

**REPORT OF THE
PAEDIATRIC COMPLEX CARE COORDINATION
EXPERT PANEL**

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Executive Summary

Introduction

Health care needs for the paediatric population have changed significantly over the past two generations. Immunizations and highly effective antimicrobials have resulted in less acute illness overall and less acute illness requiring hospitalization. Advances in diagnostics, therapeutics and medical technologies have resulted in some children who previously would have died in infancy or early childhood living longer. As a result, the prevalence of children with chronic disease is ever higher, and the complexity of the care needs for these children is increasing dramatically.

As currently structured, the health care system does not function to provide seamless integrated care for these paediatric patients with complicated lives, resulting in:

- Suboptimal health outcomes.
- Dissatisfied children and youth, and their families and caregivers, with a compromised quality of life for all.
- Busy providers who experience additional stresses and frustrations with the systems on which they depend.
- Inefficient use of health care resources.
- Inadequate health system planning.

Mandate

To address the unmet needs of this population, the Paediatric Wait Time Strategy established a Paediatric Complex Care Coordination Expert Panel (the Expert Panel) with a mandate to:

1. Offer consensus recommendations on innovative health care delivery models for the coordination of services for complex health care needs.
2. Develop guidelines for the effective implementation of potential care coordination programs at the departmental, institutional, regional, Local Health Integration Network (LHIN) and provincial levels.
3. Establish key performance measures, performance targets, outcome measures and outcome targets to be used to evaluate the success of the potential pilot care coordination programs.
4. Consider process improvements for enhanced care coordination within emergency departments.

The Expert Panel was asked to develop a care coordination model for children and youth who have the highest need for care coordination, in the expectation that if this model works well for the most complex cases, it will ultimately work for other populations. Specifically, the Expert Panel studied the needs of children and youth who:

1. Are medically fragile and/or technology dependent,
2. Have severe complex obesity, or
3. Have significant mental illness and complicating psycho-social factors.

The delivery of care and services for children and youth falls under the jurisdiction of several provincial ministries. The Expert Panel was asked to develop innovative **health care** delivery models for the coordination of the complex **health care** needs. However, as models of care coordination are developed, it will be essential that the issues of well-coordinated care and services required by these children and youth and their families be addressed across all relevant sectors.

The Expert Panel members were nominated by the 14 LHINs and included representation from physicians and administrators from paediatric academic health science centres and community hospitals, representatives of community-based programs and services, researchers, patient and family support associations, the Provincial Council for Children's Health, and one parent of a child with complex care needs. The Ministry of Children and Youth Services was also invited to observe the Expert Panel's deliberations.

Methods

The Expert Panel assigned each panel member to one of three Subcommittees representing the target patient populations. One member was asked to chair each Subcommittee and to be responsible for meeting the deliverables for that patient population. Each Subcommittee developed an operational description of the target population and an estimate of the number of children and youth in Ontario that would be included in each population.

The Expert Panel and its Subcommittees conducted a scan of selected published literature on models of coordinated care and a review of selected models for care coordination in selected jurisdictions, as identified by Expert Panel members.

Common Characteristics of These Children and Youth

The Expert Panel found that these children and youth were more similar than different, a concept that has been formally identified as a 'non-categorical' approach to complex disorders of children and youth. These characteristics drive special demands on the health care system and their families:

- These children and youth have medically complex conditions. They have chronic and often multisystem disorders with high potential for significant comorbidities. They typically require special medications and/or technologies. Their conditions can be unpredictably unstable. These individual conditions are sometimes rare, which creates challenges for community caregivers to develop the needed expertise, comfort level or resources to manage these disorders.
- These complex conditions place a high burden on the health care system, requiring highly specialized resources. These children and youth often require services from a variety of health care providers (e.g., generalist and specialist physicians, nurses, allied health providers and community organizations). Access to these services and coordination among care providers is often a major challenge.
- The high burden of these conditions is not limited to the health care system. The child's family carries a significant burden as well. Families experience both acute and chronic stress and are known to have poorer physical and mental health than comparable adults.

- In many cases, the child or youth is not the only member of the family needing care. Thus, successful treatment is dependent on treating the entire family, not just the child.

Benefits of Coordinated Care

Although the literature documenting the benefits of complex care coordination is relatively sparse, the Expert Panel did find some evidence of significant medical, social and financial benefits through care coordination for medically fragile and/or technology dependent children and youth including:

- Reductions in life-threatening illnesses, intensive care unit admissions and intensive care days
- Decreases in payments to hospitals and specialist physicians and improvements in accessibility of care, parental perceptions of communication and overall satisfaction
- Decreases in parental work loss and hospitalizations
- Improvements in quality of life.

These evaluations measured only the short-term impacts of the care coordination models. The more significant impact is expected to occur in the longer term, particularly for the complex obesity and mental health populations. If coordinated care can lead to improved health outcomes, these children will be at lower risk for related comorbidities in adulthood.

Proposed Complex Care Coordination Model

The four goals of the proposed complex care coordination model are to:

1. Improve the quality of life of children and youth with complex medical or mental health conditions and their families.
2. Improve the health status of children and youth with complex medical conditions, wherever possible.
3. Maximize time out of hospital and decrease avoidable hospitalizations, days in hospital, inefficient, unnecessary or avoidable ambulatory clinic visits, and emergency department visits.
4. Coordinate the needs of the child or youth and their family with home, community and hospital services, including the transition to adult services.

The Expert Panel believes that the basic approach to the coordination of care for children and youth with special health care needs should be structured as follows:

- A Key Worker role should be developed. The Key Worker should be identified as the single contact point for care coordination. How the care coordination responsibilities are shared between the Key Worker and the family would be determined through negotiation between the family and the Key Worker.
- For every child enrolled in the service, a most responsible physician (MRP) should be identified, depending on the child and family's special needs, circumstances and parental choice. This information should be documented in the child's care plan and updated regularly.

- The service should be available for support to families and clinicians (e.g., emergency room physicians) during regular office hours. Extended access (e.g., 24 hours a day, seven days a week) should be offered only as required.
- The model should be based on shared care between the local health care team (e.g., the primary care practitioner and other care providers in the child’s community) and the secondary and tertiary centres that provide specialized care and services to the child and family.

Specific Recommendations

1. That the Ministry of Health and Long-Term Care engage in targeted consultation with key stakeholders to solicit their input on the proposed complex care coordination model and to engage their participation in refining the proposed complex care coordination model.
2. That the Ministry of Health and Long-Term Care bring together the Ministry of Children and Youth Services, the Ministry of Community and Social Services, the Ministry of Education and the Ministry of Health Promotion to collaborate in order to ensure efficient and effective coordination and alignment of policies and programs across jurisdictional boundaries and to explore creative reassignments of existing resources dedicated to care coordination..
3. That the Ministry of Health and Long-Term Care adopt the proposed model for care coordination for children and youth with complex needs and approve its implementation on a pilot basis. Implementing and evaluating this model will require funding and support for the Key Worker role, for the coordinated clinics at secondary and tertiary centres and for data collection.
4. That the Ministry of Health and Long-Term Care commission a comprehensive inter-ministerial review of relevant policies and change or waive existing policies and/or create new policies to remove barriers to access to care, equipment and medications, expand the scope of existing services and investigate the option of direct funding where appropriate. To the degree possible, these changes should be consistently implemented across all relevant ministries.
5. That the Ministry of Health and Long-Term Care consider options to allow paediatric patients to access appropriate specialized child- and youth-focused services beyond 18 years of age depending on the needs of the youth and family.
6. That the Ministry of Health and Long-Term Care conduct an assessment of the capacity (e.g., health human resources, physical space, equipment) needed to deliver timely and quality care to children and youth with complex care coordination needs and to build the capacity where it is currently inadequate. Building capacity requires a health human resource strategy for the province, including basic and specialized training for these professionals in the care of these high-need populations.
7. That the Ministry of Health and Long-Term Care develop incentives (e.g., changes to remuneration and funding policies) to encourage individual health care providers and health care institutions to provide the care required and to support the complex care coordination activities proposed by the Expert Panel.

8. That the Ministry of Health and Long-Term Care commission a formal scan of existing models of shared care and other collaborative efforts (e.g., Interlink Nurses) and investigate opportunities to learn from and build on these networks to support the proposed complex care coordination model.
9. That the Ministry of Health and Long-Term Care commit to supporting data collection related to the planning and delivery of care and evaluation of the proposed model. An immediate first step to demonstrate this commitment would be to establish three committees (i.e., Content, Technology and Privacy and Access) to develop the electronic Child Health Network (eCHN) or other similar information system as the data collection and information management tool for care coordination for these populations.
10. That the Ministry of Health appoint a single provincial coordinator for the system of complex care coordination clinics to be developed. This coordinator's role would be to develop and implement a communications strategy, facilitate the development of educational opportunities, and work to facilitate data collection and analysis throughout the province.
11. That the Ministry of Health and Long-Term Care develop and implement an evaluation plan that defines formal performance measures and incorporates the collection and analysis of data to evaluate these measures. This plan will require the development of a strategy to measure and monitor the number of children and youth in these populations in a systematic way to support health care planning for these populations.

1.0 Introduction

1.1 *The Access to Services and Wait Time Strategy*

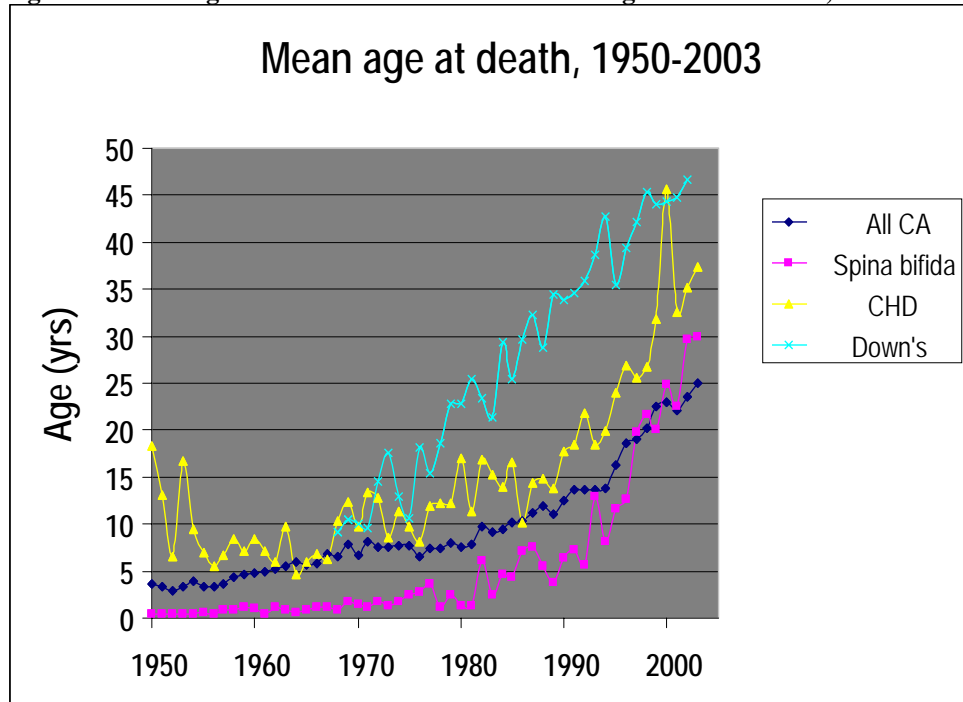
As part of its Access to Services and Wait Time Strategy, the Ministry of Health and Long-Term Care (the Ministry) identified paediatric care as a priority area. To formalize this commitment, the Ministry established a Paediatric Wait Times Strategy with a mandate to:

- Improve timely access to high-quality paediatric care for all children and youth in Ontario
- Measure, monitor and reduce the wait times for paediatric services by:
 - a) Increasing funded case volumes, and
 - b) Promoting efficient and effective care
- Provide useful and accurate wait time data for paediatric procedures to the public.

Health care needs for the paediatric population have changed significantly over the past two generations:

- Because of immunization and highly effective antimicrobials, children and youth are experiencing significantly less acute illness overall and less acute illness requiring hospitalization.
- Further, because of advances in diagnostics, therapeutics and medical technologies, some children who previously would have died in infancy or early childhood are living longer, as shown in Figure 1. As a result, the number of children with chronic disease is increasing, and the complexity of the care needs for these children is increasing dramatically.

Figure 1: Mean Age at Death for Individuals with Congenital Anomalies, 1950 to 2003



CA = Congenital anomalies

CHD = Congestive heart disease

Source: R. Wilkens, *Health Canada*, 2007

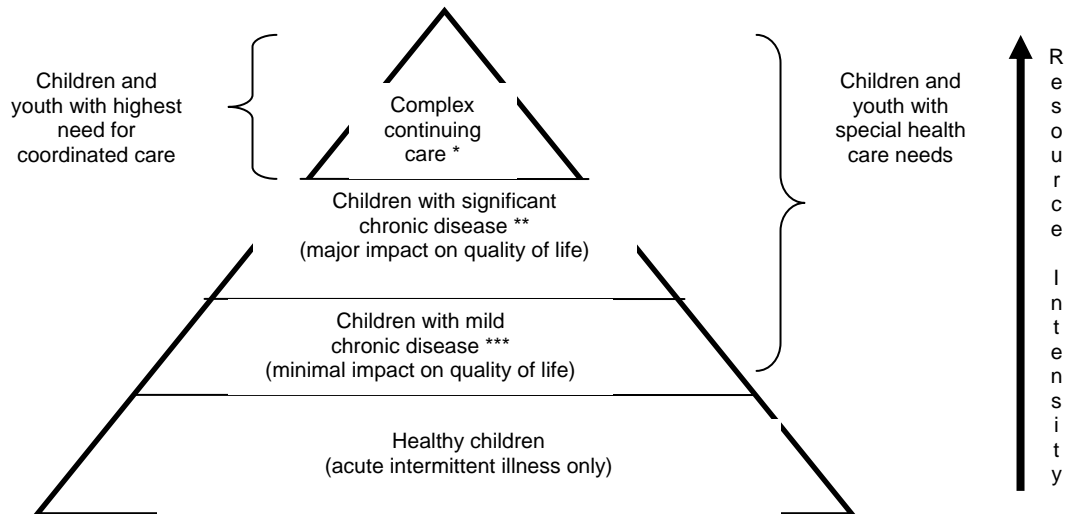
In the United States, paediatric hospital admissions associated with diagnoses of chronic conditions increased from 25% of admissions in 1962 to 55% of admissions in 2000.¹ In Ontario, these children and youth with special health care needs (CYSHCNs) comprise a small percentage of all children and youth, but consume a significant percentage of all paediatric health care resources, as shown in Figure 2.

Children and youth with the most complex medical conditions are relatively small in number and spread across the province, which makes it challenging to develop and maintain the needed expertise for this care. These children face challenges in accessing primary care because of their multiple, time-consuming issues (making them “undesirable” patients), made worse by the current shortage of primary care practitioners in Ontario. Additionally, because of the complexity of their conditions, they often require visits to multiple subspecialists in various locations to secure the care they need.

These children also pose challenges for emergency room physicians, who are likely unfamiliar with these children’s conditions and care needs. It is believed that with improved information about these children and support from knowledgeable specialists, some emergency room visits and subsequent hospitalizations could be avoided completely. Lack of information that can be accessed quickly by emergency department physicians or physicians in the intensive care unit or ward can result in the delay of initiation of vital therapies and the increased potential for medical error. Similarly, once these children are admitted to hospital, they often do not have access to the community-based care and services

needed to ensure a timely discharge, which contributes to the alternative level of care (ALC) challenges for the admitting hospital.

Figure 2: The Complex Care Pyramid



*Children or youth with significant physical or mental health care requirements (e.g., ventilator dependent, frequent and/or long hospitalizations, multiple care providers, services provided in many settings).

** Children or youth with significant physical or mental health care requirements (e.g., multiple healthcare visits/year, intermittent school absences, limitations on recreational activity, occasional hospitalization)

*** Children or youth with limited physical or mental health care requirements (e.g., can participate in most recreational and educational activities with limited absences from school).

The following vignettes illustrate the frustrations and challenges of these children and youth and their families in navigating and dealing with the health care system.

Stephen

Stephen is a cheerful two-year-old who loves outdoor activities, reading and playing with his brother and musical instruments. But life for Stephen is very different than that of other boys his age. He has spent almost one-third of his life in hospital. Stephen was born with a condition that causes inadequate oxygen delivery to many of his vital organs. As a consequence, he has difficulty swallowing and receives all his food through a gastrostomy tube and an intravenous line. He also has high blood pressure because of damage to his kidneys at birth, and low muscle tone that causes obstruction of his airways, necessitating oxygen saturation monitoring and the placement of a breathing tube in his nose to keep his airways open.

Last summer, when Stephen caught the flu, he was transported by helicopter to a tertiary care centre four hours from home. Over the next ten days, he required respiratory support and a blood transfusion for a condition that would have caused any other child simply to spend a day or two in bed at home. This winter, when he had his tonsils and adenoids removed, he spent seven days in an intensive care unit, where he developed many complications. He came close to receiving a drug that could have damaged his liver because one of the many doctors who looked after him was unfamiliar with Stephen's complex medical history. Stephen spent seven extra days in hospital and almost spent Christmas in the hospital again this year because the oxygen saturation monitor pool was empty and the family could not get the equipment that was needed.

Stephen's condition is unlikely to be cured; the goal of his treatment is to maximize his and his family's quality of life and to maximize his integration into his community. This has been difficult for his family, as the coordination of Stephen's care and advocating on his behalf is a full time job. Typical childcare options are not available to Stephen, and his father has had to leave his employment for a year to care for Stephen, causing financial hardship for the family.

Julie

Julie is an attractive, intelligent 16-year-old. After being sexually abused ten years ago, she began to display anorexic tendencies and had suicidal ideation. Over the next three years, the issues escalated until Julie was abusing herself and others. Her self esteem was non-existent and her anger, hostility and self-administered isolation were worrisome for her family. Admission to a residential treatment program resulted in significant progress until her stay was terminated due to lack of funding.

A short time later, Julie was admitted to a long-term residential treatment program four hours from her home. While there, she waited 16 months to receive a psychiatric assessment and had only two therapy sessions. After four failed attempts at residential treatment, Julie's family identified multiple programs and funding sources that would allow the family to start the transition back to her home. Many of the expected services were not available to the family. Within two years, Julie had begun cutting herself, talking about suicide on an almost daily basis, using drugs, displaying bulimic tendencies, and physically assaulting her parents when they tried to prevent her from harming herself. Julie was eventually diagnosed with attachment disorder, post-traumatic stress syndrome and a mood disorder.

Julie's family has requested 59 hours of care per week, but only 24 have been approved, and the family is still waiting to receive even these services. She has been assigned a one-on-one worker at her school. The worker has sometimes sent Julie home because the worker could not "handle her" and even "lost" her once on a school outing. The family is fearful for Julie's life and has contacted the local media to raise awareness and advocate for the services they believe she so desperately needs.

Sam

Sam has struggled with his weight all his life. By the age of four, he weighed 73 kilograms and had significant obstructive sleep apnea (OSA). He has mild developmental delay, likely secondary to chronic hypoxia (oxygen deficiency) from his OSA. He required the use of a machine (BiPAP) to help him maintain his airway open during sleep. At 14, he weighed 243 kilograms and his body mass index (BMI) was 78 (normal 18 to 25 for an adult). He had developed high blood pressure and type 2 diabetes. He was unable to walk 10 metres without becoming short of breath. Sam struggled with simple activities of daily living like tying his shoes and bathing without assistance from his mother. Due to episodes of teasing and bullying, and extreme difficulty navigating the classroom (he could not sit in the regular sized desks), Sam was now no longer going to school.

When Sam was 14 years old, he developed abdominal pain and was diagnosed with acute appendicitis. Due to his obesity, the surgeon was unable to remove the appendix via laparoscopic means and had to perform the surgery through an abdominal incision. Sam remained in the intensive care unit on a ventilator for several days due to his respiratory compromise. He then developed a serious postoperative wound infection, which was felt to be worsened by his obesity and his diabetes. Overall, complications from this relatively common childhood surgery kept him in hospital for three weeks.

Throughout his life, Sam has been seen by multiple health care providers including individuals from respirology, endocrinology, psychiatry, nutrition, dermatology and genetics. None of these services is delivered in a coordinated fashion, and they require the family to make frequent trips to hospital. Each care provider seems to focus on their own specialty and does not know the current status of Sam's other health issues. Sam and his parents must constantly repeat information that should be in his patient chart. Sam would like to receive some of his treatment closer to home; however, the family is not aware of any local resources that could help. Importantly, the treatment of his underlying obesity requires a combined medical and behavioural approach, and there is no interdisciplinary team available to provide this care for him.

As currently structured, the health care system does not function to provide seamless integrated care for these paediatric patients, resulting in:

- Suboptimal health outcomes
- Dissatisfied children and youth, and their families and caregivers, with a compromised quality of life for all
- Busy providers who experience additional stresses and frustrations with the systems on which they depend
- Inefficient use of health care resources
- Inadequate health system planning

It was recognized that Ontario needs a system built around the needs of these children and youth, and their families, rather than around the needs of providers. An opportunity was identified to expand the scope of the Paediatric Wait Time Strategy to address innovative models of care coordination to improve the management of these children's conditions. Improved coordination is expected to result in better health outcomes for both children and parents, and a more efficient and effective use of health care resources.

1.2 The Paediatric Complex Care Coordination Expert Panel

In response to this opportunity, the Paediatric Wait Time Strategy established a Paediatric Complex Care Coordination Expert Panel (the Expert Panel) with a mandate to:

1. Offer consensus recommendations on innovative health care delivery models for the coordination of the complex health care needs for three populations of children and youth:
 - a. Children and youth who are medically fragile and/or technology dependent,
 - b. Children and youth with severe complex obesity, and
 - c. Children and youth with significant mental illness and complicating psychosocial factors.
2. Develop guidelines for effective implementation of care coordination programs at departmental, institutional, regional, Local Health Integration Network (LHIN) and provincial levels.

3. Establish key performance measures, performance targets, outcome measures and outcome targets to be used to evaluate the success of the potential pilot care coordination programs.
4. Consider process improvements for enhanced care coordination within emergency departments.

The Expert Panel's Terms of Reference are provided in Appendix A.

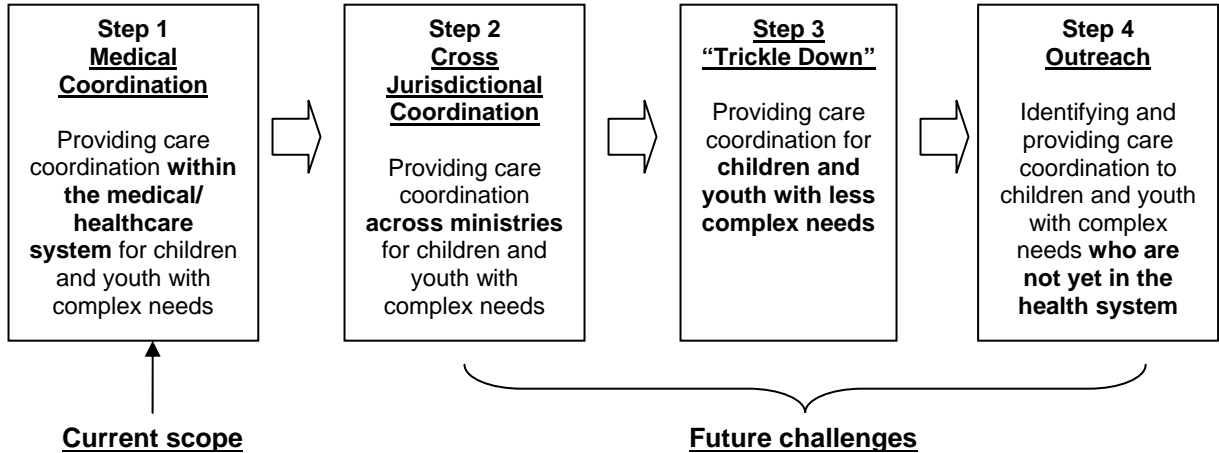
The three target populations were chosen as examples of children and youth with extremely complex care needs. It was the intention of the Expert Panel that the care coordination model could be developed based on the needs of these three groups, but that the model could then be applied more broadly to all children and youth with complex care needs.

The Expert Panel further clarified its scope by determining that care coordination would begin by coordinating care within the medical system (Step 1). Once the model is established for medical and other health care, it can and, we believe, must be expanded to include coordination with services provided by other ministries (Step 2). It was noted that, given the central importance of seamless service provision across all care sectors, the execution of Step 1 would require a careful and constant mindfulness to Step 2. Barriers to future Step 2 activities should be carefully avoided during the creation of the Step 1 model. There will also be a need to expand the proposed care coordination model to populations with less complex needs (Step 3). As the "trickle down" (Step 3) is implemented, there will eventually be a need for programs to reach out to those children who are not currently identified as being in need of these services (Step 4).

These four steps are shown graphically in Figure 3. Although Steps 2-4 are important components of the overall initiative to improve access to care for children and youth with special health care needs and those of their families, they are outside the scope of this Expert Panel and will require future consideration.

The delivery of care and services for children and youth falls under the jurisdiction of several provincial ministries. The Expert Panel was asked to develop innovative **health care** delivery models for the coordination of the complex **health care** needs. However, as models of care coordination are developed, it will be essential that the issues of well-coordinated care and services required by these children and youth and their families be addressed across sectors.

Figure 3: Four Steps to Providing Care Coordination to High Need Populations



The Expert Panel membership included representation from physicians (e.g., paediatricians, endocrinologists, psychiatrists) and administrators from paediatric academic health science centres and community hospitals, representatives of community-based programs and services, researchers, patient and family support associations, the Provincial Council for Children’s Health, and one parent of a child with complex care needs. Members were nominated by the fourteen Local Health Integration Networks (LHINs). The Ministry of Children and Youth Services was also invited to observe the Expert Panel’s deliberations.

A list of the Expert Panel members is provided in Appendix B.

1.3 Organization of the Report

The remainder of this report is organized as follows:

- Chapter 2 describes the methodology used by the Expert Panel for its research and analysis.
- Chapter 3 presents a definition for each of the three target populations, as well as an estimate of the size of the population and special challenges for each.
- Chapter 4 provides a description of the challenges in the coordination of care for these populations.
- Chapter 5 presents a framework for complex care coordination.
- The proposed model for consideration in Ontario is presented in Chapter 6.
- Performance measurement is the subject of Chapter 7.
- Implementation considerations are highlighted in Chapter 8.
- The Expert Panel’s recommendations are presented in Chapter 9.

A glossary of technical terms and a list of abbreviations used in this report are provided at the end of this report.

2.0 Methodology

The Expert Panel assigned each panel member to one of three Subcommittees representing the target patient populations. One member was asked to chair the Subcommittee and to be responsible for meeting the deliverables for that patient population.

The Expert Panel and its Subcommittees undertook the following steps to inform their deliberations and recommendations:

- A review of selected published literature on models of coordinated care.
- A review of selected models for care coordination in selected jurisdictions, as identified by Expert Panel members.

The detailed methodology used for each of these tasks is provided in the following sections.

2.1 *Published Literature*

In light of the limited time available to prepare this report, the Expert Panel relied on its members to identify relevant literature for review. Each of the Subcommittee chairs and any other members within their Subcommittee who were well versed in the body of literature on care coordination were asked to identify relevant literature.

A formal literature review was not undertaken for a variety of reasons. The focus on coordination for individuals with complex care needs is a relatively recent development in health policy research, leaving relatively few published articles on this topic specific to the paediatric population. Further, although many approaches have been tried in practice – and some are documented in the literature – there are very few studies that have documented an evaluation of these approaches.² Expert Panel members who have conducted research in this area confirmed the view that a formal literature review was not likely to provide significant additional value to inform the Expert Panel’s deliberations.

2.2 *Research of Selected Jurisdictions*

At the first meeting of the Expert Panel, a presentation on existing care coordination models in other jurisdictions was made by Dr. Eyal Cohen, a general paediatrician who has studied care coordination issues and is developing a pilot model of care coordination for the medically-fragile/technology-dependent subpopulation in Toronto. His presentation included a discussion of the “medical home” concept for care coordination and an overview of approaches from outside of Ontario, used at the following locations for medically-fragile patients:

- Specialist Hospital Model – Dallas, Texas
- Generalist Hospital Model – Milwaukee, Wisconsin
- Primary Care Model – Boston, Massachusetts
- Home Care/Habilitation Model – Stockholm, Sweden.

These institutions were chosen because they were known to Dr. Cohen either through a literature review or personal knowledge and because they represent a diversity of approaches

to coordination. As well, information on these approaches has been published, and each article has an evaluation component.

Dr. Catherine Birken presented two examples of care coordination models for children and youth with complex obesity, recognizing that although there is increasing awareness of the need for care coordination, very few models exist within this area of specialization. The two examples presented were based on the Obesity Management Program at George Washington University highlighting one model based on multidisciplinary care and a second model on non-physician care.³

Dr. Margaret Steele presented an example of care coordination for children and youth with mental health issues, the School Community Intervention Program (SCIP), which has been implemented in London, Ontario. Of particular interest in this model is the role of the Ministry of Children and Youth Services (MCYS) in the development and implementation of this model.

The Expert Panel also invited Dr. Hema Patel, Program Director of the Intensive Ambulatory Care Service at the Montreal Children's Hospital, to describe her hospital's approach to care coordination for children and youth with special health care needs. The Montreal Children's Hospital model is frequently cited as the best developed active care coordination model for children with complex needs in Canada. This service provides a coordinated clinic at a tertiary care centre that allows each child or youth to see multiple specialists at a single visit. The child's care is coordinated by a clinic-based coordinator.

The Panel also heard about Tele-HomeCare, which uses telecommunications technology to link hospital-based care providers to children, their families and home care providers in the child's home.

As well, all Expert Panel members were provided with the Canadian Association of Paediatric Health Centres' document of promising transition practices in Canada⁴.

From this review, the Expert Panel learned that there is much variability in the structure of coordination models. Although there is a small but growing body of literature describing these approaches, there are limited studies documenting evaluation of any of these approaches.

3.0 The Paediatric Complex Care Population

This chapter provides the definitions of each of the three patient populations and an estimate of the total number of children and youth in each population in Ontario. The Expert Panel found no appropriate and/or widely accepted definitions for these populations. The Expert Panel also found that, because there were no operational definitions for these populations, it was difficult to estimate of the number of children and youth within these populations living in Ontario at this time.

The definitions developed by the Subcommittees are a starting point for describing these high-need individuals. As the system gains experience in serving these populations, these definitions could be revised.

This chapter also provides a description of the common characteristics of these three populations. Although the Expert Panel established three Subcommittees to examine special requirements for each of the populations, the members agreed that the three groups had many common characteristics and needs. Indeed, the Expert Panel found that these children and youth were more similar than different, a concept that has been formally identified as a ‘non-categorical’ approach to complex disorders of children and youth⁵.

In addition to these shared characteristics and needs, the Subcommittees identified a number of special considerations for each population. Both the common characteristics and special challenges must be taken into consideration for the care coordination model. The Expert Panel’s goal was to develop the foundation for a single care coordination model that could serve the needs of many populations, with only minor accommodations for these special characteristics in each population.

3.1 Definitions for the Three Populations

3.1.1 Medically Fragile and/or Technology Dependent

For the purpose of this Expert Panel, the Medically Fragile and/or Technology Dependent Subcommittee chose to concentrate on children who have highly complex or numerous medical needs that are challenging to meet efficiently and effectively. The Subcommittee did not include those patient populations whose needs are already being reasonably well met in long-established service delivery programs (e.g., patients in oncology or solid organ transplant programs), even though these children might also be described as medically fragile.

These children and youth have health needs that are chronic, severe and complex. The specific criteria developed by the Subcommittee to characterize this population are provided in Table 1.

Table 1: Operational Criteria for the Medically Fragile and/or Technology Dependent Population

<p align="center">Medically Fragile and/or Technology Dependent Under 18 years of age PLUS at least ONE criterion from each of the following conditions:</p>						
Technology dependent and/or users of high intensity care	AND	Fragility	AND	Chronicity	AND	Complexity
<p>Child is dependent at least part of each day on mechanical ventilators, and/or</p> <p>Child requires prolonged intravenous administration of nutritional substances, or drugs, and/or</p> <p>Child has prolonged (≥ 1 month) dependence on other device-based support, including:</p> <ul style="list-style-type: none"> • tracheostomy tube care, • suctioning, • oxygen support, or • tube feeding, and/or <p>Child has prolonged (≥ 1 month) dependence on any other medical devices to compensate for vital bodily functions, and requires daily or near daily nursing care, e.g.,</p> <ul style="list-style-type: none"> • apnea (cardiorespiratory) monitors • renal dialysis due to kidney failure • urinary catheters or colostomy bags plus substantial nursing care, and/or <p>Child is not technologically dependent but has any chronic condition that requires <u>as great</u> a level of care as the above group, such as:</p> <ul style="list-style-type: none"> • children who, as a consequence of their illness, are completely dependent on others for activities of daily living at an age when they would not otherwise be so dependent. • children who require constant medical or nursing supervision or monitoring resulting from the complexity of their condition and/or the quantity of oral drugs and therapy they receive. 		<p>The child has severe and/or life-threatening disease.</p> <p>Failure of equipment or treatment places the child at immediate risk.</p> <p>Short-term changes in the child's health status (e.g., an intercurrent illness) put them at immediate serious health risk.</p> <p>As a consequence of the child's illness, the child remains at significant risk of unpredictable life-threatening deterioration, necessitating round-the-clock monitoring by a knowledgeable caregiver.</p> <p>The child has had 2 or more admissions to hospital lasting 10 or more days in the past year.</p> <p>The child has had 10 or more outpatient clinic visits in the past year.</p>		<p>The child's condition is expected to last at least 6 more months</p>		<p>Involvement of multiple health care practitioners</p> <p>Health care services delivered in at least 3 of the following locations:</p> <ul style="list-style-type: none"> • Home • School • Hospital • Children's treatment centre • Community-based clinic (e.g. doctor's office) • Other (at clinician's discretion)

The Expert Panel's scope does not include children who are **at risk** of becoming medically fragile or technology dependent. The Subcommittee highlighted that these children also need to be identified and managed for optimal outcomes and to prevent added complexities from developing.

The Subcommittee members believed that any child who meets the proposed description of this population would likely have (or at least be waitlisted for) significant home care services. Accordingly, we surveyed all 14 Community Care Access Centres (CCACs) to report the number of children and youth in Ontario who met the Expert Panel's definition of medically fragile and/or technology dependent. A copy of the survey is provided in Appendix C.

Survey respondents reported over 2,200 medically-fragile and/or technology-dependent children or youth* who currently receive care from the 14 CCACs in Ontario. Fifty-seven percent of these children require constant medical or nursing supervision or monitoring resulting from the complexity of their condition and/or the quantity of oral drugs and therapy they receive.

The Expert Panel did not survey the paediatric academic health sciences centres at this time. Such a survey will be necessary and important to further refine the estimate of the number of children and youth in this population.

3.1.2 Complex Severe Obesity

For the purpose of the Expert Panel's work, the characterization of complex severe obesity has been adapted from the Canadian Clinical Practice Guidelines on the Management and Prevention of Obesity in Adults and Children.⁶ Specifically, this patient population includes all children and youth under 18 years of age who have a body mass index (BMI) of greater than the 95th percentile for their age and gender, as well as any one of the following conditions:

- At least one significant obesity-related co-morbidity requiring specialty care. (See Table 2.)
- Other co-existing chronic illness. (See Table 2.)
- A BMI greater than the 99th percentile for their age and gender.

The Subcommittee members chose to include children with a BMI of greater than the 99th percentile to capture the young child with severe obesity who may not yet have developed comorbidities related to obesity, but is at very high short-term risk and would benefit from intervention at a younger age.

* This estimate should be interpreted with caution. Not all medically fragile children will qualify for CCAC services. For example, children with enterostomy tubes only qualify for services for a few weeks, although they continue to have the tube and be medically fragile according to the Expert Panel's definition. Also, the list of technologies used in the CCAC survey to identify technology dependency will require further discussion as this population is better understood.

Table 2: Operational Criteria for the Complex Severe Obesity Population

Complex Severe Obesity				
Under 18 years of age Body Mass Index (BMI) greater than 95 th percentile for age and gender PLUS at least ONE of the following conditions:				
<p>A significant obesity-related co-morbidity requiring specialty care such as:</p> <ul style="list-style-type: none"> • Technology-dependent sleep disordered breathing (e.g., BiPAP/CPAP) • Obesity-related type 2 diabetes/inadequate glycemic control. • Pseudotumor cerebri • Dyslipidemia – requiring medication according to the American Heart Association guidelines • Hypertension requiring medication • Severe psychosocial impairment (e.g., significant absence from school, bullying) • Psychiatric illness (e.g., eating disorder, depression recognized as meeting DSM IV criteria for psychiatric illness requiring subspecialty care) • Obesity-related orthopaedic problems causing functional impairment in activities of daily living 	OR	<p>A co-existing chronic illness such as:</p> <ul style="list-style-type: none"> • Prader-Willi Syndrome or other genetic syndromes with complicated management • Steroid-induced complex obesity with coexisting systemic illness (e.g., cancer, SLE, post-transplant) or other medication-induced (e.g., risperidol in association with serious mental illness) • Hypothalamic obesity or central nervous system tumours (e.g., craniopharyngioma) • Neuromuscular or Central Nervous System disorders (e.g., spina bifida, immobilized patient)* 	OR	<p>A BMI greater than the 99th percentile for age and gender</p>

BMI = Body Mass Index

BiPAP = Bilevel Positive Airway Pressure

CPAP = Continuous Positive Airway Pressure

SLE = Systemic lupus erythematosus

DSM = Diagnostic and Statistical Manual of Mental Disorders.

* Note that a child or youth with complex severe obesity, spina bifida and immobility would also fit the Expert Panel’s definition of medically fragile defined in Table 1.

Based on recent survey data⁷, approximately eight percent of the child and youth population have a BMI greater than the 95th percentile for age and gender. The Subcommittee estimated that about one in eight of these children has one or more obesity-related comorbidities or a significant chronic illness, resulting in an estimate of one percent of the total population meeting these two criteria. This estimate is based on known incidence and prevalence of some of these severe conditions in the general paediatric population and the members' experience in their clinical practice. In addition, an estimated one percent of the population would, by definition, have a BMI beyond the 99th percentile. Therefore, another one percent of children and youth would be included within this criterion, for a total of about two percent of the total paediatric population.

Accordingly, the Subcommittee estimated that of the three million children and youth in Ontario, one to two percent (i.e., 30,000 to 60,000 children) would meet these criteria for complex severe obesity.

3.1.3 Mental Illness and Complicating Psychosocial Factors

This population is characterized as children and youth who have multiple diagnoses of mental illness and multiple areas of demonstrated psychiatric dysfunction as well as functional impairment in one or more aspects of child or adolescent development.

In addition, a majority of the following conditions would be present:

- Significant and severe social and environmental challenges that influence the ability to benefit maximally from care.
- Inadequate response (or non-response) to standard treatment or interventions (where available) or having severe challenges in adherence to interventions.
- Complex medical concerns (e.g., intractable epilepsy).
- Demonstrated risk of severe morbidity or mortality.
- Frequent emergency department use.

This characterization is described in more detail in Table 3.

Children and youth meeting these criteria would also likely have a need for cross-sectoral interventions in more than one of the following areas:

- Mental Health Programs and Services
- Developmental Services
- Special Education
- Child Welfare
- Youth Justice Services.

Given the fragmentation of the existing system of tracking the care and services for this population, and the lack of integrated surveillance systems in Canada, it is necessary to look to other jurisdictions for an estimate of the size of this population. The MECA study⁸ suggests that children with mental illness and severe dysfunction comprise about five percent of the paediatric population.

Table 3: Operational Criteria for the Mental Health Population

Mental Health and Complicating Psychosocial Factors				
<p>Under 18 years of age</p> <p>Multiple diagnoses of mental illness and multiple areas of demonstrated psychiatric dysfunction and functional impairment in one or more aspects of child or adolescent development.</p> <p>PLUS at least three of the following conditions:</p>				
Significant and severe social and environmental challenges that influence the ability to benefit maximally from care.	Inadequate response (or non-response) to standard treatment or interventions (where available) or having severe challenges in adherence to interventions.	Complex medical concerns (e.g., intractable epilepsy).	Demonstrated risk of severe morbidity or mortality.	Frequent emergency department use and/or hospitalization.
AND demonstrating one or more of the following behaviours or characteristics:				
<p>Extreme risk taking behaviour, for example:</p> <ul style="list-style-type: none"> • Involvement with the youth justice system • Addiction to drugs or alcohol • Self injurious behaviour • Teenage pregnancy where there is a health risk to the unborn child • Eating disorders that result in a risk of morbidity or mortality. 	Chronic suicide ideation	Multiple co-morbid diagnoses, for example: Obsessive Compulsive Disorder (OCD) with Attention Deficit Hyperactivity Disorder (ADHD) and Tourette's Syndrome	Inability to attend school due to mental health concerns	Homeless or placed in care due to mental health needs (e.g., family cannot cope with child's behaviour)

Other estimates of the prevalence for mental health disorders range as follows:

- Six-month prevalence of 18.1% for one or more of four child psychiatric disorders (i.e., conduct disorder, hyperactivity, emotional disorder and somatization) in Ontario in 1987.⁹
- Up to 15.8% (child reported) and 19.9% (parent reported) six-month prevalences for mental health disorders in Quebec in 1992.¹⁰

The Subcommittee members felt, based on their experience with children and youth with mental health disorders, that the estimate of five percent having multiple disorders was consistent with the estimated prevalence for one or more disorders noted above. Based on a population of three million children and youth in Ontario, the population within the Subcommittee's operational definition is estimated to be 150,000 children and youth.

3.2 Common Characteristics and Care Needs of These Children and Youth

Regardless of the specific diagnosis, when viewed through a 'non-categorical' lens these children and youth and their families have many characteristics in common that drive special demands on the health care system.

3.2.1 Medically Complex Conditions

By definition, we are examining populations that have extremely complex medical needs. Specifically:

- They have chronic disorders associated with high care needs, and have high potential for significant comorbidities, which make these children and youth and their families high users of health care resources.
- They usually have multisystem disorders, contributing to complexity of care and the requirement for care from multiple care providers, often at multiple locations. Even within an institution, fragmentation of care is a major risk.
- Their disorders are frequently individually rare.* It is difficult for community caregivers to develop the expertise, comfort level or resources to care for these children and youth without significant support from specialists.
- They typically require special medications and/or technologies. Highly knowledgeable care providers need to be familiar with these therapies and supports. As well, back-up systems need to be in place in case of deterioration or technology failure or unexpected family disruptions.
- Their needs can be unpredictable due to the instability of their condition, resulting in a requirement for the child's full patient records to be immediately accessible when problems arise acutely.

* This is especially true for the medically-fragile and/or technology-dependent population. It is less accurate for children with mental health disorders, for whom the underlying mental health condition and comorbid conditions might be relatively common, but the impact of these conditions on their behaviour contributes to the complexity of their care.

- Many of these children are socially disenfranchised, either before diagnosis (e.g., obesity that puts an individual at greater risk of disease and of social challenges) or after diagnosis (e.g., because of the stigma of a mental health disorder or the complexity of the medical condition that limits the ability to participate in childhood activities).
- Because of the complexity of care, these children and youth are at higher risk of medical errors. A 2003 study investigated the national rates of hospital-reported medical errors in paediatric inpatients from 1988 to 1997. This study found that children with special needs or dependence on a medical technology had significantly higher rates of hospital-reported medical errors.¹¹
- These children and youth are all medically fragile, and even relatively mild exacerbations may put the child or youth at significant risk.

The Expert Panel members identified many conditions that might be relatively minor events for a healthy child or youth (e.g., a simple cold, the need for dental surgery, a minor infection) that can be potentially catastrophic ‘tipping points’ for the medically fragile population. Relatively minor surgical procedures such as appendectomy become high-risk surgeries for children and youth with severe obesity. A laparoscopic approach may not be feasible; there is a higher risk for post-surgical pulmonary atelectasis (or segmental lung collapse), requiring longer duration on a respirator and period of hospitalization. Post-surgical infection risk is greater, particularly if the child has additional obesity-related comorbidities such as type 2 diabetes.^{12,13} For the mental health population, a routine test or examination at school, a particularly challenging school project or breaking up with a friend, a family move or a change of school can cause sufficient stress for the child or youth to experience a significant exacerbation of their mental illness resulting in disengagement from school, which further compounds the child or adolescent’s psychosocial problems.

These tipping points can cause a cascade of unfortunate clinical consequences, even though the trigger may not even be a medical issue. These children and youth are fragile, and it does not take much to upset the precarious balance of their lives. A huge effort is sometimes required to restore that balance when a tipping point is reached. Ongoing monitoring and ready access to knowledgeable medical support are needed to maintain these children in the community safely and effectively.

In the treatment and management of these children and youth, parents and professionals must build, improve and sustain the children’s and youths’ resilience so that they have a greater tolerance for changes in their condition. For their families, the needed resources should be readily available to ensure the families can react appropriately and quickly to minor perturbations in their child’s health or family situation.

3.2.2 High Burden on Health Care System

The complex conditions and needs of these populations create a high burden on the health care system:

- These children and youth are frequent and high intensity users of health care resources.

- The complexity of their conditions requires that the caregivers have special expertise. For example, sleep-disordered breathing is a well recognized and potentially life threatening complication of complex obesity¹⁴ and requires formal polysomnography for adequate diagnosis and ongoing treatment. These children, therefore, need ready access to sleep laboratories experienced in the evaluation and management of these disorders in children. Of the 34 sleep programs in Ontario contacted by a member of the Expert Panel, only 14 are comfortable caring for children of all ages, an additional 11 will see adolescents, but are not comfortable seeing children under 12 (particularly in the presence of complex obesity resulting in obesity hypoventilation), and nine will see only adults.
- When access to knowledgeable providers and the individual's complete patient record is not available, the result can be unnecessary emergency department visits and hospitalizations. Because so few health care providers have direct experience with these children, many providers are uncomfortable dealing with the needs of these children and youth, particularly when the child uses complex technology (e.g., a ventilator) or medications unfamiliar to the provider. Often, these health care professionals will err on the side of caution and admit a child to hospital – or keep the child in hospital longer than is necessary – because the providers do not fully understand the risks or how to manage these disorders. One challenge for care coordination with this population will be to provide the necessary and timely support to front-line clinicians (e.g., emergency room physicians) to ensure that the system responds appropriately to the urgent needs of these children.

3.2.3 High Burden on Families

The high burden of these conditions is not limited to the health care system. The child's family, including parents and siblings, carries a significant burden as well. Families experience both acute and chronic stress and are known to have poorer physical and mental health than comparable adults.¹⁵

Discharging these children home safely places a high degree of stress and workload on families, not all of whom may be capable of dealing with these demands without significant community support. There are also challenges for schools and daycare facilities in accommodating the needs of these individuals.

Of note, the child's 'family' is not necessarily his or her biological parent. Some of these children and youth can, for example, live with a foster parent or be a crown ward. The care coordination model must also recognize that the primary care-giver and decision maker might not be the child's parent.

3.2.4 A Family Condition

In many cases, the child or youth is not the only member of the family needing care. For example, obesity is often a family condition – it has been estimated that 70% of the contribution to obesity is genetic and 30% due to environmental influences.¹⁶ Similarly, a child or youth with a mental health disorder will often have a parent with a mental health disorder.^{17,18,19}

Thus, successful treatment requires coordinated treatment of the entire family, not just the child, which demands high-functioning links with the adult health system. When effective, such links will also facilitate the transition of care of these youth when they enter adulthood.

3.2.5 Transition Issues

The challenge of transitioning care from paediatric providers to adult providers is common for all groups. The types of services and programs available change administratively when the youth turns 18 (e.g., the family is no longer eligible for in-home respite through one program). These transitions are further complicated by the need to leave paediatric providers behind, begin the task of educating the new adult providers about the child and family's unique circumstances, and adapt to service delivery models that are usually considerably different from those with which they have been familiar for up to 18 years.

3.2.6 The Aboriginal Population

Each Subcommittee commented on the challenges for Aboriginal children and youth with complex medical needs:

- When a child or youth on a reserve is medically fragile, the distance from tertiary centres can be a significant barrier to accessing the needed care.
- Obesity disproportionately affects those with lower socioeconomic status and certain minority ethnic groups, such as the Aboriginal population.²⁰
- Similarly, mental health (e.g., depression) and addiction issues are also common among the Aboriginal population.^{21,22}

3.3 Unique Needs By Population

In addition to the common characteristics and needs described in the preceding section, each of the three populations has a number of special characteristics that must also be taken into consideration in designing a care coordination model.

3.3.1 Medically Fragile and/or Technology Dependent

The need for complex equipment complicates the coordination of care for technology-dependent children and youth for a variety of reasons:

- Many of the eligibility criteria for equipment (e.g., home oxygen) are based on the needs of adult patients rather than on paediatric needs, which increases the time and effort required to obtain appropriate equipment.
- Some families are not made aware of options regarding different equipment models and may not be given access to the most appropriate model or device for their child.
- For home ventilation, the initial equipment purchase and set up is through the Ventilator Equipment Pool (VEP). The child's discharge from hospital can be delayed up to six weeks waiting for the Assistive Devices Program (ADP) to approve the equipment request and for the VEP, which does not hold an in-house inventory of most ventilators, to ship the equipment.

- There is no system for regular scheduled maintenance on this equipment. It is not clear who is responsible for ensuring that the equipment continues to function according to the manufacturer's specifications.
- The financial cost to the families is high. The ADP, which subsidizes equipment purchases for these individuals, does not pay the full price of the equipment, nor does it pay for repairs.
- The existence of multiple government-sponsored providers (e.g., the Home Oxygen Program, ADP and VEP), each with distinct criteria, policies and application forms, contributes to an unnecessarily complex application process.

The multiplicity of sources for the necessary equipment, the inconsistency of the eligibility criteria and procurement processes, the assortment of forms required, and the challenge of matching the right equipment to the child further increase the need for a knowledgeable, experienced care coordinator to help the family through the resulting bureaucratic maze, not only to obtain the necessary equipment but also to ensure that it remains functional.

3.3.2 Complex Obesity

It was noted that the complex severe obesity population does not have the same degree of need for after-hours emergency medical care (e.g., emergency room visits) that is observed with the other two populations within this initiative.

3.3.3 Mental Health and Complicating Psychosocial Factors

There is a lack of awareness among health care providers regarding typical clinical and functional presentations associated with paediatric psychiatric disorders, what services are available to manage these disorders and support the child and family, and how to access needed services. In addition, failure of families to recognize mental health disorders and concerns about stigma associated with these disorders can contribute to the unwillingness of the child or the family to seek help for the condition²³.

Children and youth with severe mental illness can function relatively normally for periods of time, with little need for medical attention during those periods. However, the relapsing and remitting nature of these conditions creates a challenge for care coordination in that the child's needs must be carefully monitored during these "normal" periods even though their needs are not as high during this time. Furthermore, seeing these young people when they are functioning well provides service providers an important perspective on their lives and abilities that is extremely useful when they are experiencing difficulties.

Similarly, the fact that a mental health disorder is invisible and can be episodic creates challenges for both diagnosis and treatment. This reality elevates the need for effective outreach services to identify individuals who would benefit from treatment and access to the proposed care coordination model.

4.0 Challenges in Complex Care Coordination

The Expert Panel proposed a framework for examining and developing an approach to coordination that defined three primary areas essential to effective coordination of care and services. These themes, which are common to all three populations, include:

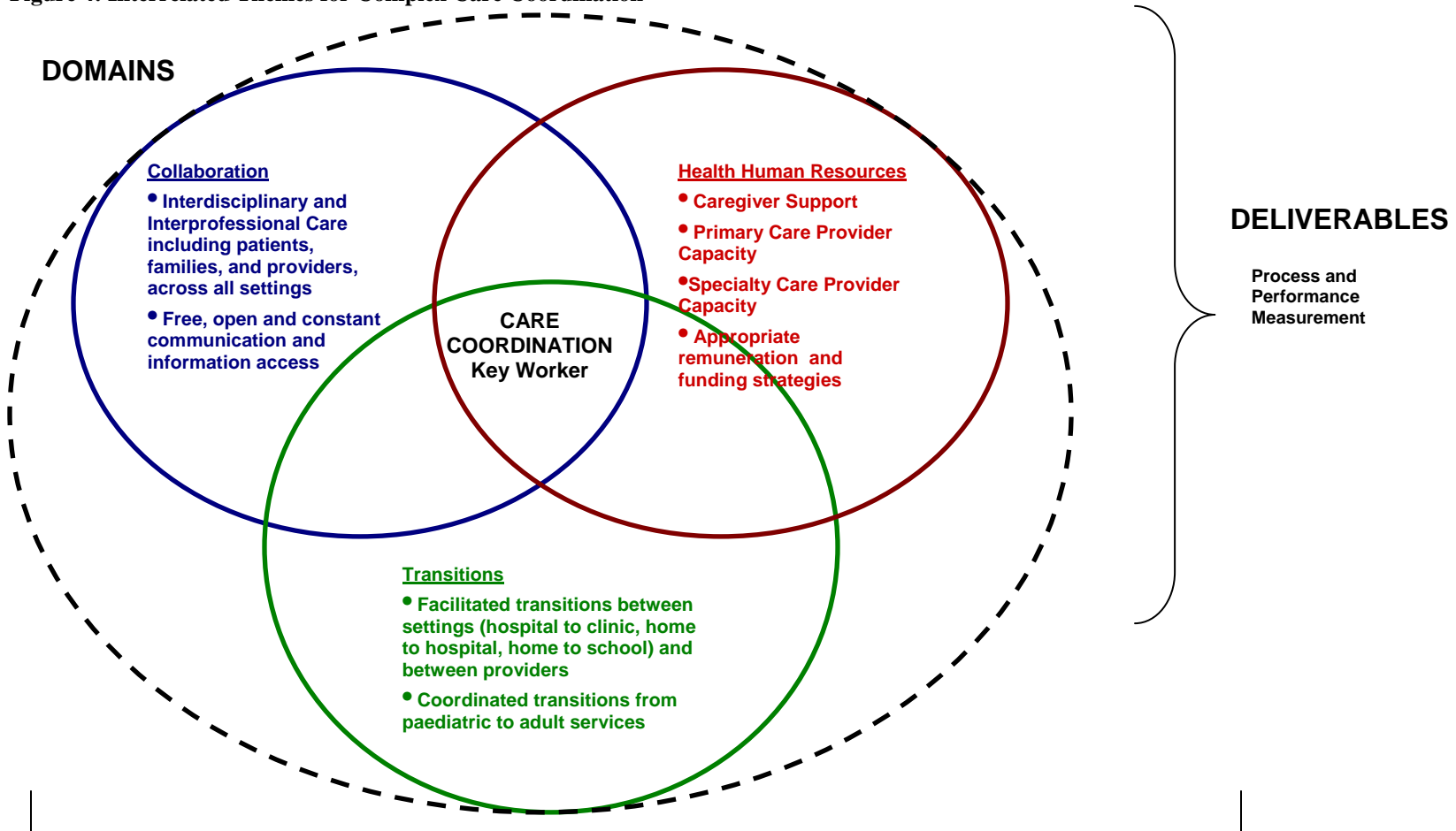
- **Collaboration** among providers across disciplines and professions and between settings and programs (e.g., within and between institutions and between institutions and communities). This collaboration requires effective communication.
- Sufficient competent and experienced **health human resources** to provide timely, appropriate and high quality care and services for this population.
- Smooth, timely and facilitated **transitions** for children and youth across and among providers and settings and over time, including, for example, the transition from home to hospital, from home to school and from paediatric care to adult care.

Although these are listed as separate elements, they are closely interrelated, as illustrated in Figure 4.

As shown at the bottom of the figure, a significant enabler for effective coordination of care is the ability to use technology, including electronic health records and secure modes of communication among the care team to facilitate decision making, the delivery of direct care and communication. An effective health human resources strategy is also essential to ensure the resources are available to deliver the needed care and services. The Expert Panel also acknowledged that appropriate and consistent intra- and inter-ministerial policy is an essential enabler for effective planning and delivery of care for these populations.

Process and performance measures are also needed to allow policy makers to monitor the effectiveness of the approach to care coordination in achieving results.

Figure 4: Interrelated Themes for Complex Care Coordination



HHR = Health Human Resources

4.1 Collaboration

4.1.1 Interprofessional Care

Inter-professional care is the provision of comprehensive health services to patients by multiple health caregivers who work collaboratively to deliver quality care within and across settings.²⁴

As noted in the previous chapter, the care needs of these children and youth are complex and involve many health care and other service providers. Within the health system, the families of these children and youth may have a relationship with several physicians (e.g., a primary care practitioner, specialists, subspecialists), nurses, dietitians, psychologists, social workers, respiratory therapists, and many others depending on the specific nature of the child's condition. The therapies and treatments recommended by these professionals should be complementary, integrated and non-conflicting, and should be comprehensive, but not redundant. To ensure appropriate and effective care, and to avoid fragmentation of care among the various providers and care settings, all care providers will have to collaborate in the planning and delivery of care and services for this population.

Effective coordination requires inter-professional teamwork. Educational institutions in Ontario are only beginning to recognize the importance of inter-professional training for health care professionals and to introduce these skills in the course curricula. All care providers will need to understand and respect the roles and capabilities of other care providers so that they can work together in the best interests of the child and family.

4.1.2 Communication

Inter-professional collaboration must be supported by effective communication between providers and settings. Currently in Ontario, few common tools or systems are available to support communication for the coordination of care for patients with complex conditions:

- Communication between the child, the family and caregivers, and health care and other service providers is not always optimal. For example, one study found that 50% of patients left their physician's office without an understanding of what they were told by the physician.²⁵
- Health care providers often do not communicate effectively with other providers (e.g., between specialists and primary care practitioners, between specialists dealing with different – albeit potentially related – medical issues, between hospital-based and community based care providers). For example, a study of 122 paediatricians found that in 49% of referrals, no information was sent to the specialist by the referring physician. Conversely, the referring physician received feedback from the specialist only 55% of the time.²⁶
- At times, communication between care settings (e.g., hospitals and community providers) is not adequate to provide effective coordination of care (e.g., planning for community services at discharge from hospital does not begin early enough, primary

care practitioners are not informed of discharge instructions, information on the child's condition is not readily available to emergency room physicians).

- Effective communication is needed within the health care system and across ministerial boundaries.

Effective communication for coordination of care can be achieved by identifying a “Key Worker”. The Key Worker model of service delivery involves assigning one person to work in a guide role with families as “*a **single point of contact** for a family, helping the family to **coordinate** their care, not only within the healthcare system, but also **across systems** (education, social services, financial resources, recreation, transportation, etc). **The main concept** of the key worker’s role is to **empower parents** by providing them with support, resources and information tailored to meet their individual needs.*”²⁷

Regardless of the specific model used to achieve more effective collaboration and communication, an inventory of available services in hospital and in the community, with contact information, will be a necessary resource to support communication.

4.2 Health Human Resources

4.2.1 Caregiver and Provider Support

The Expert Panel members identified the lack of supports for caregivers and health care providers who work with these high-need populations. Community-based paediatric health care practitioners are sometimes reluctant to take on the responsibility of caring for these complex and fragile children because the practitioners are uncomfortable or not confident in their abilities in this area. Education and support (e.g., timely access to specialist consultations) are needed to help build their confidence.

4.2.2 Appropriate Remuneration and Funding Strategies

Coordination of care for high-need individuals is not explicitly funded in the health care system:

- Current remuneration for primary care practitioners or community-based specialists does not provide incentives for taking on high-need patients.
- The coordination role for high-need individuals, whether handled by a physician or other health care professional, is not explicitly funded, except in cases where ad hoc programs have been developed and funded for specific populations.

Care coordination is an essential service that augments health care safety, quality and efficiency. Professionals and organizations engaged in health care coordination require appropriate remuneration and funding.

Administrative personnel will be needed to support the care coordination model, including the need for data entry to a common information system.

4.3 Transitions

4.3.1 Facilitated Transitions

A common challenge for children with complex care needs is difficult transitions. These transitions occur along the entire continuum of care, across settings and between providers. These transitions need to be well planned and managed. For example:

- Discharges from hospital can leave the child and family feeling insecure about their ability to manage without the formal support of the hospital.
- Even within a single institution, the transition can be problematic (e.g., transfer from the emergency room to an inpatient unit, transfer from one specialized medical service to another).
- For many of these children, the transition into school, or from one school to another, can be complex, potentially dangerous, and often traumatic.
- Within the community, the patchwork of services provided by a variety of agencies and institutions (e.g., community-based care, hospitals, schools, and private agencies) across several ministries is sometimes almost impossible to navigate. Health care providers do not always have complete information on existing hospital or community services (e.g., the nature of the services, contact information, admission criteria) to which these children and their caregivers should be, or have been, referred. Consequently, children might not even be referred to the full range of available programs and services from which they could benefit.

With any chronic condition, tertiary or more intensive therapy may be required during one phase of care, then a less intense treatment program with possible relapse and flow back and forth between primary, secondary and tertiary care levels. The care coordination model needs to ensure that these children are monitored and continue to have access to coordinated services, especially when the child is in remission for an extended period.

4.3.2 From Paediatric to Adult Services

Transitions can be even more difficult when the needed community support services do not exist. One common example across all three patient populations is the need for programs to help young adults who are leaving the paediatric system and entering the world of adult health care. Expert Panel members highlighted a need for transition programs for youth with complex disorders who are approaching 16 until they are 25 years of age, developed and managed within the child and youth health care sector in collaboration with specialty ‘adult’ services to whom the transition can be made by age 25. The following verbatim letter (in Figure 5) from an Ontario parent to the head of a children’s hospital illustrates how devastating, and in fact fatal, such service gaps can be to youth and families.

**Figure 5: Letter from Parent Advocating for Improved Transition to Adult Services
(Verbatim excerpts used with permission)**

October 200X

Dear Dr. _____,

My son X_____ was discharged from your services on his 18th birthday. I spent the eighteen months prior to this milestone reminding everyone we dealt with of this impending birthday.

There was absolutely no direction available. (Continuity nurse A) tried to help us find another doctor to oversee his care to no avail. Dr. B (orthopaedic surgeon) informed us if he needed care just to go to Emerg. The only one who seemed concerned was Dr. C (specialist). He referred us to a local (specialist). Guess where she referred us? XYZ university hospital! We went from driving 20 minutes to 1 ½ hours!

X_____ is medically fragile, technically dependent – MFTD. He has relied on your hospital for at least 14 of his 19 years. His stays have been numerous, long and complicated at times. My son has been a fighter with a very strong will to live.

I was shell-shocked to find all these people, compassionate, caring and intelligent people, had nothing to offer. No system is set up for our adult children who need specialized care. Adult doctors and adult medicine have no idea what is needed. I did say that I was terrified of what would happen in a crisis. I felt I would lose my son.

On (specific date) my son died in an adult intensive care unit at our local hospital.... Your hospital apparently would not accept him. We do realize how busy your ICU is, that is an absolute truth, but this left my critically ill, medically fragile, and very complicated son in the care of an internist, not an intensivist.

And yes this was our first venture into adult medicine with X_____. Would it have made any difference, I don't know. But we would have been sure he got the care and the benefit of very knowledgeable people of his condition and with his extensive records at hand to give us the best chance of a better outcome.

Dr. _____, what I am asking and the purpose of this letter is the hope that you and your wonderful hospital and staff are aware of the plight of families in such situations. We are left stranded, unprepared for the harsh reality of switching to adult medicine. Their needs medically, physically and psychologically don't change on their 18th birthday. We need people to sep up and find a solution for all the "X_____s" approaching their 18th birthday.

I would be happy to speak to you any time.

(Signed)...

4.4 Enablers of Care Coordination

4.4.1 Technology and Electronic Health Records

An important enabler for care coordination is comprehensive and timely information about the child or youth that is available to care providers, the child and the family. In Ontario today, elements of the required data are often only available in paper records or are stored on multiple databases that are incompatible and isolated from one another (e.g., in different settings or even different ministries). Often, the information needed is not available in the existing databases. Information held by tertiary centres is not available to community providers, and vice versa. A major challenge for care coordination will be to find a way to consolidate the current data for these children and youth in an easily accessible medium.

A further challenge will be to ensure that the child's and family's privacy is protected, while not compromising the ability of health care providers and families to access the data.

These data are needed not only for planning and delivering care, but also for system planning and evaluation. For example, the Expert Panel was unable to find reliable and timely data sources that could provide an estimate of the current number of children and youth in each of the three populations. Although this work is focused on those children and youth who are already in the system, the future expansion of this work should include outreach activities to identify additional candidates for these services. Currently, there is limited surveillance information on these populations to support this type of outreach activity.

4.4.2 Provincial Paediatric Health Human Resources Strategy

The Expert Panel members identified the lack of capacity of the health care system, particularly in the community (i.e., outside of the tertiary centres) to accept referrals for care for children with these complex lives. This lack of capacity was attributed to a number of factors:

- There is a general shortage of health care practitioners in Ontario, particularly in primary care. It is difficult even for some well children and youth to access primary care. The Canadian Medical Association recently reported that 64.7% of family physicians and general practitioners in Ontario have partially or completely closed their practices to new patients.²⁸ The Ontario Medical Association reports that 850,000 people in the province do not have a family doctor.²⁹
- Shortages of other specialist health care providers are also limiting factors for the delivery of care and services for these children and their families. Expert Panel members identified shortages of many health care professionals, including child and adolescent psychiatrists, developmental paediatricians, advanced practice nurses, publicly available psychologists, dietitians, social workers, physiotherapists, speech and language pathologists, occupational therapists.

Care coordination alone will not ensure access to the needed care and services for these children and youth. Often, the needed programs do not exist, or the wait times for services are unacceptably long.³⁰

One parent reported that community nursing resources are so limited that even though their child qualifies for more hours through the Community Care Access Centre, they can only secure 12 hours per week. When nurses are found, the family must invest significant time training these new staff, who often do not stay long, in part because they are not comfortable dealing with the child's complex needs.

An effective long-term human resource plan must be developed to address the recruitment, education and retention of the needed health care professionals.

4.4.3 Policy

Many of these children and youth need to access services in more than one ministry; and even within a ministry, many branches may provide care and services to these children and youth. As shown in Table 4, at least four ministries offer care and services for this population in the areas of physical health, mental health, behaviour, development and family supports.

4.4.4 Process and Performance Measurement

The Expert Panel recognizes the importance of a rigorous evaluation methodology to assess the merits of care coordination and particularly to assess the impact of new processes and models of care delivery from the time these are first implemented.

Table 4: Examples of Services and Programs by Ontario Government Ministries

	Ministry of Health and Long-Term Care (MOHLTC)	Ministry of Children and Youth Services (MCYS)	Ministry of Education (MOE)	Ministry of Community and Social Services (MCSS)
<i>Note that the categories in the first column are somewhat arbitrary. Many services would apply to more than one category of need, but are only shown once.</i>				
Physical health	Emergency Health Services Acute care and rehabilitation services Community Care Access Centres Ontario Drug Benefit Program Assistive Devices Program (Ventilator Equipment Pool)	Children’s Treatment Centres		
Mental health	Mental Health Programs and Services	Child and Youth Mental Health Services		
Behaviour		Youth Justice Services		
Development	Help for Children with Autism School Health Services	Infant Development Program Services for Children and Youth with Autism Spectrum Disorders Healthy Babies Health Children Blind/Low Vision Early Identification Program Infant Hearing Program Preschool Speech and Language Pre- and Post-Natal Practitioner Program Ontario Early Years Centres Student Nutrition Program Early Literacy Specialist Program Health Promotion Resource Centre Aboriginal Healthy Babies Healthy Children Akwe:go Aboriginal Fetal Alcohol Spectrum Disorder and Child Nutrition Program	Special Education Programs and Services Provincial Schools for the Deaf and Blind Section 23 Program	Services for Children and Youth with Developmental Disabilities
Child and family supports	Services from Community Care Access Centres Northern Travel Grants	Respite programs Child Well-being and Protection (Child Protection and Foster Care) Special Needs Resourcing (Child Care) Residential Services Access Mechanisms		Special Services at Home Assistance for Children with Severe Disabilities

Note: The Ontario Secretariat for Aboriginal Affairs has some parallel programs for the Aboriginal child and youth population.

Several policies interfere with the coordination of care for this population. The Toronto Community Care Access Centre³¹ assisted the Expert Panel in identifying many of these policies related to community-based care:

- *Multiple funders, policy makers and providers.* Policies, supports and geographical jurisdictions vary by ministry. Sometimes the policies are conflicting, and there are currently no drivers to encourage ministries to come together in major policy areas. The complexity of dealing with multiple ministries, with their varied mandates and procedures, creates an enormous burden for health care providers, and most particularly for the families, in navigating through the system.
- *Service issues and limitations.* Maximums in the hours of service provided through Community Care Access Centres are not adequate to meet the high needs of these populations. More flexibility is needed in determining their eligibility for care, as is currently in effect for the Aging in Place strategy. Further, there are challenges in providing services across service locations (e.g., CCACs have a mandate to deliver services in home and schools, but are not able to provide services in child care settings).
- *Resource availability and stability.* CCACs are reporting shortages of health care professionals, paraprofessionals and volunteers involved in supporting families in the community.
- *Focus on the family.* Current policies do not recognize the financial burden on families (e.g., co-payments for benefits, medical supplies and drugs not covered by current programs and services, lost income due to care responsibilities, opportunity costs). Some families have expressed a desire for direct funding to allow them to purchase services when and where they need them.

Expert Panel members also noted the following challenges attributable to current policies related to services for these children and youth:

- Age limits and specific eligibility criteria for similar programs vary within and between ministries.
- The inability to refer youth for services in the adult system (e.g., rehabilitation, mental health) until they are 18 years old often causes young people to experience unnecessarily long and arguably unfair waits for care in the adult healthcare system. A youth cannot even get on the waiting list for adult services, which creates an additional delay in accessing these services.
- The policy for the procurement of expensive medical technologies only after the purchase has received formal approval from the Assisted Devices Program (ADP) approved creates delays in hospital discharges.
- Limited billing codes under the Ontario Health Insurance Plan (OHIP) for services provided (e.g., for obesity care) and limited sessional funding are creating a barrier to access to these services by these complex populations. Health care providers (especially physicians) are not remunerated for the time they invest in care coordination.

Although the Ministry of Health and Long-Term Care has no jurisdiction over the other ministries, the Expert Panel believes the Ministry should play a leadership role in bringing all relevant ministries together to facilitate inter-ministerial cooperation in the implementation and ongoing support of the care coordination role. Monitoring and measuring the alignment between ministries will be an important process measure.

5.0 Framework for Complex Care Coordination

5.1 Benefits of Complex Care Coordination

Although the literature documenting the benefits of complex care coordination is relatively sparse, the Expert Panel did find some evidence of significant medical, social and financial benefits through care coordination for medically fragile and/or technology dependent children and youth. However, these studies have some limitations in their relevance to the Expert Panel's proposed model:

- The following studies document evaluated outcomes for the medically-fragile population only. However, other evidence suggests that the same benefits will hold true for the complex obesity and mental health populations as well.
- The studies report observations made about models of care coordination that are primarily hospital based. The reported benefits might be different for a community-based model.

A randomized control trial of 887 patients in Dallas, Texas³² measured the outcomes of a clinic staffed by a physician and a nurse practitioner available 24 hours per day, seven days a week to care for very low birth weight children. Clinic staff made a home visit at enrolment and provided ongoing parental support. This clinic reported the following health outcomes compared to the control group:

- Life-threatening illnesses were reduced by 48%.
- Intensive care unit admissions were reduced by 57%, and intensive care days were reduced by 42%.
- No reported difference in mortality was reported.

A Special Needs Program (SNP) in Milwaukee, Wisconsin assigned a primary care practitioner and a SNP paediatric nurse case manager to each medically-fragile patient (e.g., three or more major organ systems involved). Patients with the most complex needs and frequent admissions to hospital were also assigned to an SNP physician. The program provided inpatient and outpatient continuity of care. Based on an evaluation of equal pre- and post-enrolment periods, the researchers found:

- A decrease in payments to hospitals of \$20-25 million, and
- A decrease in payments to specialists of about \$2.5 million.

These savings were compared to a total program cost of \$2 million over five years. These savings were offset by some increases in costs for home and community services.³³

Studies have also demonstrated different measures of success. In a Pediatric Alliance for Coordinated Care program, six paediatric primary care practices in Boston provided a nurse practitioner for all enrolled patients, developed individualized health plans and arranged a

parent consultant for each practice. The program's investment of \$400 per child per year resulted in:

- Improved accessibility of care,
- Improved parental perceptions of communication, and
- Improved overall satisfaction.

The program also resulted in decreased parental work loss and decreased hospitalizations.³⁴

One local example of improved care coordination is the Tele-HomeCare initiative that was piloted in Ontario from 2000 to 2002. At discharge from acute care, 63 children were provided with telecommunication links in the home to connect them to hospital-based care providers. Based on a formal evaluation of 52 of these cases^{35,36}, it was shown that parents experienced a 22% improvement in their quality of life at discharge home and the quality of life improved gradually over a period of eight weeks. Parents who did not receive Tele-HomeCare services reported only an eight percent improvement in quality of life at discharge.

All of these evaluations measured only the short-term impacts of the care coordination models. The more significant impact is expected to occur in the longer term, particularly for the complex obesity and mental health populations. If coordinated care can lead to improved health outcomes, these children will be at lower risk for related comorbidities in adulthood. For example, studies in adults with impaired glucose tolerance have documented that a modest (e.g., five to seven percent) weight loss results in significant reduction of the development of type 2 diabetes (42-58% risk reduction over three years)³⁷.

5.2 Internationally-Recognized Perspectives

In developing its recommendations for a model of coordinated care, the Expert Panel drew on two internationally recognized concepts related to the coordination of care for children with chronic illnesses and disabilities: Family-Centred Service (FCS) and the International Classification of Functioning, Health and Disability (ICF).

5.2.1 Family-centred Service

Family-centred service (FCS) has been an important topic in child health for 40 years, but only in the past 15 years have serious discussions and research efforts begun to make an impact on the field of child health, particularly in the context of chronic conditions.

CanChild Centre for Childhood Disability Research at McMaster University, funded in part by the Research Branch of the Ontario Ministry of Health and Long-term Care*, has reviewed the existing literature on FCS and developed a framework for service providers to help them understand what FCS means in practice.³⁸ This framework is built on three premises:

- “Parents know their children best and want the best for their children.” Parents should be encouraged to participate in decision making, relying on the technical knowledge and perspectives of health care providers.
- “Families are different and unique.” Services should be customized for each family and its members based on their unique needs.
- “Optimal child functioning occurs within a supportive family and community context: The child is affected by the stress and coping of other family members.” The services need to reflect the needs and involvement of all family members.

Measures of parents’ experiences with FCS have demonstrated that better FCS is associated with better parent mental health, higher levels of satisfaction and lower levels of stress in dealing with the health system.³⁹ These findings have been replicated in several countries.

This framework underlines the concepts that:

- Parents are responsible for their children’s well-being;
- Chronic conditions take a serious toll on the physical and mental well-being of parents;^{40,41}
- Attention to parental needs and well-being will have an impact on their children’s lives; and
- A comprehensive approach to policies, services and programs for children and youth with complicated lives will operate through the medium of parents and families.

5.2.2 International Classification of Functioning, Health and Disability

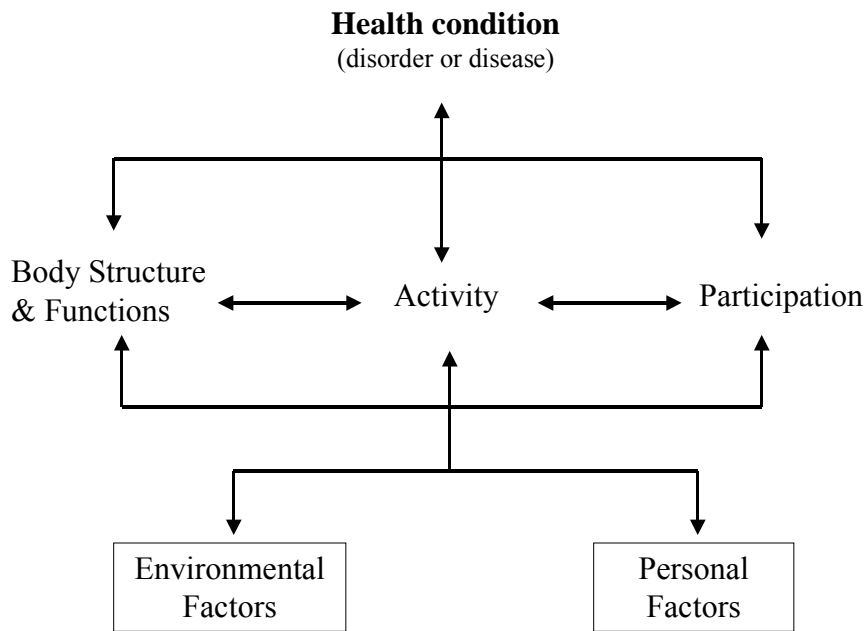
The World Health Organization (WHO) has developed the ICF, a framework for health that considers and integrates several concepts into an approach that differs importantly from the classic linear ‘diagnosis-to-treatment’ paradigm.

The basis of this framework, which is shown in Figure 6, is that any health condition can and probably does affect several aspects of a person’s life – their body, their activities and their participation. To the degree that a child or youth has a physical impairment (e.g., a problem with a body function or structure), the child may be limited in the number and types of activities that are possible, which may also limit the child’s involvement in a life situation (i.e., participation). These impacts need to be recognized so that they can be moderated by

* *CanChild* is a multidisciplinary clinical research group partially funded as a Health System-Linker Research Unit by the Research Branch of the Ministry of Health and Long-term Care, working in partnership with all 21 of Ontario’s children’s rehabilitation centres.

both environmental and personal factors* . This framework opens the door to many possible ‘points of entry’ when working with children and youth with complicated lives and their families. It illustrates clearly how biomedical treatments are only one of many possible approaches that might make a difference to the lives of these children and youth and their families.⁴²

Figure 6: International Classification of Functioning, Health and Disability (ICF)



Source: World Health Organization. *International Classification of Functioning, Disability and Health (ICF)*. Geneva: World Health Organization, 2001.

The environment must, first and foremost, recognize family as a child’s most important context (reflecting the concept of ‘child-in-family’). Thus programs, services, interventions and policies regarding children with complicated lives must address the roles and needs of parents and families as well as those of the children and youth for whom these services or policies are created.

The ICF was published in its final form in 2001. It reflects considerable international consensus and has quickly become a model for thinking about chronic illnesses and disabilities in child health.

* Personal factors are the “particular background of an individual’s life and living, and comprise features of the individual that are not part of a health condition or health states. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behaviour pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level.”

5.3 Elements of a Successful Approach

Based on the published articles identified by Expert Panel members and several existing models for care coordination in the paediatric population, the Expert Panel identified the following elements as being critical contributors to a successful approach to care coordination:

- The first requirement is for the **creation and funding of a coordination role with a specific mandate solely for care coordination**. The role could be assigned to an individual (e.g., a designated care coordinator) or a team (e.g., a clinic); however, the primary accountability for care coordination must be identified and clearly articulated. These individuals can be embedded in the care delivery system so that (a) the individual(s) have the full-time responsibility for this task, and (b) they have the back-up of the relevant teams. These individuals need to be able to act and be perceived as powerful advocates for families.
- The approach must be **patient- and family-centred**, with the family and caregiver having a major role in coordination.
- For some patient populations (e.g., medically fragile and mental health), the child, family and care providers must have **access 24 hours a day, seven days a week to subspecialist support in tertiary centres**. Communication technology (e.g., telephone, telehealth, email, web-based resources) can be an effective enabler in providing access. Outreach services can also provide back-up, but are typically not offered around the clock every day of the year.
- The care coordination service should be **culturally sensitive**.
- The approach to care coordination should be **consistent (although not necessarily identical) across regional and ministerial boundaries**.

The need for collaboration will be addressed as follows:

- The coordination role will **require the support of an inter-professional team that includes the child and family, hospital- and community-based providers, and a formally designated care coordinator**. The inter-professional team will require communication across the many subspecialty members of the team. This team will need to build partnerships that cross organization and institutional boundaries, LHIN boundaries and other geographical barriers.
- The coordination role should be **available through a single point of contact**, which could be either a single care coordinator or a single location (e.g., a clinic).
- Care and services **along the entire continuum and in all settings** should be included in the coordination mandate.

Transitions will be supported as follows:

- **Transition planning** should begin well before any transition takes place. For example, planning for the transition to adult care can begin years in advance by informing the child or youth and family about the changing roles and expectations

within the adult health care system and resource availability once the youth leaves the paediatric care system.

- The system must have **sufficient capacity that referrals can be accepted in a timely manner and in an appropriate location** (e.g., as close to home as practical). Building capacity might involve providing education and training for primary care practitioners in the care of these children or using technology (e.g., telehealth) to provide or support capacity particularly in rural, northern or remote areas.

The health human resources strategy supporting the care coordination model will include the following elements:

- Programs will be developed to provide support to caregivers and primary care providers.
- A provincial health human resources strategy will include the identification of providers where shortages are affecting access to care, and develop a recruitment and retention strategy to address these shortages.
- Incentives should encourage physicians and other health care providers to dedicate the time needed to support the care coordination role.

The Expert Panel believes that these elements should be adopted regardless of whether the care coordination role is community or hospital based and regardless of whether the role is disease specific or for the broader population of children and youth with special health care needs.

5.4 Enablers of a Successful Approach

5.4.1 Technology and Data Collection

The primary enabler for care coordination is an **information system** that includes patient data that can be used for decision-making related to the individual child's care and for evaluation of the coordination model. The patient information should include an up-to-date **one-page summary** of the child's relevant history and current care plan.

This data record could be stored in a central location (e.g., web-based) or carried by the child or family (e.g., a health passport, KIT⁴³ or 'smart card'). Regardless of the medium, the system must meet the appropriate standards for security and privacy, while allowing easy access for health care providers, children and their families from many locations (e.g., the child's home, community-based clinics and services, physician offices, hospitals).

The system should also include a **complete directory of services that are available in each community** (e.g., nature of service, admission criteria, contact information).

There is also a requirement for **secure communication links** with all care and service providers to facilitate coordination of care. This could include electronic referral systems, secure email and videoconferencing capabilities.

5.4.2 Policy Changes

The Expert Panel also identified some **policy changes** that could make the coordination role easier (see Section 4.4.3) such as allowing referrals to adult services before the youth turns 18 so that the youth can be added to the wait list well before the service is needed. A comprehensive review of current, relevant policies should be undertaken, as well as a formal complete examination of policy barriers.

5.5 The Complex Care Coordination Role

Although the care coordination role requires an inter-professional team approach, the responsibility for care coordination needs to rest with a single individual. The American Academy of Pediatrics also proposes a “medical home” model, which defines a health care setting that *“facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient’s family.”*⁴⁴

The American approach typically involves the primary care practitioner acting in the coordination role. The advantage of this approach is that the children’s conditions tend to be diverse in nature (thereby making it impractical to assign this role to a specialist or specialty clinic) and the manifestations of, and problems associated with, the conditions can change over time. A disease-specific approach might not have the breadth to cover all of the multiple care and service needs of the child and family. As well, the primary care practitioner is typically within the same community as the child, unlike a tertiary care centre that might be some distance from the child’s home.

The Expert Panel felt this option was impractical for many reasons, not the least of which was the shortage of primary care practitioners in Ontario and the lack of an appropriate remuneration strategy for this role within the current fee structure. There may also be opportunities to maximize the scope of practice of all relevant professionals (e.g., social workers, nurse practitioners, registered nurses) to address this need for care coordination.

A second option is a practice- or clinic-based care coordinator (as noted earlier, this coordinator is sometimes referred to a ‘Key Worker’) who generally has a background in nursing (particularly public health service) or social work. The major advantage of this approach is that the coordinator’s sole full-time responsibility is the coordination of care for a specified population of children and their families, which makes the coordinator potentially more accessible than a primary care practitioner and more easily able to dedicate the needed time to the coordination and communication activities that are critical to this role. Furthermore, people undertaking this role become expert in it, which conveys legitimacy so that this role is not simply a default activity. This approach was favoured by the Expert Panel, in part because it is more cost-effective and more viable in the current health human resource environment in Ontario.

If a dedicated care coordinator role is used, the incumbent should have knowledge of the roles of the inter-professional team within the community and the tertiary centre, as well as the ability to build partnerships with the child and caregivers.

The coordinator would need sufficient clinical knowledge and experience to be able to perform some medical triage and to develop an individualized service plan for each child assigned to the coordinator. The role would need sufficient status within the system for the coordinator to be able to execute key coordination functions as needed (e.g., making referrals, calling in medical support as required).

Although there is general consensus in the literature that a team approach is necessary, the optimal composition of the team has not been defined, and would vary depending on the specific patient population that is served. The Expert Panel believes that, at a minimum, the core team should include a parent and a care coordinator. Note that this does not preclude a family from choosing to continue to coordinate their child's care without the assistance of a care coordinator, nor does it impose on parents the expectation that they must accept this role should they choose not to.

6.0 Proposed Complex Care Coordination Model

6.1 Goals

The four goals of the proposed complex care coordination model* are to:

1. Improve the quality of life of children and youth with complex medical or mental health conditions and their families by:
 - Minimizing the overall impacts of the illness (including both medical and psychosocial impacts), now and in the future (e.g., reducing the burden of future chronic co-morbidity and improve the child's participation**).
 - Maintaining and encouraging child and family autonomy.
 - Improving parents' experiences and perceptions of services as being family centred.
 - Encouraging the growth and development of every child and youth.
2. Improve the health status of children and youth with complex medical conditions, wherever possible.
3. Maximize time out of hospital and decrease avoidable hospitalizations, days in hospital, inefficient, unnecessary or avoidable ambulatory clinic visits, and emergency department visits.
4. Coordinate the needs of the child or youth and family with home, community and hospital services, including the transition to adult services.

For the medically fragile and complex severe obesity populations, the care coordination will focus initially on health care services, and inter-ministerial issues will be addressed in sequence after the health system changes are in place. For the mental health population, an inter-ministerial effort is required – in fact is essential – in parallel to ensure that resources currently dedicated to care coordination are refocused to ensure coordination across ministerial boundaries and to avoid redundant investments in coordination.

6.2 Basic Approach

The Expert Panel believes that the basic approach to the coordination of care for children and youth with special health care needs should be structured as follows:

- A Key Worker role should be identified as the single contact point for care coordination. Each child and family should be assigned to one Key Worker. How the care coordination responsibilities are shared between the Key Worker and the family would be determined through negotiation between the family and the Key Worker. The intention is NOT to take any authority or access to care and service providers away from the child or family, or to impose on the family more responsibility than they are prepared, at any point, to accept. Rather, the concept is to provide each

* These goals were adapted from the stated goals for Intensive Ambulatory Care Service at the Montreal Children's Hospital, as presented to the Expert Panel by Dr. Hema Patel, Program Director.

** The World Health Organization defines participation in this context as 'involvement in a life situation'.

family access to a consistent guide and advocate to help the family navigate the many elements of the systems they and their child or youth encounter.

- For every child enrolled in the service, a most responsible physician (MRP) would be identified, depending on the child and family's special needs, circumstances and parental choice. This information would be documented in the child's care plan.
- The service would be available for support to families and clinicians (e.g., emergency room physicians) during regular office hours. Extended access (e.g., 24 hours a day, seven days a week) would be offered only for those patient populations and situations where urgent access is required – a situation that might vary from child to child and time to time among children and youth.
- The model would be based on shared care between the local health care team (e.g., the primary care practitioner and other care providers in the child's community) and the secondary and tertiary centres that provide specialized care and services to the child and family. Shared care has been defined as an "approach to care which uses the skills and knowledge of a range of health professionals who share joint responsibility in relation to an individual's care. This also implies monitoring and exchanging patient data and sharing skills and knowledge between disciplines."⁴⁵ Through the shared care model, the local clinicians would be mentored to increase their expertise with these high need populations. Shared care can be supported through technology such as telemedicine and videoconferencing.

The Expert Panel members debated the relative merits of a community- versus tertiary centre-based care coordination model. Although both had merit, many members felt a community-based approach had the following advantages:

- Children and families live in the community, and most of their needs are met in the community, not in a tertiary centre.
- There are few tertiary centres in Ontario, and all of these centres are in large urban areas with no centres in Northern Ontario.
- Children and their families can still access tertiary care through their existing formal linkages with tertiary centres.
- It is easier for services based in the local community to be sensitive to the unique cultural environment in which the child and family live.

Alternatively, a model based in a tertiary centre has the potential to offer:

- More formal accountabilities for the tertiary centre to participate in the care coordination efforts, and
- More direct access to the needed specialized medical resources.

The Expert Panel suggests that the Ministry could pilot one community-based and one tertiary-based model to evaluate the relative merits.

6.2.1 The Key Worker Role

The Key Worker would be responsible for the following interactions with the child and family:

- Acting as a central point of contact for the child and family for virtually all issues that the families identify, recognizing that the Key Worker would not need to solve all the issues, but would be responsible for following through on helping to resolve them, because their role would involve being familiar with, or finding out about, all relevant resources to address the needs of children and families.
- Providing triage when issues arise. This responsibility will require skill in assessing the acuity of the problem and helping the child and family make the most appropriate decision for care (e.g., avoiding unnecessary emergency room visits). Depending on the child's condition and the background of the Key Worker, triage for medical emergencies would be handled in consultation with the tertiary centre's medical team.
- Ensuring that a comprehensive care plan is developed for each child assigned to the Key Worker. This care plan should support interdisciplinary collaborative practice and encompass all phases of illness (e.g., acute, stabilization, pre-discharge, community-based living, emergency access).
- Developing and keeping up to date a one-page summary of critical information about the child and family and their care plan. This summary would be carried by the family or made available to any health care professional who would need information on the child's needs, care plan and care providers (e.g., an emergency room physician) through a web-based information system.
- Acting as an advocate for the child and family (e.g., funding challenges, access to services across the board including health care, education, respite, recreation).

The Key Worker would also be responsible for identifying resources in the community to provide care and services for the child and family as outlined in the care plan. Where necessary, the Key Worker would collaborate with primary care practitioners to find the available resources needed by the child and family.

The Key Worker would also be responsible for facilitating interaction and communication:

- Between the family and providers
- Between care providers
- Between the family and community services, including schools and recreational services
- Between tertiary and secondary care services and institutions
- Between ministries.

In some cases, the family will already have taken on the role of care coordinator and might be reluctant to allow a third party (i.e., the Key Worker) to intervene in their existing relationships with care and service providers. The intention is for the Key Worker to support

and complement the family's role, respecting existing relationships and the centrality of the parents and other caregivers, always seeking to empower them in their role. It is expected that each family would work with the assigned Key Worker to define how the coordination responsibilities will be shared. The extent of the Key Worker's involvement will depend on the family's capacity to take on the responsibilities and the family's preference for how this role should be shared.

Regardless of the sharing of duties while the child is young, as the youth approaches 18 years of age, he or she should be equipped with the skills, knowledge and tools to take on the role of coordinating his or her care into adulthood whenever possible (e.g., when the youth has no developmental impairment that would limit their ability to manage their own care).

The Key Worker would require the following qualifications:

- A clinical (or other relevant) background, sufficient to understand the complex medical and/or psychosocial issues related to the child's needs and care and to deal independently with the majority of the issues that arise. For complex severe obesity, this could, for example, be a social worker, nurse or nutritionist. For mental health, this could be a Child and Youth Worker, a social worker, or a mental health occupational therapist.
- The ability to build effective relationships with children and their families.
- The ability to build effective relationships with care and service providers, and with program representatives in various ministries.
- Specialized knowledge, with the potential for additional "expert" training, as needed, in the needs of the specific population being served.

The success of the care coordination model will depend in large part on how well the Key Worker role is supported:

- The role should be an empowered position, funded appropriately and supported by stakeholder organizations to allow the Key Worker to be able to work effectively within the system.
- Key Workers should have opportunities to network with their counterparts across the province.
- The title for this role should help to establish the role as a senior position that carries status and is worthy of the respect of the other members of the team and appropriate remuneration.
- The case load must be reasonable to allow the Key Worker to dedicate sufficient time to care coordination activities for each assigned family.
- In the longer term, there will need to be educational opportunities for Key Workers to enhance their skills as care coordinators.

More specifically for this care coordination initiative, there will be a need to develop, nurture and support the Key Workers. Defining a realistic role for the Key Workers, ensuring that

the role is respected by all health care providers, and providing the necessary supports to prevent burn-out in this role will determine the long-term success of the care coordination model.

6.2.2 The Coordinated Clinic

Key Workers would carry out the coordination role through a clinic or office based in either a hospital or in the community, or other agency created and/or mandated specifically to carry out this role. The preference is for the community-based coordination service to be as close to the child's home as possible; therefore, a tertiary centre would not usually be an ideal location as the home of the coordination worker or team. In cases where the child's or youth's needs are so complex, and/or their community is too remote or under-serviced to provide this case, a tertiary care-based coordination model might be necessary.

The service would include a single clinic where the child could attend and see all relevant care providers in one visit rather than coming on separate days for separate care providers. Where practical, this clinic could be located in a secondary care centre, where the same health care professions and services would be provided to match and interface with the care provided at the tertiary centres, though necessarily on a less specialized level (e.g., within the limits of community resources).*

In order to care optimally for these children, the secondary centres will need ready access not only to the health records, but also to the expertise and knowledge of the tertiary care centres. Within the tertiary care centre there will, therefore, need to be an individual or team identified as being knowledgeable about the child's health care issues. This person or team will serve as the contact point for access by either the family or the child's community caregivers into the tertiary care centre, and be responsible for coordination of the child's care within the tertiary centre, particularly amongst the different subspecialties involved. Defined medical support through a single access point or phone number for the family and community caregivers needs to be available at all times (i.e., 24 hours a day, seven days a week).

Given the complexity of these children's medical needs, in the majority of cases involvement of tertiary care level specialists will continue to be required.

Opportunities to enhance shared care, such as telemedicine and combined outreach community or tertiary specialist clinics, would be exploited to provide access to services in rural, northern or remote areas and to create opportunities for education and training of community care providers. Creating this capacity in the child's community is believed to enable more frequent follow-up, which has been shown to result in improved outcomes.⁴⁶ This capacity would also enhance the child's access to knowledgeable caregivers, which can improve health care delivery.^{47,48,49}

* For example, for the complex severe obesity clinic at the tertiary centre, the core team would include both a dietitian and an exercise physiologist. At the secondary centre, these services could be provided by a dietitian with an interest and some training in exercise therapy. If needed, highly specialized resources could travel periodically to the secondary clinic and/or use communication technology (e.g., telemedicine, videoconferencing) for consultations at the secondary centre.

The clinic would have formal agreements with all relevant care and service providers (e.g., tertiary- and/or community-based care coordinators, hospitals, specialty clinics, community-based services) defining each organization and individual’s role in the coordination of the child’s care. With the family, the Key Worker would ensure that there is clarity regarding who is to take the lead responsibility for the child’s or youth’s care, and also ensure that professionals at both clinics give common (and not conflicting) information to the children and their families.

Each clinic in a tertiary centre would be aligned with one or more secondary hospitals and would, therefore, also be expected to accept referrals from outside of its LHIN.

The range of health care professionals that might be required to participate in the clinics for each of three populations is shown in Table 5.

Table 5: Proposed Health Care Professionals at the Secondary and Tertiary Clinics

	Medically Fragile and/or Technology Dependent	Complex Severe Obesity	Mental Illness and Severe Psychosocial Factors
Physician Specialists	Paediatrician (general or subspecialist) Developmental Paediatrician Adult Psychiatrist for assessment and referral	Paediatrician with expertise in obesity treatment Endocrinologist Paediatric Surgeon Gastroenterologist/ Nutrition specialist Adult Psychiatrist or other specialists for assessment and referral	Paediatric Psychiatrist, skilled in psychopharmacology Addictions Specialist Developmental Paediatrician Adult Psychiatrist for assessment and referral
Physician Subspecialists	For common comorbidities	For common comorbidities	For common comorbidities
Nurses	Advance Practice Nurse or Nurse Case Manager	Advance Practice Nurse	Advance Practice Nurse
Other Professionals	Respiratory Therapist Social Worker Dietitian Nutritionist Pharmacist Occupational therapist Physiotherapist Dentist	Dietitian Nutritionist Psychologist Child Life Specialist Social Worker Exercise Physiologist	Neuropsychologist Psychologist Social Worker Occupational Therapist Physiotherapist Speech and Language Pathologist Educational Specialist

Note: This table is intended to show the range of health care professionals that might be needed rather than to be prescriptive or exhaustive. The staffing for any given care coordination clinic would depend on the specific needs of the children and youth attending that clinic.

Where the clinics are caring for youth approaching 16 to 18 years of age, additional services might be required to coordinate the transition of the child's care to the adult care system. One role for the Key Worker would be to work with these youth as they plan for the transition to adulthood.

For the medically fragile and the mental health populations, emergency access to medical care will be required outside of regular hours. The complex severe obesity population might also need occasional after-hours emergency care, but less frequently than the other two populations. It is proposed that each tertiary centre identify a team of specialist physicians to share a call schedule for these high needs children and youth. These physicians would be supported in this role by the one-page summary described in Section 6.2.3. A separate roster of physicians will be needed for each of the populations.

6.2.3 Information Needs

The Expert Panel expressed a strong desire for the coordination model to exploit existing information technology. The electronic Child Health Network (eCHN) was suggested as a potential starting point since it already holds much of the information needed and is available in 83 out of 150 hospitals, all Community Care Access Centres, all Children's Treatment Centres* and some physician offices in Ontario.

The current eCHN record does not have all of the information that would be required to plan and coordinate care effectively for these children; an expanded dataset is required. Expert Panel members also identified some concerns about the user-friendliness of the system and the need for either a better interface or more training for clinicians on the system.

In addition, there is a need for a short (e.g., one-page) up-to-date case summary on each child describing the child's medical condition, relevant psychosocial factors, current issues, current medications, names and contact numbers of subspecialists, and other information that might be needed by a health care provider who is not entirely familiar with the child's situation (e.g., an emergency room physician). This feature is not currently available on eCHN.

6.2.4 Education and Training

Education and training are needed for two stakeholder groups:

- The Key Workers need initial and continuing education and training in care coordination. One approach would be to invite all Key Workers to a day-long workshop once or twice a year. This would provide educational opportunities and a forum to network and exchange ideas with other Key Workers, as well as help to build a sense of identity. The development of a "community of practice" would be one way to support these professionals. Telehealth and secure intranet could also be important communication tools for the Key Workers.
- The second need for education is to help build the skill of health care and service providers outside of tertiary centres to care for these children and youth. Shared care

* Children's Treatment Centres serve children and youth up to 19 years of age who have moderate or severe disabilities and multiple special needs.

is one approach to education and mentoring. Joint rounds using videoconferencing provide another way to educate and mentor clinicians across the province.

Videoconferencing can be used in several ways:

- Clinical case conferencing can enhance collaboration and communication and provide opportunities for shared care and care closer to home for patient and family.
- Educational rounds can bring together a local or provincial network of health care providers. The benefits from this activity are not limited to providers in northern or otherwise remote centres, but can benefit all members of the network.
- The Paediatric Telepsychiatry Task Group recently recommended support for a province-wide system of consultations, education and training that exploits videoconferencing and telemedicine processes⁵⁰. This approach can enable clinicians in tertiary centres to reach children and youth in remote areas, and to help build capacity among local clinicians who would have an opportunity to work with clinicians from the tertiary centres.

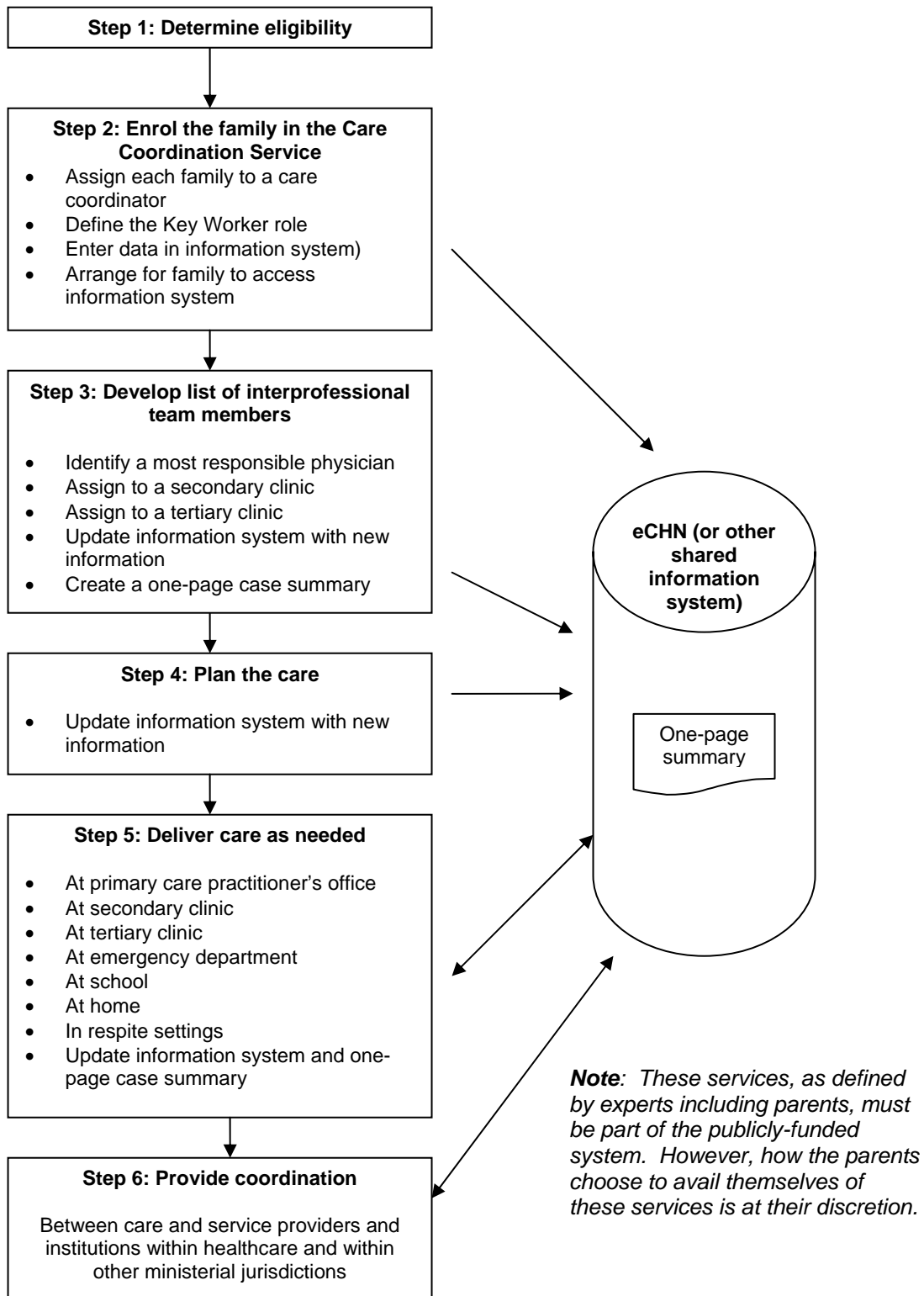
Similarly, Tele-HomeCare has been proven to be effective in easing the transition from hospital to home during the six weeks after discharge from acute care.

6.3 The Family's Perspective

The involvement of the family is integral to the delivery of appropriate care. Some parents prefer to retain primary responsibility for coordinating their child's care. However, it is not automatically the parents' responsibility or obligation to do so. The health care system needs to provide a care coordination service, and the family can choose to use the service or not.

The primary steps in the process are illustrated graphically in Figure 7.

Figure 7: Flow Chart of Processes in Proposed Care Coordination Model



7.0 Performance Measures

As part of the broader evaluative structure, the Expert Panel has identified four categories of outcomes, relevant to any patient population with complex health care needs, that should be measured:

- Improved health outcomes for children and youth with complex conditions
- Improved quality of life for children and youth and their families
- Appropriate utilization of the health system
- Stakeholder satisfaction.

As much as possible, the Expert Panel identified potential indicators to support the evaluation based on the following criteria:

- How well they reflect the goals of the proposed care coordination model.
- The quality of the evidence to support the relationship between the indicator and desired outcomes.
- The feasibility of capturing and analyzing the data needed for that indicator.

The Expert Panel members have suggested potential indicators and/or tools to measure these outcomes; however, more discussion and analysis is required to determine the most appropriate indicators to evaluate the processes and outcomes. Where there is evidence to support it, a target level of achievement against each measurement should be defined.

In addition to the specific performance measures proposed in this chapter, the Expert Panel recognizes the need for development of a rigorous evaluation process to assess how well the proposed approach to care coordination is achieving the desired outcomes. The detailed development of the evaluation framework, including indicators, targets and measures, is an important next step in this process.

7.1 *Improved Health Outcomes*

For all three populations, the impact of a coordinated approach to care could be evaluated using some or all of the following indicators:

- Improved adherence to medication or a treatment program. This indicator could be measured using a specifically designed data field in the information system, with measurements at enrolment and at regular (e.g., two-year) intervals post enrolment.
- Decrease in the number of comorbidities.
- More appropriate use of the health-care system
- Improvements in parent physical and mental health. This could be measured using patient-level data from the Ontario Health Insurance Plan (OHIP) and the Canadian Institute for Health Information (CIHI) or more specific health status tools.

- Improved communications among providers. This can potentially reduce the risk of medical errors (e.g., medication errors, lost information, duplication of investigations). One important measure, therefore, could be the number of medical errors reported for this population.
- Shortened wait times for key services (e.g., specialist consultations). This can also support monitoring of whether the coordination role is making a difference in the child and family’s ability to access care. More timely care should contribute to improved outcomes.

These proposed outcome measures are summarized in Table 6.

Table 6: Summary of Potential Performance Measures for Improved Health Outcomes

Population	Measure
All populations	Improved adherence to medication or a treatment program Decrease in the number of comorbidities More appropriate health care utilization Improvements in parent physical and mental health Reduction in medical errors Reduction in wait times for services
Medically Fragile	More appropriate health care utilization (See Table 8.)
Complex Obesity	Primary outcome: Reduction in obesity (primary outcome) Secondary outcomes: Improvement in known risk factors for sleep disordered breathing, cardiovascular disease and diabetes: <ul style="list-style-type: none"> • Lipid profile: LDL, HDL and Tg (reduction in total cholesterol of 0.3-0.5 mmol/L or approximately an 8-10% improvement).^{51,52,59,53} and/or LDL-C (3-5% improvement) and/or T-CHOL/HDL ratio. • Blood pressure: reduction in systolic and diastolic BP of 3-10 mmHg or approximately 5% reduction. • HOMA-IR – calculated measure of insulin resistance based on fasting glucose and insulin levels (lowering of HOMA-IR by approximately 1.5 units or 30% reduction) • Improvement in apnea/hypopnea index in those youth with established sleep disordered breathing
Mental Health	Decrease in the number of premature deaths or suicides Decrease in functional Impairment

LDL = Low-density lipoprotein HDL = High-density lipoprotein
Tg = Triglycerides mmol/L = Millimoles per litre
BP = blood pressure HOMA-IR = homeostasis model assessment – insulin resistance
LDL-C = Low-density lipoprotein cholesterol
T-Chol/HDL = Total Cholesterol/High-density lipoprotein

The specific measures will vary by population. For example, in evaluating the health outcomes for the medically fragile or technology dependent population, it is important to remember that these conditions are chronic and sometimes degenerative. In some cases, it is not reasonable to expect an improvement in the child's or youth's health.

The ultimate health outcome of treatment for the complex obesity population is to delay, reverse or prevent childhood and/or early onset adult co-morbidities such as sleep disordered breathing, cardiovascular disease and diabetes. These conditions are uncommon in childhood; however, they are highly correlated to obesity and improve with weight reduction^{54,55,56,57,58}. The measurable outcomes in the paediatric age range should include obesity reduction as well as known surrogate measures of future risk of obesity-related diseases including features of the metabolic syndrome^{55, 58}.

A modest reduction in BMI (expressed as standard deviation score (SDS) for age and gender) of 0.5 SDS over a six to 12 month period, or a decrease in BMI gain (approximately 10% reduction in rate of gain) compared to untreated individuals, results in improvement of risk factors related to the development of diabetes and cardiovascular disease. Furthermore, some studies have shown persistent effects up to 10 years following initial treatment. Lifestyle intervention (consisting of dietary, activity and behaviour modification) has shown equivalent responses to various pharmacotherapeutic interventions (sibutramine, orlistat and metformin)^{53,59,60,61,62,63}. In addition, psychosocial measures, such as quality of life, should be assessed⁶⁴. (See Section 7.2.)

The committee recognizes the sensitivity of weight reduction in relation to the risks of development of eating disorders, and stresses that the goal of weight reduction is a return to healthy eating and daily activity, rather than a specific weight per se. Nonetheless, monitoring of BMI as an outcome measure is an important primary outcome, as it has been documented to equate to positive health benefits in many studies.

Secondary outcome measures should include improvement in known risk factors related to sleep disordered breathing, cardiovascular disease and diabetes. The improvements listed in Table 6 have been reported in paediatric obesity treatment studies, with a BMI decrease of approximately 0.3-0.5 SDS.

For the mental health population, the focus will be on improvement in functional impairment. The Provincial Centre of Excellence for Child and Youth Mental Health's Report to the Ministry of Children and Youth Services and the Child and Youth Mental Health Indicators Panel sponsored by the Ministry of Children and Youth Services have developed a series of indicators for the mental health population. The tools used to measure these indicators are as follows:

- Child and Adolescent Functional Assessment Scale (CAFAS). The CAFAS measures the severity of functional impairment in children and youth with behavioural, emotional, or substance use problems. It can also be used to assess clinical progress and treatment outcomes.

- Brief Child and Family Phone Interview (BCFPI). This tool provides standardized scores for mental health, child functioning family adjustment, caregiver mood and family functioning.

7.2 Improved Quality of Life

The Expert Panel recommends a family-centred approach to measuring health outcomes focusing not just on the child but also on the “child-in-family”. Accordingly, the panel has suggested that improvements in the quality of life (QOL) scores be measured using standard assessment tools. This area is still a work in progress, with more investigation needed into what the most appropriate measures would be for these populations.

These quality of life perspectives could include the following measures of participation in life, including activities in the community by children and youth and their families (i.e., parents and siblings):

- Fewer missed days of school for the child
- Fewer missed days of work for the parent(s)
- Increase in proportion of children who graduate from high school
- Improved parental health.

These proposed measures are shown in Table 7.

The Expert Panel has suggested several potential tools to measure quality of life:

- PedsQL – an easy to perform, brief and validated assessment tool used in paediatric obesity studies
- KidSCREEN for children and youth aged 8-18 years
- SF-36 (short-form) for parental health status
- Measures of adult health drawn from Statistics Canada health surveys
- Global Assessment of Functioning Scale.

These measures would all require collection of the relevant data from the family. The Expert Panel recognizes that the data collection burden for the clinicians and families should be minimal.

Table 7: Summary of Potential Performance Indicators for Improved Quality of Life

Population	Indicator
All populations	Fewer missed days of school for the child Fewer missed days of work for the parent(s) Increase in proportion of children who graduate from high school Improved parental health

7.3 More Appropriate Utilization of the Health System

One of the original drivers of the paediatric wait time strategy was to ensure the appropriate utilization of emergency, critical care and acute resources. Therefore, it is important to include utilization measures such as:

- Emergency room visits¹
- Intensive Care Unit (ICU) bed days
- Acute care admissions
- Acute bed days, psychiatric bed days,
- Alternative level of care (ALC) days
- Utilization of the adult health care system by parents of these children

These proposed measures are shown in Table 8.

Table 8: Summary of Potential Performance Indicators for More Appropriate Utilization of the Health System

Population	Indicator
All populations	Intensive Care Unit (ICU) bed days Acute care admissions Acute bed days Alternative level of care (ALC) days Utilization of the adult health care system by parents
Medically Fragile	Emergency room visits
Complex Obesity	Emergency room visits
Mental Health	Psychiatric bed days

For some of these measures, a decrease in utilization is not necessarily a desired outcome. The interpretation of the observed trends must take into consideration a number of factors in evaluating the performance. For example, a shorter length of stay might mean an increase in readmissions, but still result in a total reduction in number of days in hospital for the child or youth. As another example, if a child's parent requires medical care (e.g., psychiatric care for a mental health disorder), identifying that need and arranging for a consultation and/or treatment would increase utilization of the health care system, but would, in this example, be an appropriate (and necessary) increase.

Other indirect measures of system utilization could include a measure of increased treatment capacity and/or decreased stress among care providers.

¹ A reduction in emergency room visits might be an appropriate target for the medically fragile population, but is not necessarily a desired outcome for the mental health population if, for example, the emergency room visit is timely and if it prevents hospital admission.

Utilization measures are only one side of the cost/benefit equation. To fully assess the financial value of care coordination to the overall health system, we will need to quantify the cost of service so that it can be evaluated in the context of the savings (e.g., changes in utilization of scarce and costly health care resources). To this end, measures of the cost of care coordination could be developed, depending on the nature of the coordination model that is adopted. For example, in a clinic-based model, the cost indicator could be cost per visit or cost per child (per year).

7.4 Stakeholder Satisfaction

The overall success of the coordination model will be reflected in the perceptions of the children and their families about the perceived benefits of the model:

- Overall child and family satisfaction
- Child and family perception of care, including experience of family-centredness of the services.
- Provider satisfaction

These proposed indicators are shown in Table 9.

Table 9: Summary of Potential Performance Indicators for Stakeholder Satisfaction

Population	Indicator
All populations	Overall child and family satisfaction
	Child and family perception of care, including experience of family-centredness of the services.
	Provider satisfaction

The Expert Panel proposed the following potential tools to measure child and family satisfaction:

- The NCR-Picker (paediatric) scale or the more widely used Client Satisfaction Questionnaire.
- Burden on Family Scale
- *CanChild's* Measure of Processes of Care (MPOC).
- Canadian Occupation Performance Measure (COPM). This measure is a client-specific measure in which people identify the issues they want to address in self-care, productivity and leisure. They identify important issues and the level of satisfaction they have with these services, which helps to create goals for intervention. The Key Worker could use this measure every one or two years with each family.

- Client Perception of Care^{*} measures the domains of access, appropriateness, outcomes and satisfaction using a five-point Likert scale.

7.5 Process Measures

In addition to the outcome indicators noted in the previous sections, it will also be important to evaluate processes to ensure that the proposed coordination model is well-positioned to achieve its longer-term goals (e.g., reduction of adult-onset diabetes for children and youth with complex severe obesity) and is sustainable over time. Important process considerations could be evaluated, for example, by answering the following questions:

- Has care coordination improved within individual health care providers?
- Has care coordination improved across providers and sectors?
- Do the Key Workers have the clinical and administrative supports they need to be effective?

These indicators will require additional discussion and analysis.

^{*} This tool was also identified by the Provincial Centre of Excellence for Child and Youth Mental Health and the Child and Youth Mental Health Indicators Panel sponsored by the Ministry of Children and Youth Services.

8.0 Implementation Guidelines

The Expert Panel's mandate included the development of guidelines for the effective implementation of potential care coordination programs at the departmental, institutional, regional, LHIN and provincial level.

The Panel has also included a summary of critical next steps in the development, implementation and evaluation of the proposed model of care coordination.

8.1 Leadership

During the early implementation, a single provincial lead will be needed to assume overall responsibility for the initial pilots and their evaluation. This would be a provincial role to ensure consistency across all LHINs. This role should be within a senior management position to ensure that the incumbent has sufficient decision-making authority and is credibly empowered to engage other representatives of all relevant ministries.

The incumbent should have a direct line of communication with Ministry Leads to move this initiative forward effectively within expected timeframes. The Expert Panel sees the paediatric complex care coordination strategy as falling within the umbrella of the Ministry's proposed Maternal, Child and Youth Health Strategy.

It is expected that the five paediatric academic health science centres (PAHSCs) will also take a leadership role (e.g., arrange the tertiary clinics) in their catchment area.

Once the Expert Panel report is approved, the Ministry will need to communicate the proposed changes – and its support of those changes – to all stakeholders. A formal communication strategy will be required.

8.2 Provincial Responsibilities

8.2.1 Engagement of Other Ministries

The Ministry of Health and Long-Term Care will need to create a supportive and nurturing environment for the pilot care coordination model. First and foremost, the Ministry needs to engage other ministries whose programs and responsibilities touch the lives of children directly, to solicit support for a cross-jurisdictional approach to care coordination:

- By working together, the ministries can identify resources that are already dedicated to care coordination and potentially reassign and realign these resources to achieve the goals of the proposed model. A visible commitment to working together will enhance the credibility of the proposed program and the Key Worker role.
- The inter-ministerial collaboration can also help to remove (or at least temporarily waive) some of the policy restrictions that are frustrating current efforts at coordination, access to care and procurement of needed technology.

8.2.2 Support for the Key Worker Role

The Ministry will need to develop a standard role description for the Key Worker that explicitly describes expectations of the Key Worker role. At the same time, expectations of other stakeholders (e.g., primary care practitioners, hospital- and community-based providers, hospitals and CCACs) in supporting and working with the Key Workers should be clearly articulated.

Once the Key Worker role has been defined, the Ministry will need to assign the mandate and related funding for complex care coordination to an organization that can host the Key Worker. Some members of the Expert Panel believe that this should be assigned to CCACs because they already have a mandate and are developing models for care coordination. A community-based organization was also thought to be most appropriate given that most of the care coordination needs are in the child’s or youth’s community. Other members felt the needs of these children and youth are too complex to be coordinated effectively outside of a tertiary centre.

The educational and professional support needs of the Key Workers are best managed at a provincial level to ensure provincial standards. Educational and networking opportunities can be developed through a provincial “community of practice”.

8.2.3 Investment in Supporting Technology

The Key Worker role and the broader care coordination program will need to be supported by a user-friendly, web-based information system. Three committees are needed to support the development of eCHN (or other information system) to meet the needs of the proposed care coordination model: Content, Technical, and Privacy and Ethics committees. The preliminary scope for these committees is provided in Figure 8.

Figure 8: Technology Committees to Support Development of eCHN or other information system

Content	Technical	Privacy and Ethics
Identify new data fields (e.g., BMI and percentile for obesity)	Define requirements and strategy for robust sharing capability (e.g., web-based)	Conduct a privacy impact assessment.
Define the one-page case summary	Improve user interface OR train and educate to use the current system (if eCHN is used).	Determine who can access to the data and the process to access the data.
Define accountability for data entry	Determine who will own the user interface.	Define requirements for selective data sharing.
Define access to editing	Develop a data quality plan.	
Identify data sources (e.g., labs, diagnostic imaging, electronic health records and information systems, dictated notes).		

BMI = Body Mass Index

8.2.4 Health Human Resources Strategy

One of the most significant barriers to successful implementation will be the availability of health care providers to provide timely and quality care for this population. If adequate capacity (e.g., human resources) is not available to meet the treatment needs of these children

and youth, the current level of frustration over access to care will persist. Coordination of care brings little benefit if the care is planned but not deliverable or is delayed for an unacceptably long time. A provincial health human resource strategy is a foundational element in the successful implementation of the proposed care coordination model.

8.2.5 Review of Existing Models

A final step in preparing for the roll-out of the proposed care coordination model would be to examine existing high-functioning networks for the delivery of care to high need populations to learn from them and potentially build on these networks if appropriate.

8.3 Regional Responsibilities

The LHINs will be expected to include the responsibilities for care coordination through accountability agreements with funded organizations (e.g., hospitals and CCACs). The types of responsibilities that can be incorporated into these agreements include, for example:

- Supporting the Key Worker
- Providing the necessary supports for the proposed clinics
- Ensuring after-hours access to specialists, where appropriate
- Providing support to community providers through telemedicine, videoconferencing and shared care (for tertiary and secondary centres)
- Monitoring and reporting relevant data on populations, processes and outcomes.

These requirements need to be clearly articulated and highlighted as an important part of the accountability agreements so that the Key Worker has the authority to fulfill his or her role and do the job effectively.

It will also be important for each LHIN to align itself with a paediatric academic health science centre that will act as the tertiary care institution for these children and youth when complex medical care is required.

The Expert Panel is proposing that the Key Worker role be managed either within the CCAC or in a tertiary centre for reasons noted earlier.

8.4 Hospitals

All hospitals would be expected to:

- Educate all relevant staff on the proposed care coordination model and the hospital's expected role and responsibility within this model.
- Enter into service agreements with the CCAC (as the home of the Key Worker program for each community) defining the hospital's responsibilities (e.g., establish clinics, coordinate activities with the Key Worker, assign a primary contact for the Key Worker, provide emergency access to medical care, agree to share care with community-based providers)
- Provide and share relevant data on populations, processes and outcomes.

8.5 Next Steps

The Expert Panel has identified four major tasks as next steps in the development, implementation and evaluation of the proposed model of care coordination for this population:

- Inter-ministerial consultations
- Consultations with key stakeholders
- Development of an operational plan.
- Development of an evaluation framework

The status of the Ministry's current and planned initiatives regarding these tasks is described below.

8.5.1 Inter-ministerial Reference Group

The Ministries of Children and Youth Services, Community and Social Services, Education, Health Promotion, and Health and Long-Term Care have created an Inter-ministerial Reference Group that meets monthly to discuss issues of common interest. The Expert Panel was especially encouraged to hear that the Ministry of Health Promotion is part of this group. It is important to consider secondary and tertiary prevention for children and youth, and their families, in the context of complex health issues.

This group is initially addressing fundamental issues such as the development of common definitions among the ministries (e.g., for overweight and obesity). The Expert Panel's report will be presented to the Inter-ministerial Reference Group for discussion.

8.5.2 Stakeholder Consultations

The Ministry has engaged *CanChild* Centre for Childhood Disability Research at McMaster University to plan and lead consultations with relevant stakeholders regarding the proposed care coordination model and its implementation. These consultations will engage children and their families, primary care practitioners, community service providers, representatives of services for these children and youth funded or delivered by other ministries and other stakeholders as identified through *CanChild's* planning for these consultations.

It is hoped that the consultation process can be substantially completed within six months, beginning after the Expert Panel report has been submitted to the Ministry. The planning for these consultations will build on work already conducted in this area.*

8.5.3 Operational Plan

Members of the Expert Panel expressed concern that, without an operational plan, there was a risk that the recommendations might never be implemented. It was agreed that, although an operational plan was outside the scope of the Expert Panel's mandate, it was important to ensure that this important planning phase was initiated soon.

* Considerable consultation has already been completed with some populations (e.g., families, adolescents,) through other initiatives. *CanChild* will draw on these resources as appropriate.

It is expected that the stakeholder consultations described in the previous section will provide the level of detail on key implementation issues to inform operational planning.

8.5.4 Evaluation Framework

A full evaluation of the impact of the recommendations found in this report will require considerable planning and discussion among the many stakeholders involved in developing this report. The Ministry has engaged *CanChild* to develop an evaluation framework to address relevant process and content-related questions, the scope of which remains to be more completely articulated. At this stage, the contributors to this report propose the following broad concepts as worthy of consideration as the evaluation planning begins.

From what is being proposed in this report, there are clearly a number of areas of both **processes** of service coordination and service delivery, and **outcomes** of those processes, that need to be assessed carefully. It is also essential to recognize the wide range of players who are likely to be affected by changes to the system. These include children and youth with the conditions of importance to this report, their parents, specialist health care providers in tertiary settings, community-based providers, and the educational system, to name the primary people likely to be influenced by enhancements to services for children with these conditions.

Thus, for example, one can identify and measure a host of aspects of outcomes related to the **processes** of service coordination at the system level:

- The extent of communication among players;
- Changes (improvements) in the rates of hospitalization of children and youth with complex disorders;
- The ease of acquisition of services or equipment needed by the children and youth targeted by this initiative; and
- The utilization of health services by parents.

The list of potential foci for evaluation is long. For example, one may be interested in processes as experienced by parents, front-line service providers, program managers and community-based specialists. Again, there are many players whose experience of a changed system may be important to assess.

Inherent in these perspectives is the essential need to explore any and all of these potentially important questions prospectively and longitudinally. Only by measuring at least some of the same targeted outcomes over time will we be able to evaluate what is changing, what is not changing, and what (if anything) might become more of a problem. Furthermore, these longitudinal perspectives need to include both the service and educational systems and individual children and families whose life situations are evaluated over real time.

As but a single example, one might want to assess parental health and well-being (in any of a number of ways, both subjective and objective) as changes are made to the ways that the systems work to serve them and their children in a more effective and coordinated manner.

The choice of the tools to make these and other evaluations will depend, first, on the specific questions that are posed in the evaluation process, and second, on the capacity of any tools to provide the right types of answers to those questions. At this stage, only a broad evaluative structure and philosophy are being proposed.

Specific targets of an evaluation framework should include the following:

- (i) Pilot studies need to be developed to explore options for the implementation of the Expert Panel's recommendations. These pilot coordination models will make it possible to evaluate the suitability of a host of possible outcomes and issues regarding the appropriate measures and the feasibility of collecting relevant data. Potential targets of the evaluation will likely include the health and well-being of children and youth with complex medical needs; the health and well-being of their parents and families; the responses of front-line service providers, specialists and tertiary care programs; and the processes by which communities, regions and the several relevant ministries are able to develop their systems and processes to accommodate the needs of children and youth and their families.
- (ii) Based on the findings of the pilot studies, it will be essential to develop and implement a province-wide Complex Care Coordination program, with the evaluation components built in from the moment the program is launched. This is an essential step toward taking full advantage of ongoing experience of the system to make adjustments as needed, to accommodate changing issues in health care, technology and conceptual shifts, and most importantly to evaluate the impact of these new developments on the several outcomes described above.
- (iii) It will be important for the evaluative processes to include detailed accounts of the implementation steps (successes and difficulties) of any programs and services developed to address the issues identified in this report, as well as providing details of the outcome measures used. It is very likely that other health services jurisdictions, both in Canada and abroad, will seek to learn from the experience of the Ontario Ministry of Health and Long-term Care as these proposed developments in complex care coordination are rolled out and carefully evaluated.

9.0 Recommendations

9.1 *Guiding Principles for the Recommendations*

The Expert Panel's deliberations were guided by the following principles:

- All children and youth have a right to access timely, high-quality and appropriate care
- The planning, delivery and evaluation of health care must have a family-centred approach
- Coordination of care for these high need populations must have an integrated and collaborative approach among individual providers and institutions, across all settings
- Coordination of high-quality health care services can and must result in reduced waiting times, improved health care quality, decreased health care costs and enhanced health outcomes for children, youth and their families
- Decreased wait times and, specifically improved delivery of emergency department services, are vital to the health of all Ontarians.

9.2 *Recommendations*

9.2.1 Engage Relevant Stakeholders in Consultation

Through its deliberations, the Expert Panel confirmed that the coordination of care for these high-need children and youth involves a great number of stakeholders – many professions, many sites and at least four ministries. The Panel has developed a preliminary proposal for a care coordination model. However, the support and engagement of many more stakeholders across all of Ontario will be an essential prerequisite for the success of this model. These consultations should include families, specialist service providers and representatives of programs that are funded and/or delivered by other ministries, in particular the Ministry of Children and Youth Services, the Ministry of Community and Social Services, the Ministry of Education and the Ministry of Health Promotion.

Recommendation 1: That the Ministry of Health and Long-Term Care engage in targeted consultation with key stakeholders to solicit their input on the proposed complex care coordination model and to engage their participation in refining the proposed complex care coordination model.

Program representatives can identify challenges and solutions, but cannot commit their ministries to making changes. Therefore, the Ministry of Health and Long-Term Care needs to lead a cross-ministerial process to identify and align policies and programs to support complex care coordination for these populations. The Expert Panel recommends that the Ministry start with the four other ministries that have the most contact with these children and youth, and eventually expand to include a broader range of services (e.g., the Ministry of Training, Colleges and Universities).

Recommendation 2: That the Ministry of Health and Long-Term Care bring together the Ministry of Children and Youth Services, the Ministry of Community and Social Services, the Ministry of Education and the Ministry of Health Promotion to collaborate in order to ensure efficient and effective coordination and alignment of policies and programs across jurisdictional boundaries and to explore creative reassignments of existing resources dedicated to care coordination.

9.2.2 Adopt the Model

Chapter 6 of this report describes a proposed approach to complex care coordination. This approach should be implemented and carefully evaluated on a pilot basis. The pilot should allow the proposed model to be tested for each of the three populations and across different settings (e.g., urban vs. rural vs. remote, northern vs. southern, tertiary vs. community). The pilot should also be designed to test the best host organization for the Key Worker role.

Recommendation 3: That the Ministry of Health and Long-Term Care adopt the proposed model of care coordination for children and youth with complex needs and approve its implementation on a pilot basis. Implementing and evaluating this model will require funding and support for the Key Worker role, for the coordinated clinics at secondary and tertiary centres and for data collection.

9.2.3 Remove Barriers to Implementation

The Expert Panel identified barriers to access to care and equipment, gaps in programs, and challenges in finding the capacity, particularly shortages in health human resources, to deliver needed care and services.

The following are examples of how a policy could be changed to improve access to care:

- Allow youth to be wait-listed for adult services well before they turn 18 to reduce waiting times.
- Remove (or at least waive for the pilot implementation) the limitation on the number of hours of care for which these children and youth can qualify through the CCAC.

Many suggestions were made to improve access to equipment for technology-dependent children and youth:

- Revise procurement policies regarding access to technologically complex equipment to reflect the needs of paediatric patients.
- Streamline or harmonize the application process across the various agencies, supported by a central database that lists the eligibility criteria, identifies equipment sources, provides copies of the application forms, and tracks details of the users for the purposes of audit and reporting of prevalence of use of this equipment.

- Provide greater flexibility in the procurement of equipment for technology-dependent children and youth, perhaps even considering a self-directed funding option (which could cover more than just equipment purchases).
- Revise the policies related to the provision and funding of ongoing maintenance and repair.

Recommendation 4: That the Ministry of Health and Long-Term Care commission a comprehensive inter-ministerial review of relevant policies and change or waive existing policies and/or create new policies to remove barriers to access to care, equipment and medications, expand the scope of existing services and investigate the option of direct funding where appropriate. To the degree possible, these changes should be consistently implemented across all relevant ministries.

Transition to adult care was an area of concern that was common to all three populations and was emphasized consistently as an area causing great distress for patients and their families. Improved coordination of the transition can help, but some of these youth are not ready to enter the world of adult care at 18 years of age. Their needs could be met through a dedicated program of care during the transition years (from ages 16 to 25, for example) designed specifically for these special populations, or by extending access to existing paediatric services until the age of 25 years.

Recommendation 5: That the Ministry of Health and Long-Term Care consider options to allow paediatric patients to access appropriate specialized child- and youth-focused services beyond 18 years of age, depending on the needs of the youth and family.

The effectiveness of care coordination efforts is limited by the system's capacity to accept and treat these children and youth. The Expert Panel heard that the capacity to deliver care is a major limiting factor in meeting the needs of this population.

Recommendation 6: That the Ministry of Health and Long-Term Care conduct an assessment of the capacity (e.g., health human resources, physical space, equipment) needed to deliver timely and quality care to children and youth with complex care coordination needs and to build the capacity where it is currently inadequate. Building capacity should involve a health human resource strategy for the province, including basic and specialized training for these professionals in the care of these high-need populations.

In addition to ensuring there are sufficient resources, the Ministry also needs to ensure that existing and future health care providers are not discouraged from providing services to these high-need patients or from supporting care coordination activities in their region.

Recommendation 7: That the Ministry of Health and Long-Term Care develop incentives (e.g., changes to remuneration and funding policies) to encourage individual health care providers and health care institutions to provide the care required and to support the complex care coordination activities proposed by the Expert Panel.

9.2.4 Create Necessary Supports

Several disease-specific models for care coordination have been implemented in Ontario with significant success (e.g., Pediatric Oncology Group of Ontario (POGO), the Network of Ontario Paediatric Diabetes Programs, Interlink Nurses, Children’s Treatment Network of Simcoe York). As a first step in identifying and developing the network of care and service providers, the Ministry should be looking to learn from these networks and to build on their existing relationships. This could be done by conducting a formal scan of these networks and, potentially, formalizing the networks to serve the needs of multiple diseases.

Recommendation 8: That the Ministry of Health and Long-Term Care commission a formal scan of existing models of shared care and other collaborative efforts and investigate opportunities to learn from and build on these networks to support the proposed complex care coordination model.

The Expert Panel recognized eCHN (or other similar information system) as a potentially powerful tool for the collection of data to support the planning and delivery of care for these children and youth and for the evaluation of the proposed complex care coordination model. The development of an information system for this population should be conducted in collaboration with other related initiatives (e.g., neonatal intensive care unit (NICU), Paediatric Transport – Critical).

Recommendation 9: That the Ministry of Health and Long-Term Care commit to supporting data collection related to the planning and delivery of care and evaluation of the proposed model. An immediate first step to demonstrate this commitment would be to establish three committees (i.e., Content, Technology and Privacy and Access) to develop the electronic Child Health Network (eCHN) or other similar information system as the data collection and information management tool for care coordination for these populations.

As noted in the previous chapter, a single provincial coordinator should be appointed to accept overall responsibility for the initial pilots and their evaluation.

Recommendation 10: That the Ministry of Health and Long-Term Care appoint a single provincial coordinator for the system of complex care coordination clinics being proposed. This coordinator's role would be to develop and implement a communications strategy, facilitate the development of educational opportunities, and work to facilitate data collection and analysis throughout the province.

9.2.5 Evaluate the Model

Without a rigorous and formal evaluation, it will not be possible to determine whether the proposed model is able to achieve the expected results or to assess potential improvements. This evaluation will need input from families, caregivers and health care professionals.

Recommendation 11: That the Ministry of Health and Long-Term Care develop and implement an evaluation plan that defines formal performance measures and incorporates the collection and analysis of data to evaluate these measures. This plan will require the development of a strategy to measure and monitor the number of children and youth in these populations in a systematic way to support health care planning for these populations.

Glossary

CYSHCN	<p>Children and Youth with special health care needs have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children generally.</p> <p><i>Source: American Academy of Pediatrics</i></p>
Medical Home	<p>The Patient-Centered Medical Home (PC-MH) is an approach to providing comprehensive primary care for children, youth and adults. The PC-MH is a health care setting that facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient’s family.</p> <p><i>Source: American Academy of Pediatrics</i></p> <p><i>The object of which is to provide all CSHCN with a single point of care (typically primary care) from which health care services can be coordinated.</i></p> <p><i>Source: Stille CJ, Antonelli RC. Coordination of care for children with special health care needs. Current Opinion in Pediatrics 2004, 16:700-705.</i></p>
Care coordination	<p>The state of being harmonized in a common action or effort.</p> <p><i>Source: Starfield B: Primary Care: Balancing Health Needs, Services, and Technology. New York: Oxford University Press; 1998.</i></p> <p>Unlike case management... care coordination involves integration of services beyond health care (such as schools), and does not have cost control as a central task.</p> <p><i>Source: Stille CJ, Antonelli RC. Coordination of care for children with special health care needs. Current Opinion in Pediatrics 2004, 16:700-705.</i></p> <p>The deliberate integration of patient care activities between two or more participants involved in a patient’s care to facilitate the appropriate delivery of health care services.</p> <p><i>Source: McDonald KM, Sundaram V, Bravata DM, et al. Care coordination. Vol. 7. In: Shojania KG, McDonald KM, Wachter RM, Owens DK, eds. Closing the quality gap: a critical analysis of quality improvement strategies. Stanford, CA: Standford University-UCSF Evidence-based Practice Center, Agency for Healthcare Research and Quality, 2007. As cited in Bodenheimer T. Coordinating Care – A Perilous Journey through the Health Care System. N Engl J Med 358;10. March 2008.</i></p>
Community	<p>Community settings are places where children and youth can grow and develop. These include but are not limited to: schools, day hospitals, and day care centres. Homes as living places for children and youth and their families, foster families, and volunteer or group families.</p> <p><i>Source: Children and Youth Health Care Network (CYHN)</i> http://www.cyhn.ca/Html/A.html</p>
Inter-professional Care	<p>Interprofessional care is the provision of comprehensive health services to patients by multiple health caregivers who work collaboratively to deliver quality care within and across settings.</p> <p>Source: HealthForceOntario (July 2007). Interprofessional Care: A Blueprint for Action in Ontario, Interprofessional Care Steering Committee, Government of Ontario, p. 44.</p>

Shared Care	<p>Shared care is an approach to care which uses the skills and knowledge of a range of health professionals who share joint responsibility in relation to an individual's care. This also implies monitoring and exchanging patient data and sharing skills and knowledge between disciplines.</p> <p><i>Source: Moorehead, R. (1995). Sharing care between allied health professional and general practitioners. Australian Family Physician 1995; 24(11)</i></p> <p>Shared care is the joint participation of general practitioners and specialists in the planned delivery of care for patients with a chronic condition, informed by an enhanced information exchange, over and above the routine discharge and referral letters.</p> <p><i>Source: Hickman, M, Drummond, N., Grimshaw, J., (1994). A taxonomy for shared care for chronic disease. Journal of Public Health Medicine. 16(4), 447-54.</i></p> <p>Share care is both systematic cooperation, about how systems agree to work together... and operational cooperation at local levels between different groups of clinicians.</p> <p><i>Source: Penrose-Wall, J., Copeland, J. Harris, M. (2002). Shared care of illicit drug problems by general practitioners and primary health care providers: A literature review. School of Community Medicine, University of South Wales.</i></p>
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List of Abbreviations

ALC	Alternative level of care
ADP	Assistive Devices Program
BiPAP	BiLevel Positive Airway Pressure
BMI	Body mass index
CA	Congenital anomalies
CCAC	Community Care Access Centre
CHD	Congestive heart failure
CIHI	Canadian Institute for Health Information
COPM	Canadian Occupation Performance Measure
CPAP	Continuous Positive Airway Pressure
CYHN	Children and Youth Health Care Network
CYSHCN	Children and youth with special health care needs
DSM IV	Diagnostic and Statistical Manual of Mental Disorders, version IV.
eCHN	electronic Child Health Network
FCS	Family-centred service
HHR	Health human resources
ICF	International Classification of Functioning, Health and Disability
ICU	Intensive care unit
LHIN	Local Health Integration Network
MCSS	Ministry of Community and Social Services
MCYS	Ministry of Children and Youth Services
MOE	Ministry of Education
MOHLTC	Ministry of Health and Long-Term Care
MPOC	Measure of Processes of Care
MRC	Most responsible clinician
NICU	Neonatal intensive care unit
OHIP	Ontario Health Insurance Plan
PAHSC	Paediatric academic health sciences centre
POGO	Pediatric Oncology Group of Ontario
PWTS	Paediatric Wait Time Strategy
QOL	Quality of life
SDS	Standard deviation scores
SLE	Systemic lupus erythematosus
SNP	Special Needs Program
VEP	Ventilator Equipment Pool
WHO	World Health Organization

**ONTARIO'S PAEDIATRIC WAIT TIMES STRATEGY
Paediatric Complex Care Coordination Expert Panel –
Terms of Reference**

PURPOSE:

The Paediatric Complex Care Coordination Expert Panel is responsible for examining how to improve care delivery for children and youth with special health care needs (CYSHCN). For the purpose of this Panel, CYSHCNs are defined as:

- i. Children and youth who are medically fragile and/or technologically dependent,
- ii. Children and youth with severe complex obesity or,
- iii. Children and youth who have mental illness with complicating psycho-social factors.

These three groups of CYSHCN were chosen for discussion as they are emblematic of all populations of CYSHCN. The lessons learnt regarding care coordination for these three populations of CYSHCN are meant to be applied to care coordination models for any population of CYSHCN.

The panel will discuss the establishment of interdisciplinary and multi-subspecialty care co-ordination programs for CYSHCNs within the province of Ontario, and will make recommendations on potential complex care delivery models to maximize the efficient use of healthcare resources and ensure timely, high-quality and equitable care delivery that serves the needs of this unique population of children and their families.

BACKGROUND:

The Paediatric Complex Care Coordination Expert Panel is being convened by Ontario's Paediatric Wait Time Strategy (PWTS), whose mandate is to:

- Improve timely access to high-quality paediatric care for all children and youth in Ontario
- Measure, monitor and reduce the wait times for paediatric services by:
 - a. Increasing funded cases volumes, and
 - b. Promoting efficient and effective care
- Provide useful and accurate wait time data for paediatric procedures to the public

The PWTS is expanding its scope of operation to address wait times by encouraging innovative models of care delivery.

Children and youth with special health care needs (CYSHCN) comprise a small percentage of all children and youth in Ontario, but consume a significant percentage of all paediatric health care resources. Care for CYSHCN and their families is often fragmented and divided amongst multiple health care providers, including multiple hospital-based specialists, allied health providers and community organizations. As currently structured, the health care system does not function to provide seamless care for these paediatric patients, resulting in long wait times for paediatric services, inefficient use of resources, untimely delays in the institution of vital therapies, increased medical error potential, fragmented communication, inadequate planning, dissatisfied patients, stressed and burdened families, and frustrated providers, as well as poor health outcomes and compromised quality of life. In addition, the healthcare system does not appropriately recognize the complexity of care inherent to CYSHCN. As

a result, both system structures and funding incentives for individual providers and health care organizations assuming responsibility for the care of CYSHCN is lacking. CYSHCN and their families have significant difficulty identifying willing providers and accepting providers are overwhelmed and unsupported in their efforts.

PAEDIATRIC COMPLEX CARE COORDINATION EXPERT PANEL MANDATE:

The Paediatric Complex Care Coordination Expert Panel is committed to improving timely, high-quality, equitable and efficient health care delivery for CYSHCN. In pursuit of this, the Panel is guided by the following principles:

- All children and youth have a right to access timely and high-quality/appropriate care
- Coordination of high-quality health care services can result in reduced waiting times, improved health care quality, decreased health care costs and enhanced health outcomes for children, youth and their families
- Decreased wait times and, specifically improved delivery of ED services, are vital to the health of all Ontarians

The Paediatric Complex Coordinated Care Expert Panel (“Expert Panel”) will:

1. Offer consensus recommendations on innovative health care delivery models for the coordination of the complex health care needs for three populations of children:
 - Children and youth who are medically fragile and technologically dependent
 - Children and youth with complex obesity, and
 - Children and youth with severe mental illness with complicating psycho-social factors.
2. Develop guidelines for the effective implementation of potential care coordination programs at the departmental, institutional, regional, LHIN and provincial level
3. Establish key performance measures, performance targets, outcome measures and outcome targets to be used to evaluate the success of the potential pilot care coordination programs.
4. Consider process improvements for enhanced care coordination within Emergency Departments

KEY DELIVERABLES & ACCOUNTABILITY:

This Expert Panel will report to and provide their final report (including consensus recommendations relating to the above mandate) to Dr. Charlotte Moore, Provincial Lead, Access to Service and Wait Times, by April 30, 2008.

MEMBERSHIP:

Dr. Peter Rosenbaum will chair this Expert Panel and the Paediatric Medically Fragile Children Sub-Committee of the PCCC Expert Panel.

Dr. Jill Hamilton will chair the Paediatric Obesity Sub-Committee of the PCCC Expert Panel.

Dr. Ian Manion will chair the Paediatric Mental Health Sub-Committee of the PCCC Expert Panel.

Membership will include:

- Senior Administrators
- Paediatricians/Other clinicians/Allied health professionals
- Parents
- Community members/Child and youth advocates

This Expert Panel will include representation from paediatric academic health science centres, community hospitals, primary care, community organizations, advocacy groups and LHINs across Ontario.

ROLES AND RESPONSIBILITIES OF MEMBERS:

The Expert Panel will be divided into the following three sub-committees:

- The Medically Fragile and/or Technologically Dependent CYSHCN Sub-Committee
- The Complex Obesity CYSHCN Sub-Committee
- CYSHCN with Severe Mental Illness with Complicating Psycho-social Factors Sub-Committee

Each Sub-Committee is responsible for the accomplishment of the stated Expert Panel mandate as it relates to their assigned paediatric population. In making their recommendations, each of the three Sub-Committees must give consideration to the following factors:

- Health system definitions of provincial CYSHCN programs, including operational definitions for the assigned paediatric population
- Potential information technology and telemedicine investments required for complex care coordination programs with preference given to identifying and leveraging existing systems where possible (including telemedicine, eCHN and other information system investments)
- Necessary health human resources required for complex care coordination programs
- Procedures to enhance communication and coordination of care amongst the variety of health care providers involved in care for CYSHCN, including acute/tertiary care hospitals, community hospitals, primary care providers, community care givers and family members
- Structured procedures for the coordinated transition of CYSHCN into adult care programs
- Integration of CYSHCN health care services/programs amongst or within LHINs
- Evidence-based quality control and health system accountability measurements that are directly linked to measurable outcomes.

In addition to the above responsibilities, the Medically Fragile and/or Technologically Dependent CYSHCN Sub-Committee of the Expert Panel must consider the dental needs of their population.

The following are recognized to be out of the scope of this Expert Panel but requiring future work:

- A detailed discussion on the relevant ethical issues and resolution of those ethical issues relating to the care of CYSHCN

- A detailed discussion on the challenges and potential solutions for enhanced communication between non-health care providers
- Suitable activities or avenues for the effective dissemination of results of potential care coordination programs for CYSHCN

All members are responsible for attending meetings, advising on items presented for discussion, and, reviewing and providing feedback on materials drafted.

MEETING/PROPOSED COSTS:

Prescribed members will be reimbursed for travel, meals, accommodation and other out of pocket expenses in accordance with the ministry guidelines.

FREQUENCY OF MEETINGS AND TIMELINES:

The Expert Panel will meet for at least two, and no more than 4 days, within the months of February/March 2008 in order to accomplish the work identified in the Expert Panel Terms of Reference. A more detailed timeline will be provided after consultation with Expert Panel members. Timelines may be extended at the request of Dr. Moore.

APPENDIX B: Paediatric Complex Care Coordination Expert Panel Membership

Medically Fragile Children Sub-Committee

Peter Rosenbaum, MD, (Expert Panel chair and Subcommittee chair) Canada Research Chair in Childhood Disability Research, Dissemination and Mentoring, McMaster University, Hamilton Niagara Haldimand Brant LHIN

Jane Cleve, Manager, Special Needs, Specialized Services and Supports Branch, Ministry of Children and Youth Services

Eyal Cohen, MD, Paediatrician, The Hospital for Sick Children, Toronto Central LHIN

Stacey Daub, Senior Director of Planning Services, Toronto Community Care Access Centre, Toronto Central LHIN

Joan Ferguson, V.P. Programs and Services, Bloorview Kids Rehabilitation, Toronto Central LHIN

Peter Judd, DDS, Dentist-in-Chief, Dentistry, The Hospital for Sick Children, Toronto Central LHIN

Ian MacLusky, MD, Head of Respiratory Medicine Service, The Children's Hospital of Eastern Ontario, Champlain LHIN

Linda Rothney, Executive Director, Erinoak, Mississauga Halton LHIN

Garth Smith, MD, Developmental Paediatrician, Child Development Centre, Hotel Dieu Hospital, South East LHIN

Genia Stephen, Parent, South East LHIN

Stephen Swatridge, Chief Executive Officer, Kids Ability - Centre for Child Development, Waterloo Wellington LHIN

Nancy Young, Canada Research Chair & Interim Director - School of Rural and Northern Health, Laurentian University, North East LHIN

Complex Severe Obesity Sub-Committee

Jill Hamilton, MD, (Subcommittee chair) Staff Endocrinologist, The Hospital for Sick Children, Toronto Central LHIN

Khalid Al-Harbi, MD, Paediatric General Surgeon (Surgical Lead in Obesity Program), McMaster Children's Hospital, Hamilton Niagara Haldimand Brant LHIN

Sarah Barker, MD, Paediatrician, Orillia Paediatric Teaching Associates, North Simcoe Muskoka LHIN

Glenn Berall, MD, Chief of Paediatrics and Program Medical Director, North York General Hospital, Central LHIN

Catherine Birken, MD, Paediatrician, Paediatric Medicine, The Hospital for Sick Children, Toronto Central LHIN

Teresa Bruni, MD, Consulting Paediatrician, Thunder Bay Regional Hospital, North West LHIN

Cheril Clarson, MD, Paediatric Endocrinologist, London Health Sciences Centre, South West LHIN

Stasia Hadjiyannakis, MD, Paediatric Endocrinologist, Assistant Professor of Paediatrics, The Children's Hospital of Eastern Ontario, Champlain LHIN

Mary Kaye Lucier, Executive Director, Bulimia Anorexia Nervosa Association, Erie St Clair LHIN

Ivor Margolis, MD, Chief of Paediatrics, William Osler Medical Centre, Central West LHIN

Mental Health Sub-Committee

Ian Manion, PhD, (Subcommittee chair) Executive Director, The Provincial Centre of Excellence for Child and Youth Mental Health, The Children's Hospital of Eastern Ontario, Champlain LHIN

Mary Broga, PhD, Executive Director, Windsor Regional Health Centre, Central West LHIN

Hazen Gandy, MD, Psychiatrist, The Children's Hospital of Eastern Ontario, Champlain LHIN

Frank Gavin, Co-Chair, Canadian Family Advisory Network, Toronto Central LHIN

Abel Ickowitz, MD, Psychiatrist-in-Chief, The Hospital for Sick Children, Toronto Central LHIN

Peter Kennedy, Operational Director, Mental Health Program, Hotel Dieu Hospital Mental Health Services, South East LHIN

Mary Mannella, Manager, Children and Youth at Risk Branch, Policy Development and Program Design Division, Ministry of Children and Youth Services

Robert Morton, CEO, Children's Treatment Centre of Simcoe York, Central LHIN

Margaret Steele, MD, Physician Lead, Child and Adolescent Mental Health Care Program, London Health Sciences Centre, South West LHIN

Ian Wilson, MD, Paediatrician, Assistant Clinical Professor of Paediatrics, Grand River Hospital; McMaster University, Waterloo Wellington LHIN

Other members

Dr. Charlotte Moore, Paediatric Lead, Paediatric Wait Times Strategy, Ministry of Health and Long-Term Care

Tamara Mohammed, Paediatric Wait Times Strategy, Ministry of Health and Long-Term Care

Marilyn Booth, Executive Director, Provincial Council for Children's Health

Marcella Sholdice, Report Writer

LHIN = Local Health Integration Network

CCAC Snapshot:

As you are aware the Ministry of Health and Long Term Care (MOHLTC) has commissioned an Expert Panel to better understand and make recommendations about the care coordination needs for children and youth who are medically fragile and/or technology dependent and their families. In order to inform this process, the Expert Panel requires some baseline information about the number of children requiring this support as well as some supporting information about their needs. Given the CCAC role in serving this population, a brief survey was developed to collect this information through the CCACs. A similar survey may be issued to the Children's Hospitals across the Province.

Operational Definition for Target Population

A child who is medically fragile and/or technology dependent is a child who has health needs that are severe, chronic, complex and challenging for parents and providers to meet efficiently and effectively

General Eligibility (Must meet ALL General Eligibility Criteria)

- Child under 18 years of age.
- Child has a chronic condition
- Child is dependent on technology (such as a ventilator, a gastrostomy tube, or an indwelling central catheter) OR the child is dependent on high intensity care
- Child is medically fragile
- Child's care is complex

In order to qualify, at least one checkbox of all (A through D) criteria must apply.

A) Technology and/or high intensity care dependent (Source: Office of Integrated Services for Children, 1999) [**PLEASE CHECK AT LEAST 1 LARGE BOX, AND, IF APPLICABLE, SPECIFIC SUB-BOXES (E.G. CHILD ON HOME TPN WOULD GET A CHECK FOR CHILDREN REQUIRING PROLONGED IV ADMINISTRATION AND ALSO FOR NUTRITIONAL SUBSTANCES +/- DRUGS)**]:

- Child is dependent at least part of each day on mechanical ventilators.
- Child requires prolonged intravenous administration of
 - o nutritional substances; or
 - o drugs
- Child has prolonged (≥ 1 mo) dependence on other device-based support, including:
 - o tracheostomy tube care
 - o suctioning
 - o oxygen support; or
 - o tube feeding.
- Child has prolonged (≥ 1 mo) dependence on any other medical devices to compensate for vital bodily functions, require daily or near daily nursing care, e.g.,

- apnea (cardiorespiratory) monitors
- renal dialysis due to kidney failure
- urinary catheters or colostomy bags plus substantial nursing care.
- Child is not technologically dependent but has any chronic condition that requires as great a level of care as the above group
 - children who, as a consequence of their illness, are completely dependent on others for activities of daily living
 - children who require constant medical or nursing supervision or monitoring resulting from the complexity of their condition and/or the quantity of oral drugs and therapy they receive

B) Fragility (Please check all that apply):

- The child has severe and/or life-threatening disease.
- Failure of equipment/treatment places the child at immediate risk.
- Short-term changes in the child's health status (e.g., an intercurrent viral illness) put them at immediate serious health risk.
- As a consequence of the child's illness, the child remains at significant risk of unpredictable life-threatening deterioration, necessitating round-the-clock monitoring by a knowledgeable caregiver.
- The child has had 2 or more admissions to hospital lasting 10 or more days in the past year.
- The child has had 10 or more outpatient clinic visits in the past year.

C) Chronicity

- The child's condition is expected to last at least 6 more months

D) Complexity (Please check all that apply)

- Involvement of multiple health care practitioners
- Health care services delivered in at least 3 of the following locations:
 - Home
 - School
 - Hospital
 - Children's treatment centre
 - Community-based clinic (e.g. doctor's office)
 - Other (please list) _____

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