

**Briefing Note:** Environmental Scan – Out-of-Home Respite Services for Children and Youth with Medical Complexity

**Prepared By:** KCF Home and Community Care Working Group

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**Purpose:**

To summarize findings from the 2025 environmental scan on out-of-home respite services for children and youth with complex medical needs (CMC) in the Champlain region, highlighting the current state, systemic gaps, and recommendations to improve access and equity.

**Background: What is Respite and Why It Matters**

Respite provides temporary relief for families caring for CMCs who often require intensive, specialized, and 24/7 care. Families in Canada provide an average of 38 hours/week of informal care (Canadian Institute of Health Information, 2020), balancing complex medical tasks with employment and other responsibilities. Without respite, caregivers face burnout, chronic stress, and isolation, with downstream impacts such as increased hospital readmissions of their CMCs emergency visits (Cohen et al., 2012) and, in rare cases, relinquishment of care (Feedback from Family Partners, 2025).

*“We are beyond burnt out but we have no choice but to keep going 24/7.” - Survey participant (CCCE, 2024)*

Out-of-home respite offers protected time for parents / caregivers to recharge while ensuring children continue to receive care in a safe, medically supported environment.

**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.

## Key Findings

### Recent Improvements in the Champlain Region

Although not exclusively focused on respite, these investments contribute to a stronger system of family support:

- Pediatric home and community care (HCC) integrated under CHEO in 2021, building on the recommendation of the 2017 THRIVE report to establish a distinct child and youth HCC program to ensure specialized expertise and high-quality service delivery
  - In 2023, Complex Care & Coordinated Service Planning teams realigned to HCC to strengthen collaboration and improve service delivery.
- Roger Nelson Children Hospice (RNCH) expanded bed capacity in 2024, boosting its ability to deliver both hospice and respite services.
- Planned Integrated Treatment Centre and Ronald McDonald House expansion also signal commitment to more integrated and accessible pediatric care.

### Population Growth & Demand

CHEO's Complex Care is one of the four Complex Care for Kids Ontario's sites. Enrollments have grown significantly over the past several years. Using validated CCKO program data, the program increased from 167 active patients in 2019/20 to 245 in 2024/25, representing +46.7% overall growth compared to baseline. As of mid-2025/26 fiscal year, the program was supporting 235 active patients, indicating that volumes have stabilized at an elevated level following several years of rapid expansion. The program is funded to support 200 patients and has operated above capacity for multiple years. While this dataset does not capture all children with medical complexity in the region, it provides a clearer understanding of the scale and pace of rising needs. For context, the overall child and youth population in the Champlain region grew by only 7.5% over the same period, underscoring the disproportionate increase in medically complex care needs.

### Current Out-of-Home Respite Landscape

Ottawa Rotary Home (ORH) and RNCH are the main providers, with few other community providers such as the City of Ottawa Spirit program and Partners in Parenting. RNCH prioritizes end-of-life and symptom management, limiting routine respite availability. The scan revealed that demand far exceeds capacity, with utilization of available beds in most services, near 100%.

### Key Barriers and Service Gaps

- **Limited capacity and workforce shortages** continue to constrain out-of-home respite services, resulting in facility limitations, frequent cancellations, and long wait times for families.
- **Regulatory and licensing requirements under the CYFSA** remain misaligned with the flexible, short-term nature of respite care; coupled with lack of start-up or operational funding, these factors deter new providers from entering the sector.
- **High utilization rates mask unmet need**, as many eligible families cannot access respite due to restrictive eligibility criteria, lack of capacity for 1:1 or behavioural supports, and limited scheduling flexibility.
- **Geographic and socioeconomic inequities persist.** Qualitative evidence, literature reviews and directional postal-code patterns indicate that families living in rural areas face greater barriers, including long travel distances, higher out-of-pocket costs, fewer local options, and limited transportation.
- **Cultural and language barriers** continue to affect access, particularly for Francophone, newcomer, and racialized families who face difficulty navigating predominantly English-language respite systems.
- **Caregivers experience severe burnout and navigation burden**, citing heavy paperwork, inconsistent information, and unclear referral pathways across multiple agencies.
- **A critical transition gap at age 18** leaves youth with complex medical needs with few or no adult respite options, creating an abrupt loss of support for families who continue to require intensive caregiving assistance.

### Six Key Recommendations

1. **Improve Geographic Equity** - Fund rural beds or expand direct funding with rural top-up; consider stipend model for in-home respite.
2. **Facilitate Transition to Adult Services** - Extend pediatric respite to age 21; pilot adult weekend respite with nursing support; leverage cross-sector partnerships.
3. **Streamline Navigation and Access** - Standardize referral process; create centralized navigation hub with multilingual resources; partner with schools and CHEO programs to help with family identifications.
4. **Expand Service Capacity** - Advocate cross-ministerial funding; develop transitional care programs (e.g. Saf haven Toronto model); build partnerships with rural hospitals and community agencies.
5. **Enhance Cultural Competency** - Standardize trainings, leverage CHEO cultural competency training and KCF Francophone and newcomer supports in new initiatives.
6. **Build System Integration and Collaboration** - Strengthen provider relationships; clarify roles; co-design with Family Advisory Committees.

### **What We Can Learn from Other Jurisdictions**

- Toronto (Safehaven & TCMCC): Integrated respite and transitional care programs; medically intensive community care; family-centered approach.
- BC Centre for Health Complexity: First-of-its-kind hub for integrated care and training; principles include cross-ministry collaboration and equitable access.
- Manitoba: Centralized navigation system; professionalized respite workforce; strong equity and cultural safety focus.
- National CCCE Strategy: Calls for expanded respite funding, cultural safety, workforce stabilization, and caregiver-friendly policies.

These models demonstrate scalable solutions and reinforce the need for investment, innovation, and cross-sector collaboration in the Champlain region.

### **Implications**

Despite recent pediatric care improvements, the scan underscores an expanding, underserved CMC population and persistent inequities in respite access, especially for rural, Francophone, newcomer, and high-needs families. Strengthening navigation, capacity, cultural competency, and transition supports - alongside targeted rural investment - will improve caregiver well-being, help reduce downstream acute-care use, and build a more equitable system.