



CAPHC Guideline for the Management of Medically Complex Children and Youth Through the Continuum of Care

CAPHC Complex Care Community of Practice (CoP)

April 2018

Disclaimer

This Guideline represents the views of the CAPHC Complex Care Community of Practice (CoP) and was prepared after careful consideration of the available evidence as well as a consensus building process. The Guideline does not override the responsibility of individuals and organizations to make decisions and provide the most appropriate care to children, youth and emerging adults in consultation with the patient and family/guardian.

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Guideline Development Team

Nathalie Major MD, FRCPC
Medical Director
Complex Medical Care
Service Assistant
Professor of Pediatrics
University of Ottawa

Kristen Campbell, RN MN
Program Lead
Child and Family
Saint Elizabeth

Angela Arra-Robar, RN MSN
Clinical Nurse Specialist
Complex/Medically Fragile
Children & Youth
IWK Health Centre

Cathie Badeau MHSc (retired)
Director for Women's
and Children at Trillium Health
Partners

Darren Connolly
Family Advisor
Paediatric Family Resource
Centre, Children's
Hospital London Health
Sciences Centre

Marie-Joëlle Doré-Bergeron
General Pediatrics,
Department of Pediatrics.
CHU Sainte-Justine

Anna Cooper, RN MN (retired)
Clinical Practice
Leader/BPSO Lead
Bayshore HealthCare

Tammie Dewan MD FRCPC
Pediatrician
Complex Care Program
BC Children's Hospital

**Karen Fleming RN, MN,
BScN, BSc**
Clinical Nurse Educator,
Child and Teen Unit and
Clinical Corporate Projects
North York General Hospital

Jenette Hayward MD, FRCPC
Pediatrician, Section of
Pediatrics Complex Care
Children's Hospital of
Winnipeg & Rehabilitation
Centre for Children
General Paediatrician
and Feeding Specialist,
Department of Rehabilitation
and Complex Care

Carla Hildenbrandt RN, MA
Senior Practice Consultant
Health Professions
Strategy & Practice (HPSP),
Interprofessional
Services & Regulatory Affairs
Alberta Health Services

Kim Hogan RN (EC), MN
Nurse Practitioner
Complex Care
Paediatric Medicine
The Hospital for Sick Children

Amy Miville
Parent advisor
Ottawa Ontario

Stephanie Pasher
Parent Advisor
Toronto Ontario

**Hema Patel MD,
FRCPC, MSc (Clin Epi)**
Director, Pediatric Day
Hospital Services
Complex Care Service
Medical Day Hospital
Associate Professor
of Pediatrics, The Montreal
Children's Hospital

**Isabelle St. Sauveur BSc.N,
MSc.N**
Advanced Practice Nurse,
Complex Care Service
Montreal Children's Hospital

Maria Steeds
Team Manager, Nursing
Winnipeg Regional Health
Authority

Lisa Stromquist
Associate Director, Program
Development, Strategy
and Engagement
Canadian Association of
Paediatric Health Centres

Roberta Woodgate RN PhD
Professor CIHR Applied
Chair in Reproductive
Child and Youth Health
Services and Policy Research
College of Nursing Rady
Faculty of Health Sciences
University of Manitoba

CAPHC Complex Care
Community of Practice

The Context

There is growing recognition that children/youth living with medical complexity (CMC) are a distinct group that require medical and community services beyond those that are typically required for a chronic condition (1,2). Suboptimal care for CMC creates substantial impacts to their health, the families' well-being and the healthcare system. CMC and their families require enhanced care delivery that incorporates care coordination and an integrated continuum of care that empowers the families and health service providers to promote pro-active care rather than reactive care.

The Canadian Association of Paediatric Health Centres (CAPHC) identified the need to prioritize a national effort to support system change in the approach to health care for this vulnerable population. The establishment of a Complex Care Community of Practice (CoP) in 2013 has proven to be a solid method to mobilize individuals and organizations together with families of CMC across Canada in the common goal of developing national guidelines with a vision to enhance the current standards of care for children and youth with medical complexity (CMC). CAPHC CoP members included families; clinicians from paediatric acute care, homecare, rehabilitation services, Provincial Council of Maternal and Child Health (PCMCH), health care administrators and policy makers. External stakeholders were engaged and endorsement for the Vision and Mission was received from The Canadian Family Advisory Network (CFAN) and the Canadian Paediatric Society.

Accreditation Canada was consulted to ensure that recommendations on care planning and health care transitions aligned with current standards.

The Complex Care CoP agreed that the development of Canadian guidelines would enable and influence a needed pan-Canadian change in the delivery of care for this unique population. Successful programs and services for children/youth with medical complexities and their families have been developed across the country. Yet, there remains significant degree of variation in practice and delivery of health services to this vulnerable population. The needs of CMC and their families are unique to each individual and situation. A mechanism is required in all areas of Canada to identify these individuals and the best models of care to be responsive to their care needs. Families should expect a similar level of care for their child as they navigate across systems in any province, territory or region. A national guideline for the establishment and implementation of evidence based and expert informed best models of care will minimize these inequities in health and health care access. (2)

Ultimately the goal is to standardize care for all Canadian children/youth and their families while improving safety, quality and ensuring accessible and equitable care. This process represents a strategy to implement real change for all Canadian CMC and their families.



The Issues

Children and youth with medical complexity (CMC) share four defining characteristics. The first is the presence of one or more complex chronic conditions that are often multisystem and severe. The second is a functional limitation that is often significant and causes the child/youth to be reliant on technology such as feeding tubes and tracheostomies. The third is that CMC have high healthcare utilization, requiring specialized care and services from different providers in multiple settings. The fourth is that caregivers identify high healthcare service needs such as care provision in the home and care coordination: these can have significant social and financial impacts on the family. (17) This definitional framework needs to be operationalized to help to clearly identify the population in question for the purpose of epidemiology, building knowledge, setting priorities for clinical interventions and the development of a research agenda. There is no national consensus for the definition.

CMC are amongst the highest users of the healthcare system; however, they represent a very small population. An Ontario health care study identified that 0.67% (15,771) of children fit the definition of children with medical complexity and of that 11.8% (1863) were also technology dependent. This small group of children (CMC-Technology dependent) accounted for one-third of child health provincial spending and the cost was not only related to the hospitalizations but also extended to the community setting. (4) Available administrative data across Canada isn't captured and limits the understanding of the impact of this population on the healthcare system and their families. There is a body of literature on the American data; we need similar research within Canada.

These children and youth and their families face tremendous challenges with their care in that there is no mechanism to ensure good communication between providers in hospital, and in community, including the primary care provider (PCP). The care is often fragmented, the children require frequent hospitalizations and are at greater risk of medical errors caused, at least in part, by poor communication. (5,8) These children and youth live with conditions that are frequently

rare or unknown and family members become the expert responsible for all information related to their child's condition. The parents of these children and youth learn to become navigators of a system that works in silos, adding to their economic burden and stress of having to be not only a parent, but also care giver, teacher, advocate, etc. (9, 10) There are inequities and a significant degree of variation in practice and delivery of health services to this vulnerable population.

The uniqueness of this population means that their care crosses all sectors including the hospital, community, home and school. These children and youth live everywhere in Canada, in urban communities as well as remote areas. However, the knowledge and expertise of their condition and care may be found in only a specialized tertiary care centre, often just one centre across Canada and not infrequently, outside the country. Frequently, required hospitalizations and/or a simple change in their health; or a technological malfunction in a piece of their equipment, require that they reach a tertiary care center. The primary care provider in the community is often not in the circle of care for these patients for a variety of reasons (including but not limited to: child lost in follow-up, illness requires hospital care, physician feels care is out of scope of practice, remuneration is not supportive of the time and requirements of patient care).

The care of these children and youth is too often reactive rather than anticipatory and preventive.

Parents seek recognition and acknowledgment that they are equal stakeholders because they know their child/youth best, a concept at times challenging for the providers. Families often prefer that their child receive care in the home instead of the hospital and willingly make many changes in their professional and personal lives to ensure they can personally support their child. Remunerating a parent who is the primary caregiver for their child in lieu of a personal support worker may help to alleviate some of the financial stress on families and the solve the issue of shortage of trained workers in the community.

Alleviating these factors could have a significant impact on health costs. Research study in this area is a growing field and practice is evolving. Although there is more to learn, over the last 10 years common principles have been identified that should be considered when providing services to CMC and their families. These principles are outlined in the following section.

What Exists Now?

The CMC definition referred to on page four provides a definitional framework. There remain challenges in unifying the definition for this particular population. The intention of this guideline is to provide an operational framework for this definition that is responsive in advancing the implementation of models of care in the unique settings serving this vulnerable population.

There is a diversity of chronic care models to address the clinical needs of CMC. The American Academy of Pediatrics has developed a comprehensive conceptual model of holistic care i.e. the Patient-Centred Medical Home Model: CMC have special health needs and require access to community-based services. How can the Medical Home model be operationalized into our Canadian system? The medicalhome.org site has many evaluation tools that operationalize this philosophy and some of the items could be generalizable to other settings. As part of the guideline this serves as a reference model. The Complex Care CoP acknowledges the need to identify known Canadian processes/services that can help fulfill the guideline.

This guideline represents the beginning of a review and identifies the evidence for existing processes; such as care coordination provided by a “key-worker”; medication organization/reconciliation; the care summary and plan, and measurable outcomes to assess impact.



There are care models developing across Canada to address the healthcare needs of this population. A catalogue documenting all the Canadian initiatives/ programs for CMC has been developed. Identifying the activities and services provided by the programs and their evaluation frameworks will further this work and provide evidence of impact.



In Ontario the **Complex Care Kids for Ontario (CCKO)** initiative has a mandate to develop a care model to address the unique care needs for all CMC of Ontario and has influenced the national work of the CoP.

There is evidence in the literature of care models effective in improving the efficiency of healthcare utilization and improving the health of this population. The CoP also recognized the need for ensuring that the guidelines evolve from best practice, evidence base and expert opinion. The developing body of literature remains nascent. Another aim of this guideline is to advance the development of research priorities and evaluation processes in the Canadian context leading to national standards of care for CMC that are measurable.

Purpose and Scope

This Guideline was developed to address the vision and the mission of the Canadian Association of Paediatric Health Centres Community of Practice in Complex Care.



Vision Statement

All Canadian children/youth with medical complexity and their families are provided with access to tools, supports and services that will enable integrated and coordinated care that is proactive and best suited to each child/youth's needs and environment.

Mission Statement

To establish a national guideline that will optimize the health and quality of life for Canadian children/youth with medical complexity and their families through shared decision making, while supporting the achievement of child/family identified health goals and outcomes using the best available evidence and experience-based knowledge.

The mission of the CoP is based on the following principles of care:

1. *The care is child/ youth/family centered.*
2. *The care is integrated: coordinated, collaborative, continuous, and seamless across the continuum (hospital, community and agencies/services).*
3. *The care is accessible.*
4. *The care is delivered as such that the child/youth/family is empowered.*

Other principles which were considered; flexibility and equity have been incorporated through the evidence and supporting statements. You can also find the principles defined in the Glossary of Terms [page 34](#).

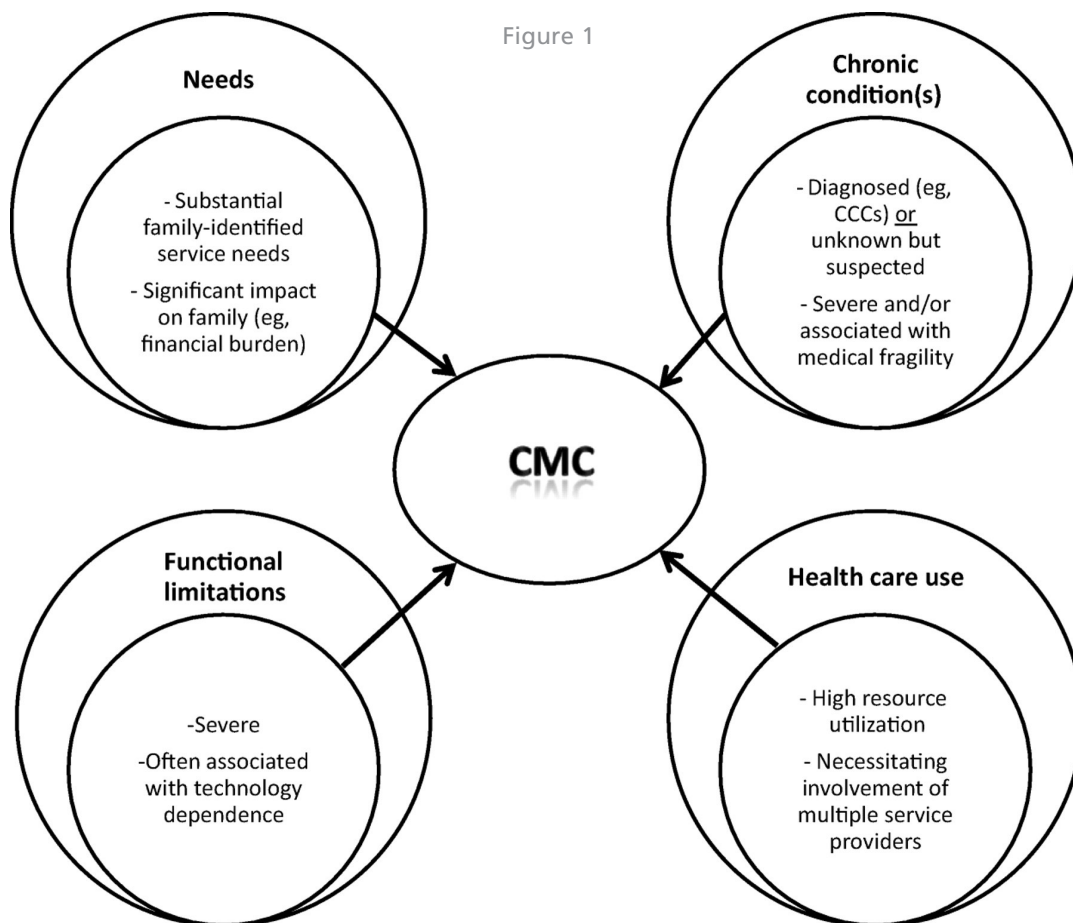
These key questions influenced the development of the subsequent recommendations:

1. *How can we support equity in access to available services for children with medical complexity across Canada?*
2. *How should children with medical complexity be identified and monitored?*
3. *What are the system barriers to delivering child and family centred care to children with medical complexity?*
4. *What actions should be taken to ensure access to and continuous care in the health care system?*
5. *What are the defined roles of each stakeholder (families, physicians, nurses, key worker, social worker, etc) involved? Are they within an expected scope of practice, training, knowledge, skill set and ability?*
6. *What are the responsibilities of the agency transferring patients between services?*
7. *What documents should be used?*
8. *What other supports (education, counseling) are required by the family?*
9. *What other supports (education, other) are required by health care professionals?*
10. *How do we identify the priority areas of research for CMC?*

Target Population

Definitional Frame

The most complex CMC are described as children/youth who share 4 characteristics (figure 1). The first is the presence of one or more complex chronic conditions that are often multisystem and severe. The second is a functional limitation that is often significant and causes the child/youth to be reliant on technology such as feeding tubes and tracheostomies. The third is that CMC have high healthcare utilization, requiring specialized care and services from different providers in multiple settings. The fourth is that caregivers identify high healthcare service needs such as care provision in the home and care coordination: these can have significant social and financial impacts on the family. (17)



Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SKM, Simon TD, et al. 2011 Mar

The intention of this guideline is to provide an operational framework for this definition that is responsive in advancing the implementation of models of care in the unique settings serving this vulnerable population.



Target Users

This Guideline is aimed at the professional groups, allied health providers, families and caregivers who are involved in the care of children with medical complexity. This Guideline is to be integrated into all areas of health care practice and policy; paediatric and adult, tertiary and community hospitals, rehabilitation, community and homecare services, administration and research.

Summary of Recommendations

Recommendation	Level of Evidence
1. Ensure that a process for clear identification of children and youth with medical complexity is in place to promote equity of services.	II, III
2. Build capacity within the healthcare system to deliver coordinated care that is holistic, comprehensive and family-centred to all children with medical complexity, closer to home	III
3. Identify a keyworker and care team for each child with medical complexity to facilitate service planning and care delivery in collaboration with the family/caregiver.	II, III
4. Develop and maintain a shared single care plan with common language and clear ownership for children with medical complexity that is accessible and updated in a timely manner.	II, III
5. Empower families by proactively supporting them to develop skills, competency and confidence to comprehensively care for their child and to advocate on behalf of their child.	II, III
6. Organizations providing services to children with medical complexity must have a strategy to transition between levels of healthcare and different care environments. (hospital – community – home – school- respite – adult services)	II, III

The recommendations were developed through a consensus process built on evidence from:

1. Literature review
2. Review of Canadian complex care programs and services through survey and consultation ([Catalogue of Programs](#)) 
3. Review of current Accreditation Canada standards as they relate to these services
4. Family experiences (collected through presentations, in person meetings, teleconferences, formal and informal meetings)
5. Results of a full day Summit that included families, Accreditation Canada, policy makers, clinicians and researchers [Summary Report](#) 
6. Experience and tacit knowledge of front line physicians and health professionals

Strengths and Limitations of Evidence

A literature search was undertaken to develop the original Mission and Vision for the Complex Care CoP that resulted in the identification of the four principles: family centered, integration, accessible and empowerment. These concepts were then used as key words in a follow up literature search that included practice guidelines, global programming, policy statements, systematic reviews, and relevant research studies related to medical complexity in children and youth from Canada, US, Australia and the United Kingdom. Medline, Cumulative Index to Nursing and Allied Health (CINAHL) and PUB Med were used to search for relevant articles (English only) using key words (medical complexity, medical home, care coordination, empowerment, care planning,).

The evidence found in the literature was appraised by the guideline development group who focused on specific recommendations. The quality of evidence from each source was rated using the following scheme:

I Evidence obtained from one or more randomized trials with clinical outcomes

II Evidence obtained from research, meta-analysis, systematic review, policy statement

III Expert opinion

Given the limited number of research articles with random controlled trials, our evidence body is composed of some quantitative studies, but mainly qualitative studies, reviews, case reports and systematic reviews. The literature scan and review were an ongoing process, as new articles and studies were published annually.

Family Participation

The Canadian Family Advisory Network (CFAN) was engaged in the development of the Mission and Vision and endorsed the document in January 2016.

At the September 2016 Summit families enrolled in various complex care programs spoke of the developing services that made a difference for their child and family. They emphasized that while they required support in caring for their children, they also willingly assumed a great deal of responsibility and recognized that they are key to their child's achievement of family identified goals and better health outcomes. They are prepared to give up work and other classic measures of quality of life to attain this. It is important for the system to also recognize their contributions, knowledge, and expertise.

The themes that came from the family presentations and subsequent discussions were foundational to the development of this guideline.

Community of Practice (CoP)

The Guideline and recommendations were developed through CAPHC's national Complex Care Community of Practice (CoP). Communities of Practice are defined as "a type of informal learning organization" (15,16). CoPs are established to address a certain issue and bring together people from different backgrounds and professions including families. These people share concerns, problems and a passion about a specific issue. The concept of CoP is shaped by three dimensions. The first dimension is mutual engagement which describes the social interaction between individuals to create a shared meaning. The second dimension is called joint enterprise and refers to the process of people working together towards one goal. Lastly, shared repertoire which is based on the use of common resources during the process of decision making. (15). Finally, while CoPs are an evolving concept, four key characteristics of CoPs: social interaction, knowledge sharing, knowledge creation and identity building exist (16).

The CAPHC Complex Care CoP was established in January 2013 and engaged stakeholders from paediatric acute care hospitals, community hospitals, homecare provider agencies, rehabilitation services and hospitals as well families of CMC. CoP members included complex care physicians, nurses, nurse practitioners, educators, researchers and other allied health professionals. Families were active participants in the process as the work evolved through the different stage of the guideline development.

For a complete list of all participants and organizations in the Complex Care Community of Practice (at the time of publication) [click here](#)

Through monthly meetings, a strong network of individuals and organizations was built to work toward the common goal of a national guideline to optimize the health and quality of life for Canadian children/youth with medical complexity. Knowledge sharing occurred via formal presentations and through informal exchanges between individuals and organizations. The sharing of resources; time, expertise, research and previously developed tools has enabled a process for guideline development that is inclusive. The shared decision making and consensus building process has ensured the voices of all stakeholders are heard equally.

Research Agenda

For any of the following recommendations, it is essential to incorporate an evaluation framework with outcome measurements and a continuous quality improvement (QI) approach to care. Without these essential activities, changes to health service delivery will be limited by the lack of insight into the population and the impact of the various models of care. A QI approach will lead to better understanding of what constitutes best practice in care delivery for CMC. The creation of a research network and agenda that includes the participation of CMC and their families will help promote better understanding in the Canadian healthcare system to overcome the issue of dealing with this small, resource-intensive population. This is out of scope of this CoP but was recognized as an important next step.

Recommendations

Recommendation 1 – Identification

Ensure that a process for clear identification of children and youth with medical complexity is in place to promote equity of services.

The purpose of this recommendation is to standardize the variables in the definitional framework to uniformly identify this population across Canada while allowing individualization of hospital/ community program criteria and interventions limited by capacity, program implementation process and funding opportunities. The criteria are to facilitate the common language to identify and operationalize the definitional framework within the definition on [page 9 - figure 1](#), with the ultimate vision to address the care needs of all Canadian children with medical complexity as per the established Canadian standards.

There is a great deal of variance when it comes to describing or defining children with medical complexity. Individuals who have the four characteristics of CMC (one or more complex chronic conditions; functional limitation; high healthcare utilization; identified high healthcare service needs) are not guaranteed to receive services of a Complex Care program.

For the purposes of this guideline we want to ensure the children who are technology dependent, medically fragile with or without a diagnosis to account for all the chronic conditions are included in the definition and will be captured through the recommendations.

Evidence Summary

The most complex CMC are described as children/youth who shares four characteristics. The first is the presence of one or more complex chronic conditions that are often multisystem and severe. The second criterion is functional limitation that is significant and often reliant on technology such as feeding tubes and tracheostomies. The third criterion is that CMC have high healthcare utilization, requiring specialized care requiring services from different providers in multiple settings: as an illustration, a child may receive care from multiple tertiary care specialists, be hospitalized frequently, and require nursing, physiotherapy, occupational therapy, dietician and respite services. The fourth criterion is that caregivers identify high healthcare service needs such as care provision in the home and care coordination: the caregiver frequently must provide medical care in addition to be a parent; caregivers experience significant emotional, mental health, physical, social and/or financial impact (17-20)

The care of the CMC crosses hospital and community services. This population is at particular risk of fragmented care and communication which can lead to “avoidable” hospitalizations, as well as medical errors, particularly medication errors, delayed therapeutic interventions and suboptimal care coordination. The families, who already face numerous challenges, carry the burden of

having to be the medical expert for their child or youth in order to navigate the system (21–23) (9-10). The purpose of a definitional framework is to unify the identification of these children across the Canadian healthcare system. This will facilitate a move towards standardizing an optimal model of care.

Definitions and designs of program for CMC vary markedly across Canada. A focused set of criteria to operationalize the definitional framework found in figure 1 is required to establish Canadian standards of care recommendations for this unique population. It is also recognized that within the definition of CMC there are existing subgroups with varying levels of complexity and ensuing care needs (24,25). There is variability in the needs of CMC and their families. For example, services needed by CMC with multiple chronic complex conditions and technology needs, with strong family and community support and little social complexity differ markedly from those needed by CMC with high social complexity and only one or 2 chronic complex conditions. A tiered program of interventions, scaled to the care needs, must be tailored for the various subgroups of this population. Chronically critically ill paediatric patients represent a subgroup of this population that are intense users of the PICU and NICU (24). A significant portion of the Canadian emerging programs evolved to address the care needs of the CMC that are technology dependent and high users of the hospital acute care services ([Catalogue of Canadian Complex Care Programs](#)). [↗](#) It is recognized that other factors such as family identified needs, psychosocial domains may be independent factors that contribute to their complexity, yet the needs of these children may not be addressed depending on the local complex care program and their set criteria (26). As programs are emerging to address the spectrum of needs of CMC, the goal should be to impact all CMC with a tiered group of interventions which are matched to current needs.

Another key consideration in developing an operational definitional framework is that the health status of these children is dynamic; the health of these children changes over time and therefore the care needs also change both predictably and unpredictably. In establishing a program, there should be consideration for

- a) flexibility in the process of intake and discharge to facilitate transitions in care support as needed,
- b) explicit links with community providers who can provide care to stable CMC and
- c) facilitated communication between hospital-based CMC programs and community providers; to meet the dynamic nature of care needs in CMC.

This population has unique intense and chronic care needs that are not met within the existing health care delivery model in Canadian paediatric hospitals and communities (27). Emerging complex care programs across Canada have defined criteria to respond to the care needs of this population within their own community. The need to standardize the care model and management for CMC is recognized by the American Academy of Pediatrics and the Canadian Paediatric Society (26,28,36).

Operational Definition based on Conceptual Definition

Answering **yes** to one criterion in each of the four variables below would indicate a high likelihood of medical complexity. This does not however indicate the severity of the complexity and/or describe the full spectrum of potential service needs.

Variables	Description		YES	NO
	Conceptual	Operational Criteria (examples for illustrative purposes and are not inclusive of all criteria)		
Family Needs	Significant impact on family in terms of financial burden, time required for direct care, healthcare visits, and unmet care needs	The cost of care at home is above and beyond what a family can reasonably afford		
		A parent must stay home to care for their child because of lack of support/services		
		Parent must stay up at night to monitor child usage, or therapy		
	Child requires significant continuous monitoring due to inherent medical fragility/risk of life threatening deterioration	Continuous GT/GJ feeds requiring frequent monitoring because of risk to child if feed stops or disconnects such as hypoglycemia or risk of entanglement		
		Ventilator dependent		
		Frequent seizures		
		Child is non-communicative and has a trach and cannot self suction or indicate distress		
Self reporting from parent who is unable to cope with the overall medical need/financial need/time needs/ anxiety/other	Parent reporting lots of stress because of fear of child's having another acute event			
	Parent reporting mental health issues/e.g. anxiety			
	Healthcare provider identified parent coping risk through use of assessment tool. (see tools and resources)			
Chronic Conditions	Having an existing condition associated with fragility; risk of a rapid and severe decompensation in homeostasis	Failure of equipment renders child at risk for life threatening event; e.g.ventilator dysfunction, VP shunt block		
	Risk of a life-threatening event	Short-term changes in the child's health status (eg. an intercurrent illness) put them at immediate serious health risk.		
Healthcare Use	High predictable health care services usage through multiple or prolonged hospitalizations and/or surgeries and/ or multiple sub specialty services	More than 2 medical conditions		
		More than 2 medical specialists		
	Healthcare services delivered in multiple settings: ex school, home, hospital Children's Treatment Centre, community clinics	Key Worker required to assist child/youth and family to obtain and navigate healthcare services		
		Complex care coordination and navigation because of family circumstances and/or language barrier/other		
	Unmet nursing/home care needs or problems with services or requires frequent support and contact with Key Worker			
Functional limitations	Unable to do activities of daily living because of impairment in one or more body systems. ex eating, breathing, elimination, mobility	Child requires prolonged intravenous administration of drugs		
		Child requires prolonged intravenous administration of nutritional substances (TPN), Central vascular line, requires non-invasive ventilation and/or tracheostomy,		
	Requires constant surveillance due to complexity of their condition, medication usage, or therapy	As a consequence of their illness are completely dependent (For a good portion of the day or night) on others for activities of daily living at an age when they would otherwise be independent		
		Mobility assistance and/or orthotics		
Dependent upon assistive technology for at least part of each day	Child has prolonged->1months dependency on other device-based support, including suctioning, oxygen support, Cardio-resp monitoring, sub-cutaneous devices and/or daily urinary-CIC			

Recommendation 2 – Capacity

Build capacity within the healthcare system to deliver coordinated care that is holistic, comprehensive and family- centred to all children with medical complexity, closer to home.

2.1 Develop, implement and sustain a supportive infrastructure for the care and services designed for CMC and their families.

This will require:

- Local leadership engagement from healthcare and community service organizations
 - *An executive sponsor to oversee implementation of integration of services and the transition to the organizational infrastructure that will oversee the complex care program/model of care as it evolves*
 - *Creation of a guiding coalition for the evolving program that includes the community service provider*
 - *A system/model that will identify and overcome inter-sectorial barriers for care delivery*
- Investment by government sectors (health, education, social/community) to support integration and re-organization to develop a dedicated team/support staff for the care model
- Core value of the family as an equal stake holder and participant at all levels in the development and evolution of a complex care model
- Dedicated funding from inter-sectoral sources to support staffing for coordination services
- Remuneration and expert support model that allows:
 - *Primary Care to provide services and support CMC*
 - *Specialists to provide services and support CMC*

Responsibility: Health care leaders, Government leaders' Advocacy groups (e.g. CAPHC, CFAN)

2.2 Establish a governance model with well-defined objectives, goals and evaluation processes.

This will require:

- Inter-sectoral agreement on program format
- Memoranda of Understanding as needed
- Core elements include: Cultural competency, patient safety, care coordination, community policy, integrated care delivery models

2.3 Develop a sustainability plan that identifies complex care as a priority and includes appropriate business planning practices.

This will require:

- Program identified as an ongoing health priority
- Federal level of support/priority in addition to Provincial and regional
- Business planning practices
 - Endorsement of the model of care
 - Planning for: staff retention long term sustainability model
 - Infrastructure must include representatives from all sectors
 - Engage all stakeholders involved with the CMC population
 - Ongoing evaluation that informs the impact/further integrate /build capacity

Responsibility: Government leaders; Health leaders; Management, families

2.4 Identify the education model required to meet the initial and ongoing education/training needs at all levels of care. *This will require:*

- Support from tertiary care agency for initial education
 - Skill development for care providers and family
- Train the trainer models for skill maintenance
- Dedicated Advance Practice Nursing roles for ongoing outreach to communities, needs assessments, program development and revision
 - Liaison with home care, acute care and primary care providers for client-specific education and management
- Use of technology (Skype, WebEx) for continuing education as well as client-specific support or consultations

Responsibility: Tertiary Centre Managers and Staff

2.5 Identify and establish the standards of clinical delivery specific for this population. *This will require:*

Development of standards that meet the requirements of Accreditation Canada in the following areas:

- Single care plan accessible to all-inter-sectorial access including families
- Key worker model/care team identified cross sectorial
- Collaboration and care coordination

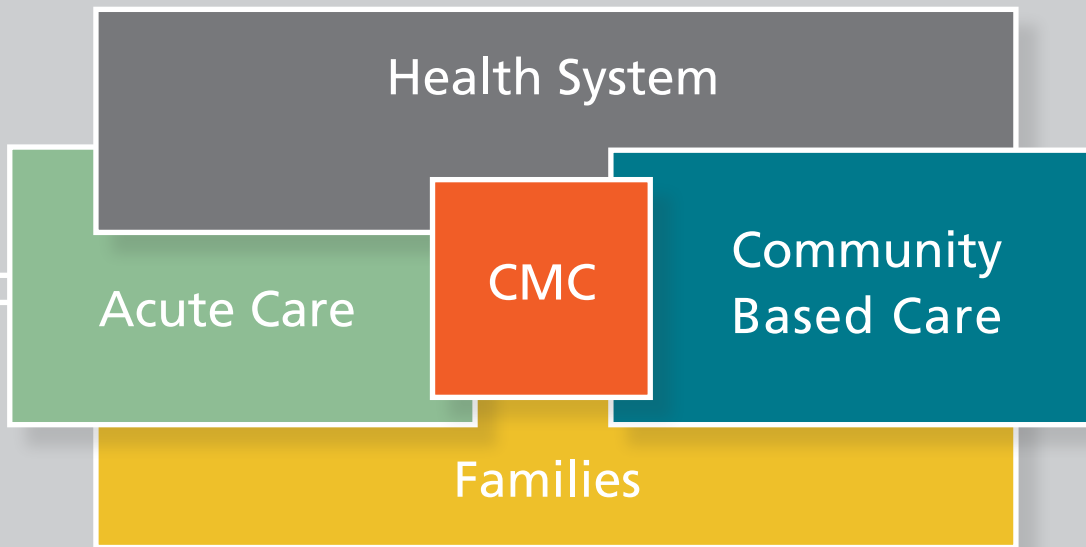
Responsibility: Interprofessional complex care team, community services and acute care hospitals, families

Evidence Summary

This unique population experiences an inequity of care delivery because of the current system design and evolution. The health care system must become more involved in policy development and forming strong community partnerships (38) to support the ongoing care of CMC. Through collaboration and capacity building in the community (encompassing education, health and recreation, social for the child), resources and programs can be developed and strengthened. Patients and families should be able to access resources in their home community. Families should be able to access integrated services for their physical and mental health, connected with the care of their child that facilitates a family care model.

In this model, the health system is charged with engaging the support of senior leadership to promote the development of programs to enhance chronic illness care (38). To improve the overall quality of care delivered to people with chronic illnesses, the health system monitors patient safety through quality management initiatives and policy development. Collaboration with the community to facilitate care coordination within and across organizations establishes the groundwork of seamless care and eases and supports transition from the hospital environment to self-care in the home.

Each sector of the health care team has a specific role in the process of transferring paediatric patients to their home communities. Ongoing written and verbal communication is essential in facilitating the process.



Health System

- Investment by government sectors in the population
- Dedicated funding from inter-sectoral sources to support staffing for coordination services
- Remuneration model that allows Primary Care and Specialists to provide extra services and support CMC



Acute Care

- Tertiary care centres provide tertiary care, subspecialist support, education and clinical support as needed to acute care centres and community based care
- Acute care provides acute illness and emergency care as able



Community Based Care

- Primary care providers (GP, NP)
- Home care services (nursing, respite)
- Community-based rehabilitation services
- Specialists
- Education, daycare
- Recreation services



Families

- Learn about child's condition and acquire skills required to care for them
- Be an active member of the care team
- Identify family care goals and participate in development of care plan
- Be involved in program development at system or hospital level

Recommendation 3 – Key Worker

Identify Key Worker(s) and care team for each child with medical complexity to facilitate service planning and care delivery in collaboration with the family/caregiver.

3.1 The Key Worker role must be recognized and supported by the organization

3.2 Role, responsibilities and limitations of the Key Worker must be explicit

3.3 A defined model to support care delivery and transition management will include:

- Communication strategies to allow for interaction and collaboration of care giving team across all settings
- A clear process for identifying and addressing client needs, changes in status and changing goals

3.4 Model must include integration with services beyond those that are health related including but not limited to financial supports, schools, community activities, equipment and housing.

Other members of the team, such as social worker, P.T., O.T., etc work with the Key Worker to identify these needs and services.

3.5 The Key Worker is a single point of contact for the family with the ability to work collaboratively creating linkages between acute care, home care, education and community agencies

3.6 The Key Worker represents the global interests and requirements of the child & family, which may include acute care, home care, education and community agencies and should facilitate engagement, coordination and communication among all providers and all settings.

3.7 The Key Worker should participate with the family in:

- Identifying and connecting with a primary care provider
- Setting child and family health goals
- Identifying non-clinical/community activities
- Identifying care needs
- Developing a comprehensive, child and family focused care plan with flexibility to adjust as goals and health care needs change
- Educating/coaching the family to strengthen their ability to advocate regarding their child's health needs/conditions

3.8 The Key Worker should facilitate and aid in planning for transitions in care:

- Transition from hospital to home
- Transition within a paediatric care system: respite services, rehabilitation services
- Transition to school and between levels of education ex. primary to high school
- Transition to adult care
- Transition planning must be part of initial care planning and updated and modified as child grows and develops to achieve child and families ongoing goals

The purpose of this recommendation is to identify the roles and responsibilities of a Key Worker recognizing that this individual will look different depending on the geographic location, family needs and resource availability. The Key Worker is part of the care team and because needs of the dynamic needs of CMC and their families the intensity of services and identity of the Key Worker may change over time and in some circumstances more than one Key Worker may be required. Children will benefit from Key Worker support based in the location where they receive the majority of their services i.e. community or tertiary care (27)

Evidence Summary

There are many examples and definitions for 'key worker'. They may be a designated clinician like a nurse practitioner (29) or a team (Complex Care team) with several roles where team members step in as required by the child and family. (30) There is also a model that may focus on either clinical or community requirements of child with structured liaison between these two areas of focus. (17)

Regardless of the Key Worker model used, to be successful there needs to be:

1. Leadership alignment around goals for the Key Worker program and requirements for success
 - a. Program must be designed around comprehensive needs of child and family
 - b. Clear commitment to improving care delivery, outcomes, quality of care and quality of life
 - c. Program must be inclusive of all services inside and outside health system with leadership alignment across continuum
2. Agreement on specific, measurable performance requirements to support quantification of value to children, providers and all partners involved with the organizational structure of the program including the funders
3. Active engagement of all partners involved in model achievement including funders and families
4. Adequate support to the 'Key Worker' team
 - a. Team must include members dedicated to model and knowledgeable of the needs of this distinct population
 - b. Supplementing core team with additional support as needed i.e. pharmacy, social work, behavioural development professionals
5. Model must be built to support internal capacity and new competencies as required. There must be sufficient time allocated for collaboration amongst members of care team. This must be captured using a dedicated plan such as 'roadmap for success' (30)

Recommendation 4 – Care Plan

Develop and maintain a shared single care plan with common language and clear ownership for children with medical complexity that is accessible and updated in a timely manner.

4.1 The care plan should be developed and maintained by the Key Worker with the input from the family and the healthcare team including the most responsible physician (either complex care clinic or primary care).

4.2 The care plan should be updated at clinic visits and after any major health status change.

4.3 The care plan should be inclusive of all the child's needs, clinical and non-clinical, including homecare, school, and community activities.

4.4 The care plan should include urgent care recommendation, resuscitation guidelines

4.5 The care plan should be part of the child's medical record.

4.6 The family, with the Key Worker will identify individuals and organizations that will have access to the care plan.

The purpose of this recommendation is to outline the purpose and information required in a shared plan. To be useful the care plan must be accessible to the family and the care team. Depending on the jurisdiction, privacy regulations and other issues unique to each setting, the plan may reside in one or a combination of places like: the electronic health record, in a patient portal, as a pdf file in the patient record, or as a paper document. There needs to be flexibility in this process but consistency in the manner of review and updates. (31)

Evidence Summary:

Care plans for children with medical complexity exist for similar purposes in different sectors of care. Children in a complex care program will have a medical care plan and may have a second care plan within the community that outlines other aspects of their needs. It is beneficial to families and children if all these needs are integrated into a shared care plan that will support family centred care and provide up to date information to aid in the planning and delivering of both clinical and non-clinical services for CMC and their families. (31) According to Adams et al, a care plan is a written document that outlines the major medical issues and care needs for a specific child and is created by the health care provider (HCP) in collaboration with the family. The document can be modified to meet a variety of needs, for example, emergency care plans, advanced directives, and comprehensive care plans. (32)

The literature supports the children with special health care needs be cared for in a medical home supported by a written medical care plan that will help to guide transition through the multiple settings where care is provided. (32)

Information to be included in a Care Plan*

Child Identification

- Name
- Date of Birth
- Provincial/Federal Healthcare number
- Secondary health insurance

Allergies/Reaction/Alerts

- Instructions for urgent care interventions, as applicable eg. seizure plan, resuscitation guidelines, etc

Important family/social information: caregiver names and contact, legal or custodial issues

- Name
- Address
- Relation to the child
- Legal Guardian and contact if different from Caregiver

Advance Care Directives

- Access to Care Directives documentation
- Contact information for care team

Diagnosis

- Primary diagnosis
- Secondary diagnoses

Short Non-Medical Description of the child

- Name they prefer to go by
- How they like to communicate
- Likes and dislikes

Family identified short and long-term care goals

- Established with the help of the Key Worker and healthcare team

Complex Care primary contacts

- Key worker name and contact information
- Most responsible physician

Emergency Department Plan

- Include: Common presenting signs, instructions or management needs that may be unique to the child
- Signs of deterioration

Medication List (include: dose, route, frequency)

- Scheduled and PRN Medication
- Compounding instructions

Nutritional information

- Dietary needs
- Parenteral and/or G-tube feeds

Technology/ Technology Support

- Ex. Adaptive seating, Mobility aids

Medical History

- Growth parameters and unusual 'normals' in vital signs or physique
- Diagnosis by Body System

Hospitalizations

- Include dates, reason for hospitalization and update care plan with any changes

Immunizations

Date and signature at each update/revision to Care Plan

List of other healthcare providers and organizations

- Include: name, contact information, role

Community Care Needs

- List of services received in community: home, school

* **Adapted from the following sources:** *Complex Care for Kids Ontario Standard: Medical Care Plan (May9, 2017), Adams et al.: Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study. BMC Pediatrics 2013 13:10., Wirth, B., Kuznetsov, A., Shared Plan of care: A Tool to Support Children and Youth with Special Health Care Needs and Their Families DECEMBER 2016, National Center for Medical Home Implementation and the National Academy for State Health Policy.*

Recommendation 5 – Empowerment

Empower families by proactively supporting them to develop skills, competency and confidence to comprehensively care for their child, navigate the healthcare system and to advocate on behalf of their child.

5.1 Parents and caregivers are provided with ample opportunity to learn about their child’s condition and acquire the necessary skills to care for their child now and in the future.

5.2 Parents and caregivers are recognized as key members of their child’s care team and their expertise should be acknowledged.

5.3 Families are engaged as partners in shared decision making and encouraged to make choices that are consistent with their values and goals.

5.4 Guidance and coaching on how to navigate the health, social, educational and developmental systems and access needed resources is provided, ideally by the Key Worker and healthcare team.

5.5 Parents and caregivers are supported in their home care management by health care providers, with differences in hospital care vs. home care acknowledged and incorporated into the care plan.

5.6 Resources and assistance are made available to families and caregivers. Care planning takes place with families and include suggestions for management of illness or complications that may occur.

5.7 Training and frameworks are in place to support health care providers in engaging meaningfully with families in this way.

5.8 Families are actively involved in program development at the system level.

The purpose of this recommendation is to set a framework for the elements required to empower families and caregivers. These elements will provide clarity of the role and responsibilities the family has as an active member of the care team and the roles and responsibilities of the healthcare system to ensure families have the capacity required.

Evidence Summary

Empowerment is an important concept to incorporate and prioritize in the care of individuals living with chronic disease and/or disability, as this enables them to take control and make decisions about their lives, leading to an enhanced state of self-efficacy. The empowered patient is knowledgeable and skilled in the management of his condition, partners effectively with professionals in joint decision-making and embodies self-determination.

The need for empowerment is clear, not only for adults living with chronic disease, but also for families of children with medical complexity. These parents and caregivers are expected to develop a high level of health literacy and often an ability to perform highly skilled medical procedures on their children. They interface frequently with health, educational and developmental support systems, providers and institutions. Clearly, management of CMC in the home setting requires family/caregiver self-efficacy as a core component.

However, these exceptional skills, judgement and capacity must be appropriately structured and supported. Although education and skills are crucial, they must be accompanied by the confidence, judgement and support to put them to use. Acknowledgement must also be paid to the considerable burden already carried by parents who are dealing with physical and emotional stress, social isolation and financial concerns. Empowering parents and caregivers in a way that is respectful, meaningful and does not leave them with overwhelming responsibility is challenging but imperative.

Educational interventions are an important component of empowering families and improving self-efficacy, as these have been shown to improve critical thinking and decision making. A study that analyzed the use of continued education and training in the community for family caregivers of ventilator-dependent children found high levels satisfaction and increased confidence in the care of urgent issues that arise. Caregivers also prioritize support from health care providers and care coordination, as well as attention to discharge readiness and the opportunity to practice homecare skills, particularly in times of transition to the home setting.

Striving to empower patients, families and caregivers in the population with medical complexity is integral to family centred care (FCC). Meaningful partnership and empowerment must be further optimized by a thorough exploration and incorporation of the family's level of understanding, literacy, language, disability, and culture in education, training and creation of a comprehensive and individualized care plan. (33)

Recommendation 6 – Transition

***Organizations providing services to CMC must have a strategy to transition between levels of healthcare and different care environments.
(ex. hospital – community – home – education – respite)***

6.1 Organizations should develop standardized internal policies and structured processes, that include strategies for communication with other levels of care to support safe and effective transitions for children with medical complexity.

6.2 Discharge planning should be inclusive of community re-integration including home care, education and other social/developmental environments where care may occur.

6.3 Planning will begin well in advance of a transition taking place; families should always be included in team meetings with the Key Worker about transition planning and should be involved in decisions about what will take place during in-hospital transitions and after they leave the hospital etc.

6.4 Hold at least one pre-discharge meeting for medical transitions with all parties involved to discuss concerns, answer questions, engage clients/families and caregivers in the care transition and understand the parents'/caregivers' perspectives on discharge readiness.

6.5 The Shared Care Plan should be reviewed and updated if necessary at each major transition in care.

6.6 A one-page summary of critical information about the child and family and their care plan should be developed and kept up to date for the family and made available to any health care professional who would need information on the child's needs.

6.7 Essential clinical information and /or resources are provided to the family and the identified circle of care upon discharge to support the clients' transition, and clients/families can ask questions.

6.8 Empower families through education about self-management; using teach back when providing information builds caregiver capacity.

6.9 Reconcile medications at care transitions and discharge and include in final transition plan. Identify ways for the client and/or caregiver to participate in the medication reconciliation process.

6.10 Care coordination must begin and be in place before discharge i.e. supplies and equipment appropriately set up in the home; transportation, caregivers (if applicable) etc.

The purpose of this recommendation is to provide guidance to improve transitions for CMC between care providers and care environments. The goal is that many of these guiding principles can be applied to transitions at any point along the entire continuum of care. Transitions and transfers of care may occur at multiple points in the child and families care trajectory, for example: within the hospital, hospital to hospital, hospital to home, admission to hospital, transition to school and / or adult care.

Evidence Summary

There are risks associated with all care transitions; miscommunication between health care providers during transfers of care can lead to serious preventable adverse events. While there has been progress in standardizing end of shift handoffs there is still complexity involved when transitioning from hospital to outpatient care/home or community with Home Care supports. Understanding the challenges that exist between healthcare settings because of variable structures, patient goals, culture and terminology may lead to opportunities for improved communication and processes. (34)

In addition to the medical risks, there are social, developmental and educational risks involved with transitions within the CMC population. Isolation from friends and family, for both children/youth and their caregivers, has a major impact on quality of life and impacts their physical and mental health (35). Discharge planning needs to include plans for re-integration into communities and school and collaboration with home health and the education system to ensure that plans are in place for medical support/intervention if required (36).

Transition of Care is included in the Accreditation Canada Medicine Standards. Below are Required Organizational Practices directly related to these standards.

8.5 A Best Possible Medication History (BPMH) is generated in partnership with clients, families, or caregivers (as appropriate) and used to reconcile client medications at care transitions.

9.11 Information relevant to the care of the client is communicated effectively during care transitions.

These are common practice recommendations for effective care transitions / discharge recognizing health settings may have best practices specific to the particular client need and medical condition i.e. home care; cardiovascular care. Discharge planning is not a one-time event but a process that takes place throughout the clients'/families' journey. Transitions / discharges need to be well planned and managed with clients/families as full partners in the discharge planning process. (33)

Tools and Resources

1) Bridge to Independence care coordination curriculum – Children’s Hospital of Wisconsin

Bridge to Independence is a program for parents and other family caregivers. The purpose of Bridge to Independence is to provide helpful information about caring for children with special health care needs. There are 12 modules, each covering a different topic. The goal is to help caregivers become more independent, make good decisions, advocate for their children, find and use resources, and increase overall comfort and skills.

Bridge to Independence is about families learning how to take action. This curriculum was developed by parents of children with special health care needs, educators, health care experts, and advocates. The modules can be used in any order that meets a family’s needs.

<https://www.chw.org/medical-care/special-needs-services/bridge-to-independence/>

2) Complex care at home for children

Developed in partnership along with families: CHU Sainte Justine, CHU de Sherbrooke, CHU de Québec-Université Laval, CUSM McGill University Health Centre, Complex Care Service at the Montreal Children’s Hospital, National Program for Home Ventilatory Assistance (NPHVA), Association Québécoise des Établissements de Santé et de Services Sociaux (AQESSS), CIUSSS du Centre-Ouest-de-l’île-de-Montréal

The information and tools are provided for parents and caregivers of children living with complex medical conditions to facilitate daily care, ensuring a safe environment for the child and family. Healthcare providers may find the materials useful for education and training purposes.

<https://complexcareathomeforchildren.com/>

<https://soinscomplexesadomicilepourenfants.com/>

3) Parent Coping/Risk assessment tools

Brief Family Distress Scale measures the level of parent or family distress, using a single-item scale. Items range from 1="everything is fine, my family and I are not in crisis" to 10="we are currently in crisis, and it could not get any worse." (1) Responses on the single item scale are positive correlated with caregiver worry, distress, child problem behaviours, and negative life events, and negatively correlated with quality of life, family hardiness, and empowerment and shown to be easy to complete by families in spite of crisis levels.

Mastery Subscale of the Revised Caregiver Appraisal Scale is a measure of self-efficacy for parents and defined as "perceived competency to meet the demands of providing and obtaining care for their children." (2) Improvements in self-efficacy for parents of youth with special health care needs is believed to be enhanced through direct support with subsequent positive impact on child, parent and service outcomes. (3) Parents rate on a Likert scale their perceived ability to care for their child's needs, and knowledge/skill in accessing services for their child. The 6-item scale was shown to have good internal consistency (Cronbach's $\alpha=0.8$).

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4) Benefits Finder – Government of Canada

The Benefits Finder is an online survey tool that uses your responses to get a customized list of benefits for which you may be eligible. It may suggest benefits from federal, provincial or territorial governments, and does not collect or track your information. The more questions you answer, the more customized your results will be.

<http://www.canadabenefits.gc.ca>

Glossary of Terms

Accessibility: Facilitating access is concerned with helping people to command appropriate health care resources in order to preserve or improve the CMC's health. There are 4 principles: if services are available, there is an adequate supply; the utilization is dependent on the affordability, physical accessibility and acceptability of services; if the services are available they must be effective in changing health outcomes; and there must be equity of access.

Care Plan: A written document that provides a comprehensive summary of the child/youth's medical conditions, medications, technologies, team members and care needs. The document developed with the family and team may include medical/services management care plans. (32)

Children with Medical Complexity (CMC): Children (for the purposes of this guideline we include from birth to 18 years old) with a unique combination of substantial family-identified service needs, characteristic chronic and severe conditions, functional limitations, and extraordinarily high health care use. (17)

Children/Youth with special health care need (CSHCN): Maternal and child health bureau definition: those children who have or are at increased risk of a chronic physical, developmental, behavioural, or emotional condition and require health care and related services of a type or amount beyond that required by children generally (1). Wide variation in medical complexity, functional limitation and resource needs among CSHCN (ie a child with asthma to a child with severe cerebral palsy/seizures/feeding tube, etc.).

Collaborative care: A network of providers that promotes enhanced communication, access to care and

optimizes service delivery. There is a relationship and partnership between providers, within the network that involves exchanging information, sharing resources, and/or coordinating services for the benefit of the child / youth and their family.

Complex Care Program: A program that provides comprehensive care coordination and system navigation to children/youth with medical complexity (CYMC) and their families.

Complex care team: The multidisciplinary team of health care providers from the child's Complex Care program who together function as the team to deliver care coordination and continuity of care to CMC and their families.

Care Coordination: The organization of patient care activities between 2 or more participants including the patient and family involved in a patient's care to facilitate the appropriate delivery of health services. This involves the exchange of information among participants responsible for different aspects of care.

Continuous care: For patients and families, the experience of continuity is the perception that the provider knows what has happened before (informational), that different providers agree on a management plan (management), and that a provider who knows them will care for them in the future (relational).

Empowerment: The process of empowerment enables people to choose to take control over and make decisions about their lives. The outcome is an enhanced state of self-efficacy. An important note is that empowerment should not be evaluated based on "compliance" or traditional outcomes.

Equity: Refers to fair opportunity for everyone to attain their full health potential regardless of demographic, social, economic or geographic strata. (World Health Organization).

Evaluation Framework: The template criteria that will provide direction for program evaluation.

Exclusion Criteria: The criteria that exclude a child/youth for the program.

Family: Person or persons who are related in any way (biologically, legally, or emotionally), including immediate relatives and other individuals in the CMC's support network. Family includes a child's extended family, partners, friends, advocates, guardians, and other individuals. The child/immediate parents-caregiver defines the makeup of their family, and has the right to include or not include family members in their care, and redefine the makeup of their family over time.

Family centered care: Child/youth and family-centered care is an approach to health care that respects the central role of the family in a child's life. Family members are critical and equal partners within the health care team. Health care professionals contribute information on health and disease and families contribute child and family specific information essential to achieving care responsive to the child/youth and family's preferences.

Flexibility: The ability to be easily modified for unique circumstances. Willingness to change or compromise to meet individual needs; this flexibility required in the healthcare system is to ensure that all involved organizations can come together to identify the care needs and overcome barriers of services/innovatively problem solve /individualize the service need within what can be done with the existing services.

Functional limitation: The National Center for Medical Rehabilitation Research framework for the classification of disability emphasizes measures across various life domains involving physical functioning, social relationships, normal activities, and community life. In this framework, functional limitation is the lack of ability to perform an essential activity typical of peers.

Inclusion criteria: The criteria that defines eligibility of a child/youth for a program.

Integrated: The World Health Organization's 2008 Technical Brief described integrated service delivery as "the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system".

Key Worker: An individual is assigned as the single point of care to the child/youth and family and will help to coordinate their care in-hospital and out-hospital, across systems (health care, education, social services, financial resources, recreation, transportation, etc.) Activities may include: help to navigate the healthcare system; being available on a regular basis; coordinate and may be required to be present at various meetings/appointments; support the family's skills, and providing parents with

additional skills or tools to facilitate empowerment; to enhance communication amongst all care providers and assure a cohesive and seamless delivery of care.

Lead physician: Is the Physician identified as the lead to support, direct the coordination of the care of the child/youth with the family and the key worker. The lead physician works in collaboration with and does not replace the child's Primary Care Provider. The lead physician could also be the PCP.

Navigation: Locating, finding and accessing health care services and resources.

Needs: CMC are characterized by substantial care needs: needs include medical care needs, specialized therapy needs, educational needs, and services needs.

Primary Care Provider (PCP): The PCP is a community physician, community paediatrician, or nurse practitioner who will provide primary care.

Proactive care: Engages the care team (including parent/child) creating standard work flow using information technology to identify gaps in patient care, anticipate complications and uses preventive care management and integrates management of chronic disease models. The goals are to improve

consistency of preventive care and improve quality of care for chronic conditions.

Reactive care: Provide care as the complications occur.

Seamless care across the continuum: Facilitated access to a well-functioning system of services that will coordinate and integrate the full range of needed child and family services, including health care, education, and social services, with the goal of optimizing outcomes for the children and families it serves.

Shared decision making: is a collaborative process that allows patients and their providers to make health care decisions together. It considers the best clinical evidence available, as well as the patient's values and preferences.

Stakeholder: Is a person that is a member of the care team of a CMC and can contribute equally to assessment, investigation and management consideration, decision, suggestion for a child's health. A parent, a caregiver can be a stakeholder.

Technologies: Medical device(s), considered to be any medical device that support the function of a body part; may require calibration, maintenance, repair, and user training.

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Conflicts of Interest: The Guideline was developed by a National Community of Practice facilitated by the Canadian Association of Paediatric Health Centres. CAPHC and its member organizations have no conflicts of interest to declare.

Guideline Management:

The Guideline was completed in December 2017. Through the regular activities of CAPHC, the Guideline will be updated every three years to include new research and the inclusion of validated tools to support implementation as they become available.

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Appendices

Appendix A – Reference list for Evidence and Recommendations

Appendix B – Mission and Vision Statement

APPENDIX A
 CAPHC Guideline for the Management of Medically Complex Children and Youth
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Reference List for Evidence and Recommendations

Author/Year	Reference	Grade	Scale
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Scale Quality of Evidence

- I Evidence obtained from one or more randomized trials with clinical outcomes
- II Evidence obtained from research, meta-analysis, systematic review, policy statement
- III Expert opinion
- A Strong Influence on recommendations
- B Moderate influence on recommendations

Appendix B

**Children and Youth with Medical Complexity (CYMC)
CAPHC Community of Practice (CoP)**

Vision Statement

All Canadian children/youth with medical complexity and their families are provided with access to tools, supports and services that will enable integrated and coordinated care that is proactive and best suited to each child/youth’s needs and environment.

Mission Statement

To establish national standards of care that will optimize the health and quality of life for Canadian children/youth with medical complexity and their families through shared decision making, while supporting the achievement of child/family identified health goals and outcomes using the best available evidence and experience-based knowledge.

The mission of the CoP is based on the following principles of care:

- The care is child/ youth/family centered.
- The care is integrated: coordinated, collaborative, continuous, and seamless across the continuum (hospital, community and agencies/services).
- The care is accessible.
- The care is delivered as such that the child/youth/family is empowered.

Definition of Children/Youth with Medical Complexity (CYMC)

The most complex CYMC are described as children/youth who share 4 characteristics (figure 1). The first is the presence of one or more complex chronic conditions that are often multisystem and severe. The second is a functional limitation that is often significant and causes the child/youth to be reliant on technology such as feeding tubes and tracheostomies. The third is that CYMC have high healthcare utilization, requiring specialized care and services from different providers in multiple settings. The fourth is that caregivers identify high healthcare service needs such as care provision in the home and care coordination: these can have significant social and financial impacts on the family. (i)Pediatrics 127(3);529-538, March 2011

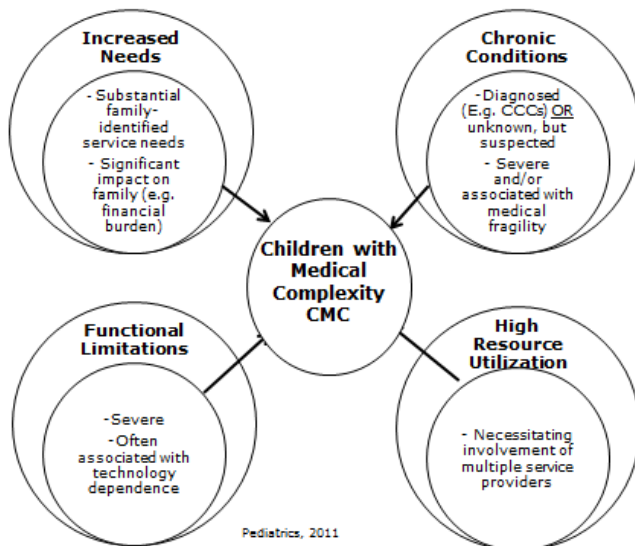


Figure 1

The Context:

There is growing recognition that children/youth living with medical complexity are a distinct group that requires medical and community services beyond those that are typically required for a chronic condition^{i ii}. Successful programs and services for children/youth with medical complexities and their families have been developed across the country. Yet, there remain inequities and a significant degree of variation in practice and delivery of health services to this vulnerable population. Families should expect the same level of care for their child as they navigate across systems in any province, territory or region, and national standards need to be established to minimize these inequities in health and health care access.ⁱⁱⁱ

The issues:

Clinical and technological advances have allowed children and youth with chronic illnesses to live longer, resulting in the need for multidisciplinary care and coordination of services amongst care providers. Although these advances indicate success in neonatal, medical, and surgical care, an almost unavoidable consequence is that some children and youth, who would not have survived in the past, now live with significant physical and neurologic disorders.^{iv} An Ontario health care study identified that 0.67% (15,771) of children fit the definition of children with medical complexity and of that 11.8% (1863) were also technology dependent. This small group of children with medical complexity accounted for one-third of child health spending^v and the cost was not only related to the hospitalizations but also extended to the community setting.

Technology-dependent children/youth with complex medical conditions are 3 times more likely to require intensive care hospitalization and are placing newer and greater demands on our current health care system.^{vi vii} They also account for 10% of hospital admissions and approximately one-quarter of hospital days^{viii ix}. Approximately 32% of these admissions are deemed to be potentially preventable, as almost 64% (two-thirds) can be attributed to system deficiencies such as poor care coordination and medical errors related to the complexities of care.^{xi,xii}

Technology-dependent and medically complex children require significant caregiver support from parents and family members, adding substantially to their families' economic burdens. Families are frequently frustrated when attempting to navigate with their child/youth across the system of care providers and ministries; the system makes them the most responsible persons in a process where they feel they have inadequate skills, support or even the confidence to assume this role.^{xiii} Physical and emotional stress, social isolation and financial burdens^{xiv, xv xvi} are common issues for parents as primary caregivers for children with complex care needs. Qualitative studies for this particularly vulnerable population, like ventilator dependent children, highlight that parents and caregivers experience tremendous emotional stress and feelings of overwhelming responsibility. Poor care coordination also results in poor health outcomes, parental dissatisfaction and medical errors^{xvii xviii}.

Alleviating these factors could have a significant impact on health costs.

Research over the last 10 years has identified common principles that should be considered when providing services to CYMC and their families. These principles are defined in the Glossary of terms. In this document the guiding principles will be adapted and used as a framework to establish recommendations for national standards of care for CYMC. These guiding principles will also help to define the core elements of an integrated complex care program that is inclusive of and responsive to the care needs and preferences of the child/youth and family.

Common Principles

1. **Child and family centred:** Child/youth and family-centered care is an approach to health care that respects the central role of the family in a child's life. Family members are critical and equal partners within the health care team. Health care professionals contribute information on health and disease and families contribute child and family specific information essential to achieving care responsive to the child/youth and family's preferences. The guiding principles of child and family-centred care are:
 - Respect families as their child's experts and as constants playing central roles in the life and care journey of their child.
 - Families are partners and equal team members in care planning and decision-making: embracing collaborative care.
 - Recognize and respect the individuality of each family based on social, spiritual, cultural and other factors as they relate to care planning for their child.
 - Support timely communication and information-sharing between the family and health care team in order to facilitate informed care planning.

2. **Integrated: Coordinated, Collaborative, Continuous, and Seamless Care across the Continuum:** The World Health Organization's 2008 Technical Brief described integrated service delivery as "the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over times and across different levels of the health system" (p. 1).
 - **Coordinated care- Common elements:**
 - i. A key worker is required to facilitate the care delivery in an organized manner.
 - ii. Each child has more than one provider (hospital and community based) that is involved in their care and facilitates collaboration and information sharing.
 - iii. Coordination is a shared responsibility that is flexible for all involved (child/youth / family and providers).
 - iv. Coordination is required because the care needs are beyond any existing program.
 - **Collaborative care- Common elements:**
 - i. Creation of a network of providers that will include subspecialties, primary care agencies and child / youth and their families to deliver the highest quality of care across settings. The network promotes enhanced communication, access to care and optimizes service delivery.
 - ii. There is a relationship and partnership between providers, within the network that involves exchanging information, sharing resources, and/or coordinating services for the benefit of the child / youth and their family
 - iii. The communication is enhanced.
 - iv. To provide comprehensive and family centered care.
 - **Continuous care:** For patients and families, the experience of continuity is the perception that the provider knows what has happened before (**informational**), that different providers agree on a management plan (**management**), and that a provider who knows them will care for them in the future (**relational**) .^{xix}

- **Seamless care across the continuum:** Once in the healthcare system, children with medical complexity will have facilitated access to the broader system of services. A well-functioning system of services will coordinate and integrate the full range of needed child and family services, including health care, education, and social services, with the goal of optimizing outcomes for the children and families it serves. Seamless communication among the providers of services and with the family is a critical component of a system of services.^{xx} Critical characteristics of a seamless system:
 - i. Coordination of child and family services.
 - ii. Effective communication among providers and the family; and
 - iii. Family partnership in care provision, and flexibility.
- 3. Accessible:** Facilitating access is concerned with helping people to command appropriate health care resources in order to preserve or improve the CYMC's health. There are 4 principles: if services are available, there is an adequate supply; the utilization is dependent on the affordability, physical accessibility and acceptability of services; if the services are available they must be effective in changing health outcomes; and there must be equity of access. For the CYMC, this should include:
 - i. Access to integrated care coordination for all children and youth with medical complexity independent of where they live.
 - ii. Access to timely and appropriate use of pediatric acute care services, specialists, consultations, community primary care providers, mental health, rehabilitation services, dental care, prescriptions, investigations, and results.
 - iii. Access to available community services, resources, funding and equipment needs and associated services.
 - iv. Access to a system that will provide timely and appropriate sharing of information such as, but not limited to, a summative medical care plan inclusive of the use of technology, and reports for all CYMC.
 - v. Accessibility and flexibility of service providers and of the services provided.
 - vi. Access to care through a variety of means including expanded hours, email and telephone communication.
- 4. Empowerment** is both a process and an outcome. This concept can relate both to individuals and communities. For the purposes of this guiding principle, the focus will be on empowerment of individuals as a process. The process of empowerment enables people to choose to take control over and make decisions about their lives. The outcome is an enhanced state of self-efficacy. An important note is that empowerment should not be evaluated based on "compliance" or traditional outcomes.

Attributes of Empowerment:

 - i. Education and skill-development.
 - ii. A partnership which values self and others.
 - iii. Mutual decision-making.
 - iv. Self-determination; freedom to make choices and accept responsibility.

Criteria for Development of a Care Model Should Include:

1. **Keyworker(s)** to facilitate service planning and care delivery in collaboration with a family / caregiver with the goal to empower the family so they can be an essential member of the team in facilitating the best care and best delivery of care to the child. (Cohen et al, 2011a).
2. **Partnerships:** active working relationships between family, tertiary care, community-based care and all stake-holders, communicating a plan of care to all. (Cohen et al, 2011b; Cohen et al., 2012).
3. **Common care plan** (Adams et al., 2013; Woodward et al., 2004).
4. Strong transparent **communication**.
5. **Care Coordination** to facilitate **accessibility**.
6. **Comprehensive care** approach to facilitate accessibility.
7. **Assessment of care needs:** identify unmet care needs/ optimize accessibility and flexibility.
8. **Measurement and Evaluation:**
 - i. Education and skill development – Does this program provide ample opportunities for parents and caregivers to learn about their child’s condition(s) and acquire necessary skills to care for their child, now and in the future?
 - ii. Partnership – Is there evidence that this program values and welcomes the input and involvement of all caregivers and health care team members in relation to the child’s care?
 - iii. Mutual decision making – Is there the expectation within this program to engage in shared decision making with families and caregivers? Are health care providers provided with training and/or frameworks to support them in this process?
 - iv. Family Self-Determination – Is the family encouraged to make choices that best reflect their own values and goals?

Other ideas for consideration:

1. It is essential that in order to provide medical care to children with complexities, continued training opportunities must be available for primary care providers to maintain competency, consistency, coordination and collaboration in the management of care delivery both in hospital and home.
2. Cross-ministerial collaboration is improved to ensure seamless delivery of services across the child’s continuum of need.
3. Services are family centered and families are equal partners in decision making.
4. Capacity building with the future goal that care is delivered for all CYMC according to these principles.

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End Notes:

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