Part 1: Introduction and the Value of Teamwork

Thank-you very much.

I would like to welcome those of you who are here today at The Hospital for Sick Children, and those of you who are with us virtually, on-line.

This is my first chance to speak with you as a "chief". And as you might imagine, I am doing a fair bit of speaking these days in that role.

But every time I get to a podium, I'm pleased to find myself speaking first and foremost as a nurse. I draw on nursing for my values as CEO, and for my sense of how a hospital and a whole health care system should really work.

Nursing tends to reinforce a very powerful perspective on health care:

- That every element of health care – from the most complex neuro-surgery, to the basics of keeping a ward clean – needs a team,
- That patients are at the centre of this team,
- And that the quality of care comes down to the quality of cooperation in that team.

As a nurse, I always worked on clinical teams. Now as an executive with responsibilities to the children of Ontario, I feel very privileged to have joined a new team encompassing the whole range of people in this room today and more.

It includes medical staff, nursing staff and health administrators. It includes researchers, teaching staff and students. It includes patients and patient advocates. It includes technologists and facilities managers.

It includes everyone at this hospital and colleagues in other hospitals.

And very importantly, it includes colleagues in Queen's Park and in the Public Service, who strive for very high standards of care to their management of this system.

I think this whole team can be quite proud of its recent achievements, because we have really changed the environment for health policy in the last two years.

We turned the health care debate from an argument between governments about money, to a discussion among experts and citizens about the best ways to improve access for patients.

And that has led directly to a whole new set of policy tools for improving care:

- We now have a Federal-Provincial-Territorial agreement that makes access to care a joint priority for all governments.
- As a real world barometer of that access, we all agree that we need to focus on reducing wait lists in specific diseases.
- We have a national health council and similar bodies in various provinces that are measuring the wait list situation and monitoring our progress
- We have an Ontario Health Quality Council, to ensure the quality of our health care services here in this province.
- We have a new joint consensus on the importance of public health and the first real funding for a national public health agency in Canada.

Clearly, it would be too much to say that these pieces solve any problems in and of themselves. But they truly do give us the most constructive environment for improving access that we have had in a long, long time.

Just think back 24 months, when conventional wisdom held that publicly funded health care was like the Titanic: A great ship that had hit a huge iceberg, called "access", and was sinking while we all fought over it.

You hear a lot less of that these days.

It's because we've started working, in the last two or three years, as a real national team across the system.

We should be proud of that.

Part 2: The Risk -- We Cannot Afford to Forget The Kids

But there is a real risk that I see, as CEO of a paediatric centre, as a paediatric nurse, and as a parent: In this great move to reform health care, we cannot afford to forget our children.

Consider the central piece of Canada's current approach to health care reform: shortening national wait lists.

Ontario is now out to cut wait times, specifically for adults, in five areas:

- Cancer surgery,
- Selected cardiac procedures,
- Cataract surgery,
- Hip and knee replacements, and
- MRI / CT scans

For children, we have urgent wait list problems in areas that don't even show up on the adult radar screen, like:

CURRENT PAEDIATRIC WAIT TIME CHALLENGES

- Genetic counseling, where an appropriate wait for counseling on cystic fibrosis, muscular dystrophy, multiple birth defects and developmental delay is three months, but the wait is up to a year and a half.
- Child Psychiatry, where a child living in the GTA must wait **18 months** to be seen at Sick Kids to be treated for an anxiety disorder.

In the adult system, one's instinct would be to re-allocate this case load among a wide range of centres dealing with similar patient populations. In the children's system, there are five paediatric academic health science centres[1] for the whole province.

Indeed, if you want a sense of just how much we risk leaving kids out of health care reform, consider the defining documents of health care policy across Canada today:

- Read through the "Ten Year Vision for Health Care" signed by the Prime Minister and the 13 premiers in September 2004.
    - This is the road-map for health care strategy in every province and territory.
    - Apart from a national immunization strategy, there is not a single mention of children anywhere in the agreement.

And it's no wonder, because kids are also missing from the key documents that led into that accord.

(Bloorview is Provincial Tx Centre)

- Of the 47 recommendations in the Romanow report, many of which are quite precise about different parts of the system, and different patient populations, not a single one even mentions children's health care.
- The sole mention of children at all in the report is with regard to a national immunization strategy.
- Senator Michael Kirby also wrote a key report on health care reform with the Senate Standing Committee on Social Affairs, Science and Technology. They released it just before Romanow, and really helped set the debate over health care reform.
- In 320 pages of Kirby's report, there is not a single mention of children, or pediatrics.

HEALTH POLICY PUBLICATIONS

Document	**Authors**	**Reference to children's health**
"10-year vision for health care"	First Ministers	National Immunization Strategy
Romanow Report	Commissioner Roy Romanow	National Immunization Strategy
"Kirby Report" Oct. 2002	Senate of Canada, Standing Committee on Social Affairs, Science and Technology	None

Clearly, in our well-intentioned rush to save publicly funded medicare, we cannot afford to neglect the special needs of a critical patient group: our children.

Indeed, children are not only forgotten in health care *reform*; the unique needs of paediatric care are not even recognized by the current system – which funds our hospital and every children's hospital the same way that it funds any adult hospital.
You'll see in a moment why that's a serious problem.

Part 3: Bad Assumptions, High Stakes, and the Need for a Values Shift

Fortunately, though, the children's health care system is relatively small, so the problems we do face – though they are dramatic and in some cases are even crises – are actually very solvable. In Ontario, we're only talking about five acute paediatric academic health science centres. And in this hospital, for instance, we're only talking about three-hundred and thirty beds.

So we can turn things around quite quickly in children's care, **if** we as a health system address two honest mistakes in our assumptions about health care reform as a whole.

First: We assumed that because the growth in Canada's health care costs is driven largely by our aging population, the best way to reform the whole system would be to address the problems of older patients, almost to the exclusion of everything else.

Second: We assumed that children are, clinically speaking, just little adults – so that by improving *adult* access to health care, we are improving children's access as well.

Let me tackle those mistaken assumptions one by one.

First, it is right that we focus on the needs of older patients. But addressing the needs of adult patients *exclusively* could put the whole system at long term risk. Because the state of our *paediatric* care today will actually determine the sustainability of the whole health care system in the years to come.

- Consider what Paediatric wait lists are really about. They really tell the story of thousands upon thousands of Canadians who can't gain access to care at a critical moment in their lives and in their body's development, when it could have made the greatest long-term difference to their health.

- Failure to help a patient heal in childhood creates a complexity of needs that could ripple through the adult system for years into the future.

Another way to look at it is to consider the same kind of algorithms that convinced us all to invest in public health after SARS. Since 2003, we have all became familiar with the math that shows a dollar spent in disease prevention multiplies in savings to the whole clinical system for years.

"Every dollar invested in children returns three dollars in future health savings." World Bank

Precisely the same math applies to paediatric care, with very dramatic results. A dollar spent treating a patient properly as a child saves the adult system three dollars in future health costs, according to the World Bank[2]. With a three hundred percent return, paediatric care is one of the most leveraged, efficient investments we can make anywhere in the whole health care system.

Indeed, if we fail to invest in children's access to their own health care system, then the work that we are all doing now to make the adult health care system sustainable could quickly come

[2] Quoted in OCYC report, referring to Tefler, D. (Rotman School of Management, University of Toronto), "Looking Backwards: How Childhood Experiences Impact a Nation's Wealth," February 2004.

undone. After all our patients graduate to the adult system in only a few years. If we don't heal them now, they'll end up on adult wait lists.

Now, let me tackle the second mistaken assumption. And it's one that even outstanding adult clinicians make from time to time. When we set health care strategies and budgets and allocate health care resources, we need to know the full degree to which children are *not* little adults.

Children are no more little adults on the gurney – or in the MRI -- than they are little adults behind the wheel.

Adults may develop Alzheimer's disease, while children can be born with cystic fibrosis – life-long chronic illnesses that will drain a patient and her family financially, socially and medically for decades.

Adults develop coronary artery disease, whereas children may be born with complex congenital heart diseases requiring multiple surgeries over decades.

Adults may develop breast or colon or prostate cancer late in life, whereas young children develop life-threatening asthma or diabetes or Crohn's disease that pose great challenges to their ability to become healthy and functioning adults.

Indeed, the strategies we are now developing to shorten adult wait times have little to no bearing on children's access to health care. In fact, in a world of limited resources, a pure focus on adult access is at the expense of children's access. Moreover, the current system makes little to no distinction between the way it funds an adult centre or a pediatric centre.
To get a sense of why children are not little adults, and why they need distinct health access strategies, consider what's going on in the rooms around you right now:

- Downstairs, on the service floor, a child is probably getting an MRI this morning. You know the scene well for an adult. You'd have a patient in the scan, a technologist operating the equipment and that's it. Relatively fast in and out. Never fast enough for the patient, of course, but relatively easy.

- The scene you would see downstairs right now in this children's hospital is very different. You might see an eight-month old infant in the scan, with the almost impossible challenge

of being absolutely still for up to an hour, even sometimes an hour and a half for brain and spine scans.

- The way you do that with an eight-month old is with sedation or general anaesthesia. So now, you don't just need a technologist, you need an anesthesiologist and you need the medical and nursing team supporting that physician.

- And it's not an easy in and out. You may need to intubate, sedate, monitor, scan, and then bring the patient to recovery and continue to monitor them. About 40% of the patients who receive MRIs at Sick Kids require sedation or general anesthesia[3].

- In an adult MRI clinic you can get a dozen scans done in a day. In a children's MRI clinic, you would be lucky to get half that many done.[4]

- That is why a child in the GTA now has to wait six weeks for a CT scan with a general anaesthetic, and 11 weeks for an MRI with a general anaesthetic[5]. Even children who do not require sedation must wait 8 weeks for an MRI scan.

- Wait times like that are unacceptable to a 50-year old, to be sure. But they present an especially serious diagnostic hurdle for a two month old, to whom 11 weeks is a virtual lifetime during a period of intense growth and development.

- So a provincial strategy to reduce wait times for diagnostic imaging that focuses on adult needs just doesn't mean much to kids.

That's just one example.
Consider something much more basic, like taking a blood pressure. Drop in on any ward here, and you'll see a resident or a nurse choosing from five different sets of blood pressure cuffs that we have to keep in stock for different sized children -- not just two kinds of cuff, as you would on an adult across the street.

We need a full stock of five different cuffs because a newborn is a different fit than a toddler, who is a different fit than a 10 year old, who is a different fit than a teenager.

[3] Dawn Greer, team leader Sick Kids' MRIs
[4] Discussion with Jeff Mainland.
[5] Data from Helen Simeon

Multiply that kind of difference across all the clinical services done in a children's hospital and one starts to get a sense of why kids don't fit into policies based on adult costs:

- Infant formula costs us between three dollars a can and fifty dollars a can. It's a cost that just doesn't figure into adult hospital budgets.

- 20 percent of our patients are being fed intravenously on Total Parenteral Nutrition, or TPN; only between 5% and 7% of adult patients are on TPN. Moreover, children on TPN can't be transferred back to local hospitals because the local hospital lacks the specialized TPN formulas required – so we keep those patients longer than adult hospitals do.

- Drug preparation at a children's hospital has unique complexity. We prepare more than 120 paediatric formulations, and more than 130 special-access drugs because of our child population.[6]

- And we have to have our own medical engineering department re-fitting and re-building adult equipment so that we can use it on kids. We had to customize our own incubator to fit into an MRI – and save money because we did that in house.

- Even our costs of labour are different, because we draw our medical staff from a very small pool of global paediatric talent. Consider that Canada now trains only one third of all the paediatric oncologists we need. Our costs of staffing reflect that shortage.

But because the children's health care system has not been seen as a distinct system in Ontario, children's hospitals have received no incremental funding for any of these incremental costs. We have been funded in the same way as any general hospital.

When you get beyond the differences in care and the consequential differences in cost;

When you get beyond the fact that the crisis in children's access is actually about different diseases than the crisis in adult access;

You hit upon a third important risk that we face when we leave children out of health care reform – the impact of a wait list on a child.

[6] Inspire, ibid.

Waiting six months for a critical surgery means something very dramatic if you're only six months old to begin with.

It's your entire life-span. During that time, a baby's body and physiology are changing. The patient who gets to the end of that wait list is clinically different than the patient who was put on it only a few months earlier.

That problem simply isn't taken into account in any provincial wait list strategy targeting adults.

So let's put that second assumption to rest. When it comes to health care, children are not just little adults. And strategies designed to reduce wait times for adults do not really do much to help kids.

Clearly these oversights must be corrected.

Part 4: A Systems Approach: Setting The Goal

We can get this right if we invest in the children's system using the same "systems approach" to our children's care that we are now taking to adult care.

That means:

- Coordinating investments *across* children's institutions.

- Ensuring that investments are based on peer-reviewed evidence for effectiveness.

- Ensuring that investments are driven towards achieving specific health outcomes in specific patient populations.

- Ensuring that investments are driven towards achieving specific operational outcomes across the children's system

This kind of system's approach ensures that we are:

- Focused on what kids actually need, not just on what institutions would like to have
- Are focused on effectiveness,
- Provide equity in care regardless of where a child first presents,
- Manage our capital efficiently, and

- We are financially accountable to the taxpayers of Ontario.

We are at important cross-roads in the development of this kind of approach. Ontario is adopting this very philosophy in the form of Local Health Integration Networks. That could be very good news, if there is a children's strategy in this move. Otherwise, there is a real risk that Ontario's existing children's centres are forced to focus so much on their own region that they can no longer work as a team across the province – leaving Ontario's kids to fall farther between the cracks.

So is it possible to take advantage of the new integrative philosophy – which is fundamentally correct – in order to create a *Children's* Integrated Health Network for Ontario?

Part 5: Putting Kids Back In Health Care Reform

It is possible to put children back in health care reform – even to create a children's Integrated Health Network -- if we treat the children's health care system as a *different* kind of system.

First, a systems approach to children's health care has to recognize that children's centres have different cost drivers and different resource needs than adult centres, and have to be funded and judged accordingly.

Second, we need to recognize that the children's system itself is made up of different kinds of pieces, each with distinct funding needs.

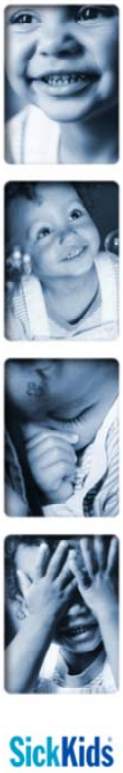
A robust children's system needs the primary care that comes from family practitioners and general paediatricians and nurses in their own offices and children's wards of general hospitals.

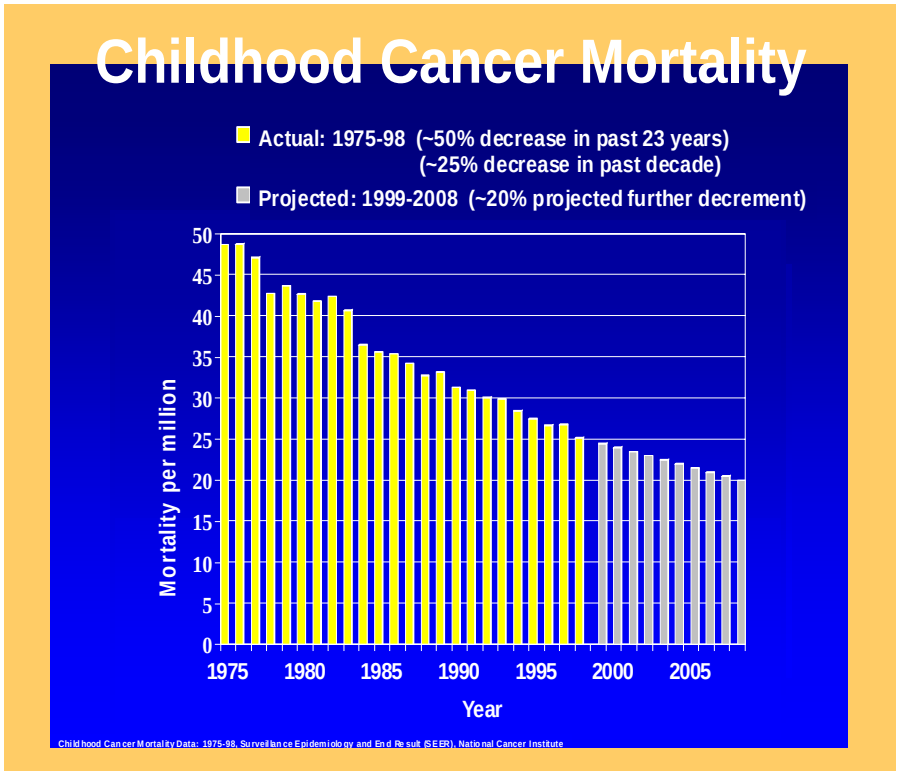
And it needs teaching centres and research just as much.

It's worth noting, for example, that the *standard* of care for a child with cancer is a clinical research trial. Child cancer patients are enrolled in clinical trials at a much higher rate than adult cancer patients – partly because it is easier to coordinate large scale clinical trials across the relatively compact children's system than across the much more diffuse adult system. The parents of our childhood cancer patients have also long recognized the great value of this approach to treatment, and are enthusiastic partners in the decisions to enroll their kids 'on protocol'.

The results are dramatic.

- The greatest declines in mortality, when correlated with enrollment in a clinical trial, are in patients below the age of 19.





- And childhood cancer overall has shown 50% drop in mortality in the last 23 years alone.

That is because we are treating most children with cancer in academic centres. Even adult oncologists -- and specialists in virtually all medical disciplines – note that comprehensive approach to clinical trials in paediatric oncology represents the ideal way to manage human diseases.

Moreover, we already have the scaffolding of a children's health care system that coordinates these different pieces, from primary care to academic research – not just across the province, but across Canada and even internationally.

PROVINCIAL COLLABORATIONS

In 20 different specialties and functions, Sick Kids already has formal and deep collaborations with other children's centres across Ontario. We already work in something of a network for

disciplines like paediatric Oncology, Cardiac Care, Endocrinology, Psychiatry and neonatal intensive care. We are starting to pool our resources to analyze children's wait lists across Ontario. And there is even a growing discussion among children's hospitals about pursuing a common strategy across the province.

Beyond Ontario, we have collaborations in cardiac care with hospitals in Nova Scotia, B.C. and Newfoundland and Labrador. And we have international collaborations with hospitals and physicians in the U.S., the U.K., Trinidad, Jordan, and Egypt.

So, operationally, the skeleton of a system that coordinates all the different components of children's care already exists.

But the funding system doesn't recognize the distinct needs of all those parts, and here is another problem that any reform of the children's health care system needs to address:

Simply put, the government assigns each patient in any hospital anywhere to a single group based on his or her medical problem. Each group is associated with a standard cost, relative to the average cost of all patients across the province.

Now, the system works fine for institutions whose whole populations turn out to match the provincial average.

But it does not recognize the incremental costs of hospitals, like Sick Kids, whose patients are generally more complex than the average.

More precisely, most hospitals have patient populations that are 25% atypical – meaning they are transferred from other centres, stay longer than average, or die – and 75% typical. That is the assumption that the government uses in its funding formulas for us.

But our role as a national referral centre means that our case mix is the reverse: 75% atypical and only 25% typical. The contrast in our neo-natal patient population is even more dramatic. A study recently completed by Colin Preyra[7] at the University of Toronto Institute for Clinical Evaluative Sciences and Jason Sutherland at the Indiana University School of Medicine showed

[7] These results are from research undertaken by Colin Preyra and Jason Sutherland, sponsored by Sick Kids hospital. The results will be submitted for peer review.

that only seven percent of Ontario's neonatal patients are atypical, while our proportion at Sick Kids' is 79 percent. [8]

Our complex patient population allows us to be a teaching hospital and a research centre. It allows the province, as a whole, to have a fully developed health care system, with a major research centre and an international teaching hospital as part of it. But when it comes to funding, that role is simply not accommodated.

Part 5: Some Hard Questions

All of this leaves all of us, in this room, with a set of hard questions:

- Are we, in Ontario, prepared to treat the children's health care system as a distinct system with its distinct needs?

- *Within* the children's health care system, how deeply do we actually want to collaborate with one another? Or do we all want to be excellent at the same things?

- And with regard to the complex case loads of academic centres, like Sick Kids, what is our proper place in Ontario -- and in our country, in fact -- for the years ahead? I believe that for a hospital like ours to play the role Ontario and Canada need us to play, research must be the standard of care. But it's not clear that the current funding mechanisms in this province can accommodate that.

Conclusion: I Am Optimistic

So there's a lot for us to work on together. But this is not at all daunting. It shouldn't be overwhelming.

I'm convinced that everything here is very achievable.

For one thing, I know that our hearts are in the right place. We all want to make these changes. And those of us in children's health care are already well down the road in terms of working together as a single, coordinated system.

[8] Discussion with MJH

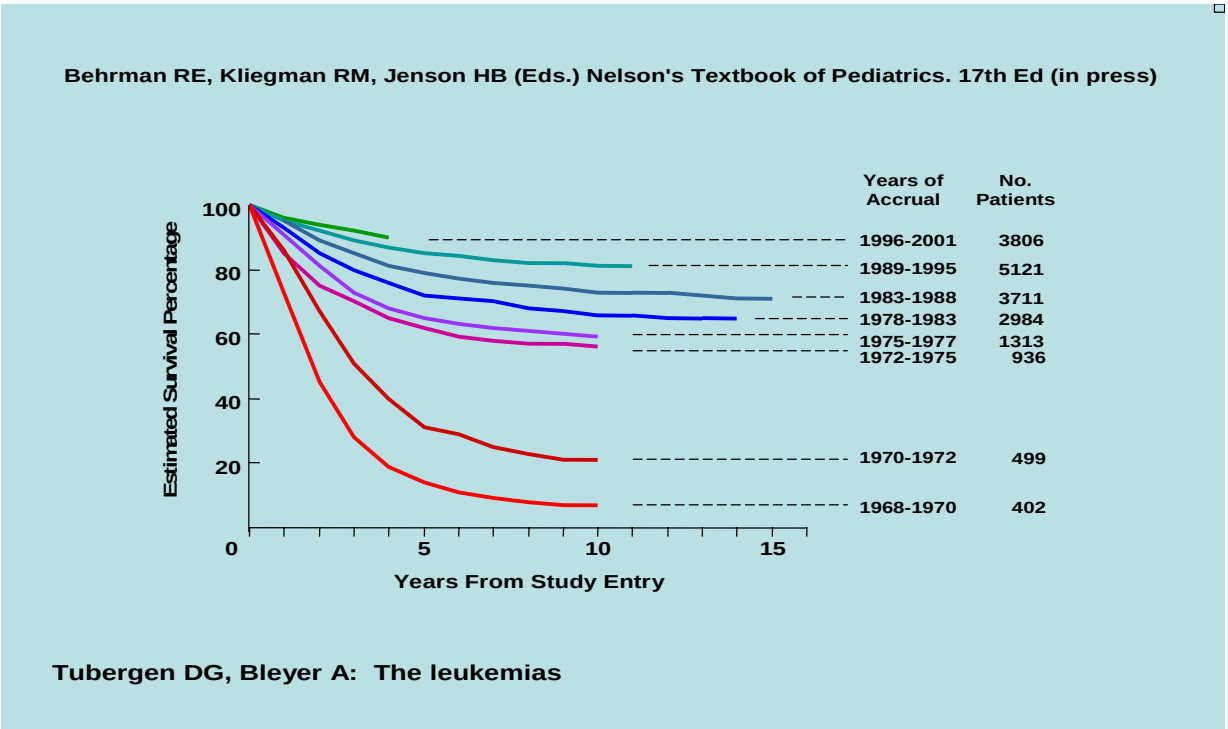
I also know that, because the children's system is compact, it is capable of moving very quickly when it's turned. This ship can turn very dramatically.

I want to leave you today with a taste of how quickly this system can move, because of its size and coordination.

To do that, let's return to some of the cancer data.

Just this month, some pretty startling data on child leukemia was presented here at Grand Rounds. And a colleague of mine said that when this slide went up another physician -- *not* an oncologist -- turned to him and whispered that this must be one of the greatest success stories in human medicine.

Tubergen DG, Bleyer A: The Leukemias, from Nelson's textbook of paediatrics).
Only 30 years ago, the chance of a child surviving more than 6 years with leukemia was less than 20%.



Today, a child walking into this building with acute lymphoblastic leukemia, has more than a 90% chance of being cured altogether. More generally, only 30 years ago, the chance of a child surviving more than 5 years with cancer was only 10%; today, 77% of all children diagnosed with cancer will be cured.

That is a mind-blowing turnaround.

But in paediatrics, it's not unusual. Because the child health care system – around the world -- is compact enough, and packed enough with talent to mobilize the newest thinking in clinical science with remarkable speed.

If you remember only one thing as you leave this hospital this morning, I hope it is this table (Tubergen table). Because it reflects our ability as a child health care system to mobilize very quickly, to change very quickly and to yield dramatic results from its change.

Yes, there is a real risk that Ontario and Canada will leave children out of health care reform. And if we do, our system as a whole – and our country as a whole – will suffer some pretty serious consequences.

But there is an enormous opportunity for the health care system at hand now.

We can get this right….

We can put kids back in health care reform.

We can set a new platform for sustainable, publicly funded medicare at the very highest level of quality for all patient populations. We can do so for the "next generation", knowing that the next generation is *already here* – in our wards and waiting rooms.

As CEO of Sick Kids, I am committed to launching a new course towards that strategy.

And I am honoured to be part of the team -- with you -- that will get this right.

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