

# CHILDREN WITH MEDICAL COMPLEXITY: THE CANADIAN LANDSCAPE

Children with medical complexity have gained attention over the past decade as an important population in need of practice and policy reform within our Canadian health care system. One study in Ontario suggests that children with medical complexity represent <1% of their entire pediatric population. Further, studies from the United States suggest that the number of children living with medical complexity is increasing.

**0.67%** OF THE PEDIATRIC POPULATION IN ONTARIO



## Who are children with medical complexity?

### FAMILY-IDENTIFIED NEEDS

- Substantial service needs
- Financial impact
- Caregiving support
- Sibling support

### CHRONIC CONDITION(S)

- Diagnosed or suspected
- Congenital or acquired multi-system disease
- Often multiple body systems involved



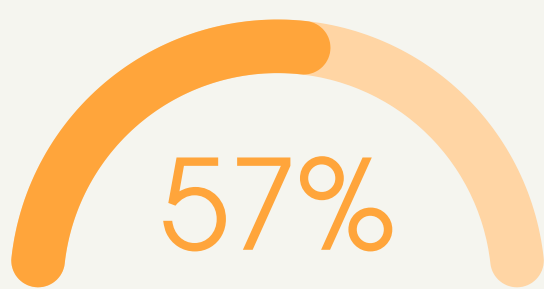
### HEALTH CARE USE

- Health resource use
- Across multiple services and sectors

### FUNCTIONAL LIMITATIONS

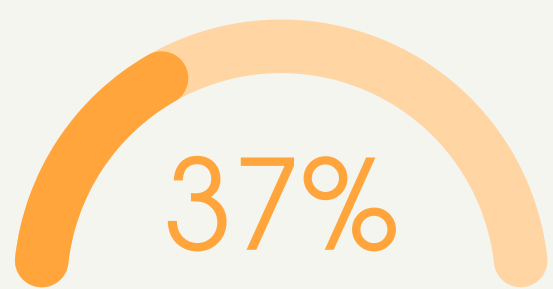
- Severe functional limitations
- Associated with technological assistance

There are currently a range of definitions used in clinical practice and research literature to define children with medical complexity. Across all definitions, there are generally four main characteristics that unify this pediatric population. However, within these concepts, specific features slightly differ (see next page).



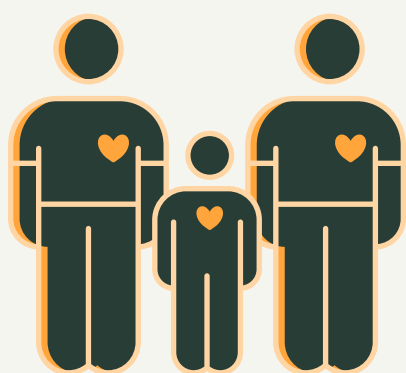
### PEDIATRIC HOSPITAL CARE COSTS

According to the Canadian Institutes of Health Information, children with medical complexity represent **57% of pediatric hospital-related costs**. Further, children with medical complexity use higher rates of emergency department visits and primary care services.



### PEDIATRIC HOSPITAL ADMISSIONS

Children with medical complexity represent **37% of hospital admissions** and have longer hospital stays in comparison to children without a complex chronic condition. Further, these children have as many as 13 different outpatient providers from 6 different medical specialities.



A range of health and social supports are needed to fully support the health of the whole family

There is a disconnect between our current health care system and the care needs of children with medical complexity and their families. To begin to design family-oriented health care programs and policies to support children with medical complexity and their families, we must first be able to develop a more accurate understanding of this important pediatric population in the Maritimes. Routinely collected health administrative data is one way we can identify how many children with medical complexity live in the Maritimes and how they use the health system. However, current methods used to identify children with medical complexity in health data have been primarily used in larger Canadian provinces or in the United States, and have not yet had their effectiveness evaluated in Maritime-based health data. This is what this research study seeks to address. **The first step in achieving this goal is coming together to discuss how children with medical complexity in the Maritimes should be defined.**

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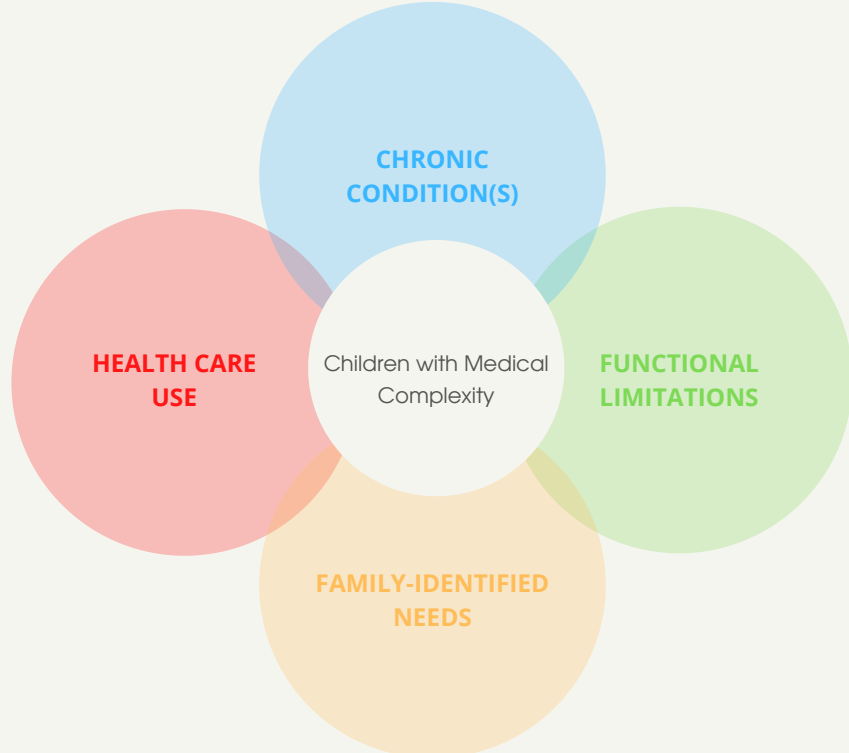


1. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttman A. Patterns and Costs of Health Care Use of Children With Medical Complexity. *Pediatrics*. 2012 Dec 1;130(6):e1463-70; 2. Cohen E, Berry JG, Sanders L, Schor EL, Wise PH. Status Complexus? The Emergence of Pediatric Complex Care. *Pediatrics*. 2018 Mar 1;141(Supplement 3):S202-11; 3. Canadian Institute for Health Information. Children and Youth With Medical Complexity in Canada. 2020;30.

# DEFINITIONAL FRAMEWORKS

## How do we define children with medical complexity?

Researchers have identified key factors within each of the four main defining characteristics of children with medical complexity. We will discuss this in our consensus meeting to see whether these factors make sense for a Maritime population and/or how we can use these descriptions to identify children with medical complexity in the community.



	COHEN ET AL.(2010)	FEUDTNER ET AL. (1999)	SIMON ET AL. (2014)	CANADIAN INSTITUTES OF HEALTH INFORMATION (2020)
FUNCTIONAL LIMITATIONS	<ul style="list-style-type: none"> <li>• Severe</li> <li>• Often require the use of medical technology</li> </ul>	<ul style="list-style-type: none"> <li>• Require the use of medical technology to optimize or sustain life</li> </ul>	<ul style="list-style-type: none"> <li>• May depend on technology for greater than 6 months</li> </ul>	<ul style="list-style-type: none"> <li>• Possible reliance on medical technology assistance to manage or treat chronic illness, and maintain essential body functions</li> </ul>
CHRONIC CONDITIONS	<ul style="list-style-type: none"> <li>• Diagnosed or suspected complex chronic condition</li> <li>• Severe and/or associated with medical fragility</li> <li>• Congenital or acquired multisystem disease</li> </ul>	<ul style="list-style-type: none"> <li>• Complex chronic conditions impacting any of the 9 main body systems</li> <li>• Expected to last at least 12 months</li> <li>• Involves multiple organ systems or 1 organ system severely</li> </ul>	<ul style="list-style-type: none"> <li>• Chronic conditions in <math>\geq 2</math> body systems</li> <li>• Progressive condition associated with deteriorating health &amp; decreased life expectancy in adulthood</li> <li>• Malignancies</li> </ul>	<ul style="list-style-type: none"> <li>• Complex chronic conditions</li> <li>• Neurological impairment</li> <li>• Single condition affecting 1 body system severely enough to require specialty care</li> <li>• Multiple conditions affecting &gt;1 body system</li> </ul>
HEALTH CARE USE	<ul style="list-style-type: none"> <li>• High resource utilization</li> <li>• Multiple care providers across various services and sectors</li> </ul>	<ul style="list-style-type: none"> <li>• Require specialized pediatric care and likely some period of hospitalization in a tertiary care center</li> </ul>	<ul style="list-style-type: none"> <li>• Use of health resources above the level for a healthy child</li> </ul>	<ul style="list-style-type: none"> <li>• High use of health care services</li> </ul>
FAMILY IDENTIFIED NEEDS	<ul style="list-style-type: none"> <li>• Substantial family-identified needs</li> <li>• Significant impact on family (e.g. costs, caregiving burnout)</li> </ul>	<ul style="list-style-type: none"> <li>• Not mentioned</li> </ul>	<ul style="list-style-type: none"> <li>• Not mentioned</li> </ul>	<ul style="list-style-type: none"> <li>• Require ongoing medical support to monitor and maintain their health</li> </ul>