Provincial
Council for
Maternal and
Child Health

building a brighter future

Pursuing the Possible

An Action Plan for Transforming the Experiences of Children and Youth who are Medically Fragile and/or Technology Dependent

The Provincial Council for Maternal and Child Health (PCMCH) is accountable to the Ministry of Health and Long-Term Care and has two distinct roles. First, the PCMCH generates information to support the evolving needs of the maternal-child health care system in Ontario. Secondly, the PCMCH is a resource to the maternal-child health care system in Ontario to support system improvement and to influence how services are delivered across all levels of care.

PCMCH hosted a meeting of the Advisory Group on the Coordination of Care for Children and Youth who are Medically Fragile and/or Technologically Dependent in May 2011. The Advisory Group was charged with identifying priorities and recommending strategies for the achievement of a coordinated system of services delivered in community and hospital settings. The May meeting focused on the recommendations of the 2008 Report of the MOHLTC's Paediatric Complex Care Coordination Expert Panel. Forty participants from across the province explored two objectives a) opportunities to improve care/service coordination while leveraging successful models and b) enablers and system barriers that must be considered when planning changes. Twenty seven recommendations were put forth with several priorities emerging. A Steering Committee was commissioned to drive an implementation plan focusing on policy barriers and service improvement. This paper is a culmination of many Council and Advisory Group discussions and advances a vision and initial plan for change.

Provincial Council for Maternal and Child Health

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Executive Summary

With advances in diagnostics, therapeutics and medical technologies, children who previously would have died in infancy or early childhood are living longer and the complexity of their care and social needs is increasing dramatically. These medically fragile children and youth are highly dependent on technology and/or others for activities of daily living. Their life-long and round-the-clock care needs are a significant challenge for families, service providers and the health, social service and education systems.

The Hard Truths

Due to their frequent and high intensity use of health care resources, **medically complex children and youth are driving paediatric health care costs**. Children/youth who are medically fragile and/or technology dependent account for less than 1% of the paediatric patients yet consume about 32% of child health care spending – about $419 million a year[1] in healthcare spending alone[i].

While the amount of care these children received is substantial, the quality of care is largely suboptimal.[ii] **The required 'system' of services and supports is failing children and youth who are medically fragile and/or technology dependent**. Health services are challenging to coordinate and navigate because:

- The children interface frequently with the entire continuum of health care services (i.e. acute, rehabilitation, home and primary care) and receive care in a variety of locations, including school.
- The complexity and time consuming nature of their care contributes to unnecessary barriers to accessing services and delays in receiving and/or transitioning between services.
- There are significant gaps in the transition from paediatric to adult services that create unacceptable risks and challenges for this population and their families.

The patchwork of services required by this population are provided by a variety of organizations in a variety of settings and funded by four different Ministries (Ministry of Children and Youth Services; Ministry of Community and Social Services; Ministry of Education; Ministry of Health and Long-Term Care). Navigating one of these systems is daunting – navigating four is complicated and overwhelming.

The consequences of the current 'system' include suboptimal health outcomes and compromised quality of life for children and youth who are medically fragile and/or technology dependent. For their families, the impacts include financial, marital and employment discord; acute and chronic stress; and poorer physical and mental health than comparable adults.[iii]

The Vision for Transformation

In alignment with government and families' priorities, the Provincial Council for Maternal and Child Health believes it possible and necessary to transform the system. **We envision a life-long and family-centric approach to supporting children and youth who are medically fragile and/or technology dependent that goes beyond meeting medical needs to understanding the importance of the child and their family being integrated within the local community and experiencing a better quality of life**. This approach will be characterized by:

- A single point of access for services that crosses organizational and ministerial boundaries
- Services that are integrated and wrapped around the family in their home and community while being coordinated across ministries, across locations, across the care continuum and over the life-span by competent, committed care providers

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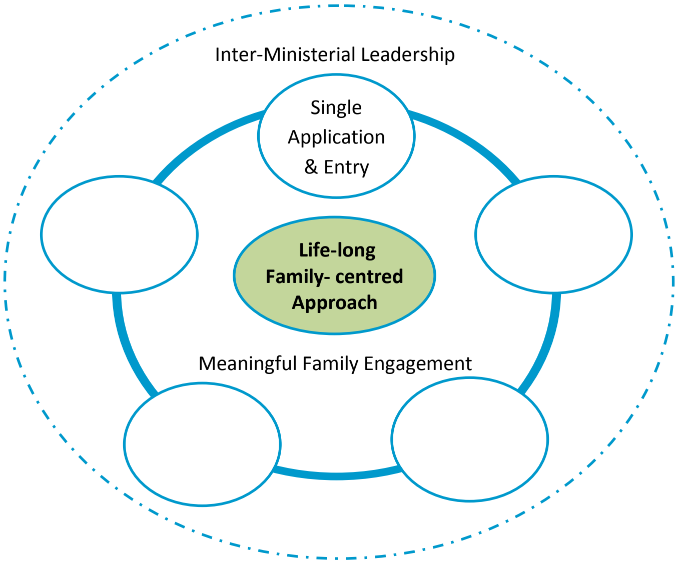
[1] Data did not include non-MOHLTC costs (e.g. MCYS Children Treatment Centre expenditures, EDU expenditures for school board delivered services) or indirect health costs associated with family caregiving. Data on rehabilitation utilization, private drug & home care coverage was incomplete. As such, the total impact is underestimated.

- Empowered, skilled families with control and choice related to determining how allocated funds are spent and services delivered
- Multiple Ministries understanding the unique challenges of children and youth with complex needs and their families and working together with aligned policies and a common aim

Initial Action Plan

Recognizing that system redesign around a specific population is a multi-year commitment, we are prepared to start with five strategies in 2013 that will make a substantive and positive difference in the lives of these children/youth and their families while moving the system towards the vision:

1. **Single Application & Entry** - starting with the design of a single application process
2. **Integrated Complex Care** – leverage existing models to build a replicable model for Ontario
3. **Self-directed funding** – expand model to families interested and able to manage service delivery
4. **Peer Support Network** – build website to enable capacity building between families
5. **Transitional & Adult Services** – develop shared understanding of service needs



Two key enablers would support the creation of a life-long, family- centric approach to caring for children/youth who are medically fragile and/or technology dependent and their families:

- **Meaningful Family Engagement** – starting with the engagement of families in the planning and implementation of each of the five strategies
- **Inter-ministerial Leadership** – starting with an inter-ministerial leadership group (Health and Long-Term Care, Education, Child & Youth Services and Community and Social Services) to lead strategies

Collaborating to Pursue the Possible

Children and youth who are medically fragile and/or technology dependent comprise a small population. As such, we have a real opportunity to make a tangible difference – and we believe the time is right to take action. To achieve the needed transformation we will need the support of the full system, including government. We are not asking for money but are asking government to embrace the moral and financial imperative by:

- Committing to work together with providers and families to transform the system over time towards a vision of creating a life-long, family-centric approach to caring for children/youth who are medically fragile and technology dependent and their families
- Commissioning an inter-ministerial committee to lead the advancement of the five strategies in 2013
- Committing to inter-ministerial advancement of policy supportive of this population

While transformation does not come easily, we believe the effort will be worthwhile. With your commitment and collaboration, we can make a substantive improvement in the health status and quality of life of children and youth who are medically fragile and/or technology dependent and their families.

Pursuing the Possible:

An Action Plan for Transforming the Experiences of Children and Youth who are Medically Fragile and/or Technology Dependent

Children and Youth who are Medically Fragile and/or Technology Dependent

With advances in diagnostics, therapeutics and medical technologies, children who previously would have died in infancy or early childhood are living longer and the complexity of their care needs is increasing dramatically.[iv] Although there is no consistent definition of medically fragile, a recent study estimated that over 15,770[2] children and youth in Ontario have complex chronic health conditions that are typically associated with significant functional limitations.[v] As illustrated in Appendix B, children who are medically fragile are often dependent on technology and/or others for activities of daily living and require constant monitoring by experienced caregivers as changes in their status can put them in a serious health crisis. Multiple agencies, organizations and practitioners are typically involved in their care with services being provided in health care settings, in schools, in the community and at home. Their life-long and round-the-clock need for care is a significant challenge for their families, service providers and the system.

Meeting medical and health needs is just part of the picture for children and youth who are medically fragile and/or technology dependent. As with other children, they are involved in their local community and participate in age and developmentally appropriate social and recreational activities. They develop independence and life skills to the extent possible and prepare for adulthood. The difference lies in the ongoing and individualized support that this population requires to participate in these every-day life activities. They often require specialized personnel and environments to support them in activities of daily living – many need help with feeding, toileting, dressing, mobilization, and communication. They may require home modifications and special equipment, clothes, and shoes that need to be adjusted over time as they grow and they often have special transportation needs.

The Hard Truths

The experiences of medically fragile and/or technology dependent children and their families demonstrate many of the hard truths identified in the February 2012 report by the Commission on the Reform of Ontario`s Public Services (Drummond Report).[vi] Most notably, that a small and vulnerable population is driving a significant proportion of health care costs and that the required 'system' of services and supports is failing children and youth with complex health needs.

Complex cases driving costs

Due to their frequent and high intensity use of health care resources, these medically fragile children and youth consume a significant percentage of all paediatric health care resources.[vii] In a recent healthcare study, we learned that children/youth who are medically fragile and/or technology dependent account for less than 1% of paediatric patients yet consume about 32% of child health care spending – about $419 million a year in healthcare spending alone[viii].

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[2] Numerical data referenced in this white paper pertain to a population of medically complex children that is slightly different in definition than the population of focus for this white paper (i.e. includes children with single complex chronic conditions who are not technology dependent, some of whom would not necessarily be medically fragile).

Despite a wide range of diagnoses, this population has many similarities that drive special, resource intensive services from the health system:

- The multisystem nature of their disorders generates a higher complexity of care needs, the potential for significant co-morbidities and the requirement of lifelong care, often from multiple care providers and specialists in multiple locations across the province. [ix] In fact, recent analysis[x] indicates that children with medical complexity (CMC) have:
    - on average, a median of 13 distinct physicians from a median of 6 distinct medical specialties providing outpatient care, with consistently higher medians among those who are technology dependent;
    - high home care service utilization rates, with rates being significantly higher among those who are dependent on technology assistance; and
    - high hospital readmission rates, particularly for CMC who have multiple complex chronic conditions and are dependent on technology assistance.
- This population can have disorders that are rare and often require treatments, therapies, medications and/or technologies (e.g. ventilators) that demand providers with specialized knowledge and skills. This, combined with the fact that children and youth with the most complex health needs are spread across the province, makes it difficult for formal and informal providers in all sectors and settings to develop and maintain the needed expertise, comfort level and resources to care for this population without significant support from specialists. [xi]
- Relatively minor events for a healthy child (e.g. a cold; change in family circumstances) can be potentially catastrophic tipping points for medically fragile children and youth. These tipping points can cause a cascade of clinical consequences and significant effort may be required to restore and stabilize health. [xii]

Clearly, the expensive and complex health needs of these children and youth and has the potential to overwhelm the health system and divert paediatric resources. Unfortunately, however, while the amount of care these children received is substantial, the quality of care is largely suboptimal.[xiii]

<u>The system is failing children & youth who are medically fragile and/or technology dependent</u>

The healthcare system, which is designed to address the needs of the majority, disadvantages the paediatric population and further marginalizes children and youth who are medically fragile and/or technology dependent:[xiv]

- These children interface frequently with the entire continuum of care (i.e. acute, home, primary and rehabilitation sectors) and across a variety of settings, including schools. Not surprisingly, access to providers and coordination of services is a major challenge. In addition to the sheer number of specialists and appointments, the complexity and time consuming nature of their health care needs is a barrier to accessing primary care and other services. Care is often fragmented, uncoordinated and associated with non-proactive care planning and health information mismanagement.
- When these children do access needed health providers, it is not uncommon for the provider(s) to be challenged by limited availability and access to the child`s complete patient record. This contributes to unnecessary delays in service, emergency department visits and hospitalizations. Once admitted to hospital, the challenges of accessing the community based services needed to ensure a safe and timely discharge exacerbates the Alternate Level of Care (ALC) situation

experienced by Ontario's hospitals. With improved patient information, specialist support and communication between providers and sectors, these delays could be minimized and the potential for medical errors reduced. A single, comprehensive, electronic plan of care accessible by the full continuum of care and service providers is essential to enabling this communication.

- As increasing numbers of medically fragile and/or technology dependent youth survive into adulthood,[xv] the need for ongoing complex care and transitional support continues to grow. Challenges transitioning from child to adult services are significant for children and youth with complex medical needs. There is often significant gap between when the services targeted to children and youth cease and when the young adult is eligible for or can access services in the adult system. When they do, the child and their family are responsible for educating new adult providers about their unique health needs and circumstances and must adapt to reductions in service and considerably different service delivery models. The transition challenges are compounded by the realities of parents' own aging-related changes in health and circumstance. With lengthy wait times for residential care, supportive housing and long-term care – as well as limitations in appropriateness of these settings or the ability to meet the complex needs of medically fragile and/or technology dependent young adults. As illustrated by the media coverage in Appendix C, families are becoming desperate to find supports for their young adult children and to ensure that they will not be lost in the adult system after they turn 18 and 21.

Beyond the healthcare system, the patchwork of educational, community and social support services required by this population are provided by a variety of organizations in a variety of settings and funded by a number of different Ministries. The introduction of the Ministry of Children and Youth Services in 2003 spoke to the need to make it easier for families to find and access services. The challenge lies in the fact that this population often needs services from four ministries (Ministry of Children and Youth Services; Ministry of Community and Social Services; Ministry of Education; Ministry of Health and Long-Term Care). Navigating one of these systems is daunting – navigating four is overwhelming. Even if a family becomes skilled in identifying, accessing and coordinating services, they quickly experience:

- Multiple government-sponsored providers with distinct eligibility criteria, policies and application forms resulting in unnecessarily complex application processes.
- Administrative processes that are redundant and unnecessary (e.g. families are asked to complete many different applications containing the same information and to repeat these application processes at regular intervals).
- Complicated funding architectures, which were not created with this population in mind, make it difficult for families to understand what is possible and to cobble together services from what is available.
- Constraining policies and regulations that are not aligned with family needs (e.g. policies that dictate the type of worker that is allowed and do not provide families with any control over the selection of the worker limit the ability to truly meet the needs of the child and their family).

The consequences of the current system on children and youth who are medically fragile and/or technology dependent include suboptimal health outcomes and compromised quality of life.[xvi] The impact on their families is also notable. Caregivers are often socially disenfranchised as caregiver responsibilities limit their ability to participate in activities outside the home. Even with support they suffer financial, marital and employment discord; experience acute and chronic stress; and have poorer physical and mental health than comparable adults.[xvii]

The Vision for Transformation

Many of the families of children and youth who are medically fragile and/or technology dependent are passionate, articulate and vocal advocates for their child/youth. They have clearly articulated that they need information; coordinated care and service within the context of their family's needs; someone to help them navigate the ministries and corresponding systems; and improved transitions – across health service provider settings, into and out of the school system, and into adulthood.[xviii] Most importantly, families have repeatedly indicated that they want more control and choice about how allocated funds are spent and services are delivered. They want a 'basket of services' tailored to their unique circumstances – health, home support, developmental, rehabilitation, respite, and recreational services - and they want an opportunity to manage all or some of it on their own.

The future system envisioned by these families is entirely consistent with, and enables the advancement of, the strategic directions outlined in the Drummond Report and *Ontario's Action Plan for Health Care.* This includes the shifting to a system built for high quality, efficient and patient-centric chronic care service delivery that features coordination along the complete continuum, a main point of contact for service recipients, service delivery in the home and patient-centric payment schemes.

In alignment with the government and with families, the Provincial Council for Maternal and Child Health (See Appendix A) and its Advisory Group on the Coordination of Care for Children and Youth who are Medically Fragile and/or Technologically Dependent also believe that it is both possible and necessary to transform the system. Building on the 2008 Report of the MOHLTC's Paediatric Complex Care Coordination Expert Panel, we have developed a shared vision and initial action plan for achieving a coordinated system of services built around the needs of children who are medically fragile and/or technology dependent and their families rather than the needs and preferences of providers and administrators. We believe this transformation can be achieved through system improvements that enable existing resources to be utilized differently and we are ready to put our knowledge and proven ideas into action to achieve efficiencies. We are not asking for government funding to do so – but we are asking for your shared commitment and collaboration to enable change.

The Vision

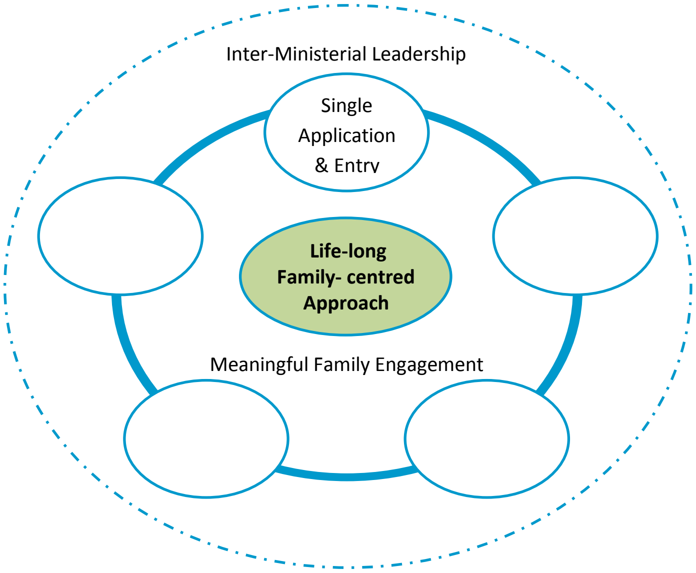
We envision a life-long and family-centric approach to supporting children and youth who are medically fragile and/or technology dependent that goes beyond meeting medical needs to understanding the importance of the child and family being integrated within the local community and experiencing a better quality of life. This approach will be characterized by:

- A single point of access and application for funding and services that crosses organizational and ministerial boundaries
- Services that are integrated and wrapped around the family in their home and community while being coordinated across ministries, across locations, across the care continuum and over the life-span by competent, committed care providers
- Empowered and skilled families that have control and choice in how allocated funds are spent and services delivered
- Multiple Ministries understanding the unique challenges of children and youth with complex needs and their families and working together with aligned policies and a common aim

	Current System		Transformed System	Initial Action Plan
Accessing Services & Funds	• Families struggle to navigate a labyrinth of access points, processes and rules in an attempt to cobble together supports and services • Multiple applications and assessments for multiple providers and ministries. Slow response times. • Lack of inter-organizational collaboration and understanding, lack of focus on the continuum.	Life-Long Family-centred Imperative	• A single point of contact helps family explore options • One application completed for all publicly funded programs and services • Timely service decisions • Ability to plan for subsequent years	Quick Win: • Single Application & Entry
Care Planning & Coordination	• System designed around provider needs • Families overwhelmed by complexity of coordinating appointments with multiple providers in multiple locations • Families and providers frustrated by fragmented communication; the lack of a comprehensive coordinated care plan; and poor cooperation between organisations and across sectors		• System designed around needs of these children/youth and their families • Care Coordinator actively engages family and all providers in development of an age-appropriate, goal-oriented, shared and comprehensive care plan • Care Coordinator works with family and providers to ensure linked, coordinated services that minimize inefficiencies • Information technology is maximized. A single shared electronic care plan enables seamless communication and access to the full continuum of service providers.	Quick Win: • Integrated Complex Care
Control & Choice	• Only one option: service provision (type of service, type of provider, hours and location of service) determined by professionals within restrictive policies, regulations and organizational practices • Service delivery mismatched with child/youth and family needs and limits ability to be independent • Families frustrated with constant rotation of workers and resulting need to constantly train workers on complex needs of the child/youth. • Barriers to self/family-managed care		• To reflect the range of caregiver interest and capacity, system offers degrees of control and choice – from provider-managed and directed to family self-managed and directed services. • Portable self-directed funding enables individualized, flexible, lifelong supports • The resulting flexibility enables families to be more engaged in their community. • Families able to hire, train and retain workers with appropriate skills • Barriers to self/family-managed care lifted	Quick Win: • Family-managed Funding
Caregiver Capacity	• Family carries significant burden. Balancing competing family and financial demands is challenging and often isolating. • Limited caregiver skill and capacity for managing care. • Barriers to respite services • Limited time and ability to learn coping strategies from other caregivers.		• Caregivers have the strength, skills, stability, confidence and knowledge to be true partners in care planning, coordination and management. • Respite services support caregiver health and wellbeing • Peer support and networking for caregivers reduces isolation and is a safety net and source for educational resources and programming.	Quick Win: Peer Support Network

				Initial Action Plan
Transition & Adult Services	• Gap between when child services cease and eligibility for adult services begins • Reduction in services and different models of service delivery from child to adult system • Limitations to community and home based supports challenge the ability of family caregivers to continue supporting young adults at home, particularly as caregivers age, necessitating consideration of residential options and/or to cease external employment • Many residential settings are unable to meet complex medical needs • Nursing homes designed for end-of-life care for the elderly are not an appropriate or ideal option • Long wait times for residential care and long-term care, and limitations in ability to meet complex needs and to provide appropriate setting for young adults	Life-Long Family-centred Imperative	• Gap between end of child services and eligibility for adult services eliminated • Transition assessment occurs 12-36 months before transition to enable an appropriate level of support for a planned, smooth & timely transfer to adult services • Access to a single online resource for resources and tools related to transitions for families • Appropriate complex care and services in adult system, including transition support for adult service providers • Timely access to age-appropriate community-based care, residential care, supported living and/or long-term care options that effectively meet the needs of medically fragile and/or technology dependent adults	Quick Win: • Defined transition and adult service needs
Enabler: Inter-ministerial Leadership	• Constraining policies & regulations • Poor alignment across jurisdictions, including inconsistent eligibility criteria and fragmented funding approaches • Service delivery improvement efforts share common goals but are focused primarily on within-ministry transformation		• Cross-jurisdictional approaches to care coordination and service delivery • Resources reassigned and realigned to enable achievement of the life-long family-centred approach • Inter-ministerial collaboration removes policy and process restrictions that frustrate coordination, access to care and technology procurement	Quick Win: • Inter-ministerial leadership group to champion system redesign for Children and Youth who are medically fragile and/or technology dependent
Enabler Family Engagement	• Families want to be involved in decisions that most effect the health and well-being of their child/youth • Starting to include families at decision-making tables (e.g. Ministry of Community and Social Services Partnership Table) • Increasing readiness and awareness of benefits of public involvement in planning, implementing and evaluating quality improvement initiatives		• Families engaged as partners in decision-making regarding the planning, implementation and evaluation of efforts to improve the services that effect CMC • Families feel empowered as effective partners for change	Quick Win: • Meaningful engagement of Family Representatives as partners in advancing the action plan

Initial Action Plan for Transformation

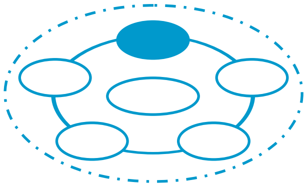


We recognize that system redesign around a specific population is a multi-year commitment and might be overwhelming to contemplate. As such, we are recommending and are prepared to start with five strategies that will make a substantive and positive difference in the lives of these children/youth and their families while moving the system towards the vision.

These strategies can be advanced discretely or implemented in an integrated fashion in order to achieve synergies (e.g. pilot the single application & entry with families participating in the integrated complex care model of care). Whether implemented separately or together, our goal is to utilize quick tests of change to implement each change and quality improvement strategy in 2013.

The required changes will not be easy and will not happen overnight but, by working together, our vision can become a reality. Inter-ministerial leadership will be a key enabler for achieving our vision and action plan commitments. We invite the government to embrace the moral and financial imperative of this opportunity and ask that an inter-ministerial group be commissioned to lead system redesign around this patient population – a system of care that is truly life-long, family-centred, adds value, and is sustainable.

Quick Win Strategy 1- Single Application & Entry

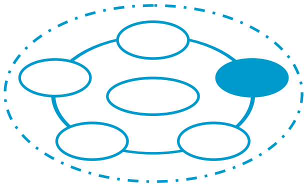


Description: A single application and entry point for all services offered to this population by the four ministries has the potential to: reduce the administrative burden for families that already have a significant caregiving burden; meet the information requirements of the multiple agencies providing funding or services to this distinct population; and eliminate duplication and redundant administrative processes. With one access point to the system of care and a single application process duplicative administrative services will be reduced and the system can repurpose the funds to provide much needed direct services.

Progress to Date: Examples include demonstrated success in implementing a shared multi-ministry single application for Enhanced Respite Funding.

Next Steps: We are prepared to start by establishing a small group, with inter-ministerial representation, to work with PCMCH to identify multiple current applications and to redesign and test a streamlined single application.

Quick Win Strategy 2- Integrated Complex Care

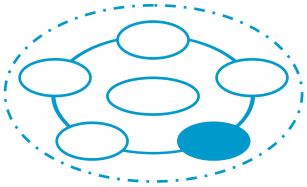


Description: Targeted and structured complex care interventions, such as intensive care coordination, are seen to have high potential in mitigating unnecessary expenditures for children with medical complexity.[xix] A family-centred approach – where a family's needs are understood and the family is fully engaged and integrated into the care team – is central to integrated complex care models. Inter-professional and inter-organizational assessments, sharing of information, setting of goals and treatment plan options, and coordination of services are core to these models. The child and family are encouraged to participate in the design and delivery of wrap-around care and contribute to ongoing refinements in the plan based on changing needs and concerns In this model. An integrated service delivery team coordinates care, provides consultation and enables providers to assume management of children and youth who are medically fragile and/or technology dependent in community and primary care settings closer to home. This promotes more collaborative care management among providers and helps build the child and family's confidence and capacity.

Progress to Date: Several promising models of care targeting children and youth who are medically fragile and/or technology dependent have been developed and tested in various parts of the province. This includes the Children's Complex Care Navigation Program in North Simcoe Muskoka LHIN; the eShift project in Southwest LHIN; Integrated Complex Care Clinics in Barrie, Orillia, Mississauga and Brampton; the Children Treatment Network of Simcoe York, the Integrated Complex Care Model (ICCM) in Toronto Central LHIN and the Paediatric Complex Care Coordination Pilot Project in Champlain LHIN. A number of these models are working on the development of shared electronic care plans.

Next Steps: We are prepared to leverage these models to build a replicable model that can be spread across the province.

Quick Win Strategy 3- Family-Managed Funding

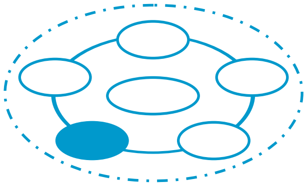


Description: Direct funding programs enable clients or their designated caregiver, based on a pre-determined needs-based budget and established care plan goals, to determine the amount and type of service and support required, who delivers it and when it will be delivered. An accountability agreement articulates the fiscal roles and responsibilities of all parties involved. The literature is clear and Ontario families of children who are medically fragile and/or technology dependent agree – for parents interested and capable of taking a more active role in managing the delivery of their child's services, self-directed funding can make a positive difference. For the health care system, direct funding programs can save public dollars.

Progress to Date: We have pilot tested a direct funding model in the CCAC environment with family caregivers of children who are medically fragile and/or technology dependent. Evaluation results indicated family-managed funding improved health outcomes and quality of life while providing flexibility, independence and freedom for families. The pilot project also generated a reduction in direct service delivery costs while increasing the amount and flexibility of service provided to the child/youth.[xx]

Next Steps: We are prepared to improve this model based on evaluation results and expand it to a subset of other families of children/youth who are medically fragile and/or technology dependent, recognising that policy change is needed to make direct funding possible.

Quick Win Strategy 4- Peer Support Network

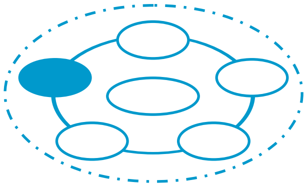


Description: Families with children/youth are the most experienced caregivers for this population and have a tremendous amount of knowledge to share with others who need support.

Progress to Date: Family Alliance Ontario and other organizations already have mandates that extend to families of children/youth who are medically fragile and/or technology dependent.

Next Steps: We are prepared to work with one or more organizations such as the Family Alliance Ontario to provide vehicles for families to share knowledge, tools and networking opportunities. We suggest starting with a website dedicated to providing information and enabling families to connect.

Quick Win Strategy 5- Transitional & Adult Services

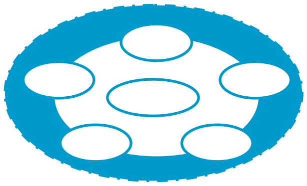


Description: As a foundation for developing a strategy for enhancing transitional and adult services, it is important to develop a shared and prioritised understanding of the existing and expected service needs of youth and young adults who are medically fragile and technology dependent. This will enable strategic investments that enable supports and alternatives for young adults who are medically fragile and/or technology dependent.

Progress to Date: The Ministries of Health and Long-Term Care (MOHLTC), Children and Youth Services (MCYS), Community and Social Services (MCSS) and Education (EDU) have issued an RFP related to care in the long term for youth and young adults with complex care needs. The deliverables will be a proposed definition of 'complex care needs', a profile of the needs of youth and young adults with complex care needs who will require or already require adult services, and recommended best practices for successfully transitioning these youth to adult services that will continue to meet their needs.

Next Steps: Following the selection of the successful proponent for the RFP, ensure that the profile and needs of youth and young adults who are medically fragile and technology dependent are will be effectively captured. Advocate for inclusion of alternatives that address these most complex needs.

Enabler: Inter-ministerial Leadership Group

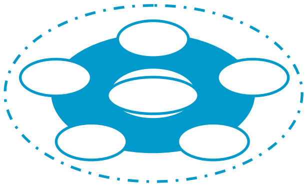


Description: A key enabler for the creation of a life-long, family- centric approach to caring for children and youth who are medically fragile and/or technology dependent and their families is inter-ministerial collaboration and leadership among the ministries with shared responsibility for the services that support these children and their families. We are seeking your commitment to work together to transform the system over time towards this vision starting with an inter-ministerial leadership group (Health and Long-Term Care, Education, Child & Youth Services and Community and Social Services) to lead the advancement of the five strategies outlined above. To make a substantive and positive difference in the lives of these children/youth and their families, we are requesting inter-ministerial transformation over time as demonstrated by policy, regulation and practice changes.

Progress to Date: Examples of inter-ministerial collaboration and leadership include partnership on *Ontario's Policy Framework for Children and Youth Mental Health* and the joint RFP noted above. Our conversations with Ministers, politicians and bureaucrats a shared sense of urgency and a willingness to work together to advance solutions for children who are medically fragile and/or technology dependent.

Next Steps: We ask that an inter-ministerial group (Health and Long-Term Care, Education, Child & Youth Services and Community and Social Services) be commissioned to begin leading a system redesign for children & youth who are medically fragile and/or technology dependent, starting in 2013 with the four strategies outlined in the initial action plan.

Enabler: Meaningful Family Engagement



Description: Facilitating the meaningful involvement of informed and confident families of children and youth who are medically fragile and/or technology dependent, those most affected by the decisions we are making, will strengthen the effectiveness and sustainability of changes made towards our vision. These families have lived experience and expertise regarding the strengths and challenges in service delivery for this population. By providing participants with the information they need to be involved in a meaningful way and communicating how their input affects the decision, we will make stronger decisions.

Progress to Date: There are examples of public participation in both government and service provider environments including: the Joint MCSS/MCYS Developmental Services Partnership Table and the Toronto Central CCAC Self-Directed Funding pilot project (noted above) which was co-designed with family representatives. Many service organizations, as well as the Ontario Association of Children's Rehabilitation Services, have family advisory councils that enable family engagement.

Next Steps: We propose the engaging family representatives as partners in the planning and implementation of each of the five strategies.

Collaborating to Pursue the Possible

Based on the consequences of the current state of service delivery and support for children and youth who are medically fragile and/or technology dependent and their families, as well as the provincial economic situation, the status quo clearly cannot continue. Substantive system changes are needed now, before this population of children and youth who are medically fragile and/or technology dependent grows further, and before today's youth reach the transition point into the adult system.

We believe the time is right to take action. Providers are willing to change, parents are ready and willing to help and many government staff and politicians acknowledge the need and are ready to help. It's an ideal environment for transformation.

We are realistic in our expectations. We realize that change takes time and transformational change does not come easily. Nevertheless, we believe the effort is worthwhile for the system, for the families and most importantly for the children and youth who are medically fragile and/or technology dependent. Our action plan outlines the first steps to get there but to achieve transformation we will need the support of the full system, including government.

We realize the province is facing serious economic pressures. We are not asking for money. We believe we need to think differently about how to use existing funds. However, transformation will take more than good will. We are asking the government to embrace the moral and financial imperative of this opportunity by:

- Committing to work together with providers and families to transform the system over time towards a vision of creating a life-long, family-centric approach to caring for children and youth who are medically fragile and/or technology dependent and their families
- Commissioning an inter-ministerial committee (Health and Long-Term Care, Education, Child & Youth Services and Community and Social Services) to lead the advancement of four strategies in 2013 that will make a substantive and positive difference in the lives of the families and their children/youth
- Committing to assist with inter-ministerial advancement of policy supportive of this population

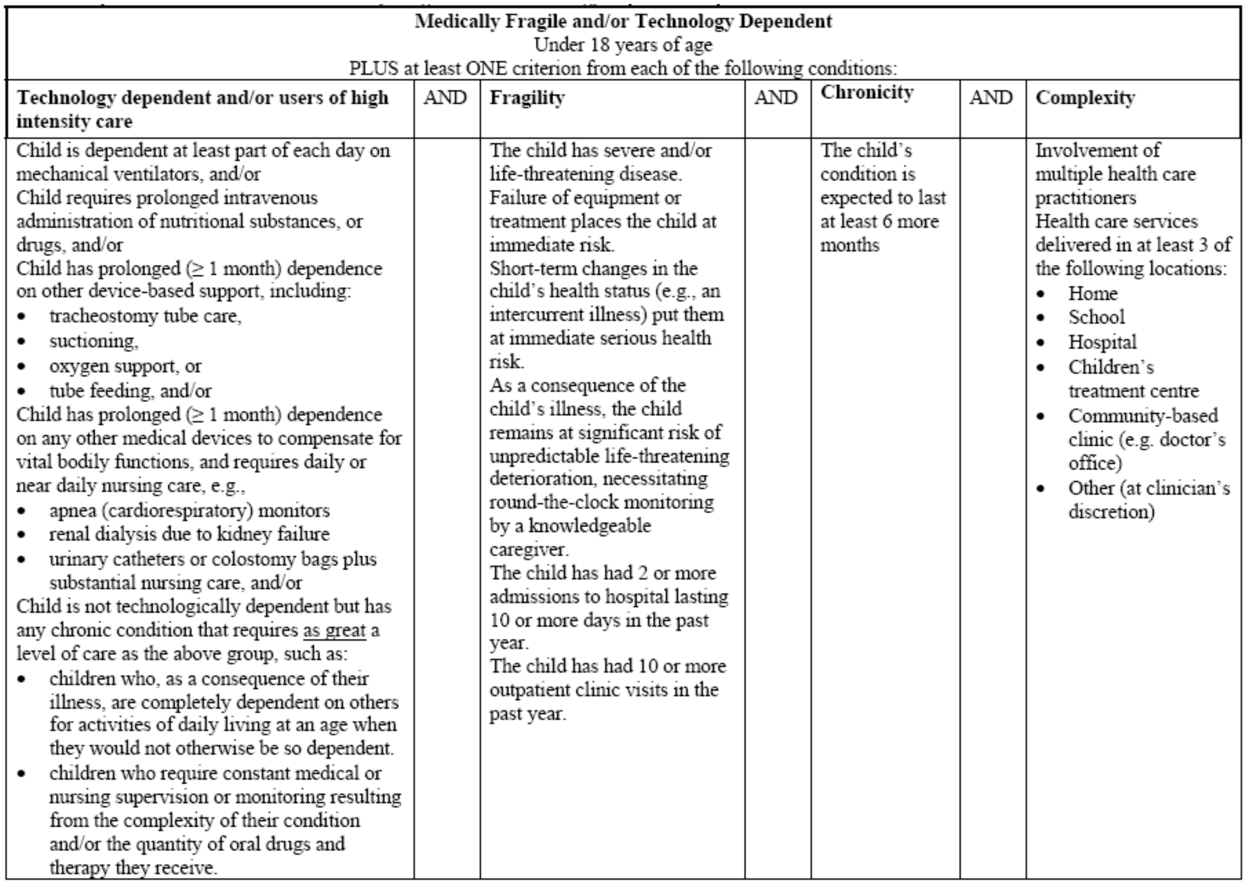
With your commitment and collaboration, we can: [xxi]

- Improve the quality of life of children and youth who are medically fragile and/or technology dependent and their families
- Improve health status/stability of children/youth who are medically fragile and/or technology dependent, wherever possible
- Maximize out of hospital time, reduce avoidable hospitalization and length of stay, inefficient/unnecessary/avoidable ambulatory clinic visits and emergency department visits.

There is no room left siloed service improvement efforts. There is only room to focus on what is best for the children and families who are counting on us. Together we can make a significant difference.

Appendix A: Definition of Medically Fragile and/or Technology Dependent

There is no consensus definition of medically fragile and/or technology dependent. For the purposes of this white paper, the definition outlined in the following table[xxii] was used.



Medically Fragile and/or Technology Dependent Under 18 years of age PLUS at least ONE criterion from each of the following conditions:						
Technology dependent and/or users of high intensity care	AND	**Fragility**	AND	**Chronicity**	AND	**Complexity**
Child is dependent at least part of each day on mechanical ventilators, and/or Child requires prolonged intravenous administration of nutritional substances, or drugs, and/or Child has prolonged (≥ 1 month) dependence on other device-based support, including: • tracheostomy tube care, • suctioning, • oxygen support, or • tube feeding, and/or 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., • apnea (cardiorespiratory) monitors • renal dialysis due to kidney failure • urinary catheters or colostomy bags plus substantial nursing care, and/or Child is not technologically dependent but has any chronic condition that requires as great a level of care as the above group, such as: • 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.		The child has severe and/or life-threatening disease. Failure of equipment or treatment places the child at immediate risk. Short-term changes in the child's health status (e.g., an intercurrent 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.		The child's condition is expected to last at least 6 more months		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 (at clinician's discretion)

It is important to note, however, that the definition above is slightly narrower than the definition used to calculate the numerical data referenced in this white paper which pertain to the population of children with medical complexity (CMC). This broader CMC population includes children with single complex chronic conditions who are not technology dependent, some of whom would not necessarily be medically fragile. For the analysis of health care costs associated with children with medical complexity, the researchers used International Classification of Diseases (ICD-10) diagnostic codes within three clinical categories relevant to children with medical complexity: neurological impairment, complex chronic conditions, and technology assistance[xxiii].

Appendix B: PCMCH & the creation of the Vision for Transformation

The Provincial Council for Maternal and Child Health

The Provincial Council for Maternal and Child Health (PCMCH) is accountable to the Ministry of Health and Long-Term Care and has two distinct roles. First, the PCMCH generates information to support the evolving needs of the maternal-child health care system in Ontario. Secondly, the PCMCH is a resource to the maternal-child health care system in Ontario to support system improvement and to influence how services are delivered across all levels of care.

Members

Dr. Mary Broga	VP, Family and Children's Services Windsor Regional Hospital
Dr. Denis Daneman	Chair, Department of Paediatrics, University of Toronto Paediatrician-in-Chief, SickKids R S McLaughlin Foundation Chair in Paediatrics
Dr. Kim Dow	Neonatologist, Kingston General Hospital
Dr. Peter Fitzgerald	President, McMaster Children's Hospital and Executive Lead, Women's Reproductive Health and Newborn Care, Hamilton Health Sciences Centre
Jeffery Hawkins	Executive Director Hands – The Family Help Network
Dr. Shoo Lee	Pediatrician- in- Chief Mt. Sinai and Neonatologist-in-Chief, SickKids Head, Division of Neonatology, University of Toronto Women's Auxiliary Chair in Neonatology
Joanne MacKenzie	Director, Maternal, Child and Oncology Programs, Markham Stouffville Hospital
Dr. Teresa O'Driscoll	Chief of Staff, Meno Ya Win Health Centre, Sioux Lookout
Dr. Charmaine Roye	Chief of Medical Staff, Brant Community Healthcare System
Dr. Gary Smith Vice-chair	Paediatrician, Orillia Soldier's Memorial Hospital and LHIN 12 Lead for Obstetrical and Newborn Care
Dr. Mark Walker	Maternal Fetal Medicine Specialist – University of Ottawa/ The Ottawa Hospital Senior Scientist Ottawa Hospital Research Institute – Perinatal Epidemiologist
Mary Jo Haddad Chair	President and CEO, The Hospital for Sick Children
Michael Barrett	CEO, South West LHIN
Anne Stark	Administrator, Child and Parent Resource Institute, MCYS
Laura Pisko	Director, Standards, Programs and Community Development Ministry of Health Promotion and Sport

Advisory Group on the Coordination of Care for Children & Youth who are Medically Fragile and/or Technologically Dependent

PCMCH hosted a meeting of the Advisory Group on the Coordination of Care for Children and Youth who are Medically Fragile and/or Technologically Dependent in May 2011. The Advisory Group was charged with identifying priorities and recommending strategies for the achievement of a coordinated system of services delivered in community and hospital settings. The May meeting focused on the recommendations of the 2008 Report of the MOHLTC's Paediatric Complex Care Coordination Expert Panel. Forty participants from across the province explored two objectives a) opportunities to improve care/service coordination while leveraging successful models and b) enablers and system barriers that must be considered when planning changes. Twenty seven recommendations were put forth with several priorities emerging. A Steering Committee was commissioned to drive an implementation plan focusing on policy barriers and service improvement. This paper is a culmination of many Council and Advisory Group discussions and advances a vision and initial plan for change.

Members

Stacey Daub	Chief Executive Officer	Toronto Central Community Care Access Centre
Eyal Cohen	Staff Physician, Paediatric Medicine Division	The Hospital for Sick Children
Bernard Lamontagne	Senior Planner, Planning, Integration & Community Engagement	Champlain LHIN
Robert Morton	Board Chair	North Simcoe Muskoka LHIN
Tanya Lindsey	Manager of Resources	Timiskaming Child and Family Services
Sharon Marsden	Senior Policy Advisor, Community and Population Health Branch Health System Strategy and Policy Division	Ministry Of Health and Long Term Care
Anne Stark	Administrator - Child and Parent Resource Institute	Ministry of Children and Youth Services
Barbara McCormack	President	Family Alliance
Genevieve Obarski	Executive Lead, Program Implementation -	Change Foundation
Marilyn Booth	Executive Director	Provincial Council for Children's Health
Doreen Day	Senior Project Manager	Provincial Council for Children's Health
Laura Visser	Lead, Integrated Family Centred Care for Children with Health Complexity	Toronto Central Community Care Access Centre

Appendix C: Kobi, Signa & Joshua's Story

Signa is a single, socially isolated parent raising a healthy 6 year old son, Joshua, alongside an 11 year old daughter, Kobi, who is deaf and confined to a wheelchair. Kobi is unable to control her bowel or bladder, is susceptible to daily seizures, has continuous tube feedings and requires frequent suctioning. Kobi requires 24/7 care. She was admitted to hospital twice in the past year, the local Children's Treatment Center for respite once and has had over ten visits to medical specialists in the same timeframe – some requiring travel outside her community. Kobi receives services from four different ministries and many agencies and providers. Signa is unable to work outside the home as she provides 35-50 hours of direct care for Kobi each week. She is beginning to experience her own health issues and is worried about Kobi's care should she become ill. Her son Joshua is showing signs of developmental delay at school and he doesn't understand why they have to stay home all the time. The family has not had an outing together since Joshua was born.

The Family's Current Reality

Accessing Services & Funds

- *Signa reviews information she is given or finds and searches government websites.*
- *She completes over 10 repetitive applications that go to 4 Ministries.*
- *She forgets which applications she's completed and submits the same one three times. She calls each program weekly to find out the status of her application.*
- *Service decisions come back one-at-a-time over a 2-4 month period.*

Control and Choice

- *Signa is struggling to manage the number of agencies and workers involved in Kobi's care*
- *She is tired of having new workers & upset by having to train them when they come*
- *Signa is frustrated by agency policies that do not help her create a family environment*

Care Planning & Coordination

- *Signa is overwhelmed with the number of medical appointments that Kobi needs and getting her to/from the appointments. The schedule is set by the clinics.*
- *She tries to remember to notify home care when Kobi is not available but frequently forgets. Workers show up & a series of phone calls ensue.*
- *Signa experiences chaos if Kobi is admitted to hospital. She worries about Joshua & Kobi alike.*

Caregiver Capacity

- *Signa is concerned about the possibility of not being able to care for her family – for health, financial and caregiver responsibility reason. She is not sure how to plan.*

Kobi, Signa & Joshua`s Possible Reality

Accessing Services & Funds

- _Signa has one phone number to call and a designated care coordinator to help explore available options in the health, community support and education systems._
- _She completes one application for all provincially funded programs and services. Service/funding decisions are known in 2 weeks. If a new program becomes available, Signa is notified._
- _Signa, with support from her Care Coordinator, pursues other service and funding opportunities as appropriate._
- _Signa's point person works with Kobe to compile a complete picture of what Kobi and the family can expect for funding/service over the next year._
- _They discuss whether Signa is able & willing to manage some/all funds on behalf of Kobi_

Care Planning & Coordination

- _The Care Coordinator facilitates a meeting of all professionals who support Kobi at home, school and community in order to develop a single coordinated, comprehensive, goal oriented and age-appropriate care and education plan that maximizes Kobi's safety, health, learning and participation potential._
- _All providers use a common shared electronic record to support Kobi which enables team communication and collaboration. The family has access to this record in order to assist with the self-management of funds and services._
- _The Care Coordinator who works with the family and clinical leader(s) to schedule appointments, lab work, and x-rays on the same clinic day._
- _Specialists agree to provide consultation via videoconference while Kobi is at the clinic._
- _The Care Coordinator oversees transfers to and from hospital to ensure a smooth transition_
- _Kobi's community-based care providers are automatically notified of significant changes that affect the shared care plan._
- _Inter-professional care conferences are planned as needed and updated care plans are posted securely in the electronic health record._

Control and Choice

- _Signa elects to self-manage Kobi's personal care funds & services – she continues to use CCAC services for in-home and school nursing._
- _She has hired a core team of workers that attend to all of Kobi's personal care needs – regardless of location (home, library, park)_
- _Kobi and her worker use Saturday mornings to take her brother Joshua to the local park_
- _They are planning an overnight family trip to a friend's home on a lake – the worker will accompany them_

Caregiver Capacity

- _Signa is connected to another family that has volunteered to be her peer mentor_
- _Regular respite is scheduled to enable Signa to care for herself and spend 1:1 time with Joshua_
- _Signa's Care Coordinator has worked with her to put contingency back-up plans in place for Kobi and a plan of care for Joshua if she needs to stay at the hospital with Kobi._
- _Signa has been connected to agencies that will help with financial planning, will preparations and life transitions._

Appendix D: Media Coverage

Parents make 'heart−wrenching' choice; Terminally ill man, wife surrender their disabled daughter to care facility (Toronto Star)

http://www.thestar.com/news/canada/article/1263591--father-s-terminal-cancer-forces-family-to-surrender-care-of-disabled-daughter

Published: September 27, 2012

SARNIA - When Wilma Arthurs dropped her daughter off at a short−term care facility last week, only she and her husband knew they would not be bringing her home.

"Our daughter Emilia is currently in respite care with you. We are informing you that we will not be picking her up and are surrendering care of her to you," Arthurs wrote in a letter delivered five days later.

"We love Emilia very much and have done all we can for her in life. This is the most difficult and heart−wrenching decision we have ever made."

Emilia, 21, has autism, epilepsy, cortical deafness and the cognitive abilities of a pre−schooler. Her father, Chris, has terminal colon cancer that has spread to his liver, lungs and lymph nodes.

As her husband's condition deteriorated, Arthurs realized she could not care for Emilia on her own. The fiery, active redhead needs 24−hour supervision and help eating, bathing and dressing.

This is the second time in six weeks that a desperate parent has left an adult child at a respite home in Sarnia. And, as wait lists grow, officials say the Arthurs' struggle is becoming all too common.

"Unfortunately, this is happening more often," said Alan McWhorter, interim executive director of Community Living Ontario. "We're in the kind of desperate straits now where clearly people have priority needs, but there's no capability to respond."

There are 6,000 people in Ontario waiting for around−the−clock residential care. Emilia has been waiting for nearly five years.

The family receives $9,100 in annual funding from the Ministry of Community and Social Services. That covers a weekend in a respite home a month, plus a few hours a week of a caretaker's help − far short of the $300 a day that 24−hour care would cost.

Arthurs, 58, hopes her daughter can stay at the home permanently because staff know her well and it has the necessary safety features, but that is not likely to happen, says John Hagens, director of Community Living Sarnia−Lambton "Your heart kind of sinks for these families," he said. "When I read the letter, and knowing the situation, they just can't cope." Hagens said he will ask the ministry for emergency funding. In the meantime, Emilia will stay in the respite home while Hagens reaches out to other community agencies for help. If that fails, the most likely option is an old−age home.

This is the second case locally in six weeks.

When Colleen Cunningham left her son at a respite home in late August, she, too, hoped the ministry would step in.

The mother, a double−lung transplant recipient with severe rheumatoid arthritis, felt she could no longer care for Nathan, 21, who suffers from cerebral palsy.

Hagens requested emergency funding, and Mayor Mike Bradley wrote a letter on the mother's behalf, all to no avail.

Nathan was transferred to a nursing home last week.

A ministry spokesperson said the province must balance demand with available resources.

"We work tirelessly with a network of community support providers, including agencies, health care and residential care providers," said Christina Wilkinson. "We exhaust all possible resources."

The Arthurs have long been advocates of increasing funding to families of disabled children. In 2008, Wilma Arthurs created the Real People Campaign, a website that shares dozens of stories about families' struggles to care for their kids.

Since Chris, 59, was diagnosed with cancer in 2010, caring for Emilia became nearly impossible, Arthurs said.

She is non−verbal, has no sense of danger and doesn't know her own strength. When she gets frustrated, she pushes people or bites herself, Arthurs said.

The young woman was a "daddy's girl," and always wanted her father to play with her, she added.

"She doesn't understand that he's sick. She gets to pulling at him, like she's wondering, 'Why aren't you taking me for drives? Why aren't you looking at books with me?'"

At one point, Chris had to lock himself in the bedroom because he couldn't tolerate the pain of Emilia tugging at him.

The respite care home is only a 15−minute drive from their Sarnia home. When they visit, she seems very happy and comfortable, Arthurs said.

"Emilia has given us so much in life, so much joy," Arthurs said. "She's just one heck of a busy, hard−to−manage young woman.

We're going to miss her terribly."

Mom leaves disabled son in agency's care

http://www.torontosun.com/2012/08/29/mom-leaves-disabled-son-in-agencys-care

Published on August 29, 2012

SARNIA, ONT. - A Corunna, Ont., mom who has been fighting for a residential group home bed for her son kept her word.

Colleen Cunningham didn't pick up her son Nathan, 21, from respite care with Community Living Sarnia-Lambton Tuesday afternoon.

Cunningham, 47, a double-lung transplant recipient, has been her son's primary caregiver, struggling to help him with daily tasks while coping with severe rheumatoid arthritis.

Nathan has cerebral palsy and requires 24-hour care. He can communicate using a picture board, but he needs help with everything from brushing his teeth to being put to bed.

“Nathan knows when I dropped him off I wasn't going to pick him up; whether he understands fully I'm not sure, but he loves going to the apartment because he loves all the other kids there,” Cunningham said.

John Hagens, executive director of Community Living Sarnia-Lambton, confirmed Nathan is in the agency's care.

“When someone is not able to take them back for whatever reason, then we can't put that person on the street and we will try our best to reunite that person with their family,” he said. “That's our first priority.”

For the last seven months, Cunningham has tried to get her son into a group home. However, officials with Community Living Sarnia-Lambton have been told there's no new funding available from the ministry of community and social services.

The ministry has said it’s invested $575 million in new, ongoing funding for developmental services since 2003 — including $25 million this year for urgent-need residential and community-based services.

Hagens said a group home spot for Nathan would cost between $100,000 and $150,000 a year. Currently, there are 180 people waiting for a residential group home bed in Lambton County.

“As long as there remains a huge gap between need and funding resources, we're going to run into more situations of families not having a choice,” Hagens said. “Our respite program where people come in for short periods of time is vulnerable to people exercising that decision...”

Only once before has a client been left in respite care with Community Living Sarnia-Lambton, Hagens said. The agency has no formal protocol for how to handle the situation. “For us, it's basically a day-to-day event as we try to process this,” he said. If Nathan can't return to his family, Hagens said several health-care options will be explored, including a nursing home. But, he stressed, a long-term care home isn't ideal.

“From the optics point of view, to have a young man who's active and otherwise healthy, in a home for seniors and the aged — is that the type of community inclusion we want for people with disabilities?” he asked. “Is that where we're heading as a society? I struggle with that.”

Cunningham said she’s received plenty of positive feedback after she decided to share her and her son's story with QMI Agency.

It has kept her spirits up over the last few days, she said.

“It's really helped me through it.”

Case exposes health care flaws

http://www.thestar.com/opinion/editorials/article/1113555

Published on Tuesday January 10, 2012

TORONTO - Wayne Rumsby takes care of his 17-year-old son, Mark, in his Toronto home. Mark has a rare neurodegenerative disorder.

Mark Rumsby was born with a rare neurodegenerative disorder. He's 17 now and not expected to live out the year. His family desperately wants to get him into a facility that can provide the medical care Mark needs but they've been turned down for reasons ranging from funding restraints to the complexity of his needs.

If Mark's case is too "complex" for experts in a hospice to handle, how on earth are his parents supposed to manage at home?

Thanks to Star reporter Anita Li's inquiries the family has a temporary fix: government-funded, near round-the-clock nursing care at home. It's better for Mark, certainly, but it's still not the appropriate level of care for him.

With access to day and night in-home nursing care Mark has, in effect, the opposite problem of most sick and frail Ontarians who can't get anywhere near the number of government-funded home care hours they need to remain safely in their homes. But, at its core, it's still the same problem that plagues our health care system and prevents it from efficiently spending its $48-billion annual budget: the wrong type of care, in the wrong place.

The best – and most affordable – health care system is one where people get the right care, at the right time, in the right place. It's not one where Ontarians go to emergency rooms for basic health services because they either don't have a family doctor or can't get an appointment on the weekend when they're sick. It's not a system where thousands of frail seniors stay in hospital beds because there are waiting lists at long-term care homes. It's not a system that allows a hospital to send a patient home without sufficient home care support, only to have her wind up back in hospital in an even worse state.

And, finally, it's not one where a 17-year-old gets near round-the-clock nursing care at home because he can't get into a hospice that can handle his medical needs and care for him in his final months.

Health Minister Deb Matthews knows this, of course. "We really have a come a long, long way. But we know there's more to do," Matthews said. She was speaking about hospice care but she could just as easily have been talking about any aspect of our health care system.

She and her predecessors have already put in place many health reforms that provide both better and cheaper care. Ontarians have access to more doctors, more after-hours clinics and more home care than before. It's all in an effort to reduce hospital and long-term care costs down the line. And, given the combination of Ontario's provincial deficit and sluggish growth projections, more change is certainly on the way for the health sector, which gobbles up 42 per cent of provincial spending.

Mark Rumsby's case provides the latest stark reminder that our health care sector is still a long way from where it needs to be.

No place for her head

www.simcoe.com/mobile/news/article/1267792

Published on December 21, 2011

COLLINGWOOD - This year, the Dillon family of Nottawa is living the story of Christmas.

Their baby needs a bed, but there's no room at the inn.

In fact, Jessi is no longer an infant, she's 21, but she needs as much, if not more, care than a baby. Both the Ministry of Health and the Ministry of Community and Social Services agree that Jessi needs care, and she officially qualifies for every program available. Trouble is, there's no room in any of those programs for her, and no more funding to add a spot.

Out of options, her parents have had to basically abandon her at the G&M.

"We're here with her everyday," says her mom Leslie.

Jessi's mom and dad don't want to walk away from their daughter. But they cannot give her full-time care without help, and, right now, they're not getting help.

Jessi Dillon was born on May 12, 1990 with Cornelia de Lange Syndrome.

She was one of 12 babies born at the Collingwood General and Marine Hospital that day. She was the first grandchild in her family, and the only child born to her parents Leslie and Gary who were married just three years when Jessi was born.

Jessi has never walked, never talked and cannot eat food since it causes excruciating pain.

Her life has been punctuated by countless visits to the General and Marine hospital and to Sick Kids hospital in Toronto.

Jessi's syndrome is rare - only about one in 30,000 babies are born with it, and until a few years ago, those born with it, didn't live long.

She's had too many surgeries to list, the results of which include metal hardware in her spine and hips and a high-tech feeding tube that slowly puts nourishment into Jessi's intestines.

"That was the best Christmas ever," says her mom, recounting the story of Jessi's late December surgery that gave her the feeding tube. "She was discharged on December 24. We raced Santa up the 400. We had the most beautiful, ugliest Christmas tree ... [Jessi] was laughing and getting full, and then she had to go on a diet."

Leslie and Gary have spent every day of their 21 years with Jessi fighting to get her what she needs. The feeding tube was no exception.

Jessi was nine years old and weighed 26 pounds when her parents sat with her in the emergency room at Sick Kids hospital. Though doctors wanted to wait, Jessi and her parents convinced them of the urgency, and Jessi was given a feeding tube that bypasses her stomach and her esophagus.

Leslie stayed home with Jessi full-time for 17 years. She now works two part-time jobs.

Gary works full time at Blue Mountain Resort as an electrician on 12-hour shifts.

Jessi graduated from Collingwood Collegiate Institute's life skills program this past June. And this summer, her parents took turns using up holiday days to stay at their custom built Nottawa home with their daughter.

"We built our house for Jessi," said Leslie, adding that doorways are wider, and her room is equipped with specialized mechanics.

In October, Jessi fell ill with a urinary tract and E. Coli infection. For the first time, Leslie had to call an ambulance for her daughter.

Jessi returned to General and Marine Hospital, and there she remains.

If her parents take her home again, they will continue to "suffer in silence," said Gary.

They've been forced into a corner, and have rallied each other to take up their daughter's cause for the sake of "all of the Jessies in Ontario."

In fact, Jessi graduated with three other young adults who need constant and specialized care. None of those graduates have been able to get into a day program or a group home. They all enjoyed five days a week at school with a nurse, learning, socializing and enjoying purpose driven tasks.

They have all been sent back home to their parents, cut off from their peers and active routines.

"School was their reason to get up in the morning, now that reason has been taken away," said Gary. "Who is more needy? They deserve to have a life too. Our government has turned a blind eye."

The only offer on the table is to have Jessi put on a waiting list for a nursing home.

But one fact remains: she's 21.

She'd be competing with her 92 year-old great-grandmother for a spot in a nursing home.

"It's not appropriate," says Leslie.

When she was at home, Jessi received nine hours a week in respite care - or, in her eyes - nine hours a week with Aunt Yvonne, Jessi's second mom. Though not technically an aunt, Yvonne has been taking care of Jessi for nearly her whole life.

Since Jessi has a feeding tube, she's classified as medically fragile, which means she also received funding for 12 hours a month with a nurse when she was at home. Her parents had arranged for the nurse to come to their home in Nottawa for six hours every other Saturday while they went to work. But it wasn't enough.

Jessi is on waiting lists for day-away programs, group homes, respite care, home care and whatever else is available.

"There are waiting lists everywhere," said local e3 Community Services executive director Gordon Anton, adding he feels frustrated. "We try to do what we can internally to free up resources ... it's a political decision in terms of how much money is invested."

He knows how important e3 services are for families and for anyone with developmental or physical disabilities.

"Families need to have the ability to go out and work and have a break," said Anton. "All of us need to get out and do things through the course of the day ... the people in our program need help being active ... we give them better quality of life. That's fairly critical support."

Gary and Leslie have worked hard to navigate Developmental Services Ontario and the provincial ministries that oversee the programs Jessi has qualified for. They've been forced in circles while Jessi undergoes hours and hours of testing, but they won't back down. They're pioneers forging a path through bureaucratic wilderness so their daughter can have a better life.

"This isn't just about Jessi - this is about the system," said Gary. "The system is so confusing, and I swear it's on purpose so people just give up."

Gary is thinking about the other young people set to graduate from CCI's life skills program next year.

"There are more people who need this care," he said. "If you change the name, the story's the same."

"We're in this fight," said Leslie.

MPP Jim Wilson brought the Dillon's fight to the legislature, speaking up during question period to challenge the Liberal government and John Milloy, Minister of Community and Social Services.

"Minister, the government spends a lot of money to keep Jessi in hospital," said Wilson in the legislature. "Is there not a more dignified way to take care of Jessi's needs?" asked Wilson.

Milloy told the legislature that his ministry is committed to making sure "that people are placed in the most appropriate setting." He promised to look into the Dillon's case.

"I suppose we are getting attention because we did what we did," said Gary. "We said we're leaving her here."

Though they are pioneers, they are not alone in their fight. Both Leslie and Gary have nothing but praise for the G&M hospital and the staff looking after Jessi.

Gary recalls one doctor stopping him in the hall to tell him that he and his family deserved service from the system. Jessi's own doctor has said she won't release Jessi from hospital until there is evidence that Jessi will receive adequate care when she leaves - whether that care is given at home or at a group home.

"I don't feel guilty about asking for this service," said Gary. "We do deserve help as do other folks in the same boat."

"Getting respite for home care is just so we can go to work," said Leslie.

This Christmas, if all goes well, Jessi will get a 24 hour pass from the hospital to have Christmas eve dinner with her family. They've all given donations to the General and Marine Hospital's Tree of Life campaign in lieu of gifts this year.

While she's at home in her custom made bedroom, she'll spend some time with her golden retriever, Riley and her cat, Jerome. But on Christmas day, she'll return to the General and Marine hospital - unless there's a miracle, and someone finds room for Jessi.

References

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[i] Cohen E, Berry J, Camacho X, Woodchis W, Anderson G, Guttmann A (December 1, 2012). *Patterns and Costs of Health Care Use of Children with Medical Complexity.* Pediatrics Vol 130(6).

[ii] Cohen E, Bruce-Barrett C, Kingsnorth S, Keilty K, Cooper A, Daub S. (October 2011). *Integrated Complex Care Model: Lessons Learned from Inter-organizational Partnership.* Healthcare Quarterly Vol 14 (Special Issue).

[iii] Ministry of Health and Long-Term Care. (May 2008) Rosenbaum, Peter MD, Expert Panel Chair. Report of the Paediatric Complex Care Coordination Expert Panel.

[iv] Ministry of Health and Long-Term Care. (May 2008) Rosenbaum, Peter MD, Expert Panel Chair. Report of the Paediatric Complex Care Coordination Expert Panel.

[v] Cohen E, Berry J, Camacho X, Woodchis W, Anderson G, Guttmann A (December 1, 2012). *Patterns and Costs of Health Care Use of Children with Medical Complexity.* Pediatrics Vol 130(6).

[vi] Commission on the Reform of Ontario's Public Services (2012). *Public Services for Ontarians: A path to sustainability and excellence.* Queen's Printer for Ontario, 2012.

[vii] Ibid

[viii] Cohen E, Berry J, Camacho X, Woodchis W, Anderson G, Guttmann A (December 1, 2012). *Patterns and Costs of Health Care Use of Children with Medical Complexity.* Pediatrics Vol 130(6).

[ix] Ministry of Health and Long-Term Care. (May 2008) Rosenbaum, Peter MD, Expert Panel Chair. Report of the Paediatric Complex Care Coordination Expert Panel

[x] Cohen E, Berry J, Camacho X, Woodchis W, Anderson G, Guttmann A (December 1, 2012). *Patterns and Costs of Health Care Use of Children with Medical Complexity.* Pediatrics Vol 130(6).

[xi] Ministry of Health and Long-Term Care. (May 2008) Rosenbaum, Peter MD, Expert Panel Chair. Report of the Paediatric Complex Care Coordination Expert Panel

[xii] Ibid

[xiii] Cohen E, Bruce-Barrett C, Kingsnorth S, Keilty K, Cooper A, Daub S. (October 2011). *Integrated Complex Care Model: Lessons Learned from Inter-organizational Partnership.* Healthcare Quarterly Vol 14 (Special Issue).

[xiv] Ministry of Health and Long-Term Care. (May 2008) Rosenbaum, Peter MD, Expert Panel Chair. Report of the Paediatric Complex Care Coordination Expert Panel.

[xv] Spalding, KL, Hayes, VE, Williams, AP, McKeever, P, (2002) Analysis of Interfaces along the Continuum of Care: Services for Children with Special Needs and their Families. Hollander Analytical Services.

[xvi] Ibid

[xvii] Ibid

[xviii] Family interviews conducted by Toronto Central CCAC (2008). Unpublished Report

[xix] Cohen E, Berry J, Camacho X, Woodchis W, Anderson G, Guttmann A (December 1, 2012). *Patterns and Costs of Health Care Use of Children with Medical Complexity.* Pediatrics Vol 130(6).

[xx] Direct Funding Pilot Program Review (April 2012). Report Forthcoming. Toronto Central CCAC

[xxi] Ministry of Health and Long-Term Care. (May 2008) Rosenbaum, Peter MD, Expert Panel Chair. Report of the Paediatric Complex Care Coordination Expert Panel.

[xxii] Ibid

[xxiii] Cohen E, Berry J, Camacho X, Woodchis W, Anderson G, Guttmann A (December 1, 2012). *Patterns and Costs of Health Care Use of Children with Medical Complexity.* Pediatrics Vol 130(6).