case STUDY series

December 2018

THE CHANGE FOUNDATION
ENGAGE, EXPLORE, EVOLVE

ACHIEVING TRUE PARTNERSHIP:

Three case studies of patient- and family-centred pediatric care in Ontario

ABOUT THE CHANGE FOUNDATION

The Change Foundation is an independent health policy think-tank that works to inform positive change in Ontario's healthcare system. With a firm commitment to engaging the voices of patients, family caregivers and health and community care providers, the Foundation explores contemporary healthcare issues through different projects and partnerships to evolve our healthcare system in Ontario and beyond. Created in 1995 through an endowment from the Ontario Hospital Association, the Foundation is dedicated to enhancing patient and caregiver experiences and Ontario's quality of healthcare.

Acknowledgements

To encourage unfettered discussion, we promised not to name the many patients, family members and staff we interviewed for these three case studies. Unfortunately, that leaves us unable to thank those dedicated and generous people who made time in their busy days to help us in this work. But we could not have succeeded without a great deal of help. Thanks, therefore, are due to the people who gave us the big picture on who is working on patient and family integration in Ontario, to others who organized meetings and interviews, and to the people who dug through their archives and their e-mails and even boxes under their desks to provide documents and other resources for review. Very special thanks are due to those who agreed to be interviewed, and kindly responded to many follow-up questions as well.

The Change Foundation contracted Jane Coutts to undertake the interviews, background research and analysis, and the writing of this case study. Jane is a talented writer and editor with 15 years experience as a journalist, including 10 years at the Globe and Mail, five of them as the health policy reporter. We are indebted to Jane for presenting this case study on patient- and family-centred pediatric care in clear and powerful language.

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we're proud to have been
part of the journey
toward more patient and
family-centred care

MESSAGE FROM THE PRESIDENT AND CEO

When The Change Foundation started our work in patient engagement in 2010, it was a bit of an uphill battle. Though many healthcare organizations were excited to find new ways to connect and collaborate with their patients and families, models of practices and toolkits to facilitate those interactions were hard to find in Ontario. Our contributions have ranged from research reports, policy suggestions, funding opportunities for organizations interested in working in partnership with patients and families, and practical tools and training opportunities.

Today, it's a different story, with Ontario's healthcare sector significantly increasing its commitment to patient and family engagement. There is legislation, such as the *Patients First Act*, a growing number of patient and family advisory councils, and individual patients and family members serving on committees, helping to orient new staff and educate health practitioners. There are also a number of other mechanisms increasingly being used to hear from patients and families — on-line forums, kiosks in hospitals, survey panels. As well, patient and family-centred services have been included in Accreditation Canada's quality standards.

As Ontario's leading healthcare think-tank, we're proud to have been part of the journey toward more patient and family-centred care by supporting the development of new resources and sharing patient and family insights over the years. Now, we are continuing that role by identifying and showcasing leading patient, client, and family-centred practices around the province through a series of case studies, intended to share ground-breaking ideas that healthcare organizations can adapt and apply themselves.

Our series begins with case studies of three pediatric centres — the Neonatal Intensive Care Unit at Mount Sinai Hospital, part of Sinai Health System, Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview), and the Children's Hospital of Eastern Ontario. There are several children's hospitals in Ontario doing excellent patient and family engagement but we could not profile them all. We chose these three centres to capture the experience of introducing patient and family-centred care in a wide range of services and specialties, offered by different types of organizations.

Meaningful and effective patient- and family-centred care is a continuous journey. Case in point: Mount Sinai's introduction of family integrated care in its Neonatal Intensive Care Unit (NICU), which is a tertiary care centre for newborn, mostly premature, infants. The hospital's model of care was introduced as a pilot project and further studied as a randomized cluster trial involving hospitals across Canada and in Australia and New Zealand.

Based on Estonia's "humane care," Mount Sinai's "family integrated care" makes parents integral members of a baby's care team. Supported by nurses as they provide routine care, and with educational and other resources always available, parents are central to their child's NICU journey, speaking at daily rounds and involved in all care decisions. The Mount Sinai model is being looked at and adopted by hospitals in many countries, including China, the U.S.A. and Britain. We believe, however, that other organizations can learn from Mount Sinai's NICU, regardless of their healthcare focus.

The second case looks at client- and family-centred care at Holland Bloorview Kids Rehabilitation Hospital in Toronto. Clients come to them for care for a wide range of diagnoses including acquired brain injury, cerebral palsy, developmental delays and autism spectrum disorder.

Holland Bloorview had long been considered a leader in client- and family-centred care, but in 2008, it launched a move to codify and formalize what it was doing. What had once been a matter of instinct and kindly impulse had become a subject of academic research. The hospital wanted to ensure it was following best practices and put an end to uneven efforts to involve clients and their families in its functions. It sent dozens of parents and staff to conferences put on by the Institute of Patient and Family Centered Care to learn how to apply its core concepts of dignity and respect, information sharing, participation and collaboration. On return they worked to introduce, support and encourage the adaptation of those concepts through a hospital-wide initiative called *Unleashing the Passion*. Almost 10 years on, we look at how the hospital maintains some of the highest standards for patient and family engagement in the country.

In the last of our three pediatric patient- and family-centred care studies, we look at the work the Children's Hospital of Eastern Ontario (CHEO) has done to renew its model of child, youth and family engagement. Like Holland Bloorview, the hospital had a long record of patient and family engagement, including the oldest family advisory council in Canada. But it realized recently that efforts to involve patients and families in its operations had been allowed to slide in the five years since its last effort to "optimize" engagement. Moreover, its advisory bodies did not reflect the demographics of the community it serves.

Starting in the summer of 2017, CHEO gave itself less than a year to co-design a framework for patient and family engagement and develop a plan for integrating it into (almost) every aspect of hospital function. Unlike the other two organizations in this series, we are not looking at CHEO's engagement model after it has been tested over time. However, the Lean-based continuous-improvement approach it is using means the knowledge developed for the renewal process became an essential component of understanding and building the overall plan. We think both the approach and the lessons so far are worth sharing now.

MESSAGE FROM THE PRESIDENT AND CEO

We're very excited to bring you these three case studies of efforts to hear and learn from the voices of Ontario's young patients and their families. Some of the knowledge they can bring to us has been gained through the most painful of experiences; some is the result of long hours of enforced observation; all of it represents great generosity of spirit. Patients and families who take the time to fill out a questionnaire, participate in a study, or sit on a committee may or may not benefit directly from the input they offer us, but they are always sharing wisdom in the hope it will improve care for others. We owe them our thanks and our deepest attention.

Cathy Fooks
President and CEO
The Change Foundation

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EXECUTIVE SUMMARY

Three case studies of patient and family engagement in Ontario pediatric care

At The Change Foundation, we believe listening, engaging and working with patients and caregivers is fundamental to improving, redesigning and reimagining Ontario's health-care system. But we also know there is no single, right way to engage patients and their families, and that partnership between healthcare providers and patients and families can take many forms. These studies of patient and family engagement approaches at Mount Sinai's Neonatal Intensive Care Unit, Holland Bloorview Kids Rehabilitation Hospital and the Children's Hospital of Eastern Ontario are profiles of carefully constructed efforts to increase the role of patients and families in shaping the care, values and operations in each institution.

We took similar approaches with each of the three subjects of these case studies, selecting the three sites after talking to key informants on who was doing interesting work in advancing patient- and family-centred pediatric care in Ontario. Then we held discussions with leaders at those organizations, looking for information to help us select sites with worthwhile stories, ideas and experiences to share.

When we had settled on a site, we asked our contacts in the organization to arrange for us to interview key respondents. We had developed an interview guide, broadly covering the evolution of patient- and family-centred care in the organization, its results and impact and lessons learned. However, questions were adapted to reflect the different situations of our three study sites. Completed case studies were sent back to those interviewed for their input.

The three examples in this study are too dissimilar to have produced a list of perfectly matched best practices. They have different mandates and clientele, and range from a single ward with 62 beds to a general pediatric hospital that serves a huge swath of the east end of the province. They all had long-standing, if somewhat ad hoc, traditions of engaging patients and families, but while Holland Bloorview and CHEO sought to bolster engagement throughout their operations, Mount Sinai's NICU was focused more narrowly on making parents fully integrated members of their baby's care team.

Nevertheless, our review found significant similarities among the hospitals. They are discussed individually in the full-length case studies that follow, but for this summary we have grouped the similarities under four themes: The Starting Point, The Best Route, Roadblocks, and Cruise Control.

The Starting Point

Holland Bloorview Kids Rehabilitation Hospital was formed in 1996 through a merger of Bloorview Children's Hospital and the Hugh MacMillan Rehabilitation Centre. Both had family advisory councils, and Bloorview had introduced a youth advisory council that same year. But a decade later, engagement efforts across the hospital varied widely — families were deeply involved in some areas and projects and not at all in others. There was no definition or standards for client- and family-centred care — most staff believed they practised it, but there was no means of measuring that.

In CHEO's case, the decision to reinvigorate child, youth and family engagement came at a time of considerable upheaval. The hospital had just merged with its neighbour, the Ottawa Children's Treatment Centre, introduced electronic health records and had recently introduced a continuous quality improvement project to streamline hospital operations. Through it all, it was becoming clear that attention to engagement had slipped since a renewal effort five years earlier. Just 10 per cent of projects actually had a patient or family representative directly involved. For the rest, it was common to present an idea (sometimes after it had been acted on) to the Family Advisory Committee and consider that adequate engagement.

Mount Sinai's decision to introduce family integrated care was not driven by a sense its engagement efforts weren't good enough. Instead, a new department head arrived, who believed the care the NICU was giving could be substantially improved by integrating parents as full members of the care team.

One shared feature of the starting point of each hospital's journey was a realization that listening to and valuing the voices of patients and families improves healthcare. When Mount Sinai started having parents present their children's cases during daily rounds, providers were given insights into the babies' progress and needs by the people most completely attuned to them.

Holland Bloorview clients often receive care for years at the hospital and those long-term relationships can give a sense of engagement. But that did not prevent problems from arising, or mean they would be handled well. The Family Advisory Council had become a place to air grievances, but it had no real means of addressing them, which only led to more frustration.

CHEO's patients come from a complicated mix of backgrounds: Francophones and Anglophones, Indigenous children, recent immigrants and refugees. The longstanding family and youth advisory councils, made up of people with the language skills and time to attend monthly meetings at the hospital, didn't reflect that mix and the voices of the younger children were scarcely heard. Parents and staff tended to think they could speak on behalf of the youth and children, but often it would turn out their perspectives did not mesh.

The Best Route Forward

Perhaps the most significant similarity among the hospitals is how each took a conscious, evidence-based, meticulously planned and executed approach to improving patient and family engagement. Sinai's introduction of family-integrated care for premature infants began with close study of the Estonian model, which was applied through a rigorously designed pilot project then followed up with an international randomized controlled trial.

At Holland Bloorview, the CEO at the time stated explicitly that good intentions and a history of working well with patients and families were not enough — the hospital had to learn from and adopt research evidence emerging on patient- and family-centred care. The hospital based its renewal on the work of the Institute for Patient and Family Centered Care in Maryland, which included developing a change-management framework to create a common vision, ensuring goals and concepts were clearly communicated to everyone, and applied evenly across the institution.

CHEO also sought to create a clear plan and approach to engaging children, youth and families. It appointed the manager of patient experience (who oversaw the family and youth advisory councils) and the team leader for quality improvement (who was in charge of the hospital's Lean project) as co-leads, and used a combination of Lean and co-design methods to build a clearly defined framework for engagement.

All three sites in the case studies understood the essential role of leadership in making patient engagement a priority throughout their organizations. Family-integrated care was the brainchild of Mount Sinai's pediatrician in chief. The executive lead for child, youth and family engagement at CHEO is the chief of staff/chief medical officer, the highest-ranking health professional in the hospital. The champion of change at Holland Bloorview was the CEO.

All the hospitals also understand the power of stories to unite patients, families and professionals and remind them of the reasons they all want to improve care. Hearing first hand of a family's struggles, or a staffer's reaction to getting input for an improvement idea focuses people in a unique way.

Roadblocks

Staff resistance to change proved a problem in all the hospitals. Change can be hard for people, and years of flavour-of-the-month management ideas have bred a certain amount of cynicism in healthcare workers. At Mount Sinai, nurses suspected family integrated care was an effort to reduce nurse staffing levels; others felt their expertise was being disregarded. Some staff at Holland Bloorview had similar concerns, when they interpreted "patient-centred care" to mean doing everything patients and families wanted, rather than working in a partnership. At CHEO, some physicians feared greater engagement would open them up to a barrage of complaints.

As a result, all the hospitals recognized the importance of putting a lot of effort into educating staff. For one thing, the ad hoc approach, where everyone applied their own concept of what engagement was in their own way, had not worked. For another, no one wanted engagement to be seen as an optional extra; making people aware of its benefits was the best way to ensure it was not just given lip service.

All three hospitals, at some point, found it useful to remind doubting staff why they had gone into healthcare — to provide the best care possible. One interviewee, who had worked at another hospital when it introduced family integrated care, said it had won nurses over by heavily emphasizing its developmental benefits for babies. And as a staff member at CHEO said, "The easy sell for staff is that this is why they went into healthcare — to help families."

However, as one change leader at Mount Sinai said, it is not realistic to expect everyone to start out as enthusiastic as the project team. At Holland Bloorview, facilitators went back as many times as it took to some groups to help them work through concerns about having a parent added to their team. CHEO, just starting its process, is encouraging staff to work independently, using its framework and other tools to add child, youth and family engagement to their work, but a support team will be available to help them through the process.

Both CHEO and Holland Bloorview emphasized to staff that not every effort would succeed and mistakes would certainly be made — the important thing is to be open to working to fix them together.

Cruise Control

None of our case study sites want to let their commitment to patient and family engagement slide. Both CHEO and Holland Bloorview know firsthand that can happen, and are working on constantly reinforcing it. At Mount Sinai, the move to family integrated care was itself a result of commitment to continuous improvement. Now that it's in place, family integrated care is supported by four pillars, all aimed at reinforcing the practice and delivery of it: parent education, nurse education, environmental support and psycho-social support. That last, which can mean professional help, but most often refers to peer-to-peer support, is also an important part of patient and family-centred care at the other hospitals.

Holland Bloorview's volunteer structure includes mentors (to work with families new to the hospital) and faculty (who bring the voice of experience to individuals and groups of providers and others); both groups have a mandate to support client- and family-centred care. CHEO is building child, youth and family engagement into the project approval process and counting on standard quality improvement methods, including regular measurement of selected indicators, to show when engagement needs a boost.

The following case studies provide more details on how these three institutions — Mount Sinai's Neonatal Intensive Care Unit, Holland Bloorview Kids Rehabilitation Hospital, and CHEO — are working to develop, establish and support patient and family engagement for the long term.

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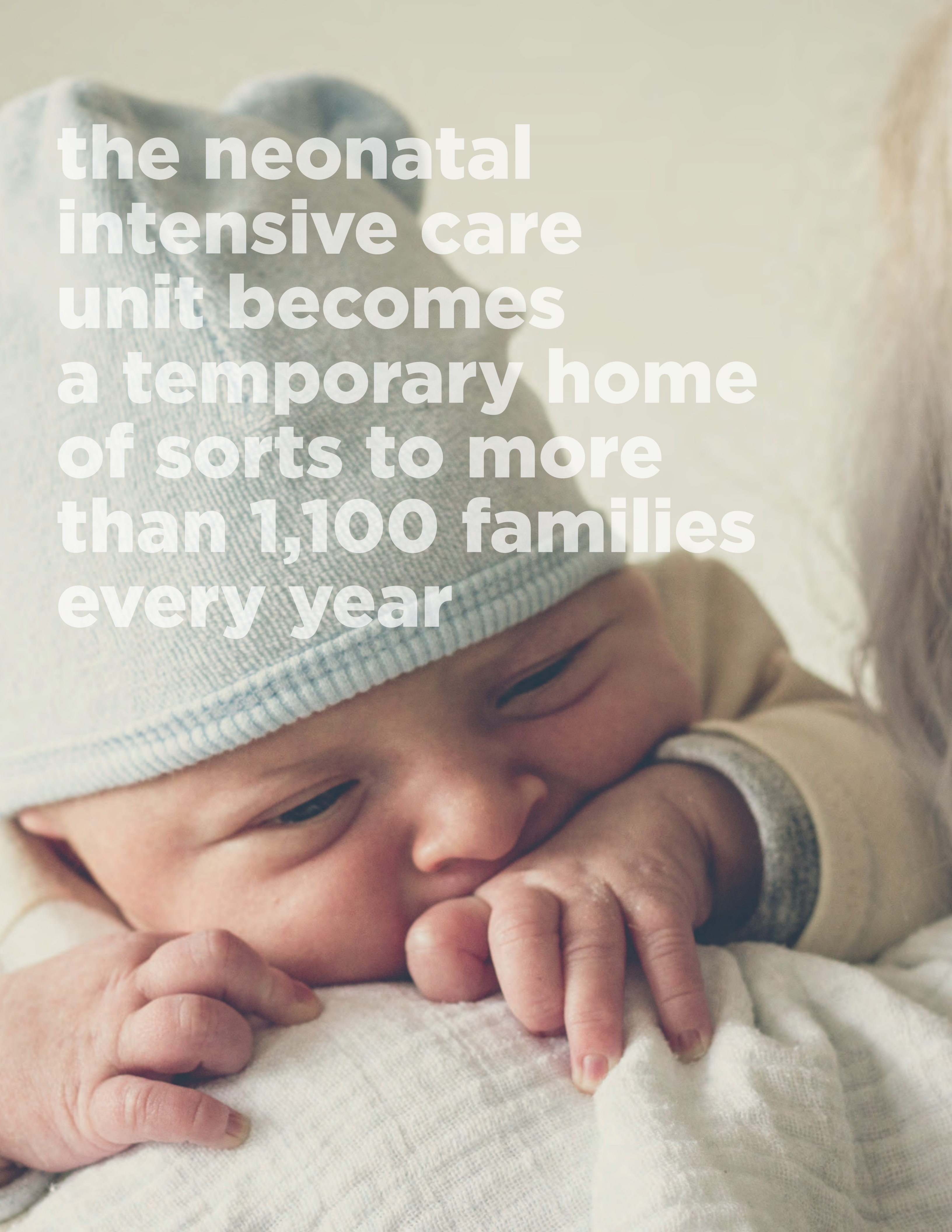

the neonatal intensive care unit becomes a temporary home of sorts to more than 1,100 families every year

FAMILY INTEGRATED CARE AT MOUNT SINAI HOSPITAL'S NEONATAL INTENSIVE CARE UNIT

Description

The neonatal intensive care unit at Mount Sinai Hospital in Toronto has 62 beds in small separate rooms that also offer chairs, beds, cupboards and whiteboards for tiny patients' parents. Their effect is not precisely homey, as those details can do little to make the isolette, monitors, infusion pumps and suction pumps, tubes, scales and oxygen paraphernalia anything close to cosy. Indeed, the décor would rightly be called sterile.

Nevertheless, the neonatal intensive care unit (NICU) becomes a temporary home of sorts to more than 1,100 families every year, as parents and children together struggle to overcome the dangers of a severe illness in a newborn[1], or extreme pre-term birth — and the disadvantages of being subjected to high-intensity care at a time when crucial, delicate systems are developing in the baby's body and mind. Equally important, however, are the crucial, delicate bonds developing between child and parents.

The unique design of Mount Sinai's neonatal intensive care unit is intended to nurture both, through its system of "family integrated care." FICare, as it's commonly called, is an approach that makes parents of its infant patients members of the care team. Under the guidance of nurses, parents (predominantly mothers) provide active care for their infants, learning to feed, hold, wash, change and keep track of their child's progress. Nurses and other staff teach, provide support and perform the more technical care.

Motivation for Change

There was no crisis in care, nor any widespread worry over quality in the neonatal intensive care unit when Dr. Shoo Lee arrived to take over as pediatrician-in-chief and director of the Maternal-Infant Care Research Centre at Mount Sinai Hospital in 2009. A highly respected

> "The infant's well-being in the unit is better protected by parental presence — but the other piece is, the family's well-being post discharge (and therefore the infant's long-term outcome) is also affected by the NICU experience. I think that's something that's becoming more and more evident — parental stress, lack of parental attachment and parental depression are all contributors to long-term abnormal outcomes for children." *[Staff]*

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[1] All parents with babies in the Neonatal Intensive Care Unit are part of their child's care team, however, only premature infants were included in the study.

neonatologist and health economist, he is also a professor of paediatrics, obstetrics and gynaecology and public health at the University of Toronto.

In addition to his remarkable professional qualifications, Dr. Lee was a change agent: he arrived determined to introduce "Humane Neonatal Care," launched in Estonia in 1979 by Dr. Adik Levin. Humane care grew from Dr. Levin's belief that the way neonatal intensive care was practised—babies separated from their parents, boxed up in isolettes and subjected to frequent, often painful interventions in bright, busy, noisy nurseries—was inherently bad for delicate newborns.

> "We know this environment is very abnormal for baby in the NICU, and parental presence can really modify that and protect the baby. It's not what they came out of the womb for and everything is wrong about it, even though it keeps them alive." *[Staff]*

Under Dr. Levin's guidance, mothers became babies' primary caregivers. They were expected to spend 24 hours a day in hospital, while the child's contact with healthcare professionals and high-tech interventions was kept to the minimum possible. And it paid off: children under humane care gained weight faster than those cared for in a traditional way.

The approach had another remarkable benefit. Research shows parents of preterm babies can suffer depression and anxiety, even post-traumatic stress disorder, especially in traditional care, where parents may be allowed only brief visits and minimal physical contact with their children.[2] That, in turn, is believed to have an impact on the long-term development of premature infants. Spending the time your baby is in intensive care as an active caregiver, rather than a helpless bystander, reduces parent stress and helps forge strong, essential bonds between mothers and their babies.

Dr. Lee wanted to bring all those benefits to Canadian preemies and in Sinai's NICU, he found fertile ground for the idea. Staff members interviewed for this case study describe him as passionately interested in parents. Concern for parents was already well-established in Mount Sinai's NICU, where weekly parent-education classes had been introduced in 1984, and a buddy system for parents of preemies in 1991. For many at Mount Sinai, a Canadian version of humane care seemed like the next step they had been waiting for. No one felt the NICU was doing badly,

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2. Ionio, C., et al. Mothers and Fathers in NICU: The Impact of Preterm Birth on Parental Distress Eur J Psychol. 2016 Nov; 12(4): 604–621.

but learning of such a clearly superior approach was motivation enough to push further. The decision was made to launch a pilot project, testing Humane Care on premature infants and their families. Staff neonatologist Dr. Karel O'Brien was put in charge of making it happen.

CULTURE CLUE

The notion of family-centred care was introduced in the 1970s, and specifically linked to neonatal intensive care in the 1990s. Often, though, the concept of considering the impact of a child's illness on her whole family remained peripheral, given lip service but having little impact on actual care. Healthcare providers at Sinai's NICU, however, had a track record of working closely with parents and were open to putting theory into practice.

The journey — Introducing a new kind of care

Sinai's family integrated care program began with a trip to Estonia organized by the hospital in 2010. A group of NICU doctors, nurses and parents travelled to see for themselves the Humane Neonatal Care Initiative.

"The leading principles of this unit are 24-hour care by the mother, with assistance from nurses and hospital staff as necessary; promoting breastfeeding whenever possible; minimal use of technology; and little contact between baby and medical and nursing staff who might expose the infant to pathological microbes. These principles help to maintain the biological and psychological ties between mother and infant."[3]

> "You need to teach parents what they don't know. You need to teach them how to parent a preterm infant, and you need to teach them how important they are in the preterm infant's life…but you also have to give them the skills to interact with the medical team in a way that's good for them and good for the team. If they are going to be there and taking care of their infant, you need to help them be able to lead the baby's care over time and take a more active role in decision making." *[Staff]*

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[3] Levin, A. The Mother-Infant Unit at Tallinn Children's Hospital, Estonia: A Truly Baby-Friendly Unit. BIRTH 21:1 March, 1994

The Estonian initiative was partly driven by a shortage of nurses, but shaped by Dr. Levin's belief that "a psychological and biological umbilicus" should bind mother and child together during the early weeks of life. Dr. Levin believed hospital care — whether for preterm or sick newborns — disrupts that bond, to the detriment of both parents and children.

Humane Care's impact was far-reaching. There were "considerable decreases in the number of infectious diseases in infants and in the duration of intravenous infusions and antibiotic therapy."[4] There was also a remarkable difference in weight gain: premature babies cared for by their mothers had mean weight gains of 769 grams from admission to age 30 days. Babies cared for by nurses had mean gains of 490 grams.

After Dr. Lee heard Dr. Levin speak that first time, he wrote a research proposal to try a version of humane care at his previous hospital, but the effort did not get off the ground. Convinced of its value, Dr. Lee brought the idea with him to Mount Sinai.

People interviewed for this case study gave several reasons for the success of family integrated care. Because of the NICU's strong history of working closely with parents, humane care seemed a natural fit. Crucially, Mount Sinai's NICU also had an active parent advisory group, which provided a source of committed people to go on the trip to Estonia, and to work on a steering committee with Mount Sinai's researchers, nurses, social workers and the parent support nurse for the next year on how to adapt humane care for the Canadian context.

The steering committee launched a literature review. The research funding included money to pay parents on the committee a small amount to participate in the review and planning phase. They found information on the kind of care that interested them was in short supply—and what there was mostly came from developing countries.

> "We spent many days, many hours around a table, asking what is it like for a parent...What were the physical barriers, what were the invisible barriers, the cold shoulder, the attitude? What do you think would engage you at the bedside? What do you need to know? If a parent has a choice of going back to work or a choice of being here with the baby, we needed to give them a purpose. They needed to feel they have a purpose at the bedside." *[Staff]*

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[4] Ibid.

The questions the committee wanted answers to were, first, what was necessary to increase parental presence in the NICU, and second, what would be necessary to create the change process? As suggestions emerged, they were examined to determine whether the change would benefit both babies and their parents.

Gradually, a four-pillar model emerged to form the foundation of family integrated care. The pillars were:

PARENT EDUCATION:

People need to be taught how to parent a pre-term child. That includes everything from understanding the importance of parents' presence in a tiny infant's life and development, to learning how to give hands-on care (whether that's changing minute diapers or providing essential skin-to-skin contact), to learning how to interact with the medical team, and gradually to take on the role of expert in their own child's health. The weekly parent education sessions Sinai had been offering since 1984 provided a solid base for this pillar.

NURSE EDUCATION:

The demands FICare puts on nurses cannot be underestimated—and was considered the greatest challenge to integrating families in care by everyone interviewed for this case study. Essentially, nurses have to release their roles as the experts in caring for infants and become, instead, expert mentors and facilitators of parental care. That takes more education and ongoing support than anyone had anticipated when the project was launched.

ENVIRONMENTAL SUPPORT:

Traditional NICUs are designed on a factory model, with the "products" (preemies) arranged to be worked on efficiently. But if families are going to be equal partners in care, at the very least they need to be accommodated with comfortable chairs, screens for privacy during breast feeding and pumping and places to rest and make a cup of tea and keep lunch. (Mount Sinai initially adapted a traditional NICU; four years after the launch of the pilot project, it moved to new space that offers small private rooms for each family).

PSYCHO-SOCIAL SUPPORT:

The trip to Estonia taught the group from Mount Sinai that in intensive care, parent-to-parent support was almost as important as nursing support. A buddy program and a program offering help from "veteran parents" were established long before FICare was introduced, but once the research project began, the roles of veteran parents were increased — some were involved in the research committee or the roll out of the research. Others did more in the parent education program, which was increased from two sessions per week to five.

The pilot study for family integrated care began recruiting infants admitted to the NICU March 1st, 2011 and continued, involving four infants at a time, until April 30th, 2012. Children with congenital anomalies and those thought unlikely to survive were excluded.

In the study, one parent had to commit to being the primary caregiver. That meant being in the NICU every day to look after their babies, and be involved in rounds. Daily educational sessions were mandatory, with presenters ranging from veteran parents and family support nurses to respirologists, pharmacists and lactation consultants. Results of the pilot study follow later in this paper.

Starting the journey to family integrated care

Most people interviewed for this piece credited powerful leaders at the NICU level as the reason FICare succeeded. "As the head goes, so wags the tail," one said. Many felt the revolution in care the project represented dodged possible resistance from upper management because of its status as "just a pilot project," which limited concern. Later, the hard evidence from the pilot project showed its effectiveness—and since then, has helped bolster neonatal units in other hospitals looking for approval to launch FICare themselves.

Part of developing the right culture for sustaining family-centred care is getting administration to recognize and admit it is not delivering on promises about it. The trouble is, healthcare at all levels is notoriously poor at recognizing failure to achieve a true focus on the patient. But that was where another of the Mount Sinai NICU's strengths came into play: its longstanding close engagement with parents of preemies. There are always parents eager to talk about the difference family integrated care made for them. "Parents' stories have been the biggest thing for getting buy in," one person said. The stories of the hardships of standard care and benefits from FICare never fail to move people, those interviewed said.

One of the biggest struggles FICare faced was low support from some NICU nurses. People we spoke to said, however, that the international interest in what Mount Sinai has achieved with FICare has done a good deal to reconcile doubters—from the administration on down—to the innovation.

> "Everybody talks the talk about being centred around patient needs, patient values, but it's really difficult to hear about that from patients, because where have we created the opportunity?"
> *[Staff]*

CULTURE CLUE

Success builds its own culture—so the high profile Mount Sinai's NICU gets by demonstrating FICare's positive impact, both scientifically and anecdotally, makes the staff proud of the work they are doing — which in turn increases their support and commitment to FICare.

The unanticipated obstacle

The people who travelled to Estonia and then spent a year adapting Humane Care for Canadians were inspired, driven, and thrilled when family integrated care made its debut in March of 2011. True believers all, it had not occurred to them everyone would not be as happy as they were. That was a serious oversight.

As long as family centred care remained largely theoretical, or manifested as encouragement for more compassion, consultation and an increased family presence in the NICU, no one's jobs really changed much. That was true both for those who had little contact with families—respiratory therapists, for instance, or specialist physicians — and for those who worked most intimately with them, the frontline nurses.

Many specialists reacted positively to family integrated care, precisely because it put them more in contact with parents. One of FICare's most important tenets is that parents should attend daily rounds, preferably presenting their child's case each day. Suddenly, the patient is a little person with a name, a personality that needs to be understood and respected and mum and dad offering insights to it ("He's not himself today, there's something wrong," one mother said, before her child's urinary tract infection was diagnosed).

> "Nurses who work in intensive care units or ORs or emergency, we're all intensivists. We do a really good job of interpreting technology, and being able to adapt it according to the baby, or whatever the situation is, we're doers, we work on adrenaline...the trouble is, we have a lot of difficulty marrying those two, the emotional side, the parent side and the job we are there to do." *[Staff]*

CULTURE CLUE

If we're really committed to this, and we really think taking care of the patient is as important as taking care of the disease, that means changing some of what we do in nursing. And in medicine. *[Staff]*

A lot of nurses, on the other hand, saw trouble looming. As a profession, nursing has had a rough few decades. Nurses make up the largest share of hospital professional staff, and are often hit hard by layoffs. Permanent jobs can be hard to find. Finally, their profession itself is often called into question, portrayed as a series of practical tasks that could be entrusted to less-educated (and less expensive) workers.

Not surprising, perhaps, that Mount Sinai's NICU erupted with rumours that parents were being involved in care so the nursing staff could be cut. That didn't happen, but it did mean the nursing staff was not predisposed to favour FICare.

The bigger challenge, though, was to nursing culture. NICU nurses were used to hearing parents tell them "You've been such a wonderful nurse—we wish we could take you home. No one can look after him as well as you." That didn't bode well for parent-child bonding or long-term health outcomes, but being responsible for sending a preemie home healthy was the key measure of success for many NICU nurses. It was also what they were trained for, while teaching parents was not. The shift to "You've been such a wonderful teacher — you've made us feel so confident taking him home," was a huge adjustment; some nurses loved it. Others did not.

> "Gone are the days when there was no one at the bedside. That's hard for some people to give up. It's hard for some people to say, OK, you change the diaper — and you have to stand back and hold your hands behind your back, because you can do it faster, and some dads, it takes them four diapers. It's a true shift in mindset, and it's a tough one." *[Staff]*

Added to the fear of job loss and the discomfort of culture change is uneasiness at feeling under observation. And in a sense, of course, the whole point is to watch nurses—parents feel enormous trepidation handling the child that has come so suddenly and frail into the world; most are desperate for guidance.

> "I may be a pain in the butt, to be sitting there 10 hours a day by the bed while you're working, but I'm really not looking at whether you're doing the right thing or not, because I trust you are." *[Parent]*

It has to be said not all families readily feel that kind of trust. Parents are usually under terrible stress when they have an infant in NICU. Some knew ahead of time their child was at risk, for others the arrival at the NICU is a surprise—but all parents are caught in a whirlwind of fear and desperation, with the possibility of crisis hanging over them every day. "You see us at our very worst" one mother said. The pressure on parents often erupts as friction with staff—and most often, the nurses.

The people at Mount Sinai have learned a great deal from their failure to anticipate a possible negative reaction from nurses. "The biggest change, up front, is the change in nursing role. We should have spent more time, up front, exploring that." However, they knew the response must not be to blame those nurses (and it is by no means all) who are uncomfortable with FICare. Rather, they seek to encourage acceptance of a different kind of reward system, to change the culture from "I'm best at everything" to "It's best when parents do it." (Although there are limits. One nurse involved in training says she cuts nurses uncomfortable with FICare slack for a while, but if they keep on complaining eventually just says "You don't like it? Tough.")

There are a number of ways to improve reception of FICare among nurses. Those who are strong supporters act as role models, and bring others along. One interviewee who was working in a different NICU when it introduced family integrated care said they had emphasized its developmental benefits for babies, rather than how it empowered parents, to reduce the perceived threat. Several people interviewed said it would help if education in family-centred care started in professional school. Others thought giving nurses more time to join parents in the education sessions would help—not because they do not know the material, but because they would learn so much about parents' fears and doubts.

It's interesting that some people said young nurses were more likely to resist FICare, because they are less confident about their skills, where experienced nurses are relaxed and happy to share, while others said young nurses who have known no other approach are comfortable with FICare, but older nurses stick to entrenched rules and struggle with giving them up. In response there's an effort to figure out how to identify characteristics that suit job applicants to the work—"if you get your reward from doing IVs, FIC is not for you."

Finally, evidence is just as important for persuading nurses of FICare's benefits as it is for administrators. The data—better weight gain, almost double the rate of breast feeding, far fewer infections—are compelling. But it's the stories from parents that capture hearts. As one mother explained, family integrated care lets mums be mums.

> "There are so many wires when you first see the child. A two-pound baby! There were monitors and sensors, the thing on the toe and the breathing tube and the feeding tube and the IV and the big line, and you're like —oh my God, can I even touch this thing? Family integrated care brought that back to me, that yes, I can be a mum, despite the ventilator and what has happened to me. It gave me back the sense of being a mum. And it was very important for me to be educated on what was happening, that took away the fear from me, because I was very scared of losing him." *[Parent]*

Results

Family integrated care was introduced at Mount Sinai Hospital through a randomized controlled trial.[5] The primary outcome assessed in the study was weight gain, which is a good measure of success for premature infant care. Rates of breastfeeding, critical incident reports and death were all measured, as were several common health problems for premature infants, including hospital-borne infections, necrotizing enterocolitis, bronchopulmonary dysplasia, intraventricular hemorrhage and retinopathy of prematurity.[6]

CULTURE CLUE

Taking care of a premature baby means taking care of the whole family. But the culture that makes that possible is not an inherent feature of today's hospitals. It must be cultivated, it will grow when you work hard at integrating families into care.

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[5] O'Brien,K. et al. A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. BMC Pregnancy Childbirth. 2013; **https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/1471-2393-13-S1-S12**. Funded by the Preterm Birth and Healthy Outcomes Team and an Alberta Innovates – Healthy Solutions Interdisciplinary Team grant.

[6] O'Brien,K. et al. Ibid.

Children under FICare suffered fewer complications often seen in preterm infants and 82 per cent of them were breastfeeding at discharge, compared to 45 per cent of the controls.

Mothers who gave their babies active care in the study were less stressed at discharge than mothers in the control group. In interviews, they spoke of the calmness and confidence the program had brought them. Both increased weight gain and lower parental stress are known to produce better long-term outcomes in premature babies.

The pilot study was followed by a cluster randomized controlled trial (a method for testing interventions on groups of subjects) between April 1, 2013 and August 31, 2015. A total of 26 tertiary-level neonatal intensive care units were involved—19 in Canada, six in Australia and one in New Zealand. Infants in the study were born at 33 weeks or less gestation. The 26 sites were randomly assigned—14 sites to provide FICare to a total of 895 infants and 12 sites to give standard care to 891 babies.

The results, published in *The Lancet Child & Adolescent Health* journal (**https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(18)30039-7/abstract**) bore out what the pilot study had already shown: "FICare improved infant weight gain, decreased parent stress and anxiety, and increased high-frequency exclusive breastmilk feeding at discharge, which together suggest that FICare is an important advancement in neonatal care." [7]

Findings showed:

- after three weeks, weight gain was greater in the FICare group;
- average daily weight gain was significantly higher in infants receiving FICare (mean daily weight gain 26·7 g vs 24·8 g for standard care);
- high-frequency exclusive breastmilk feeding rate at discharge was higher for FICare infants (70%) than standard care (63%);
- at day 21, parents in the FICare group had lower mean stress and anxiety scores than parents in the standard care group;
- no significant differences between groups in mortality, major morbidity, duration of oxygen therapy and duration of hospital stay.

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[7] O'Brien, K. et al. Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. The Lancet Child & Adolescent Health, Volume 2, Number 4, p229-304, April 2018

> "The doctors present the results of this study, which are all tangible things. But the empowerment, the confidence we have as parents, the skills we gain, are not tangible. You can't measure in a study, I don't think, what people become because of the experience of being in the hospital and gaining knowledge by being involved in the baby's care from the beginning. That is the most important thing."
> *[Parent]*

Including parents in rounds is another aspect often singled out as a powerful result of FICare. Now that the study is over, it is not mandatory (though it is strongly encouraged) for parents to attend or to speak at rounds; but parents say "it makes you feel heard, it makes you feel part of the team." In the past, even if parents were present, rounds happened as if they were not there, until someone at the end would ask if there were any questions. Now, particularly as babies get closer to discharge, parents are an integral part of planning. "This way, it's not an afterthought."

Key Lessons

1. Nothing is a more powerful driver of patient- and family-centred care than patient and family stories. If you think you haven't got the space, or the support, or the resources to make family integrated care possible, start small: start with families telling their stories of how current care is failing them.
2. Providers at every level may need help to accept that parents are integral to good care, and that recognizing parents as true partners improves outcomes.
3. Leadership from the top is essential for success. But leadership can also come from someone just a couple of steps ahead of you: at Sinai, individual nurses led parents in care, and empowered parents brought each other along.
4. Link family integrated care to the organization's quality improvement plan and the accreditation reporting process. Don't look for quick fixes. Family integrated care requires continuous support and reinforcement.
5. It is unrealistic to think everyone who needs to be involved in delivering family-centred care will be as enthusiastic as you are. Take the time to hear concerns and bring others along.
6. Integrating care requires changes in the nursing role and a shift in the mindset about the role. Don't blame and shame those who resist. Understand that change is hard for people. Hear them, and address their concerns, and ensure they get education and support to help them with the change.

7. Parent-to-parent support is also critical to success. Parents helping parents — as "buddies," as mentors, as veteran parents — needs to be built into family-centred care.
8. Teach family-centred care, including how to mentor and teach, from the earliest years of healthcare education — and include the ability to communicate with families in assessments of nursing skills.
9. Family integrated care is not about the budget, or the space or technology: it is about relationships among people. The philosophy can work even with limited resources.
10. Family integrated care needs support from the administration. Bring in family members to tell their stories, and leverage data to win support.

> **"I can tell you with FICare, there are a lot fewer parents who are not visiting than there would have been 10 years ago."** ***[Staff]***

throughout its 119 years, Holland Bloorview has focused on improving the lives of children and youth with disabilities and complex medical needs

HOLLAND BLOORVIEW KIDS REHABILITATION HOSPITAL

Description

There's a compelling drum beat permeating the busy main entrance to the Holland Bloorview Kids' Rehabilitation Hospital on this rainy summer afternoon. From a corridor, the drummer leads a snaking parade of children, moving in their own ways to the beat while people nearby — at reception, in the resource centre, in the coffee line — bop along.

A parade of kids having fun, in the middle of the day, in the middle of all the daily business of a specialized rehabilitation centre for children and youth: it's a pretty good metaphor for the client- and family-centred care for which Holland Bloorview is well known and widely respected.[8]

Holland Bloorview is a busy place. In 2016-2017 it served 7,499 clients, 583 as inpatients and the balance through 55,395 outpatient visits. Those clients had 1,114 unique diagnoses. The most common for inpatients are acquired brain injury (35 per cent) and cerebral palsy (25 per cent); 18 per cent have other developmental disorders. The top three outpatient diagnoses are developmental delays (27 per cent), cerebral palsy (21 per cent) and autism spectrum disorder (20 per cent).

The hospital opened in 1899 as the Home for Incurable Children. Over the next century, the work it did evolved as much as its name, and the hospital expanded its services in a succession of more modern facilities. In 1996, Bloorview Children's Hospital merged with the Hugh MacMillan Rehabilitation Centre to form the Bloorview MacMillan Centre. It operated in two sites until today's building opened in 2006; the organization has since been renamed Holland Bloorview Kids Rehabilitation Hospital. Throughout its 119 years, Holland Bloorview has focused on improving the lives of children and youth with disabilities and complex medical needs.

Motivation for Change

Both Bloorview Children's Hospital and the Hugh MacMillan Rehabilitation Centre had family committees before their amalgamation and Bloorview had created a Youth Advisory Council in 1996, the year they merged. Many people interviewed for this case study said the unique nature of pediatric rehabilitation — clients may get care and support from an organization for years — leads to close bonds with caregivers and makes getting involved with the hospital itself seem a natural next step.

But neither a tradition of family participation nor user committees necessarily ensure meaningful roles for clients and families in the operation of an organization. Client-centred care

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[8] Holland Bloorview's term, client- and family-centred care, is used most frequently in this paper, but we've used patient-centred care to refer to the broader theory, or where that is the phrase used in source material.

had evolved piecemeal at Holland Bloorview and that resulted in uneven practices around the hospital.

> "There were these pockets everywhere, so you had a family advisor over here, run through this program, but these family advisors did nothing to support any work that was happening over there and there was no intent to grow it, it was unique to that program…it was just pockets, pockets of great ideas, but no pooling of resources. There was inconsistency in all of it, even giving parents subway tokens, or getting them childcare was inconsistent. None of it was a central vision, everybody was doing little bits of great things here and there." *[Staff]*

That lack of a cohesive vision for client- and family-centred care was also reflected in the core component for family involvement at Holland Bloorview, the Family Advisory Committee: it was drifting. Its advice was too often sought only after ideas and plans had been decided on, and for which no input was really welcome. Family members were frustrated. "What we were doing was tantamount to tokenism," one staffer recalled.

Meanwhile, in the absence of other outlets, the committee had become the place families went to air grievances. Since that was not its intended purpose, it had no formal process for dealing with these complaints, which only added to the frustration of members. "I couldn't see how what we were talking about around the table was having any impact on the hospital," one parent on the committee said.

None of this went unnoticed by the CEO of Holland Bloorview at the time, Sheila Jarvis. One interviewee described her as having "patient-centred care in her DNA," and said she never made a decision without consulting clients and their families. But Jarvis, who had been following developments in patient-centred care around the world, felt the hospital was resting on its laurels.

Spurred on by the founding of the Institute for Patient and Family Centered Care in Bethesda Maryland in 1992 — created to promote "collaborative, empowering relationships

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9. http://www.ipfcc.org/about/ Institute for Patient and Family Centered Care website, retrieved October 11, 2017.

among patients, families, and healthcare professionals[9]" — patient-centred care was moving from something most health professionals assumed they were doing by default to an area of research, expertise and proven best practices.

"Sheila had the fortitude to say 'I know we do a good job at this, I feel confident about that, but we can't just keep doing what we're doing, because the science is changing out there and we need to pay attention to that science, and I'm expecting us, holding us accountable, to be ahead of that trend.'" *[Staff]*

In a thesis written at the time, one now-former staff member wrote:

> "Staff knowledge and expertise related to [client- and family-centred care] is often rooted in 'good intentions' rather than the most up-to-date evidence. This underscores the need for a refreshed [client- and family-centred care] strategy, including a shared definition and vision, along with intensive education and skills development to ensure that healthcare providers have the most up-to-date knowledge and skills….'Good intentions' are not enough to support the needs of clients and families." [10]

Concern over the state of client- and family-centred care had not arisen in a vacuum. Following the move to its new facility, Holland Bloorview developed a new strategic plan for 2007-2012, and also drafted new mission and vision statements, reflecting the hospital's growing role as an academic health sciences centre. It was a time of transformation for Holland Bloorview and Jarvis — with the full support of senior staff — decided to seize the opportunity to refresh client- and family-centred care as well. In July 2008, a committee of staff, family and clients was created to work on that. Its mandate included:

- developing a working definition for client- and family-centred care;
- reviewing recent work in the area at Holland Bloorview;
- reviewing the literature;
- analysing "strengths, opportunities, aspirations and results;" and
- sending out a confidential online survey to all staff, plus family and youth advisors.

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[10] Brown, Susan. (2009). Unpublished University of Guelph master's thesis, "Client and Family-Centred Care Model of Service: Opportunities and Barriers to Integrate Strategy in Operations in a Pediatric Rehabilitation Environment. Pg. 5

CULTURE CLUE

Don't assume patient-centred care will evolve naturally after some background work and a bit of guidance and encouragement for staff. Holland Bloorview built a comprehensive strategy for change on a rock-solid foundation of research and planning.

Nearly 80 per cent of survey respondents believed client- and family-centred care was integrated as a core value of the hospital, and 93 per cent said its mission and vision reflected the principles of patient-centred care and promoted partnerships. However, comments showed many staff regarded client- and family-centred care as an "add on" that took extra time. And while 80 per cent of staff knew of the existence of the Family Advisory Committee and 78 per cent of the Youth Advisory Committee, only 70 and 74 per cent, respectively, could say what their roles were.

In October of 2008, four senior staff from the hospital travelled to an international conference put on by the Institute of Patient and Family Centered Care. The preparations for the journey to better client- and family-centred care were complete and the project was named *Unleashing the Passion*.

The journey to patient- and family-centred care

The journey — starting with the basics

While client-centred care had been practised and valued for years at Holland Bloorview, it had never been formally defined. According to Brown's thesis, that meant "each staff person

Client- and family-centred care is:

- An approach to care that is grounded in mutually beneficial partnerships among healthcare providers, children, youth and families.
- An approach to the planning, delivery and evaluation of healthcare.
- Founded on four core principles, including dignity and respect, information sharing, participation, and collaboration.
- Based on the understanding that the family plays a vital role in ensuring the health and wellbeing of their family member.

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11. Brown, Susan. (2009). Ibid. Pg. 6

interprets [client- and family- centred care] differently, and judges their actions and those of others without the benefit of a shared definition or vision.”[11]

Client- and family-centred care – there are many definitions of the concept; Holland Bloorview adopted the Institute of Patient and Family Centered Care and presented it publicly at the official launch of *Unleashing the Passion*.

The four core principles of the Institute of Patient and Family Centered Care are:

- **Dignity and Respect.** Healthcare practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing.** Healthcare practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.
- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration.** Patients, families, healthcare practitioners, and healthcare leaders collaborate in policy and program development, implementation and evaluation; in research; in facility design; and in professional education, as well as in the delivery of care.[12]

With guiding principles in place, Holland Bloorview could proceed. The four senior leaders came back from the 2008 conference convinced they needed a change-management framework for the work they were undertaking. The days of piecemeal change were over.

Unleashing the Passion was formally launched in December of 2009 with a two-day training event featuring speakers from the Institute of Patient and Family Centered Care. It was

CULTURE CLUE

“Honestly, if you don’t put it within a framing plan, I just don’t know how you shift a culture and how you create that common vision and figure out what levers for change you need and how you communicate and how you measure it if you don’t have those things.” ***[Staff]***

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12. Institute for Patient- and Family-Centered Care, Bethesda, MD. Adapted from: Johnson, B. H. & Abraham, M. R. (2012). *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities*. Retrieved from http://www.ipfcc.org/about/pfcc.html October 11, 2017

MILESTONES ON THE ROAD TO CLIENT AND FAMILY-CENTRED CARE

1996	The Hugh MacMillan Rehabilitation Centre and Bloorview Children's Hospital merge to become what is now called the Holland Bloorview Kids Rehabilitation Hospital.
2006	New, state-of-the-art building opens
2008	July: A committee of staff, family and clients is created to deliver on CEO Sheila Jarvis's vision of re-energizing client- and family-centred care at Holland Bloorview
	October: four senior staff travel to an Institute of Patient and Family Centered Care conference and return committed to ending piecemeal improvement by creating a change-management framework
2009	First staff member assigned to work full time on establishing the family leadership program and family engagement strategy
	December: Launch of *Unleashing the Passion*, the official corporate strategy behind re-energizing client- and family-centred care
2010	Holland Bloorview starts regularly sending groups of staff and family leaders to Institute of Patient and Family Centered Care conferences, a practice it continues today
2011	Family Leadership Program formalized
	The Client and Family Integrated Care team is created, and dedicated staff assigned
2012	First meeting of the Family Research Engagement Committee

Ongoing: The hospital continues to assess, evaluate and renew patient- and family-centred care

focused on building the staff's understanding of client- and family-centred care and patient engagement and learning the common language around its principles. Long-time client and family volunteers were brought in to talk to the group (it's now standard practice at Holland Bloorview to open meetings with accounts of experiences, usually from patients and families, but also from staff, discussing recent experiences). The goal of the meeting was to begin building acceptance of the new culture the hospital hoped to create *before* changes were brought in.

Another important step in refreshing client- and family-centred care was to completely rethink the roles and structures of client and family engagement. A working group, 50 per cent staff and 50 per cent family advisors — reflecting the new, carefully structured approach to change — developed a charter and project plan before looking at every aspect of volunteering.

> "The initial part was really about the structures that needed to be in place. I think probably Holland Bloorview was far more successful at achieving that culture change because it was primarily driven through education and the experience of having patients and families working together and that caused staff to change." *[Staff]*

Among other changes, volunteers were renamed "family leaders," to emphasize their expertise and the importance of their contributions to the hospital. The working group also set out to increase the number of family members and clients involved (as at many organizations, a core group turned up again and again to help out). The working group was hoping to diversify its volunteers, to reflect differences such as children's conditions and ages and how long the family had been involved with Holland Bloorview. Staff were often reluctant to approach parents who were already under a great a deal of stress, but found parents were usually pleased to be asked.

In tandem with work being done at Holland Bloorview, a steady stream of staff and family leaders were being sent to conferences at the Institute of Patient and Family Centered Care. Educating as many staff and family leaders as possible at the Bethesda centre was seen as essential for integrating understanding of and support for client- and family-centred care into everyday practice at the hospital.

Mixed groups of three or four family and staff went together; the hefty cost was covered by the hospital's Foundation. The groups would return, brimming with enthusiasm and knowledge which not only transformed their work but encouraged others who might be having doubts.

> "We could really see a shift in culture once we started sending 'intact teams,' people who already worked together on various mandates. They would go down together because we didn't want just a lone wolf trying to effect change, and they would come back part of this whole new community of practice." *[Staff]*
>
> "We got crazy excited because we couldn't believe what they were doing in the States. It was amazing, and we could so get there." *[Family leader]*

Gradually, experience and enthusiasm for change were spreading through the hospital.

The Journey — multiple steps built the path for families

People interviewed for this case study describe a remarkable feeling of excitement and energy that engulfed Holland Bloorview in the early months of *Unleashing the Passion*. One staff member described how she would run to work in the morning, despite telling herself it wasn't a race, it was a marathon, it needed pacing. The key to keeping all that enthusiasm from turning into chaos, the staff person said, was the use of change-management frameworks, and carefully following the processes they had established.

The transformation of the Family Leadership Program was a case in point. First, the role of family leader was analysed, and its requirements defined — including an ability to respect diversity and different opinions, to work collaboratively and to guard confidentiality.

Leaders were organized into three streams: advisors, who help shape policies and programs through committee work, special projects and working on documents; mentors, who provide peer support to other families; and faculty, who make presentations at grand rounds, talk about their experiences one-on-one and to groups, work with professionals in training, do role playing with families or in simulation exercises and make presentations at conferences.

But that's just one of multiple levels of change that went into creating meaningful roles for family leaders. There were more:

- Hours were spent attending committees, assessing what and where family leaders might best contribute.
- A formal application and interview process for leaders was set up, to try to make the best use of each person's talents and interests.
- Education sessions were held to bring leaders up to speed on a committee's topic.
- Staff had to apply to have leaders work with them, including defining what the committee or project was about and what a leader could contribute.

> "There may be places where they shouldn't spend their time because no matter what, it has to be meaningful. If we are bringing them to the table and actually not asking their opinion, or there's no way to incorporate their feedback, then please, let's just not bother." *[Staff]*

Nevertheless, it was rough going for some family advisors early on, before all the changes to the program were in place. They often felt left out of discussions and worse. “It was pretty intimidating. Not being prepared, and staff cancelling meetings at the last minute and then forgetting to tell the parent, or just not even giving them any information, so the handouts would go to everybody but the family advisor,” one parent said.

Slowly, rules began to evolve for committees. Some basic rules of etiquette were introduced. For example, family advisors were not to be singled out in a way that marked them as outsiders, but staff were to remember to introduce themselves and to provide background for what they were saying. Family advisors had to be brought in at the very beginning of a project — agendas, goals and the plans to achieve them were not to be created without family input. Advisors were not to be asked “for the family perspective,” because all ideas were to be treated equally. “We would never say, ‘we want to hear the doctor’s perspective,’ ever, they are experts and we want their knowledge, their expertise,” one staff member said. Family expertise was therefore also what they were looking for.

The Journey — negotiating roadblocks on the staff route

Efforts to introduce client- and family-centred care in all hospital activities were by no means focused only on clients and family. In fact, people interviewed said family members and clients embraced rethinking care and were keen to learn how to do it effectively. Many staff members, on the other hand, were much more cautious. The approach to building staff’s capacity to be client- and family-centred was equally thoughtful and multi-layered, but it met with more resistance than it had from families.

As noted, there were formal sessions in patient-centred care from the Institute of Patient and Family Centered Care when *Unleashing the Passion* was launched and during trips to Bethesda for conferences. They were intensely reinforced over the next months and years in many ways. Bloorview’s relatively small size — it had a staff of about 1,300 at the time — meant those leading change could get a lot of face time with a lot of people. But, as one staff person said, “You can never do enough talking.”

CULTURE CLUE

“It was about knowing where you would easily be able to go first and testing the waters and trying out your methods and then getting to the place you need to be, where people are ready and comfortable to make that move and feel safe.” *[Staff]*

> "Change is not easy, changing your practice is not easy, you're doing things you believe are right — and are right. We weren't telling anybody they were doing things wrong. We were saying, what an opportunity, always presenting it back as this amazing opportunity, look at all these people who are willing to come to the table and help us." *[Staff]*

Change agents went to every committee and group, to talk about introducing family members to the process. Some groups were receptive at once, others were not. One committee, which handled medication errors, feared family members might react with horror or outrage. The people leading change returned again and again, until finally they brought a family in to talk to the committee, and then added a member who was both a nurse and parent of a client.

At the same time, other committees were adjusting to and benefitting from the gradual introduction of family leaders to different roles. Because of Holland Bloorview's size, staff members are often assigned to more than one committee or project. Those who experienced working with families in one role could reassure staffers they knew through other work.

Honesty helped as well.

> "We were very open and honest and blunt. We said, there's going to be bumps and we're totally going to make mistakes, but that's OK, we're fine with making errors in how we do this together. We'll have to say this isn't working, or we're not going to match well to the initiative, or we're going to have to apologize, and our patients will probably have to apologize, but we're in it together...I think the other piece was that we were a very collaborative team, we were always willing to come to the table and have those discussions." *[Staff]*

One example of how staff were helped to move toward the new culture is in the way the Institute for Patient and Family-Centered Care's four core principles — dignity and respect, information sharing, participation, and collaboration — were adopted. Holland Bloorview made a conscious decision to integrate them into everything it did. That meant, for instance, that as the programs for things like patient relations were developed their design was based on the four principles. They had to reflect dignity and respect, information sharing, participation, and collaboration.

But the hospital went further, and grounded the principles in reality by assigning specific actions to each one. In patient relations, for example, the standards for respect and dignity dictate that staff always introduce themselves to the child and family, saying what their role is and why they're there. Furthermore, as part of training, new hires are taught the behaviour associated with each principle, and then given the chance to practice it in simulations.

CULTURE CLUE

The behaviour called for in client- and family-centred care is clearly defined, taught, and practiced. There is no assumption it is somehow latent in air, to be absorbed by breathing.

The Journey — barriers and dead-end streets

No amount of planning, educating and open mindedness could avert every issue that arose as Holland Bloorview struggled toward changing the nature of care within its walls. Some were easy to deal with — case in point: despite having prided itself on being patient centred, Holland Bloorview still had set visiting hours. That's not putting clients and families first. Similarly, although Holland Bloorview's uptown location is pretty, it is not handy for restaurants and other conveniences — but the cafeteria was closed on weekends. Those were quickly dealt with — visiting hours were abolished and families can pay to eat what the kitchen was preparing for in-patients on the weekend.

Other issues were more challenging. "I would have loved for [culture change] to be organic, but it wasn't," one staff member said.

There were a lot of reasons behind staff resistance to change. One in particular was the fear that "client-centred care" meant you had to do whatever the client and his or her family wanted. It took education and experience for staff to see that partnership doesn't mean acting on every request, and more for them to learn how to work closely with clients and families on achieving the best care. One staff member disliked the term "client- and family-centred

CULTURE CLUE

"We do a really good job of tying their input to the final issue. That is tangible, that's their pay. Why are they in this? To make a difference, so we highlight how they have made a difference." ***[Staff]***

care" for that reason: "I like the word 'team' better. I try not to put them on a pedestal. I try to put them at the same exact level as we are because…I think that's where partnership happens."

There was an echo of that in the way some family leaders had to be encouraged to be forthright in committee proceedings. Staff were told to shift from asking "Do you have any questions?" to which the answer was almost always no, to "What questions do you have on this?" which was more inviting. Some family advisors had to be told the hospital would learn infinitely more from having its failures pointed out than its successes.

> "We created that space so people could speak from that frame."
> *[Staff]*

Gradually, clients and families started asking hard questions and challenging the staff. It was an adjustment for all: "Staff want to present their knowledge and their expertise. We're not saying they don't have expertise, but they put it together and bring [a finished plan]. They never felt comfortable bringing a conversation, and that's where we really shifted," one staff member said.

One change leader said people's inability to picture a new way of working was the biggest barrier to change. Overcoming it, she said, was done by putting patients and families on hiring committees; the impact was clear. "You're going to shift the culture because you're going to hire a different kind of person…That infusion of change happens over time, but the process change actually will lead to culture change."

Occasionally, academic and professional standards don't allow for client and family engagement. When family representatives first sat on grant committees, for example, they sometimes made recommendations that could not be changed because of the grant's requirements; now they're told in advance what's non-negotiable, so they don't feel their efforts are wasted. They are also brought in earlier now, while projects are being developed and their experience can tie research questions to real-life issues. People interviewed agreed client and family involvement has changed Holland Bloorview research for the better.

Another problem is that clients and families may want care delivered in a way that practitioners feel is outside their scope of practice, or not in keeping with their professional standards — as when parents of children with autism wanted assessment reports as fast as possible, while college standards call for long, detailed reports. But re-examination of what the requirements really said allowed a shift in the way the reports were prepared.

Frontline staff members at the hospital experience the reality of patient- and family-centred care differently, and several people said it has not been adequately developed at the hands-on care level.

> "There can be a pretty big disconnect between the frontline and the big picture. We try to take a proactive, thoughtful approach of reinforcing important parts of the culture [for them]." *[Staff]*

That includes training and other activities and "telling the story over and over again."

One of Holland Bloorview staff's most common objections to client- and family-centred care was they were too busy for it. Many characterized it as an "add-on" — nice to have, but potentially getting in the way of real care.

> "Time was always brought forward as a factor, time constraints, 'I don't have time to talk to more families,' but you know what, if we just spend a couple of extra minutes, we find it comes back to us later, because things come out at the beginning, and not as we're trying to figure out what's not working, or why it's not working." *[Staff]*

The Journey — road signs to success

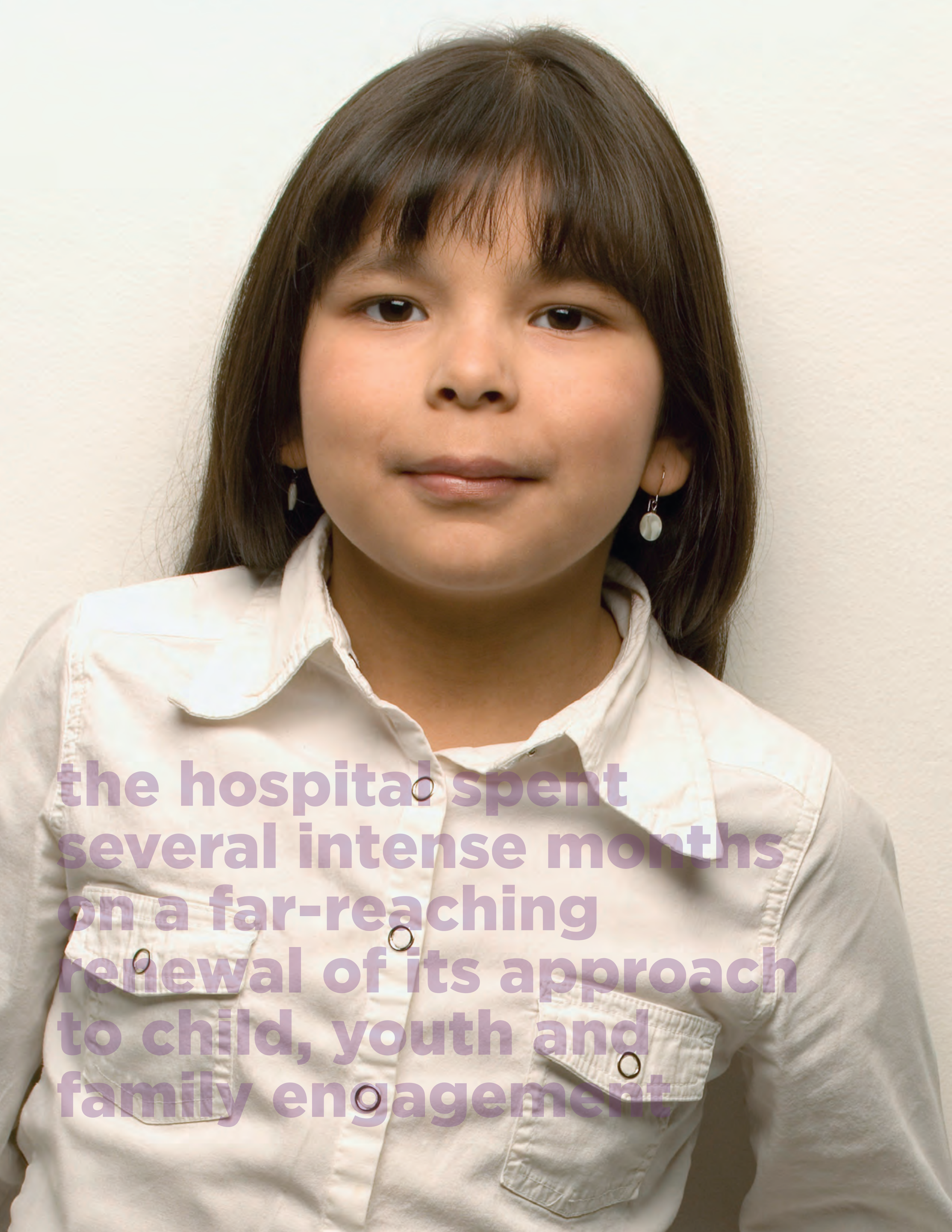
Culture change may be the hardest of all things to quantify. What's the baseline (after all, Holland Bloorview's history spans three centuries). How do you measure the instincts of people coming to work every day? Where does a family's gratitude for any kind of help at a difficult time end and appreciation of superior care begin? We asked people we interviewed to tell us what successful client- and family-centred care at Holland Bloorview looked like, and when they knew the culture change would succeed. Here are some of their answers:

- “The leadership’s commitment. The leadership said, this is our mandate, we have to do it. And it was so helpful, not just verbal support, but that they understood it, they could talk about it and how it would be meaningful, they went out and got training.” *[Staff]*
- When people started acting on the Institute for Healthcare Improvement’s motto of ‘Nothing about me without me.’ “We started getting more requests to engage patients and families in core planning and decision making. People wouldn’t have a meeting or set up a committee without having caregivers present; we wouldn’t have an event, we wouldn’t have an AGM without having patients there.” *[Staff]*
- Artificial barriers faded away. “When there were no more silos. Well, not no more, but they’ve definitely broken down between the staff side and the parent side. There’s not that little bit of distrust anymore.... There’s more acceptance on the staff side of families being involved in different things, and actually an expectation now that families will be involved, and understanding of what true partnership is.” *[Family leader]*
- “When I knew it had really taken root was when people who had historically [spoken on behalf of patients] gave up their agency on that and welcomed others to the table to speak.” *[Staff]*
- “When I see them starting to ask for our input, that’s when I know that it’s a real partnership. They’re not just going oh yeah, we have families here and they tell us things. It’s ‘we’re asking for them, we want to know what you think.’” *[Youth Advisory Council member]*.
- Reminding staff what drew them to work in healthcare to begin with. “Most people who go into healthcare do it because they want to serve and provide care and support those in need. If we could connect people to what brought them into healthcare in the first place, we thought it would have a big impact.” *[Staff]*
- When the Family Advisory Committee went from being drifting and ineffective to essential. “It’s such an important forum for getting family input on ideas and projects that there are not enough meetings in the year for everyone who wants to come.” *[Staff]* There’s a careful screening process to get on the agenda, and people who don’t make the cut often turn up early just for the chance of some informal feedback before the meeting starts.

Key Lessons

1. Begin with deep research and careful planning. Ask: Where has patient-centred care been introduced effectively? What are the best approaches for us to try? Where should we start?
2. Use established change-management theory to build your framework for change and develop your plans. Adhere to it.
3. Build a robust collaborative structure collaboratively. No part of the process can be exempt from working together.
4. Managing large-scale change is a long-term, full-time job. Appoint a senior staff member to be in charge. Give the project the resources, human and financial, it will take to get the job done. Keep the work high-profile.
5. Be generous in the time you give to preparing people for change, but don't wait to start making changes. At Holland Bloorview, hearing from and working with clients and families, and seeing how their new roles were improving the hospital, was the most powerful tool of all for spreading support for client- and family-centred care.
6. Don't waste time trying to win over the "resistors," people who won't welcome change no matter what.
7. Branding is important. Keep drawing attention to patient-centred care in every aspect of operations: name it, credit it, have a logo for it and encourage its use.
8. Link client- and family-centred care to the quality and safety movements (new accreditation standards should help that). Any perception patient-centred care is just enhanced customer service would make it easy to cut as a frill.

> **"There may be places where they shouldn't spend their time because no matter what, it has to be meaningful. If we are bringing them to the table and actually not asking their opinion, or there's no way to incorporate their feedback then please, let's just not bother."** ***[Staff]***



the hospital spent several intense months on a far-reaching renewal of its approach to child, youth and family engagement

CHILD, YOUTH AND FAMILY ENGAGEMENT AT THE CHILDREN'S HOSPITAL OF EASTERN ONTARIO

Description

It's a rare joint meeting of the Family Forum and the Youth Forum at the Children's Hospital of Eastern Ontario (CHEO). On the agenda is an after-hours tour of waiting rooms — the hospital is looking for input on possible improvements. The discussion starts with practical comments on the spaces from everyone, but when the group returns to the boardroom, it quickly divides down age lines: the teens stay focused on what would make waiting rooms better, while the adults leave that behind to complain, at length, about their experiences waiting.

It's a pretty good illustration of why the hospital spent several intense months on a far-reaching renewal of its approach to child, youth and family engagement — teens and parents clearly need to speak for themselves. Furthermore, the 20 family representatives and half dozen youth are a tiny proportion of the people CHEO serves each year — but reaching that broader community has been a challenge — a one-size fits all approach to engaging with stakeholders has not worked.

The Children's Hospital of Eastern Ontario and Ottawa Children's Treatment Centre (which we'll call CHEO) is proud of having what is, at 26, the oldest family advisory committee in Canada (and, it suggests, possibly in North America and even the world). But recently, in the midst of several big changes — merging with the Ottawa Children's Treatment Centre, switching to electronic health records and introducing Lean efficiency methods — the hospital realized that efforts to involve patients and families in its operations had been allowed to slide in the five years since its last effort to "optimize" engagement.

This case study looks at the work CHEO has done to renew its model of child, youth and family engagement, an effort to go beyond its heavy dependence on two consultative groups and integrate engagement into every aspect of hospital function. Unlike the other two organizations in this series, CHEO's new engagement model has not been in place long enough to test its impact. However, the continuous-improvement approach it is using means the knowledge developed for the renewal process became an essential component of understanding and building the overall plan. We think both the approach and the lessons so far are worth sharing now.

Motivation for change

CHEO and the Ottawa Children's Treatment Centre (OCTC) have long been close neighbours, separated only by a driveway. OCTC provides bilingual specialized care for children and youth with multiple physical, developmental and behavioural needs. CHEO is a full-service pediatric hospital, serving Eastern Ontario, Western Quebec and Qikiqtani region of Nunavut. In 2017-18, CHEO had 6,664 admissions, 75,961 emergency department visits and 175,421 day-clinic visits.

The two organizations share care for some 2,000 children; some physicians and other providers work for both. Until recently, however, families saw mostly barriers: services were rigidly separated, charts weren't shared and information didn't flow, even if you saw the same specialist on both sides of the driveway.

A few years ago, the two organizations created a task force to look for ways to work together, mainly administrative, such as OCTC switching from a private IT provider to use CHEO's in-house IT, and the two doing a Lean review to improve referrals. In January 2015, they held a joint board retreat, expecting to come up with recommendations to reduce duplication. But a CHEO executive who was there remembers a comment one of the two parent representatives on the task force made.

"She said — I'm paraphrasing — 'you know, I had a son with complex medical needs. It would have been nice for him to have been born into a system that wasn't as complex.'" That, the CHEO official believes, was a pivotal moment for everyone there, and on October 1, 2016, the two organizations formally became one.

Both organizations had active family and youth advisory councils. Because OCTC was smaller, and had long-term relationships with children and their families, their family engagement was more organic and responsive. CHEO's was more formal, revolving around the two forums. In addition to input from their monthly meetings, the hospital drew on the forums when it needed patient and family representatives for tasks such as budget committees, or interviewing candidates for high-profile jobs. There were some projects — like redesign of the oncology services — that very consciously involved patients and family in the co-design process.

> CHEO views patient engagement as any process that involves patients and/or their families or caregivers in problem solving or decision making and uses their input to make decisions.
> — *The Patient Engagement Assessment and Planning Tool*

More broadly, however, only about 10 per cent of projects (such as a piece of research, or designing a program) actually involved child, youth or family representatives. For the most part, people tended to think consulting the Family Forum was their only option for engagement; the family representatives sometimes sent them on to the Youth Forum, which was frequently overlooked; and the voice of children was not really heard. In the face of the merger, engagement needed a rethink and alignment.

"We wanted to build a strategy that would work for the new integrated organization that everyone could be proud of and that would help us be that "stronger as one" tagline we keep talking about," one staff member said. "We knew that when it came to engagement, that would be really true. We could learn from what each group was doing well and build it in so that people could actually do it."

External forces were also compelling more attention on engagement. Patient and family engagement is a strategic priority for Accreditation Canada; it is included in Ontario's Excellent Care for All Act; and Health Quality Ontario requires hospitals to include engagement in their quality improvement plans. It is also integral to Solutions for Patient Safety — a network of more than 130 children's hospitals working together on safety goals, which CHEO belongs to; and to CHEO Works, the hospital's continuous quality improvement program, both of which try to embed engagement in all their processes.

The Journey to child, youth and family engagement — the vehicle

CHEO began the engagement project in June 2017 with an ambitious deadline: to launch in April 2018. But it did not start completely from scratch, instead naming as co-leads for the project the manager of patient experience and the team leader for quality improvement and strategy. They set out to build a very concrete plan for boosting engagement, based on CHEO Works/Lean methods and Health Quality Ontario's high-level engagement framework[13], creating a clearly defined framework that included a focus on measurement to test whether engagement improves.

> "What I really wanted to build here was something that people could see themselves in, a step-by-step process to actually engaging people. That's where the methodology became such an important part of the whole process, not just the outcome."
> —*Renewal team member*

Another strength of the highly structured approach, a team member said, is that it should allow CHEO to hear from the families and patients whose ideas have largely gone untapped. "The framework will allow for those voices to come through, those families that aren't going to come and sit on your advisory council, who aren't going to engage in a typical way." They also hope it will give more of a voice to 12 to 18-old year patients, and a new voice to those under 12 for whom there had previously been no formal efforts at engagement.

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[13] www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf

The drive to hear more voices

When CHEO began the renewal project, its goal was to co-develop an engagement framework and program that would bring input from children, youth and families to all aspects of CHEO and OCTC, including personal care, programs and services and overall running of the organization. Key to that was hearing from all the voices they were developing the program to capture. It was a tall order.

The drive to hear more voices — children

The lack of children's voices was a particular concern going into the renewal; the hospital had "been remiss" in one executive's phrase, on the issue over the years.

"I personally am a big believer that kids as young as four and five can really help us get there... parents think they are representing the voice of their children and they have a very poignant voice to bring, but often it's a little bit different," one hospital executive said.

One important point several interviewees emphasized is the need to approach children differently than youth and adults. They live in the moment and are very concrete — so asking them what they thought of care a month later won't work, and they aren't about to speak for others, or in the abstract. They also don't, as a rule, like speaking to strangers.

For all those reasons, the renewal team turned to the hospital's child-life specialists — who use play with children for its therapeutic and developmental benefits — to learn what children were thinking. It's an area CHEO child-life specialists had considerable expertise in already. Having children draw and explain pictures, or set up and talk about a dolls' waiting room, for example, are well-established ways to get their ideas on an issue.

> "I think kids can give a lot of wisdom around all sorts of very complicated things as long as it's presented to them in the right way... you can ask them 'how can we make this easier?' Kids understand easy and hard." — *Renewal team member*

The drive to hear more voices — youth

The renewal project faced a different range of issues in engaging youth. Walk in the door of CHEO, and you see a lot of teddy bears and primary colours. Calculated to cheer frightened toddlers, the décor risks literally adding insult to injury for someone 10 years older. So do the attitudes that go along with it.

One youth interviewed said physicians often have trouble shifting gears when they're dealing with an older teen. "This is going to sound terrible but when you're as knowledgeable as I am about my medical condition, and the doctor says, 'Oh well, this is what we're going to do today honey,' it's like, no, listen, I have been in ICU, I have had pretty much every test there is, I don't need you to count down from three as you give me a needle."

The attitude problem can extend into being taken seriously about hospital issues. People who visit the Youth Forum, the interviewee said, while they listen respectfully, can be surprised when their proposals are criticized, and often haven't thought to talk to patients before going ahead with their ideas and presenting the results to the forum.

CULTURE CLUE

It can be a hard lesson for parents to learn about teens, and for providers to learn about families — but however experienced you are, you cannot predict what individuals will feel in a given situation. You need to let them speak and you need to hear what they have to say.

One of the team members told the story of a pilot project to include patients and families more in rounds. They presented the idea to the Family Forum and got a very enthusiastic response from the parents — but also a recommendation to ask the Youth Forum for reaction. Expecting a similar response, the doctors were surprised to be deluged with concern from the younger group about privacy.

"You could see the folks who came to speak really hadn't thought that through, because the parents were just so excited to be involved," one observer said. The teens were also generally in favour, but with deep reluctance to hear the details of their roommate's condition, and likewise to be overheard, "…a completely different lens on how it should be implemented that the parents never even thought of."

It can be a challenge even to get staff to engage youth in their care, a team member said. "It's easy to speak to mom and dad. I don't want to say they don't value [the patient's] voice, but maybe they don't think they're as important to connect to. We spend so much effort on keeping parents engaged and in the loop, which is essential and important, but we don't always do a good job with children and youth."

One staff member admitted providers tend to think they know what families think already. "As a clinician I can say we definitely get a sense that we work with so many children and

> "We did one group with youth from the children's treatment centre and one key thing that came out of that group was 'Look at me and speak to me. You may look at me and see a disability or assume that I have whatever issue related to communication. Regardless, speak to me, speak directly to me, not just my parent.' That's a really powerful message, not just for kids who might have a disability where you might make assumptions about what they can understand, but for all the youth we treat here. We hear over and over from our youth that they feel their voice isn't as strong when their parent is in there." — *Renewal team member*

youth and families and so many times their experiences are similar, we assume they all have the same feelings about them."

Serious issues with engaging youth arose as the renewal team began its work. Bluntly put, recruiting young people to participate in the project proved far more difficult than anyone had expected. The team started off confidently, assuming that posters around the hospital and a social-media campaign would net them enough interested youth to create a steering committee for those who wanted to be most involved, as well as a support crew made up of those who didn't want to commit to regular meetings but could be used to bounce things off.

The first efforts, done in conjunction with recruitment for the adult steering committee, flopped. Posters were redesigned, social media messages changed and — nothing. The Youth Forum member interviewed suggested that not many teens have enough interest in healthcare to sign up for a committee, and young patients who are motivated to volunteer for a health cause are more likely to get involved in activities related to their own condition.

In the spirit of failing fast and learning fast, the renewal team just kept trying new approaches. Two young staffers started hauling a whiteboard around the hospital, doing pop quizzes in waiting rooms, asking questions as simple as "What does good care look like?" in hopes they might get chatting and recruit youth that way. "I think we maybe got one," said one of the whiteboard workers.

They finally had some success by going outside the hospital, to young people active in other volunteer work, promising food at meetings and a chance to get the volunteer hours Ontario students must have to graduate from high school. "We got an awesome group with great ideas, but not a lot of CHEO experience," a team member said. "But there are universal things, beyond healthcare we needed to know, about how to communicate and get feedback from youth, whether it's a hospital or a school or a sports organization."

One of the members of what came to be called the Youth Representation Council said the timing was bad for students — the council's work began in August and extended into the fall, a time when his friends are focused on the transition back to class. And between school, part time jobs and sports, teens are busy. "But there's always good people who are willing to sacrifice their time to improve things," he said, adding that many considering a career in medicine would be interested in helping the hospital, even if they have not been patients.

The drive to hear more voices — parents

Everyone involved in the renewal project was aware of a serious flaw in CHEO's engagement efforts over the years: they concentrated on the Family Forum and the Youth Forum. Both, while in theory open to all, in practice only work for people fluent in English, available to attend every month and happy to participate in meetings. The vast geography CHEO serves, and its multicultural clientele, are serious barriers to hearing from a truly representative sample of the hospital's community.

Even within the city, it can be hard to get participants. One hospital staff member pointed out adult hospitals looking for volunteers usually draw heavily on retired people to fill all the roles they need patients and families for. "Parents of kids are busy. Parents of sick kids are really busy," the staffer observed.

The people working to improve engagement are particularly concerned with reaching those families they generally refer to as their most vulnerable or marginalized clients: newcomers to Canada, the Inuit and Indigenous population the hospital serves, and those in poor socio-economic circumstances. (One CHEO survey found roughly 50 per cent of children coming to the emergency department were in housing need — that is, they didn't have stable housing or their families were spending too much on housing, at the expense of other necessities). "I don't know how many of those folks are on our Family Forum, right?" a staff member said.

Recruiting participants from vulnerable groups proved very challenging for the renewal team, but taught them essential lessons for their ongoing engagement efforts, they say. Fairly early on it became clear to them they were unrealistically expecting people to come to them — assuming, essentially, that putting out the word CHEO needed help would inspire people to sign up and turn out. But, as noted, parents are busy. Not many are looking for

CULTURE CLUE

"We've learned this along the way in several ways, it's just such a no brainer, but instead of asking folks to come to us to help us and give us the information to help us get better, we really, really lived the mantra we know to be true — we need to go out to folks and we need to build relationships with the community." — *Renewal team member*

more obligations, so the CHEO team focused instead on meeting parents and youth through groups or activities they were going to anyway.

Nowhere was that more strongly demonstrated than when a member of the team went to a meeting at an Indigenous centre and was told firmly that they were not interested in taking part in the project because CHEO had never made an attempt to build a relationship with them and was simply coming for help when it was convenient. "We've now been backtracking with them guiding us on how do you get to the relationship where they will want to partner with us. They want discussions between our CEO and their executive director, a kind of relationship feeling so this isn't just tokenism. That was a good lesson. You can't just rush in."

Close work with Inuit families over the years made approaching that community a little easier, but there were still important cultural lessons to be learned. The meeting was facilitated by a member of the community at their centre; there was interest in participating, but CHEO's traditional approach to bringing a volunteer on board had to be modified, when it proved too rushed and invasive for comfort. Even with those already familiar with CHEO, it took time to build trust and take the relationship further.

On another occasion, CHEO staff looking for input at a Chinese-language new mothers' group found themselves dispensing advice on sleep and nutrition. "We were looking for committee members, and they just wanted to know when they could feed the baby peas," one laughed. Once again, the hospital was reminded to understand and meet client and families' needs before focusing on its objectives.

The struggles to recruit for the engagement project taught the team an important lesson for longer-term involvement of families in CHEO's activities: "We've realized you can't just have one model so you need multiple ways to get input, to get the voice. People contribute differently," one team member said.

CULTURE CLUE

it will always be essential to offer a variety of ways and levels of participation.

> "In the process of going out and asking for people we've learned so much. Because we wanted to have workshops with people, we had to figure what makes them come to a workshop, which is exactly the same as what you need to know for engaging them. We had to engage them in this, so that taught us how to engage them in everything else." — *Renewal team member*

Even those willing to attend meetings want to do it at different levels. Some people who would not want to serve on a committee might attend a one-off workshop to deal with a particular problem (as they did for the engagement renewal). Others might like to work on specific projects, perhaps a piece of research or a quality-improvement plan.

Then there is another level, people who are prepared to give their opinion. Options include electronic consultation — the hospital already has a "quick poll" group of more than 1,000 families, which it turns to when it needs a rapid response to a question; that's an approach that could be expanded. One idea people in the engagement workshops liked was reaching people through CHEO TV, which plays on big screens in the waiting rooms. It might scroll up an invitation to participate in a survey — text 123, and you get the questions.

> "We have to have tons of different ways for people to get involved at their own pace and in their own time, in multiple channels. So web based, app based, phone based. No one strategy is going to work for everybody. We have to be flexible." — *Renewal team member*

The journey — bringing staff and physicians along

Care providers at the hospital have supported engagement over the years and the renewal team counted it as an early success that they were overwhelmed with staff requests to serve on the steering committee ("It would have been 10-to-1 staff to parents if we'd accepted them all," one said). Nevertheless, others remain wary of engaging more closely with members of the family.

One parent interviewed said she hoped the tools the renewal team have created will encourage those providers to take a risk on working more closely with families, which she suspects many actually fear. "It's got to be a little bit scary for clinicians to approach patients because you might assume they're just going to complain about this or that, and if you've had a bad experience that involves the health of your child, then it's a very emotional thing. So the tools will help find a way to engage that's safe and collaborative."

The on-line tools will require lots of support, team members said. They will not just be given a link and told they're on their own. However, the team is hoping the online tools will encourage staff to act independently on at least smaller engagement projects, because the instinct to clear everything with the patient experience staff creates bottlenecks.

The team isn't worried people making their own decisions on engagement might go too far: "In this organization, in healthcare, people are very risk-averse, so I'm not worried about people going crazy," a team member said. She added that if it's working well, if parents complain about something, a unit manager will invite them to participate in finding a solution instead of just acting to mitigate the issue.

Members of the renewal team know busy staff members can be skeptical of "flavour-of-the-month" management schemes that add to their work pressures. "In the end, if it allows you to provide better care, then your job is easier," one said, but admitted "When you're trying to get people to do things they're not used to doing, it's always going to feel like more work." The goal is that engagement will feel no more of a burden than meeting safety standards, another said. "If we can build it into practices, build it into workflows, build it into EPIC [the electronic health record]…I'm hoping it will just feel like a really comfortable evolution that people won't even see as something different."

Several renewal team members said having the chief of staff as the executive sponsor on the project is key in winning support from other physicians and providers at the hospital.

CULTURE CLUE

"The easy sell for staff is that this is why they went into healthcare — to help families. They didn't go into it to help physicians, they didn't go into it to help the Lean folks, but they did go into it to help families." — *Staff*

The journey — milestones

How all this theory will translate into practice remains to be seen (which is to say, measured and evaluated). But people at CHEO are already pointing to some successes.

Despite its rocky start, the interviewee from the Youth Representation Council thinks both its process and the outcome were very successful. Based on a plan developed by a youth member, the Youth Representation Council held a series of facilitated meetings featuring lots of open-ended discussion questions. At the end, a plan emerged. "We just answered questions, right? We give our opinion, and combined with the opinions of the children and the parents, it turns into a beautiful well-designed structure. It's amazing — there's guidelines we didn't even know we were talking about."

In fact, more than one person interviewed noted that while the language was different, the essence of the guidelines produced by the (adult) steering committee and the Youth Representation Council was the same. They became the guiding principles of the engagement framework:

- A place for all voices
- Real respect
- Committed communication
- True partnership
- Learning and growth

The youth representative interviewed thought the strategy that produced them was brilliant. "If you talk about guidelines, you know suddenly everyone's brain springs into bureaucracy, but when you say, hey, what do you want, something like that, we're able to just kind of say what we want. Then adults — not just adults, good minds — they're able to transform those opinions and interests to guidelines, right into the plan."

On a more personal level, he was pleased that the dedicated youth space he had proposed (a teddy-bear-free zone, essentially, where youth could gather away from smaller children) had been well-received; team members pointed out it was not an idea that any adult had come up with. The other youth interviewed counted among her bigger accomplishments the installation of a tray of universal chargers in the emergency department, so teens could keep connected when they unexpectedly find themselves at CHEO. The Youth Forum subsequently gave out grants to get chargers installed on every floor.

Another sign of success, the renewal team thought, was that most of the hospital's vice presidents were vying to have management of engagement added to their portfolios.

Arrival — the Engagement Framework and Assessment Tool

Untested though it is, the team is regarding the engagement planner as a success, insofar as they have designed what they set out to design. While a formal, hospital-approved engagement process will be mandatory in some high-priority areas, more day-to-day activities will be managed on the frontlines.

The Engagement Framework (below and right) has two parts — the guiding principles and the engagement strategies. As one staff member described the framework, the principles

OUR GUIDING PRINCIPLES OF ENGAGEMENT

This is what engagement should feel like at CHEO

The Best Life for every Child & Youth

CHEO ensures the voices of children, youth and families help guide the care, research and future of the organization.

A place for all voices	A safe, inclusive and accessible place open to sharing diverse ideas and removing barriers to participation
Real Respect	Mutual respect achieved through trust, sharing honestly, protecting privacy and valuing lived experience
Committed Communication	Open, direct, clear and consistent communication to ensure shared purpose, expectations and outcomes
True partnership	Sincere, meaningful and balanced partnership with a commitment to benefitting all
Learning and growth	Learning that supports personal development and increases capacity to identify, and collaborate on, common goals

ENGAGEMENT STRATEGIES

This is what engagement could look like at CHEO

ACROSS THESE DOMAINS: 1. Personal Care 2. Programs & Services 3. Policies and Governance

Sharing Information Variety formats, languages and methods	**Giving Feedback** Open, relevant & honest dialogue	**Partnership & Consultation** Clear expectation & commitment
Child • Peer Mentorship • Use CHEO TVs • 1:1 with Tools • Website • Newsletter for kids • Posters by Elevators	**Child** • Drawings/Artwork • Online with parents' help • Tablet at bedside • Interviews solo or group • Graffiti Wall	**Child** • Supported by clinical staff/physician • Just in time • Group discussion
Youth • Use teaching videos • Use email and texting • Maximize MyChart • Visuals in the hospital • Always include Youth • Leverage schools • Use social media • Youth website/App	**Youth** • Electronic Surveys • Pool of Youth advisors via Social Media • Focus Groups • Value Youth voice • Website • Have surveys in MyChart • Use existing groups	**Youth** • Include Youth in all parts of process • Respect Youth schedules • Reduce obstacles to participation • Dedicated Youth space • Face to face meetings • Go to Youth in community

Families
• Enhance MyChart; info while on wait list
• Instructional Videos
• Use CHEO TVs and website better
• Leverage People
• Volunteers
• Peer mentors
• Home visits
• Social Media (more partnerships to ensure our home community shares)
• Apps (virtual self-triage, way-finding)
• Hands on teaching Labs
	Families
	• Use peer support and community groups as Focus Groups
	• Have providers promote feedback mechanisms
	• Offer call-in line to leave message
	• iPad Kiosks at exits
	• Use MyChart post visit for just in time feedback
	• Improve Website info
	• Apps to push out opportunities
	• Family faculty at our gatherings (Town Halls, Board, start of projects)
		Families
		• Telephone Support
		  • Nursing support
		  • D/C phone call
		  • Virtual Triage
		• Enhance awareness of and recruitment for advisory roles (community groups, apps, website info)
		• Leverage time while children are receiving care
		• Offer drop ins
		• Participate at distance – zoom, skype
		• Add 1:1 time to existing appointments
		• Build on feedback data

are what engagement will feel like and the strategies are what it will look like. The level of engagement ranges across a spectrum from sharing information, to giving feedback, to partnership and consultation. Whatever the best approach is for the situation, the engagement strategy will always adhere to the guiding principles.

The Patient Engagement Assessment and Planning Tool (see Appendix 1) is completed to help determine the level of engagement that should be undertaken. A very low to low score indicates that no engagement is necessary; a low to moderate score suggests sharing information and informing; a moderate to high score recommends getting feedback; and a high to very high score means consulting or partnering to co-develop a new process or service.

The journey — the next stage

The people interviewed for this case study know what they hope will happen. They want all CHEO's patients and families to feel their voice is valued. They want staff to consider engagement in everything they do and find their work the better for it.

"It's really a continuous improvement plan," one team member explained. "So we are certain that it's not perfect. We don't have it right. We've done, I think, a really good job of building a great framework and a tool kit plan, but we're going to start doing this and realize wow, that didn't work or this could be a lot better...so our implementation sustainability plan has to include the ability and the flexibility to continually evolve and continue to learn from what other people are doing. Otherwise we'll be in the same boat we're in now, where we have a great framework that we don't touch for 10 years and then we'll look back at it and go 'oh wow, we don't do this at all anymore.' We don't want to be reinventing the wheel. We want it to keep rolling."

Key Lessons

1. Having children, youth and families share their experiences constructively is the only way to make things better.
2. Make engagement a priority strategic direction, and track with measures that are reviewed regularly — and followed up on — by the executive committee.
3. There is a risk in engaging patients and families, but don't wait until you have a perfect system in place before you start — it will never happen.
4. Staff's reward is seeing patients do better. Show how they are.
5. Go to your patients and clients where they are to look for help; don't make them come to you.
6. Change your culture so patients and families are the first thing everyone thinks about.
7. The time people have and the issues that matter to them are all different: be flexible and creative in how you try to engage people and offer multiple layers of involvement.
8. Families are realistic and they'll understand if you can't act on their advice, but make sure to go back to them to explain why you can't.

Appendix 1 — CHEO's Patient Engagement Assessment and Planning Tool

Questions	Very Low	Low	Moderate	High	Very High
1. How important are the potential impacts to children/youth/families?					
2. What is the potential for complaints from children/youth/families related to the project or decision?					
3. What degree of participation do patients/families appear to want?					
4. What is the potential for patients/ families to influence the decision-making process?					
5. What levels of resources are likely to be available to support patient/family engagement?					
Multiply checks by weight and	x1	x2	x3	x4	x5
Enter column score					
Add total of all five column scores					
Divide total score by the number of questions	/5				
Average score					

Scores:

1-2 Very Low to Low – recommendation: no engagement necessary

2-3 Low to Moderate – recommendation: inform

3-4 Moderate to High – recommendation: get feedback

4-5 High to Very High – recommendation: consult or partner if feasible

IN CLOSING

Destination

Premature babies used to be packaged like goods on display in a factory showroom: encased in shiny boxes, bathed in light, warm, sterile and arranged for the convenience of the clinicians who came and went. Somewhere, hovering in the background (and only during approved hours), were anxious parents. It was no environment for a tiny, fragile being forced to develop in an atmosphere almost as different from what nature intended as can be imagined.

In the case study on Mount Sinai Hospital's neonatal intensive care unit, we see how much that's changed. There, babies are protected from light, noise and, as much as possible, cared for by and held close to the people who love them most.

That sort of shift from an almost-industrial model to a human (and humane) approach to care lies at the heart of all three case studies. Mount Sinai Hospital, Holland Bloorview Kids Rehabilitation Hospital and CHEO are at different stages of the journey from technical, process-driven care to integrated care that involves patients, clients and families in forming the care they need and shaping its delivery as well as the environment it's delivered in.

Despite different types of patients and clients and different ranges of services, there are strong similarities among the three organizations in these case studies. Each moved consciously from good will and well-intentioned efforts (appreciated but often piecemeal) to carefully constructed models of care based on thorough research, extensive consultation and evidence-based, established frameworks. Monitoring, assessment and evaluation are common to each.

Each of these hospitals recognizes the need for support from leaders on staff and among families. Each puts great care into recruiting and preparing its partner clients and families for their roles, aware of the risks of token involvement and the tendency to assume one can speak and decide for others. Each has learned the hard way how much time and work it takes before some staff can see the reasons for change and accept changes in the way they've always worked. There were other common lessons:

- Always include patient and family partners on committees and projects and on the front-line, always keep the focus on patients and families in everything you do
- Tell stories, there is no more powerful tool for change than listening to the voice of experience
- Base your work in established change-management theory

- Make patient and family-centred care central to the organization’s mission, give it staff, keep it on agendas and in plans. Don’t let it be an add-on that’s dropped when people get busy
- Keep reminding staff of why they went into healthcare — to help patients and families

Healthcare organizations all over Ontario are working to integrate patients and families into care in better, more meaningful ways. These three organizations that are working with some of the most fragile patients we have are giving a strong lead.

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