

# The Perspective of the CEO

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#### How It Came About

I was CEO of the Children Hospital of Eastern Ontario (CHEO) when the program for complex children was initiated. This program was described in detail by Governance International on their website (www.govint.org) under the title A partnership model for children with complex medical conditions: The Champlain Complex Care Programme in Canada.<sup>1</sup>

> Over the past 40 years, CHEO has established itself as a world-class centre providing leading-edge treatment and compassionate care for children and youth aged 0 to their 18th birthday. CHEO's large service area includes not only Ottawa, but also Eastern Ontario, Western Quebec, Nunavut and parts of Northern Ontario.

> With more than \$243 million in annual revenues, CHEO is the second largest hospital in the Champlain Local Health Integration Network (LHIN), and has more than 2,500 doctors, nurses and additional staff dedicated to providing the best possible care for the children and youth of our community. CHEO is one of only a few stand-alone pediatric hospitals in Canada, and has more than 6,600 admissions, 7.700 surgeries and 171.000 clinic visits each year. It also has one of the busiest pediatric emergency rooms in the country, treating more than 69,000 patients a year.<sup>2</sup>

I was CEO from 2006 to 2011 and, in this capacity, I had regular meetings with our Family Forum, a group of parents of children using CHEO's services. In late fall 2008, during one of these meetings, parents talked about the burden of caring for children with very complex problems. I heard about the challenges facing families with very heavily handicapped children who needed to see up to fifteen different specialists, use life sustaining equipment, and receive services from CHEO as well as other establishments like the Ottawa Children's Treatment Center (OCTC) (an outpatient rehabilitation service) and the Community Care Access Center (CCAC) (home care) in addition to their regular paediatrician, frequent visits to the Emergency Room and occasional hospitalization. The case study provides data about the number of visits patients made to the various clinics, emergency room usage and days of hospitalisation.

I heard these parents describe how they had become case managers because there was no coordination among service provider organisations, and between providers within CHEO. That involved numerous phone calls to get appointments and multiple visits to specialists scheduled on different days because they could not coordinate these visits on the same day. It meant repeating the same story over and over again and missing time from work for medical visits. Some parents, and in particular women, had to leave

<sup>1</sup> Elke Loeffler, Shaundra Ridha and Dr. Nathalie Cook-Major, "A partnership model for children with complex medical conditions: The Champlain Complex Care Programme in Canada," http://www.govint.org/good-practice/casestudies/a-partnership-model-for-children-with-complex-medical-conditions.

the workforce to become full time caregivers. I heard about couples whose marriages failed because of the stress generated by the situation. It was clear that the lack of coordination and support to parents carried a very high social cost, much greater than the cost of providing care.

These parents were not aggressive. Rather, they were resigned. They needed help but did not believe it would ever come.

## **Raising Awareness**

I was touched by their testimony and promised them I would find a way to help. At the following meeting of our senior management team, I put this topic on the agenda. We had a good discussion about what approach might help these parents. Everyone around the table agreed that this was a major problem but expressed concerns about the resources needed. Some were unsure whether this was part of CHEO's mandate. Three ideas emerged:

- The need for a case manager or point of contact. This means one person would know the child, be aware of the full case, coordinate appointments, and ensure there is a common chart for the patient. Parents would have one number to call.
- The need for a most responsible physician. Since these children were seeing a large number of physicians, there was a need for one physician to coordinate their medical care, talk to the other physicians involved and keep track of the evolution of the case.
- The need to involve other organisations providing services to these children. Although CHEO is by far the largest provider of health services to children in the region, it is not the only one and services are not integrated. All of the children with very complex problems received services from at least one other organisation. To ensure full coordination, these organisations needed to be involved.

#### **The Initial Steps**

I contacted my colleagues from OCTC and CCAC and met one on one with them. They immediately saw the potential benefits for the children and their families and accepted my invitation to a meeting to explore possibilities without hesitation. Also present were CHEO's VP Patient Care, a parent representative, an interested paediatrician and a few other professionals from CHEO. It was agreed to establish a governance structure made up of representatives from the three institutions (Coordinated Access was added later), the parents, and the Champlain Local Health Integration Network (LHIN). The programme partners established a governance structure to ensure evidence based decision making including a Steering Committee consisting of family members and senior executives from each partner organization and an Advisory Committee consisting of family members and middle management from each organization, as well as a Programme Team that is CHEO-based and runs the day-to-day programme.

The partners set up an inter-disciplinary programme team consisting of a project manager, several nurse coordinators and a Most Responsible Physician (MRP). The project manager and the MRP were CHEO-based, the care coordinators were based in each partner organization and were assigned the patient and family based on an assessment of the unique care needs required and which organization or combination of organizations could best meet those needs. Allied health care provider services (dietician, social workers, physio, etc.) were provided in kind by each organization. Each of the partners in turn linked to community providers, including respite care, service coordination, education, public health, palliative care, etc.<sup>3</sup>

The Advisory Committee explored various options about what a program might look like. Their work was not always easy since members sometimes had a tendency to focus on problems rather than solutions (for example the lack of a common electronic health record) and did not always resist the temptation of defending their service rather than focusing on the overall interest of the child. But as they reported to the CEO group, they received clear guidance to overcome these difficulties. The cooperation among CEOs was outstanding, for three reasons: first, their clients would benefit from better coordination; second, there was no attempt by CHEO to control the program on its own; third, I already had excellent working and personal relationships with them.

The main impediment was funding. My colleague from the CCAC informed me that her organisation would have a small surplus that year. They had received funding they were unable to spend by year end. A particularity of the Ontario funding system is that, unlike hospitals, CCAC must return year-end surpluses to the Ministry. A joint request to the LHIN was made to transfer surplus funds (more than \$300,000) to CHEO. The request was approved. With CHEO's Department of Paediatrics funding "the most responsible physician", there was now enough funding available to finance a one year pilot project.

CHEO provided supervision, through one of its directors, as well as space and administrative support (HR, Finance, IT, purchasing, etc.) to the initiative. The other partner organisations were not in a position to provide funding; this was clear from the start.

<sup>3</sup> Loeffler, Ridha and Cook-Major, "A partnership model," http://www.govint.org/good-practice/case-studies/a-partnership-model-for-children-with-complex-medical-conditions.

## **The Pilot Project**

Some 33 children and their family participated in the pilot project during the first year of the program. At the end of the first year, we were again fortunate to secure funding from the CCAC, even though the CEO at the helm of the organisation had changed. The incoming CEO was also enthusiastic about the project, but signalled that this was the last time CCAC could help fund the initiative. The pilot was extended for a second year.

'Overall, results from the pilot show improved access to care, increasing system throughput and providing long awaited coordination of services for families in Ottawa and surrounding areas, allowing them to "normalize" their households, return to work and lead a family life as close as possible to normal.'<sup>4</sup>

## **Social Benefits and Local Costs**

The case study reveals that the program generated savings for the health system of close to \$1M per year, mainly due to the reduced number of hospital days needed by the participants. These savings, however, are not net savings. Reducing the number or duration of hospitalisation does not allow hospitals to reduce the number of beds or reduce staffing since others replace these patients. The positive result is to reduce wait lists. Similarly, a small increase or reduction in the number of patient visits in the Emergency Room has negligible overall financial impact since the hospital must maintain its 24/7 infrastructure (physician, nurses, lab, radiology, etc.). It may actually negatively affect performance indicators since a reduction in the number of visits increases the cost per visit and may make the hospital look less efficient.

The fundamental problem with initiatives of this kind is that those who bear the direct cost, i.e. the organisations involved, do not benefit from the results in a manner that translates into direct savings. The benefits are distributed across the health sector and society. The patients, their families and society are the primary beneficiaries.

Those who benefit from the program are:

- The families themselves, who save on visits to the specialist, lost time at work, and even from being able to get back into the workforce.
- The employers of these parents because of increased productivity and reduced absences from work.
- Society as a whole.

## **The New Synthesis**

In my view, this case illustrates the need for a different way of thinking about the role of public organisations and the relevance of the New Synthesis' three lenses:

- Positioning: "The way we frame a public policy issue or position the contribution of public agencies has a direct impact on the solutions that will be found and on their ability to address current challenges."<sup>5</sup> In this case, this meant looking beyond the specific role of CHEO as a care provider to expand its reach to families, and to enhance the social impact of how its care was delivered.
- Leveraging: "Leveraging recognises that no individual, agency or government possesses all the tools and levers to generate the results we aspire to achieve as a society."<sup>6</sup> This project could not have been achieved without the cooperation of several health agencies.
- Engaging: "In every country, there are powerful examples of how a different sharing of responsibilities between government and citizens contributes to better results, higher user satisfaction and lower costs."<sup>7</sup> The idea behind this initiative came from the parents and they were involved in every step of the design and operation of the program.

## Conclusion

I left CHEO in November 2011 as the pilot project was in its second year. I am proud that CHEO and the partner organisations were able to find funding to continue and even expand the program. My greatest reward for launching this initiative came shortly before I left when some parents came to the Family Forum and at the Board of Trustees to express how this program had changed their life. It was a deeply emotional event and a powerful reminder of the importance of never losing sight of the public mission served by organisations such as these. Nothing could be more satisfying for a public administrator.

<sup>5</sup> Jocelyne Bourgon, "Leading Transformation: The New Synthesis In Action" (Ottawa : Public Governance International, 2014).

<sup>6</sup> Jocelyne Bourgon, "Enforcement and Safety" (Ottawa: Public Governance International, 2015).

<sup>7</sup> Jorgen Tholstrup, Empowering Patients to Need Less Care and do better in Highland Hospital, South Sweden. 2012. Available from: http://www.govint.org/good-practice/case-studies/empowering-patients-to-need-less-care-and-dobetter-in-highland-hospital-south-sweden/

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