more if needed	$28.75/day	67	53	DSW & Equivalent
Adult Respite - Fee For Service	3	16-50	356 days/year	as per individual contract	per determined contract	$325.00/day	14	14	DSW & Equivalent
Adult Day Program - Funded	6	18-50	Sept - June	90	set schedule Mon - Fri	$10.00/day	6	6	DSW & Equivalent
Adult Day Program - Passport	13	18-50	Sept - June	as per individual contract	time negotiated with each family	$95/day	13	13	DSW & Equivalent

The Ottawa Rotary Home (ORH) Number of Respite Days Provided per Month

	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	Year End Total
Children's Regular Overnight Respite	59	124	109	239	298	83	82	179	102	89	91	116	**1571**
Multipel Special Needs (Medically Com	18	54	61	52	62	162	119	58	81	157	123	75	**1022**
Adult Respite - Funded	95	144	116	169	168	162	119	58	81	157	123	75	**1467**
Adult Respite - FFS	0	12	31	29	55	14	42	76	55	78	71	41	**504**
Adult Day Program	60	60	60	60	60	120	120	120	128	128	129	130	**1175**
	232	**394**	**377**	**549**	**643**	**541**	**482**	**491**	**447**	**609**	**537**	**437**	**5739**

Note: ORH does not have a waitlist - every client has access to respite, though they may not always get their preferred dates and are instead offered alternative options within a few weeks.

RNCH # of Respite Admissions, Days of Care And Utilizations

Roger Nelson Children's Hospice (RNCH) Respite admissions and utilizations

FY	Respite Admissions # of admissions	Respite Admissions # of Days of care	% of days of care of all admissons at RNCH
2019/20	222	1043	42%
Last Yr. Comparison	Not Avaialble	Not Avaialble	Not Avaialble
2020/21	87	360	22%
Last Yr. Comparison	-61%	-65%	-48%
2021/22	142	603	31%
Last Yr. Comparison	63%	68%	40%
2022/23	198	949	43%
Last Yr. Comparison	39%	57%	40%
2023/24	260	1324	54%
Last Yr. Comparison	31%	40%	25%
2024/25	284	1336	51%
Last Yr. Comparison	9%	0%	-5%

Additional information from RNCH:

- RNCH offers families up to 28 days of pre-booked respite care per calendar year. Additional respite days may be made available depending on schedule gaps, cancellations, or periods of lower capacity.
- Emergency respite care may be provided for up to 48 hours when primary caregivers are temporarily unable to care for their child due to acute illness or injury. While not commonly used, this option is available to ensure safe care during urgent situations.
- Some children remain in the palliative care program for the duration of their lives. In other cases, patients may be discharged from the program if they are doing well or no longer meet the palliative criteria. RNCH services are available to eligible patients until their 19th birthday.
- At present, there is no formal system in place to track declined respite requests. Families may choose to be added to a waitlist for specific dates; however, availability cannot be

guaranteed. The Admissions Coordinator receives requests via phone, email, MyChart, and in person.

- Families may choose to discharge from their respite stay early. This information is not formally tracked. In cases where patients become ill during their stay, they may be discharged home; this is informally monitored.
- RNCH also provides additional services that may impact on respite capacity and availability. These include symptom management, transition-to-home admissions (for a maximum of 48 hours following hospital discharge), and end-of-life care.
- In 2024, 88% of families reported satisfaction with the availability of respite admissions at Roger Neilson Children's Hospice (RNCH), and 94% expressed overall satisfaction with the care their child received. In 2025, satisfaction with respite availability decreased slightly to 77%, while overall satisfaction with care remained high at 93%.

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