



Transcript: Beyond Band-aids: Collective Action to Right-Size Children's Healthcare Systems

Connected by purpose. Driven by passion. This is Children's Healthcare Canada's SPARK: Conversations podcast series.

Katharine: Welcome to SPARK: Conversations, Children's Healthcare Canada's monthly podcast series. SPARK: Conversations is one component of Children's Healthcare Canada's SPARK Knowledge Mobilization Program. During the 2024-25 fiscal year, SPARK: Conversations will be dedicated to Right-Sizing Children's Healthcare Systems. Thanks to our SPARK Conversations: Podcast Sponsor, the IWK Health Centre for their ongoing support. I'm Dr. Katharine Smart and today I'm delighted to be speaking with Julia Hanigsberg.

Julia joined Holland Bloorview Kids Rehabilitation Hospital as its President and CEO in 2015. She has spent her career in government, post-secondary education, and healthcare as a champion for transformation, innovation and excellence.

Prior to joining Holland Bloorview, Julia spent 9 years at Toronto Metropolitan University prior to which she worked in the Ontario government including roles as Counsel to the Deputy Attorney General, Counsel and Special Advisor to two Secretaries of Cabinet and Chief of Staff to the Attorney General of Ontario.

Julia has degrees from McGill University and the Columbia Law School University. She is a four-time Women's Executive Network Most Powerful Women Top 100 honouree and was inducted into the Women's Executive Network Most Powerful Women Hall of Fame.

Julia has served on numerous boards, has completed her ICD.D. designation and currently Chairs the Boards of Directors of Children's Healthcare Canada and Solutions for Kids in Pain. She is Vice Chair of the Ontario Hospital Association and sits on the boards of OECM, the Holland Bloorview Kids Rehabilitation Hospital Foundation and the Kids Health Alliance. In addition, she serves on the CEO Committee of the Toronto Academic Health Sciences Network, and she was appointed by the Ontario Ministry of Health to the Governing Council of the Provincial Council for Maternal and Child Health.

So, I think we have an excellent guest today to help us dive into this issue of how we Right-Size children's health care. Children's Healthcare Canada is on a mission to "right-size" children's healthcare systems. From coast to coast to coast, and across the continuum of care, children, youth, and their families are experiencing long and costly delays for essential and time-sensitive healthcare services. We'll explore what this means in real-world contexts along with the collective action required to change the way systems work and interact and intersect. Welcome Julia.

Julia: Well, thank you. Yeah. Thank you, Katharine, for that warm welcome. It's great to be on the podcast. And, and as you inferred, this is an area of huge passion for me. And I'm really thrilled to be able to talk to *you* of all people, who also I know has a huge passion for children's health and well-being and children's healthcare.

Katharine: Yes, we definitely have that in common. And I would suggest or suspect, this is probably a very big interest for both of us. So, I'm really excited about the work that's happening and just the progress that's been made. So, let's dive into it for our audience to kind of bring them up to speed with this work that's been happening over the last couple of years. So, we as we said, we know Children's Healthcare Canada has really set its sights on this mission to "right-size" children's healthcare systems. From your perspective, what prompted this new priority for the Association?

Julia: Yeah, it's a great question. We heard from across our membership; and Children's Healthcare Canada represents members who provide services across the continuum of care for Canada's children. And we heard consistently across the board, that the decades of underinvestment were impacting delivery of children's healthcare, lack of access to primary healthcare was putting huge pressures on the specialty service to children's healthcare providers. And of course, children themselves are a growing population, and their healthcare needs are becoming increasingly complex. And finally, we know that overall, the healthcare system is under a huge amount of pressure. We hear that every day. Canada's families experienced that every day. And that sort of long term set of underinvestment has really proved itself to be coming to a culminating point that we really felt like we need to act. There were a couple of other things that really were impactful to us at Children's Healthcare Canada. One was once again, the UNICEF report card, where Canada underperformed - being in the bottom quartile of the wealthiest countries in the world. The pandemic, of course, was a huge struggle for everybody, but it *really really* demonstrated gaps in care for children. And then last winter, winter 22-23 with what we all call the tripledemic, the combination of influenza, RSV, continued COVID impacts. Along with supply chain issues that meant families didn't have access to those routine things they use to help with children's health, like baby Tylenol and then routinely used antibiotics for children. So those were some of the factors that led to getting us where we are today, or really recognizing as an association, what was going on for children's healthcare, and our pressing sense that we need to act.

Katharine: Absolutely. So true. And you know, it's really interesting to me when we talk about this. And when you talk with friends and colleagues, people that aren't in children's healthcare directly. People are quite shocked, right, when you share that number that, we're one of the bottom performers in OECD countries. That Canada is investing, you know, sort of half compared to other similar countries in children. That we don't have a national children's strategy. You know, these are things that people find, really, I think, quite surprising. So, I think shining that light there, and just that recognition that as our

population grows and evolves, you know, that number of people needing these services is increasing. And we just haven't had a plan to catch up or to sustain. And I certainly see that in my own work as a pediatrician and the complexity issue, like you mentioned, for sure. So you know, here we are, and like much of our healthcare system, there hasn't really been a plan. And I think it's really concerning, you know, when we see that what that means for kids and I think that the new report coming out from Children's Healthcare Canada, No More Band-aids is really helping us understand the impact, the long-term impact, of ignoring this problem. So Julia, like help our listeners understand, when we say this "right-sized" healthcare systems for children. What does that look like? Why the focus on children and not just everybody, because we know the whole healthcare system is obviously struggling? What's different about healthcare for children and youth?

Julia: Yeah, so two comments on that. First of all, our Beyond Band-aids advocacy is for a healthcare system that is responsive to Canada's families. So, we know that a fully functioning healthcare system is going to be a healthcare system that works best for kids and families. So, we do advocate for better access to primary care, as an example. However, the specialized nature of children's healthcare and the needs of children require their own solution and their own strategy. And when we say that we mean accessible health care, equitable healthcare for kids. Evidence-informed - having the research behind it, and connected healthcare systems that are purpose built for kids. You know, often we say, children are not just small adults. And people say, well, what does that actually mean? And what it means is that the trajectory, the developmental trajectory of a child, means that their healthcare needs have particular times or windows of care that are crucial. And if you miss those windows, that can mean lifelong impacts for children.

There are so many examples, I'm sure you see them all the time in your practice, where you are frustrated by the waits for specialized care that your patients are suffering from, you know, we see it in my organization, Holland Bloorview, as a specialty children's organization. We see it in surgical wait times, that can be over a year for children who require complex orthopedic surgery. And that means that that child is not able to develop over that period of time as they would and that can have lifetime impacts for them. The other thing that we sometimes say is that being a child itself is not a diagnosis. So we need to think about wrapping around that the quality of life factors, what sometimes referred to as a social determinants of health. All of those factors around the child and family, so they can develop to their best possible lifelong outcomes throughout their childhood, and well beyond.

You know, oftentimes in a strapped healthcare system, and as Canadians know, we don't really have a healthcare system. We have 13, healthcare systems. All of whom are very strapped, often in a strapped healthcare system, governments kind of play whack-a-mole. They hit the problem that's right in front of them. And that's why I think we're hearing a lot from funders about the gray tsunami, and we understand that seniors' healthcare is critically important. I'm a sandwich generation person myself, so I'm seeing it from both ends. I understand how important that is. But we can't let that get in the way of long-term planning for the health and well-being of Canada's children. And that means funding children's specialty healthcare services in the way they need to be funded, to enable kids and families to have the quality of life that they want.

Katharine: Yeah, of course, I'm absolutely on the same page as you. And I think you're so right that

tyranny of the urgent has so much to find our approach to healthcare, rather than a thoughtful, planned out long-term approach. And I think that's absolutely why children, especially right now are really paying the price for that lack of planning. And I think the other piece I think a lot about and, again, I find a lot of people that aren't working directly with children don't understand. Is how that early childhood trajectory impacts your entire life as an adult and not I think people, you know, think about it, perhaps from sort of a mental health, social opportunities perspective. But I don't think people also realize the impact on people's physical health and the direct tie to adult chronic disease, which, of course, is what is really impacting our healthcare system right now, to childhood adversity. So, we're literally changing the genetics of these children. We're setting them up for chronic illness. And these are things and that our healthcare system has to deal with down the road. So I really think making that link in people's minds between healthy children, thriving childhoods, optimizing health for kids, both socially and physically, sets those kids up not only to have good mental health, to be productive and happy members of our society, but also to be physically healthy. And that physical toll of chronic disease is one of the big reasons our healthcare system is not functioning. So, I think sustainability of the healthcare system, as a whole in the long-term depends on what we do today, for children. So, I think it's really incredible to see Children's Healthcare Canada, you know again, that Beyond Band-aids, really trying to bring awareness to this issue, because it's so critically important. And I often find, you know, when you speak to people about this, they're quite surprised. They didn't they haven't made that connection.

Julia: Yeah, that's why it's so important that we be talking about this. Because you're right, you know, the average Canadian isn't really thinking about this, you and I, because of our day jobs are thinking about this all the time. But we really need to make sure that average Canadians understand these important issues, because it's Canadians, it's voters who our politicians will listen to. And ultimately, that's where the funding decisions get made. By what Canadians prioritize with either their vote or their voice. And so really making sure that we are helping people to see the big picture is one of the things that I love about Children's Healthcare Canada taking this advocacy on and having this conversation today.

Katharine: Absolutely. I totally agree. You know, and another issue, I think that we're talking a lot about right now as a society, but also in healthcare systems and healthcare in general is around health equity. This is obviously a huge issue, again, for children, youth and families. So how does that concept of health equity fit into this idea of "right-sizing" healthcare systems? And you know, again, when I think about the children I serve in my work, and I'm sure you see this in yours as well, children living in poverty, families who are newcomers to Canada, racialized families, often Indigenous families. What needs to happen outside of the healthcare systems that can be influenced from within, to bring equity to those equity-deserving groups?

Julia: Yeah, absolutely. It is a critical issue. We need to ensure that when we're right-sizing children's healthcare, we're right-sizing children's healthcare for all children and families across his across this country. Whether they live in rural and remote areas, you know, and you serve in your day-to-day work, whether they live in any part of the country. So it's more than just the idea of what care they receive from a healthcare perspective. What circumstances are we as Canadians going to prioritize for living? And so, you know, one of the things that Children's Healthcare Canada is very proud of is the Inspiring Healthy Futures Initiative. And that's a partnership between our organization, with the Pediatric Chairs

of Canada, UNICEF, and the CIHR Institute for Human Development, Child and Youth Health. And really, what IHF is about is making youth and families a priority for Canada. So that in anything that our country is funding, doing, or governments are looking at. That they're looking at that through a lens of children and youth health. And you know, Katharine, you're catching me on the day after a federal budget. So, you know, I couldn't help but take a look at the budget from the perspective of children and families. And, you know, a good example is a commitment to a National School Food Program. We know if kids are hungry, kids aren't learning. So it's a great example of how do you address issues before they become child health issues by investing in children's well-being. And another example is a consultation on a National Caregiver Strategy. Families are the essential unit for children and if we're not paying attention to the full family to caregivers, then we're going to, ultimately, in all the ways that you were describing, also not be able to serve the long-term needs of children and the adults who they will become. So, it's that combination of the social determinants of health, how do we serve every young person who needs. Whether it's through school, through healthy eating, through access to services, all of those things, and then quality of healthcare that need to partner together to improve the long-term ability of children to thrive.

Katharine: Yeah, absolutely. And that's really what we're talking about isn't it, is about thriving. We want a country where kids can live their best childhoods have what true well-being, be thriving and their families. And I love how you talked about the impact on families, the importance of family caregivers, because I think that's another place our system really struggles, right? Often when we're treating children that we kind of pull them out, you know, psychologically from their families in terms how we think about their problems, the way our services work, you know, they're focused sometimes on the child without recognizing the impact on the family. And I thought one of the other really great things in the Beyond Band-aids report, was how it looked at the economic impact of families and caregiving. And that's something we don't talk about, also. What's the impact on our economy of all these families who cannot be working because they're caring for their children. So, you know, this issue of this as a family community issue, I think, is so important, because the impacts are going much beyond the child as an individual. And I think those of us who work with children and families, you know, think like that. But our systems aren't always set up to really look at the family as a whole and address the needs of caregivers, and sometimes other children in the families while looking at the child who's our "patient". So that perspective, I think, is really valued.

What I also love about the work of Children's Healthcare Canada is, you know, not only are they shining a light on what the challenges are, what the struggles are ahead of us, which is important to understand and define. But they've taken it to that next step of offering solutions, which I think is so important, right? Because so much of the dialogue right now around healthcare is everything that's wrong with the system. And that's important, because we need to level set what we need to fix. But what we also need is, *what do we do?* And that's what people in positions of power want to hear from us, right? That's always the question. What should we be doing? And I think Children's Healthcare Canada has come forward with this report that offers a path forward, clear recommendations. So can you walk us through that, you know, what's it going to take? And who has a role to play in achieving this vision that we've been describing of thriving, healthy children and families?

Julia: Yeah, absolutely. I think we're very practical about this. We don't want to just surface the problems, we also want to be part of co-creating the solutions. And it's really a product of both individual and collective action, both for our government and for everybody else in society. So let me start with our governments and what we're asking from them.

From the Federal Government; we're looking for the establishment national frameworks and targets to guide health planning and care delivery, and to ensure that healthcare systems can achieve meaningful improvements in child physical and mental health outcomes. We're talking about data. We're talking about being able to be held accountable for the outcomes that children and families deserve.

For our Provincial and Territorial Governments, we want to see established dedicated child health funding envelopes to ensure the sustainability of children's healthcare systems, and give security sustainable, consistent, reliable funding to children's healthcare professionals and organizations across the full continuum of care. And that's really important. And I have to acknowledge that we've seen some of this in the province where I am today, in Ontario. Where last year, our Government made a \$330 million investment in children's healthcare. So that's a bit of a demonstration project to show that provinces can make children's healthcare a priority, and they can fund it. Where we make it clear what they're buying for those dollars in terms of the long-term impact on children's health and well-being.

We're also looking to children's healthcare delivery organizations, hospitals and other healthcare delivery organizations, and healthcare professionals to work together to collaborate to create an ecosystem of care for children. And that's about really effectively addressing not only the physical healthcare needs of children, but social, mental health, developmental needs, easier access to the resources they need, centralized knowledge, information, knowledge mobilization of evidence, and also improving local capacity. So that's something we can all work together to do.

And then for child health professionals, healthcare advocates. We need to be elevating the voice of children. We need to elevate the idea of ensuring that the Canadian public, just like we were saying the average Canadian, our friends who aren't working in the children's healthcare system. They as well as the media, decision makers and others understand the critical challenges that are facing the child health system right now and that are facing children, youth and their families. And that they understand that they can be part of making these tangible solutions a reality, if they lift up their voice.

Katharine: That's wonderful. Such a comprehensive perspective, really, I think, looking at all the players and calling everyone to the table, right. Like, let's get together, let's get coordinated. You know, and I think one of the things you said you know, about that need for data transparency, accountability. That's really one of the core pieces, isn't it. So that we all know where we're going, where we are tracking progress. And I think that's one of the things right now, that makes it so difficult when you have so many players, and no real way to know. Where are you? Where are you going? How do we measure if we're getting there. It's really hard to track that progress, and then communicate back to citizens like, Hey, this is where we're at on this really important goal. So I think, you know, some of those fundamental things are really important and also just making it clear to everybody like, what's your role in this. Because there is a role for everybody to play. And you know, and we've talked about this a little bit like why other Canadians should care about this. But let's talk about that a little bit more, you know,

if we don't do this, if we just maintain the status quo? What does that mean for Canada's kids?

Julia: So, you know, I sometimes talk to families in the halls here at Holland Bloorview about what brought them to my hospital. And it really reminds me that every Canadian family is one event away from desperately needing our children's healthcare system. So just today, I was hearing from a family who's really struggling with the weight they're experiencing, for their child who suffered a serious concussion. Who for close to a year has been unable to fully attend school. It took them months to get from their primary care provider, to seeing a physician here at Holland Bloorview, a specialist here. It's going to take them months before they're able to see a therapist because of waitlists we have here in my organization. And it's taking them months to get a much-needed MRI. That's one individual family story. Multiply that by millions across the country. And that family until they needed those services, they probably weren't thinking about this. They probably didn't even know they were wait times. They expected that they'd get that appointment the day after their child needed it. So, the impact is there for many children today. It is a possibility for every child in Canada. And as you said earlier, that long-term burden of chronic disease, the long-term impact on the quality of life, and the quality of health of all Canadians; is determined by how we invest in how we care for children and youth. And so that's why we're so passionate. It's what we do today is going to have an impact long after you and I are out of this business. When we're not working anymore, those kids of today are going to be needing what, what Canada has and should have been providing them.

Katharine: Yeah, absolutely. And thanks for sharing that patient's story. I think like those examples of what it really looks like for people, right, in brass tacks, real terms. This is the day-to-day. I think is so important. And again, you know, when you think about the impact for that child of a year of their life. Not being able to attend school normally, not being able to participate in their daily activities and just not feeling well, right, these ongoing symptoms. And that's what we see, I think so much of right? With kids with chronic conditions, whether it's physical or mental health, that you know, these things get entrenched, it gets harder to function. And the problems get bigger and more complicated to solve and ultimately need more resources. And those children as you've been discussing, right, lose that developmental gains, they lose that learning. They lose that connectedness with friends and family. And that's what I find so heartbreaking with those stories. And I really want our listeners to think about is imagine being that family every day seeing your child suffer. Waiting, waiting, waiting. No answers, no plan, nothing changing. And like you said, that's just one family. And there's millions of people going through that. So I think that's just so important for us all to think about is it. Like you said, we're all one event away from that being our child, our friend or family, loved one. It's just so important that we really think about how much we can do better for kids.

Julia: Katharine, let me just mention one other thing. I haven't mentioned our frontline healthcare providers very much. And that kind of story of an individual child causes so much moral distress to the individual physicians, nurses, therapists, all the providers. Because they want to be able to provide that timely care. And as organizations were really having a tough time, retaining all those highly specialized and highly educated staff. We're having trouble recruiting new people into those roles. So, what you sometimes hear about in the media is the health human resources crisis. Those are individual people who are struggling to provide the care that Canada's children needs. And it is so important that we support them in their work. People like you, caring for children every single day. And that we create the

circumstances where people want to work in this complex system. They see the ability to do the great things and the things they care about in healthcare. So we need to be able to offer really wonderful jobs for people in healthcare as well, and really support them to do their best work. No one wants to keep a child waiting for months to get their service. That's not what anyone when went to medical school, went to nursing school, became a physiotherapist, whatever it is. This is a crushing burden on the people who work in healthcare as well. And I owe you thanks for what you do Katharine and everybody who works in children's healthcare across this country, is doing tremendous work. And really this Beyond Bandaid's work is about helping them and helping you to do what you and they care the most about.

Katharine: Yeah, I love that you brought that up. Because I think, you know, as we know, burnout amongst healthcare professionals has exponentially increased since the pandemic. It's an ongoing challenge. And I think you really hit the nail on the head there, right? So much of burnout is a systems issue. It's not about individual resilience, it's about working in a system where you can't get your patients what they need, and the moral distress of facing that every day. And you're absolutely right, you just constantly having to disappoint people with information that's not helping them is really hard. And I think you're absolutely right, no one wants to do that. And I think a lot of people take that on personally, they're working extra, they're burning the candle at both ends, you know. To try to solve these problems on that individual level by doing more and more and more. And that's not a sustainable solution. So, I think you're absolutely right. If we want to maintain our workforce, have people healthy address burnout; we've got to get at these systems issues, because that's really the root cause. So let's.

Julia: and we've just gotten used to it, right? We've just gotten used to it, you know. I see, you know, it's funny. I see a daily dashboard about pediatric capacity in the Toronto Region. It's one of the wealthiest regions of this entire country, extraordinarily well served. Simple, green, yellow, red capacity. I never have seen it green. Green is under 97%.

Katharine: Oh, wow.

Julia: That's what green is. Under 97%. So that means we are persistently expecting hospitals, children's hospitals, to be operating and children's wards and community hospitals in my region to be operating at 100% or more. And that's what that's what has become normal. So, part of Beyond Bandaid's, that Children's Healthcare Canada is working on. Is kind of waking people up to the thing that we think is normal, is not normal. It's not right. It's not doing what we want it to do for anybody, especially for children. And especially for the people who work in children's healthcare and are providing their care.

Katharine: Oh, absolutely. That has got to be the message. Just incredible. And you're right. It's what we've normalized. It's what we've come to expect. We've got to change that fundamentally, to motivate people to do something about this crisis. So where to from here? We know that Children's Healthcare Canada has identified right-sizing. We've talked about what that means, how to do it. The Beyond Bandaid's report is painting kind of the way for us, that campaign. So walk us through it, what are you guys going to do? How are we going to shift Canadians to care about this issue?

Julia: Absolutely. So you're going to be part of it Katharine. The SPARK podcast over the next little while, are all going to be focused on right-sizing children's healthcare and the Beyond Band-aids campaign. For the public and for you know, our membership. Starting off next month, people are going to be seeing a lot of information in the media. We're going to be releasing the report. We're going to be holding Town Halls for Children's Healthcare Canada members, both in English and en Francais. And we're going to be ensuring that through, not only this podcast but our other activities, including our conferences in 2024 and 2025. Our engagement with parliamentarians and also meeting with our local MPs and MPPs across the country. We're going to be explaining the report, explaining the practical solutions that we have. And really working with partners to socialize this idea of right-sizing. Its vision, its requirements, the collective action that's required with all Canadians. So we can all be speaking with one voice and making this a priority for our country.

Katharine: Amazing, and I'm so grateful to be part of this work, part of sharing this message. Because like you, it is definitely my passion, both personally and professionally. So Julia, help us with your 30 second elevator pitch. You're in the elevator, you've got that decision maker, that key decision maker in front of you. It's your opportunity to close the sale in 30 seconds, what's the pitch? Why should right-sizing children's healthcare be a priority, now, given all the other competing priorities facing Canada?

Julia: So, three things to remember. Healthier kids today, are healthier adults tomorrow. Investment in child health today means greater wellbeing and a healthier Canada into the future. And finally, if you don't like either of those, it's a pay now or pay later situation. And kids are simply too important to wait.

Katharine: Thank you, Julia. It's been an absolute pleasure speaking with you today and pulling the curtain back on this really critical issue. I really appreciate your time and sharing your perspectives and your day-to-day learnings.

Julia: Katharine, thank you so much. It was really fun to talk to you. Thank you for your constant advocacy on behalf of Canada's children and families and for the work you do every day in your local community.

Katharine: Thank you. And thanks again to SPARK: Conversations podcast sponsor, the IWK Health Center, for their support. Stay safe and be well. To stay up to date on all our SPARK offerings, including upcoming podcast episodes, visit our website at ChildrensHealthcareCanada.ca and subscribe to our SPARK: News biweekly e-bulletin if you haven't already. Thanks for listening to SPARK: Conversations. And before we go, show some love for your new podcast series by leaving us a review and then join us again next month. Thanks everyone.