

HEALTH COMES HOME: A CONVERSATION ABOUT **CHILDREN WITH COMPLEX HEALTH NEEDS**

PART 3



CHILDREN ARE ONE THIRD OF OUR POPULATION AND ALL OF OUR FUTURE.

- SELECT PANEL FOR THE PROMOTION OF CHILD HEALTH, 1981

Throughout this series of papers, we have presented viewpoints regarding the future of Ontario's society and health care system. We have selected the year 2027 as a future reference point to consider the world as it may unfold and bring a longer-term perspective to present day discussions around health system transformation. As explored in the previous paper, our aging population and the related rise in chronic health needs create the imperative and the opportunity to think differently about the future delivery of care. Perhaps more than any other group covered through this series, Ontario's children with complex health conditions and their families require more timely and remediate action, as well as thoughtful consideration about opportunities to create a better future.

For Ontario's children with complex health conditions and their families, the status quo has a longstanding list of shortfalls and frustrations around the integration and coordination of services. The complexities of caring for Ontario's children with complex health issues is compounded by the needs of families to navigate no fewer than three public systems (health, social services, and education) and, an intimidating array of narrowly construed programs and eligibility criteria. While Ontario's Ministry of Children and Youth Services' primary responsibility is special needs policy, programs and services for children and youth, three other ministries (Ministry of Community and Social Services; Ministry of Education, and Ministry of Health and Long-Term Care) also have significant responsibility for children and youth policy and programs. Not surprisingly, a particularly troublesome challenge facing Ontario's children with complex health conditions and their families is determining who – from the complicated array of ministry and programmatic structures above – will provide the services and financial resources to look after their needs. This lack of coordination and inability to easily navigate relevant services where and when they are needed increases the already stressful circumstances of the parents who care for Ontario's children with complex health conditions.

As we shift our focus to towards 2027 and a longer-term view, Ontario's challenges will change with the nature of our society and demographics. Just as seniors have been and are expected to continue to live longer as a result of advances in medical and supportive technologies, children with complex health conditions are living longer lives. To support them in reaching their full potential for independence and quality of life, our health, social and education systems will need to continue to adapt how they come together to meet the needs of individuals as they progress through life.

Among the implications of Ontario's demographic reality as it relates to children with complex health conditions are: i) more children will transition from paediatric health, social and educational services and programs to adult-oriented systems, where the gaps between service providers and programs are wider; ii) there will be more adults with complex health conditions who often require more intensive care and support as they experience conditions associated with their health (e.g., premature aging, pain, depression, fatigue, functional challenges); and, iii) Ontario's caregivers may face greater demands than ever when faced with the needs of caring for their children with complex health conditions as well as their aging parents.

As with previous papers, our discussions with health system leaders surfaced some key questions as a starting point for a longer-term perspective that emphasize that laying the groundwork for meaningful change must begin today.

Among these questions were:

What should we expect from our health system?

How will we come together to meet the needs of patients?

How will we pay for a transformed system?

How will we value and care for our informal caregivers?

Throughout our interviews and research, it was clear that Ontario's families face a fragmented

array of programs and services that do not yet achieve the full potential we should expect of the investments made. As a result, we must re-examine the complicated architecture that has been established around Ontario families and develop new models to ensure that relevant and valued services are provided to meet the individualized needs of children living with complex health conditions.

TOWARDS 2027 REVISITING THE FUNDAMENTAL TRUTHS

Throughout this series, we have continued to outline some of the ways in which 2027 will differ from today. These have included technological advances; the aging of Ontario's population; Ontarians' expectations of our publically insured health system; and, emerging constraints on our capacity to respond with more public resources alone.

In this paper, we examine the above trends through the lens of children and families coping with complex health conditions. The implications that these trends have in shaping our future world will have profound effects in shaping how we transform our health, social and educational systems to meet future demands as we approach 2027.

Children with complex health needs are living longer thanks to advancements in technology and health care

While the number of children in Ontario has remained relatively stable, there has been a significant increase in the prevalence of various childhood conditions, such as autism and attention deficit disorders. There have also been advancements in health care, medicine and technology that are benefitting children with highly complex health conditions – who in the past would succumb to their conditions early in their young lives – enabling them to live longer and survive into adulthood.

Some studies report that due to improved treatments, an estimated 90 per cent of paediatric patients with complex chronic illnesses will reach the age of 20.¹

90%  **OF CHILDREN WITH
COMPLEX HEALTH NEEDS ARE
NOW LIVING INTO ADULTHOOD.**

For example, a child born with cystic fibrosis during the 1980s could expect to live approximately 14 years. By 2000, that life expectancy had increased to 18 years.² A child born today with cystic fibrosis can expect to live well into his or her 30s, 40s and beyond.³

Children with complex health conditions

- It is estimated that among Canadian children 0 – 19 years:
 - Between 7-8 per cent have a physical disability
 - Between 10-12 per cent have some degree of cognitive deficit
- Approximately 15,770 children and youth in Ontario have complex chronic health conditions

Source: http://www.canchild.ca/en/childrenfamilies/resources/health_families_children_disabilities_national_roundtable.pdf

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

Cystic fibrosis is just one of a multitude of complex health conditions faced by some of Ontario's children and their families. However, treatment of it is illustrative of the advancements of medicine and approaches to health care that will continue to extend the life expectancy of children living with complex health and resulting social, education and other complex needs into their adult years.

Too often however, these advancements in our capabilities to extend and improve the lives of children with complex health conditions are not met with the same rate of progressive policies and funding responses. This leaves Ontario's families to navigate and make sense of multiple programs offered by disparate provincial ministries to arrive at improved health and social outcomes for their children.

As Ontario's children with complex health conditions age, the needs that must be met by their parents and the health system evolve. These demands will increasingly challenge our health system planners to implement new and more integrated responses to meet growing and changing needs. Additionally, as children age, so too do their parents – as Ontario's parent's age, their capacity to deliver the

¹ <https://www.bcma.org/news/bcma-strives-%E2%80%98close-gap%E2%80%99-youth-complex-chronic-illnesses>

² <http://www.disabled-world.com/health/respiratory/cystic-fibrosis/life-expectancy.php>

³ <http://www.lung.org/lung-disease/cystic-fibrosis/>

same amount of physical and emotional energy and financial resources to support the lifelong needs of their children is diminished, requiring other mechanisms to step in and fill the gaps of aging family caregivers.

Evolving constraints in our capacity to care for and fund the needs of Ontario's children and young adults

Family caregivers are central to the lives of children with complex health needs and provide an extraordinary level of time, energy and finances to meet the health and support needs of Ontario's children. Health, social and education system planners and administrators often take for granted the overwhelming contribution parents make to caring for children with complex health conditions. An essential function that parents play is in the navigation of our various health, social and educational systems.

With the increase in life expectancy, children with complex health conditions grow to become adults with complex health conditions. Often, the need for high levels of health, social, educational and support for these individuals continues throughout their life and health trajectory. As a result, parents and family caregivers face a lifetime of physical, psychological, financial and emotional burdens. The challenges encountered by families supporting children with complex health needs often results in a greater number of chronic physical conditions and poorer psychological health including greater stress, distress, emotional problems and depression for care givers of children with complex health needs.⁴

In planning ways in which to transform our health, social and educational systems, we will need to examine the ongoing capacity of Ontario's families to provide the same degree of support that they have to date. In addition, we will need to plan for the needs of more children with complex health conditions transitioning to adulthood and how we will care for these individuals at home and in community settings.

Great expectations

Ontarians consistently express their commitment to a widely-held set of social values, the highest of which is the right to access publically insured health care services. While important pieces of

legislation have established a broad framework and have been instrumental in setting Canadians' expectations of what is provided by public insurance, provinces – in the face of a decreasing share of the health care burden being shared by the Federal government – have regularly extended coverage of provincial insurance programs to cover services that were demanded by advancements in health care and to meet the expectations of the electorate.

As a result, the lines have become blurred as to what must be paid for by public insurance; what we expect to be paid for by public insurance; and, what we have the means to provide as publically insured services. As the health care system shifts from services provided in hospitals and by physicians to one that provides an increasing range and amount of services at home and in the community, health system planners and government will be pressed to manage expectations for health care services without crowding out other vitally important public programs.

Technology underpinning the art of the possible

Perhaps more so than for any other group of Ontarians, advancements in technology have the potential to transform the lives of children living with complex health conditions and their families. They will grow up with technology and will become increasingly reliant on its ability to enable them to live a more empowered and independent life.

- Cars will be automated and directed by the blind
- Eye controlled technology and advancements in neuro implants may give voice to people who struggle to communicate effectively in today's world
- Robotic devices will lend sensory feedback and dexterity to the performance of daily tasks that currently depend on the constant presence of caregivers
- Wheelchairs will climb stairs and other obstacles, freeing occupants from the constraints of today's infrastructure
- Convergence and innovative use of consumer technology will enable more affordable health and assistance solutions for children and adults with complex health conditions to live more independently

⁴ http://www.canchild.ca/en/childrenfamilies/resources/health_families_children_disabilities_national_roundtable.pdf

- Advances to prenatal screening and identification of children who are at greater risk and predisposition to certain disabilities and/or disorders can create the opportunity to either significantly change the health status and outcomes for children through earlier interventions or better prepare families to meet their health and social needs.

These and other revolutionary innovations will provide an opportunity for children with complex health conditions to continue to enjoy life outside institutions; and, be cared for in their preferred care settings at home and in the community, building a greater quality of life and more independent lives where possible.

OUR OPPORTUNITY

THE FUTURE OF A MORE EFFECTIVE HEALTH SYSTEM IS OURS TO LOSE.

Through this series of papers, we have consistently explored the ways in which the often fragmented players of our health and other public programs may work more closely to meet the needs of Ontarians today and as we approach 2027. In other words, *how will we come together to meet the needs of children with complex needs and their caregivers?*

The lack of coordination, the duplication of effort and the inability to access relevant services where and when they are needed unnecessarily increase the level of family distress. What is well understood is that no single response from health, social, educational and other public providers will alleviate the challenges felt by Ontario's families in working across multiple systems and providers.

Instead, we must develop system responses that provide the capability to quickly respond to the care and supports required to meet the variety of needs experienced. These responses must balance the need for a universal approach to early childhood development, parent education and screening (e.g., Ontario's Healthy Babies, Healthy Children) with the need for more comprehensive and targeted resources for those children and families who require it.

The table on the following page highlights a cross-section of some of the various needs experienced by Ontario's children with complex health conditions and their family caregivers. The intensity of these needs will vary as the child develops into adulthood.



High-level needs

Illustrative View of Varied Nature of Needs for Children with Complex Health Conditions and their Caregivers

Social Integration Needs	Like all children, the need to develop friendships and take part in meaningful social development activities and social integration
Care coordination / Navigation	<p>Understanding and gaining access to disparate health, social and educational services and funding available</p> <p>Coordination and duplication of effort working between primary care, health, community care, social and educational providers</p> <p>Disparate availability of services across Ontario</p> <p>Identifying the most responsible/appropriate service provider to access information and/or services</p> <p>Coordinated, planned transitions from paediatric to adult care systems</p>
Information sharing	Limited availability and access to the child's complete patient record contributing to unnecessary tests and delays in service and visits to emergency departments
Engagement in their care and self-management	Development of effective life and coping skills including problem solving, self-reliance, self-advocacy and making informed choices that enhance their well-being
Psycho-social support	Support from families, friends, and communities is associated with better health. The caring and respect that occurs in social relationships buffers against health problems.
Education	Education supports and skills to support learning and social integration at school
Clinical / Medical / Pharmacological / Oral Care	<p>Likelihood of frequent medical interventions and visits (planned and unplanned) and hospitalizations</p> <p>Access to adequate primary care with training and expertise in caring for complex children</p> <p>Health promotion and disease prevention</p> <ul style="list-style-type: none">- Individuals with physical/developmental disabilities may be limited in their amount/capacity for physical activity, increasing the risk of disease and disability <p>Complexity of care may present challenges in accessing prevention and treatment services (e.g., access to basic dental care requiring sedation for children with disabilities)</p>
Hospice Palliative Care	Access to inter-professional health care providers with specialized skill set to support hospice palliative care needs of children and their caregivers
Cognitive / Behavioural	Timely access to health care professionals to address and manage behavioural problems for more effective learning and well-being within home and educational settings
Assistive Technologies	<p>Continued access to technology meeting the pace of physical and cognitive development (e.g., technology and assistive devices that accommodate normal physical growth)</p> <p>Maximizing independence and minimizing need for personal assistance from others balanced with medical dependency on technology (e.g., ventilators)</p> <p>Incorporating electronic and information technology to enhance their ability to communicate</p>
Ongoing needs of informal caregivers	<p>Coping and respite care to mitigate exhaustion and isolation due to high demands of caregiving</p> <p>Effective navigation and advocacy on behalf of child with complex health conditions</p>

These needs will vary greatly by individual health and family circumstances. Health, social and educational system planners therefore need to realize new ways to provide families and children with complex health needs with the services that deliver the most value. In addition, the complexity of the interplay of needs illustrated above is amplified as children transition across their life stages and into adulthood. Many programs and services are housed under dedicated children's models aimed at delivering a more integrated set of services with health, social and educational providers playing a much more active role in guiding and navigating children and their families to the most appropriate care and support. However, when the child reaches adulthood, a number of these programs and direct supports cease, leaving the individual and his or her parents or caregivers to navigate and advocate in a new adult-oriented system that is often even more fragmented than they have experienced in the past. In Ontario, the Provincial Council for Maternal and Child Health, has sought to address this by developing an action plan with five priority areas for immediate action for children with complex health needs and their families:⁵

- The creation of a single application and entry point for families,
- Integrated complex care,
- Self-directed funding for families,
- Development of a peer support network for families, and
- Improving transitions to adult services.

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 their local community and experiencing a better quality of life.

Source: "Pursuing the Possible, Provincial Council for Maternal and Child Health

Getting Lost in Transition: Improving transitions from children to adult services

The needs of Ontario's children with complex health needs do not go away when they reach the age of 18. However, many of the programs, services and structures they have grown up with and relied on for care and support change or disappear completely once they reach arbitrarily defined age limits. What is more distressing is that while so much of life may comprise unanticipated challenges, meeting the needs of Ontario's children with complex health

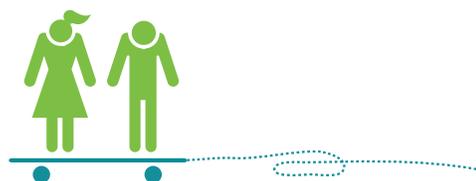
needs transitioning to adult care is not one of them. Many of the needs are well known and studied in great detail. Our failure is a lack of planning for the future of these children and how we, as a health, social and educational system payers and providers will disrupt our own models to help these individuals reach their full potential of independence, choice and support the families that care for them. For example, important elements that help to manage the transition may include ensuring that individuals have access to the right tools and resources including:

- Early initiation of transition planning and an individualized transition plan
- Warmhand-offs/transitions between the paediatric and adult care systems that fully recognize the importance of patient and family engagement
- Skills and capacity to manage medications, attend health care appointments, and self-direct care
- Access to a family physician with the patient's background and with the appropriate skills and expertise to support management of the patient's complex set of needs
- Support in transitioning between educational settings (e.g., to post-secondary education) and/or to the workforce and the ability to find and maintain regular employment
- Skills to meaningfully participate and integrate into the community and social circumstances

Through better orchestrated transitions from paediatric care to adult care, we may improve their health outcomes as well as reduce health system utilization and cost (e.g., emergency department visits and hospitalizations).



MANY OF THE PROGRAMS, SERVICES AND STRUCTURES THAT ONTARIO'S CHILDREN WITH COMPLEX NEEDS RELY ON CHANGE OR DISAPPEAR COMPLETELY ONCE THEY REACH A CERTAIN AGE



⁵ Pursuing the Possible, Provincial Council for Maternal and Child Health, 2012

Implications for Ontario's Children Transitioning to Adult Care and Health System Utilization

Examples of services that may be reduced or discontinued for children transitioning to adulthood may include Special Services at Home funding, Enhanced Respite funding, school health services, children care programs and respite programs. In addition, paediatric organizations are often staffed and funded to provide multi-disciplinary approaches (e.g., nursing coupled with social work) to caring for the medical and/or psycho-social needs of patients, whereas, adult facilities or specialists are frequently more compartmentalized.

Studies illustrating the impact on care through transition has found patients increasingly less likely to adhere to medications, schedule and attend regular physician visits and are more likely to rate their health as poor when compared to their time before transition to adult care.

The above impacts on patient health and wellness post-transition to adult health care systems are reflected by increased hospitalizations and emergency room visits. One study demonstrated that patients who maintained the same physician after transition were 77 per cent less likely to be hospitalized for their diabetes-related condition as those who were provided a different physician after transition.

Source: http://www.canchild.ca/en/childrenfamilies/resources/health_families_children_disabilities_national_roundtable.pdf

As a result of the impact on health outcomes because of gaps in the transition of children with complex health needs moving to adult care, other jurisdictions have introduced enhanced clinical care coordination roles to reduce unnecessary hospital admissions and acute interventions, thereby reducing overall health system costs.

The needs of children with complex health conditions and their families vary over the course of life stages and in accordance with the individualized needs associated with their health and family circumstance. As a result, our health system will need to evolve to ensure the public resources invested derive the most value for money in delivering services that are relevant and required by Ontario's families and children with complex health conditions.

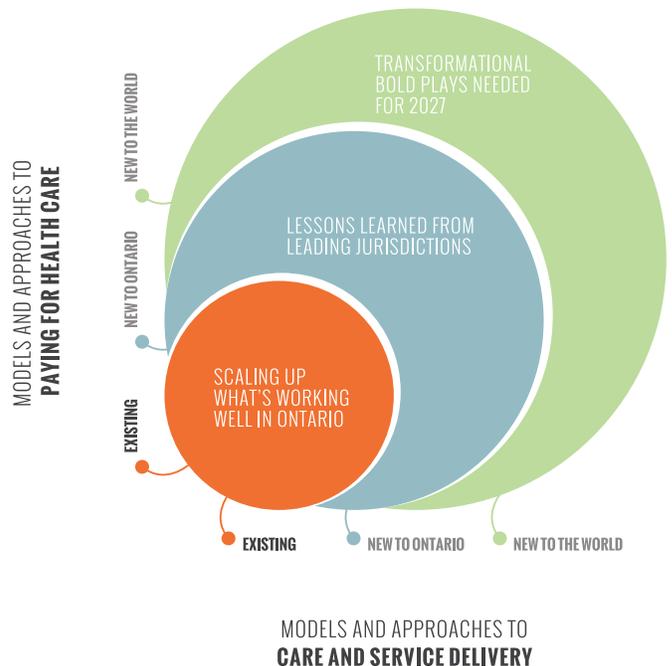
Stepwise Towards Transformation

Through our discussions with health system leaders across Ontario, as with other aspects of our health system, it was clear that gradual changes and transformation are needed in how we organize, pay for and deliver services to meet the needs of Ontario's children with complex health conditions and their families.

While many health system leaders were quick to point to positive developments that have put Ontario on a trajectory for change and transformation, they were equally quick to point out that much work lies ahead of us. Recurring themes for this patient population and others were the need to scale up the impact of effective models in place in Ontario today, the need to import valuable lessons learned from other jurisdictions facing challenges similar to Ontario's, and the need for a longer-term perspective with which to take on some of the more fundamental questions that would liberate Ontario's talent and ingenuity.

These questions include: How will we continue to pay for health care? What will we expect from each other, that is; what health services will society provide? What will we expect from families and informal caregivers? And, how might communities at large come together to care for Ontario's children with complex health conditions across their trajectory of life and spectrum of health, social and educational needs?

STEPWISE TRANSFORMATION FOR ONTARIO



Scaling up what's working well in Ontario

Recent work in Ontario has identified that a small proportion of health system users account for a disproportionate degree of health system spending. Children with complex health needs are among the

so-called 1 per cent and 5 per cent of high users of health system resources. In fact, analysis by the Provincial Council for Maternal and Child Health indicates that less than 1 per cent of paediatric patients in Ontario consume approximately 32 per cent of all spending on children's health care – totalling \$419 million per year.⁶



LESS THAN 1% CONSUME 32% OF ALL SPENDING ON CHILDREN'S HEALTH CARE

What's more, the above costs are those born by the health system alone and do not account for the costs distributed across other social, educational and community services. This underscores our need to better understand a more complete picture of needs and public services accessed by individuals and specific patient populations in Ontario. Our efforts to reorganize and transform health and other services around the needs of patients should be aimed at an integrated understanding of key elements of health and social case management information through the use of analytics.

In developing Ontario's recent mental health strategy and its initial focus on children, the province has turned an important corner in its recognition and deliberate intent to improve the services and financial support to Ontario's parents. These efforts need to extend beyond the mental health strategy to benefit all families in Ontario with children with complex health conditions.

Much of what is needed to better address Ontario's children with complex health conditions might well be taken from the pages of Ontario's emerging approach to Health Links which is working to foster a "low rules" environment for integration and collaboration to improve the ways and means of providing health services. For example:

- The provision of a network of linked health (plus social and educational) service providers to collectively manage the needs of Ontario's greatest-needs patients

- Working in partnership with family and community to move smoothly through the system and ensuring they do not fall through the "gaps" in care
- Working among providers to clearly establish who the "most responsible provider" will be
- Adopting more proactive measure to meet and manage ongoing care needs.

A promising research-based model for addressing the school-based health needs of children was developed by the CanChild Centre for Childhood Disability at McMaster University. The Partnership for Change model, which was piloted in the Central West and Mississauga Halton CCACs, focuses on building school and family skills and capacity to create supportive, adaptive environments for children. While the model was developed to address the needs of children with developmental coordination disorder, it has the potential to be adapted to address other health needs.

Ontario is also modelling the potential of technology enabled models of care. The South West CCAC has implemented a technology that allows it to scale up the impact of the relatively few nurses with advanced training in paediatrics through its *eShift* program. The program connects personal support workers working in the homes of patients to paediatric Registered Nurses to maximize the use of advanced health care resources, maximize professional scopes of practice, reduce patient visits to the emergency room, and enhance access to nursing care in rural and remote areas of the province to name a few.

With an increased understanding of the specific services and needs of Ontario's children with complex health conditions and their families, we will be better able to make deliberate and strategic choices in where we focus our health and other system resources to yield the best possible outcome at lowest feasible cost.

Following are some examples of success occurring across Ontario demonstrate the possibility of coordinating care across multiple sectors and providers through effective sharing of information, and integration of health, social and education professionals through the ongoing single-point-of-contact case coordination.

⁶ Pursuing the possible – Provincial Council for Maternal and Child Health, 2012 http://www.centralwestlhinc.on.ca/uploadedFiles/Public_Community/_v2_Work_of_the_LHIN/Core_Action_Groups/3.%20For%20Reference_Pursuing%20the%20Possible_PCMCH%20Action%20Plan_%20Final_Jan%202013.pdf

Children’s Treatment Network of Simcoe County and York Region

The Children’s Treatment Network of Simcoe County and York Region provides comprehensive, coordinated care and services to children with complex physical, developmental and communications needs. Through the Network, organizations work with the family to develop a coordinated “single plan of care” to adapt to the child’s needs as they develop.

The model has reduced the need for families to navigate the often fragmented children’s service systems in which information is not readily shared among providers (e.g., physiotherapy, seating and mobility, occupational therapy, speech and language pathology, audiology, augmentative communications, neuropsychology, feeding, and developmental paediatrics).

Underpinning these efforts are tools including a shared electronic record and shared information across over 40 service provider organizations and agencies that comprise the child’s care team.

Scalable Benefits for the Rest of Ontario

- Single and shared plan of care among a multi-professional / organizational care team
- Single plan-of-care case coordinator who works with the family to identify the vision for their care
- Shared electronic health record among providers to update and share changes and progress made

Holland Bloorview Kids Rehabilitation Hospital / The Toronto Rehabilitation Institute

LIFEsplan (Living Independently and Fully Engaged):

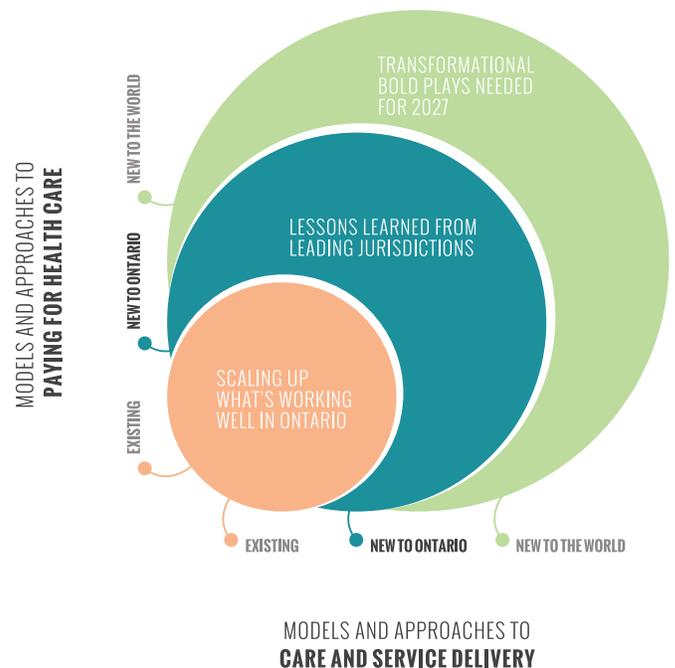
LIFEsplan is a partnership program of the University Health Network-Toronto Rehabilitation Institute and Holland Bloorview Kids Rehabilitation Hospital. The program was initiated to address the need for a coordinated approach to transitioning young adults from paediatric to adult services and the need for the development of specialized adult services for individuals with childhood onset conditions. LIFEsplan offers a single point of access where young adults can meet with an expert interdisciplinary team that is familiar with their specific needs. LIFEsplan delivers services for young adults with cerebral palsy and acquired brain injury (ABI) sustained in childhood, transferring from paediatric to adult care. The primary goal

of the service is to effectively link clients with childhood onset disability to specialized adult services and maintain this linkage (and resulting service provision) over time.

Scalable Benefits for the Rest of Ontario

- Single and shared plan of care among a multi-professional / organizational care team
- Single plan of care case coordinator that works with the family to identify the vision for their care
- Sustained linkages with providers to improve health, well-being and participation, and prevent secondary conditions
- Manage and ensure appropriate use of health system
- Youth Facilitators who share personal experiences; discuss living and participating in adult life as a person with a disability

STEPWISE TRANSFORMATION FOR ONTARIO



Lessons for Ontario from other Leading Jurisdictions

In addition to models that have proven their value in the Ontario context, health system leaders and our research surfaced examples of other jurisdictions dealing with similar challenges in new and innovative ways.

Through the distillation and thoughtful consideration of what is working well in other health systems,

Ontario may be able to import key lessons learned for adaptation and deployment within the Ontario health system.

Government of Alberta – Care coordination for children with complex needs⁷

The Children and Youth with Complex Needs (CYCN) Initiative fosters collaborative planning and service coordination for the benefit of children and youth with complex needs. The program coordinates services delivered from a number of ministries, including Alberta Children and Youth Services, Alberta Education, and Alberta Health and Wellness. Local cross-sector teams support comprehensive case management for children and youth in their area. The local team determines the need for support and an integrated service plan, and then refers the patient to the Regional Review Team. Each service provider at the review determines their involvement, contribution of services, supports and resources to the coordinated service plan. When appropriate, students are supported in their transition to additional supports under adult services.

Lessons for Ontario

- Formal care coordination across ministries
- Local and regional supports coordination
- Supports for transition to adult services

Dutch Persoonsgebonden Budget (PGB) – Increased support for patients and caregivers⁸

The Netherlands has had a strong, collective long-term care system since the late 1960s. Introduced as an experiment in 1995, the Dutch Persoonsgebonden Budget (PGB) was generally adopted in 2001. PGB uses a national assessment tool implemented by local assessment boards to determine eligibility. Following assessment and approval, the individual who receives the care can arrange for professional care services (from either a market or a non-profit organization) or can employ an individual, including family and caregivers, to provide care.

The system also provides support to caregivers. The caregiver can deduct medical expenses and other related expenditures from their annual taxes in

relation to the care receiver where these expenses exceed 11.2 per cent of income. The employed caregiver also receives 10 days care leave per year. The employer pays 70 per cent of wages and the government compensates the employer.

Lessons for Ontario

- Patients choose between government-supported care or employing their own preferred care using government funds
- Standardized assessments across the country
- Tax deductions for caregivers for medical expenses
- Paid care leave for caregivers

The Austrian Pflegegeld – Cash for care program that promotes flexibility and choice⁹

In 1993, Austria reformed long-term care policies to include not only the elderly, but all dependent persons. The Austrian federal government set up a social insurance scheme for dependents that gave a care allowance to all people meeting established criteria based on a medical grid. This system has had no fundamental changes since it was implemented in 1993. The Austrian Pflegegeld has seven levels of needs and each level corresponds to a range of monthly hours of required care. People are assessed and provided care regardless of income. The provinces are responsible for residential and semi-residential services and home care, and the allowance's beneficiaries can choose how to spend their benefit.

Lessons for Ontario

- Financial support regardless of income
- Standardized assessments across the country; needs assessment that determines hours of care
- Federal funding
- Local services that cater to the unique needs of the population
- Choice and flexibility in services

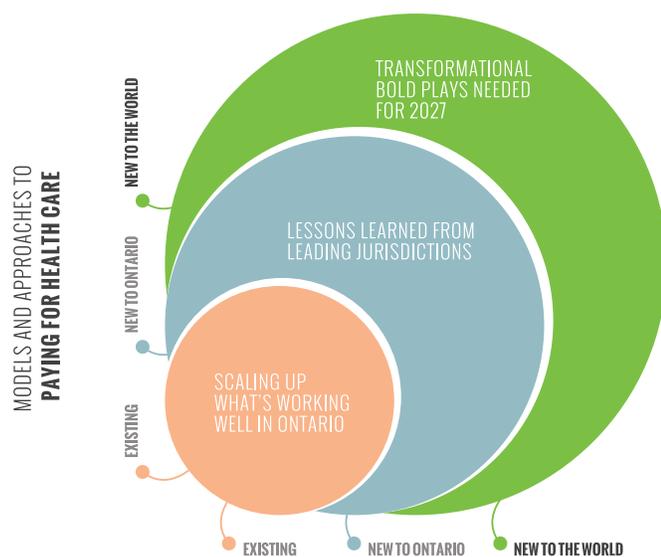
⁷ <http://www.education.alberta.ca/media/4971259/cyconfactsheet2010.pdf>

⁸ Da Roit, B., & Le Bihan, B. (2010) Similar yet so different: Cash-for-care in six European countries' long-term care policies.

The Millbank Quarterly. 88(3), 286-309. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3000929/>

⁹ Da Roit, B., & Le Bihan, B. (2010) Similar yet so different: Cash-for-care in six European countries' long-term care policies. The Millbank Quarterly. 88(3), 286-309. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3000929/>

STEPWISE TRANSFORMATION FOR ONTARIO



MODELS AND APPROACHES TO
CARE AND SERVICE DELIVERY

Towards Transformational Bold Plays needed for 2027

As with other patient populations we have examined through this series of papers (people with chronic conditions, seniors with complex health conditions and people requiring hospice palliative care), Ontario's parents and their children with complex health conditions face a daunting degree of fragmentation in terms of how they access services across the health, social and education systems. Incremental advancements are not likely to deliver the levels of transformation required to meet the needs of Ontario's children with complex health conditions and their families. *Today*, too many families have to undertake heroic efforts to navigate and advocate for access to services provided by our overly complicated health, social and educational systems. The services that are provided often do not meet the needs and individual circumstances of Ontario's families. The structures in place and the way in which we prescribe how services are accessed regularly risks under-delivering on the value for money received for both families of children with complex health needs and Ontario's taxpayers. Ontario system planners therefore will need to more fully include Ontario's families and informal caregivers in the co-design of how they receive care and support across disparate services; and, solicit their ideas and ongoing involvement of

redefining what a high-performing system would look like for them.

Towards 2027, children with complex health conditions will continue to live longer and fuller lives owing to advances in medical and assistive technologies. As they live longer lives however, health system planners will be pressed to continually deliver access to high-quality care and services. In addition, health system planners will not have the same reserves of what has been an indispensable resource in providing the majority of care: *parents* of Ontario's children with complex health conditions. As Ontario's parents age and experience their own age-related health issues – brought on, in part, by a more stressful and demanding life spent as caregivers – Ontario's health system planners will face mounting and more dire challenges ahead.

In responding to the needs of Ontario's children with complex health conditions today and towards 2027, government and health system planners will need to focus their efforts and gain clarity on some fundamental questions: How will we pay and provide relevant services to meet the needs of Ontario's families and children with complex health conditions? And, what will we expect of our informal caregivers and each other as a society?

How will we pay?

One of the greatest assets that Ontario's children with complex health conditions have is the love and devotion of their parents as caregivers. These caregivers are also a vital resource to the Ontario health, social and educational systems. All told, family caregivers to Ontario's children with complex health conditions provide countless hours of care, support, personal financing and health system navigation.

However, within the current funding envelopes and program and ministerial structures, families spend far too much non-value-added time making sense of eligibility requirements, applications, and gaining access small pockets of funding. What's more, the available funding is often restrictive in terms of who may provide the service, what type of services can be provided, how many hours that services can be delivered and where they can be received. In sum, many of the public resources allocated to providing services including home and community care to Ontario's families with children with complex health conditions do not deliver the full value that could

be otherwise realized by the families themselves investing in the services most relevant to them.

To provide the greatest value for public resources invested, we must re-examine the restrictions and barriers to providing the services that best meet the needs of Ontario's families. This includes revisiting limiting policies, professional regulations and organizational structures that restrict the options available to Ontario's children with complex health conditions. Other jurisdictions have explored potential options that may be put into practice to better serve Ontario's families and taxpayers.

Choices for UK Caregivers¹⁰

In an effort to provide caregivers with more control over the services and support they receive public funding for, the National Health Service (NHS) has implemented programs that allow for personalization enabled by total control of the support services needed.

- *Direct payments* can be provided by social services to allow services to be directly purchased, to hire a caregiver (that may include a family member), and/or to acquire equipment to meet the individual's care needs.
- *Personal health budgets* are being introduced in April 2014 that is intended to provide an amount of money to support an individual's identified health and wellbeing needs. These needs and the amount of money available will be a result of planning and agreement with local NHS teams and the individuals or families requiring out of hospital services.

In addition to caregivers as an indispensable resource enabling children to reside at home, assistive devices can be another vital component of caring for children with complex health needs. Ontario's assistive device program provides up to 75 per cent of the cost of approved assistive devices. Despite this level of support, many Ontario families struggle to afford the high cost of assistive devices and keep pace with replacement costs as children grow and mature. Similar to the case of restrictive policies for caregiver support, many users find the funding criteria for assistive devices too stringent forcing people to use devices that do not meet their needs, or to go without assistive devices.¹¹

Given the pace of innovation and the increasing cost of assistive devices, Ontario health system

planners will face increasing demand for funds to enable Ontario's children with complex health conditions to continue to reside at home. In addition, the demands are likely to become increasingly personalized due to the varying nature of needs of individuals and their families. To meet the needs of Ontario's children with complex health conditions, we will need to develop more responsive approaches to determining what level of funding the province provides to support children with complex health conditions in their homes and how to meet the individual needs of their families and caregivers.

Finally, compounding the resource challenges and questions related to how we will pay for services to meet the demands of children with complex health conditions is the aging of Ontario's parents as caregivers. This will place increased demands on the Ontario home and community care sector as they age and their capacity to provide the vast majority of care to meet the needs of their children diminish. With this diminished capacity will come increased requests for direct services and respite care which have been shown to increase as caregivers age in other countries.¹²

What should we expect from our families, informal caregivers and each other?

As we have discussed throughout this series of papers, informal caregivers provide an inordinate amount of the care and support to Ontario's children, adults and seniors in need of home and community care. For Ontario's children with complex health conditions – their parents and families are the chief source of this care and support.

PARENTS OF CHILDREN WITH COMPLEX HEALTH CONDITIONS OR DISABILITIES OFTEN SUFFER FROM CHRONIC CONDITIONS THEMSELVES, INCLUDING STRESS AND DEPRESSION, AND AS A RESULT MAY EXPECT TO PAY BETWEEN 2.5 TO 20 TIMES MORE IN MEDICAL COSTS THAN THE AVERAGE PERSON, ON TOP OF THE HIGH COST OF THEIR CHILD'S CARE NEEDS.



¹⁰ <http://www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/Financialhelpwithsupport.aspx>

¹¹ http://tetra.sa.utoronto.ca/files/2009/07/report_regular.pdf

¹² pp. 26 (http://www.cha.ca/wp-content/uploads/2012/11/Respite_Care_in_Canada_EN_web.pdf)

While this level of support has been an unaccounted for resource to Ontario's health system, it is not without its costs. For example, caregivers of children with complex health needs often report a greater number of chronic physical conditions and exhibit poorer psychological health including stress, distress, emotional problems and depression. Additionally, parents of children with complex health conditions or disabilities may expect to pay between 2.5 and 20 times the amount in medical costs alone, expect greater absenteeism at work or lost wages as a result of having to leave the workforce entirely to care for their child, and expect a greater need for respite care and/or accommodation for regular children's programs.¹³

As a result, our society and health system planners must take a more accurate account of the considerable capacity Ontario's families and informal caregivers provide to the system. We must also categorize support for Ontario's caregivers as investments in the ongoing sustainability of our system and re-shape policies and practices to better support and sustain them as an invaluable health, social and educational system resource. To this end, a number of recommendations from the health system leaders and research conducted as part of this series of papers have surfaced.

These include:

- Streamline programs and services and increase the capacity of caregivers to effectively navigate health, social and educational systems
- Increase the level of empowerment of caregivers to control the nature of the care and support they receive
- Increase caregiver relief and respite services
- Incorporate the needs of caregivers within health policy and practice frameworks

CONCLUSION

Ontario's children with complex health conditions and their families face a dizzying array of impediments in their pursuit of care and support. The complicated structures that have been erected over time through disparate public systems (i.e., health, social service and education) and siloed ministries have created well-meaning, but isolated and seemingly disconnected programs. As a whole, these programs do not deliver the full potential in meeting the individual needs of Ontario's families of children with complex health conditions.

The advancement of health care treatments and technology will continue to improve the life expectancy of Ontario's children with complex health conditions. As well, these advances will translate into overall growth of this population whose needs and impact will extend beyond their childhood into adulthood. Our public policies and practices must keep pace with the needs of Ontario's families and help them to achieve the best possible health and social outcomes for their children. As the parents (and primary care givers) of Ontario's children with complex health needs age, their reduced capacity to provide the same levels of care will need to be met by new ways to fill the gaps, while enabling informal caregivers to continue to play an instrumental role in supporting their young and adult children with complex health conditions. Moreover, given that we know when these transition points for this population occur and what the needs are, we must do a better job by being more proactive in developing transition plans and supports that meet the specific needs and circumstances of a given child and his or her family.



FAMILIES CARING FOR CHILDREN WITH COMPLEX NEEDS AND ELDERLY PARENTS AT THE SAME TIME GIVE COUNTLESS HOURS TO THE HEALTH CARE SYSTEM.

¹³ http://www.canchild.ca/en/childrenfamilies/resources/health_families_children_disabilities_national_roundtable.pdf

Our responses must clearly establish a mature dialogue and grounded expectations from government, informal caregivers, and society as a whole. We will also need to reduce the level of caregiver distress and frustration by: enhancing coordination of existing services, providing greater freedom and empowerment to deploy public resources that best meet the individualized needs of Ontario's families, supporting caregivers as they age with additional resources and respite, and fully incorporating the ongoing needs of caregivers in the development of policies and practices.

Looking Ahead

Whether it is looking at our current health care system through the eyes of people with chronic conditions, seniors with complex health needs and people requiring hospice and palliative care, or children with complex needs and their parents and/or caregivers, what is clear is that **we can no longer be reactive in our approach to transforming how we work to better meet the health and social needs of Ontarians.** Our world is rapidly changing on a number of different fronts such as our demographic profile, societal expectations, and technology to name a few and the needs of people will also continue to evolve as the world around us evolves. As a result, it is imperative that we critically evaluate the systems, structures and conventions of today and consider strategic alternatives to enable our health system to be able to transform and keep pace with society's needs.

As we have indicated in this paper and the preceding two papers, we must start an earnest dialogue now to begin to discuss fundamental questions such as:

- How do we develop clearly defined approaches to how we pay for health care?
- How do we enhance the health and wellness of Ontarians in their homes and communities?
- How do we encourage traditional and non-traditional players and solutions to address society's challenges?

How Ontario responds to these and other key questions is critical and the resultant answers will take time to implement. Given the importance of the challenge before us, in our fourth and final paper in this series we will outline options and considerations for how we advance the discussion and move towards action. We need to act now if we are to be ready to meet Ontarians' demands and expectations of our future health care system.