

SPARK: Conversations | Season 5, Episode 5



# CHILD HEALTH RESEARCH:

## The Foundation of Rightsizing Child Health Systems

With Special Guest:

**Dr. Christine Chambers**



### Transcript:

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 the critical topic of right sizing children's healthcare systems. Thanks to our SPARK Conversations podcast sponsor, the IWK Health Center, for their ongoing support. I'm Dr. Katharine Smart, and today I have a very exciting guest for you, Dr Christine Chambers, who's joining us from the East Coast.

So, for those of you who don't know Dr. Christine Chambers, let me tell you about this very impressive woman. She is an international leader in the study of children's pain, and an innovator in patient engagement, partnerships and knowledge mobilization. As a clinical psychologist and a national voice for children's health, Christine creates purposeful conversations and connections with diverse groups to move research from ideas to impact, improving the daily lives of children, youth and their families. Twice named one of Canada's top 100 Most Powerful Women by the Women's Executive Network, Christine has published over 200 articles in peer reviewed scientific journals and is recognized as one of the top 2% of the most cited scientists in the world. As scientific director of the Institute of Human Development, Child and Youth Health at the Canadian Institutes for Health Research, or CIHR, Christine is steering a bold vision to foster research that promotes better beginnings, vibrant childhoods

and empowered youth. She is a professor and a tier one Canada Research Chair in children's pain at Dalhousie University, and a faculty member at the Center for Pediatric Pain Research at the IWK Health Center. Her acclaimed research program has helped establish Canada as a leader in children's pain research. She is also the scientific director of Solutions for Kids in Pain or SKIP.

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, 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. Right sized healthcare systems for children are accessible, equitable, connected healthcare systems designed for the needs of children, youth and their families. For this episode, we will explore the important role that child health research and children's health systems research plays in right sizing children's health systems to serve children, youth and their families. So welcome, Christine, to the podcast.

**Christine:** Thanks so much for having me.

**Katharine:** I'm really looking forward to this discussion today. You know, I think for many of our listeners, research can sort of feel like something that's kind of, you know, in the ivory tower, and maybe not something they know a lot about. But as you and I know, it's fundamental to how we advance science for children and to have that impact that we've been talking about in our introduction. So, can you tell our listeners a little bit, what is child health research? What is its role, what is its value, and why is it so critical to this mission of right sizing children's healthcare systems?

**Christine:** Yeah. I mean, I think you're so right. I think research sounds sometimes like a mystical thing that's not necessarily essential to delivering healthcare, improving healthcare, but those of us who do research, and I think people who really take an evidence-based approach to medicine, know that research underlies everything that we do, you know, as clinicians, right? It's what helps to discover new treatments, to discover new ways of preventing, you know, illness and other types of issues. So really that research is kind of the underpinning of knowledge and knowledge generation. And of course, it's really important when knowledge is established that we mobilize it, so it actually improves the lives of children and families. But research is really informing everything that we do, and it's how we improve care. And you know, there have been some incredible research discoveries that have benefited children's health and wellbeing over the years. Vaccinations is just one example, incredible example of how science has transformed, you know, healthcare for children. But there's many other examples, you know, in particular areas, such as in oncology, the dramatic, you know, improvement in treatments for children with leukemia, for example. So, you know, research really is an integral part of healthcare, and it's why I'm so glad we're part of this conversation around right sizing healthcare for children.

**Katharine:** Yeah, absolutely, I totally agree, and I certainly know in my 20 years career as a clinician, we've seen so many changes in some of these different diseases that, you know, were a death sentence before, and now the survival is so optimistic, and that oncology is one great example. Can you tell our listeners a little bit more about what is CIHR and what about the scientific lead that you are, your program, your institute? What are you doing and what is your role there, exactly?

**Christine:** Yeah, so CIHR is the Canadian Institutes of Health Research, and we're Canada's Federal Funding Agency for Health Research. So, we're the organization that scientists across the country, if they do health research, they would write grants to try to secure funding to be able to, you know, leave their labs to support their discoveries and their innovations. CIHR has been around for over 20 years now, and it's really a very broad funding agency in that we encompass all aspects of health, from basic science to health policy and health services research. Within CIHR, there are 13 different institutes that are kind of themed in particular areas of health. So, I have the pleasure of leading the institute that's focused on Human Development, Child and Youth Health. So, we call it IHDCYH short, and so we have a broad mandate, and we work together very closely with the other 12 Institutes. There's Institutes on, you know, an infection and immunity. There's Institute on gender and health. So really, between the 13 institutes, we cover most of the major, you know, health areas, and we complement the open funding competitions that scientists apply for twice a year by offering various strategic initiatives. So, we deliver funding opportunities in areas that are of, you know, a high priority for the Canadian government, or in areas that we think need to be addressed to help kind of build the health system and the health research ecosystem, like funding early career researchers. CIHR has roughly about a billion dollar a year budget, we and the institutes have just over 8 million a year. So, it's a relatively small amount of money that the institutes have to be able to try to advance some pretty big goals.

**Katharine:** Yeah, absolutely. And what are some of those goals that you have in your portfolio for children, youth and families?

**Christine:** Right, so our strategic focus over the last number of years has been in a couple of critical areas where our vision is better beginnings, vibrant childhoods and empowered youth, and so we've been developing different funding opportunities to address each of those areas. So, some major investments include our Healthy Youth Initiative, which has been elevating the role of youth in addressing youth identified health issues in the health research context, but we've also had major initiatives in mental health in the early years, which is an area that is often overlooked. We're really excited to be launching our implementation science chairs, which are covering the broad range of human development, child and youth health, because I'm a passionate believer that, you know, all this great science is critical, but if it's not actually put into practice and implemented and disseminated, it doesn't benefit anybody in that so we're really helping to build capacity there. We have various early career researcher competitions and try to fill gaps, such as in supporting secondary data analysis. So, we generally keep a very active communications presence and try to promote to the community what all of our different funding opportunities are for. And of course, all the other institutes offer and sometimes partner with us in different funding opportunities so that we're able to contribute and collaborate on a broader scale as well.

**Katharine:** It's incredible and incredible breadth and span of work that you're doing, you know, right from the bench to the bedside, and reaching out into communities as well, which is incredible. You referenced a little bit about the funding for CIHR, the funding for the institutes, and then, of course, we've heard a lot about the impact that you're trying to have. So, where does Canada stack up to other countries? You know, are we doing enough? Are we investing enough in child health research? Where are we in that battle?

**Christine:** Yeah, it's interesting. I mean, when you compare us to say NIH, for example, the National Institutes of Health, and, you know, often people haven't heard of CIHR in Canada. So, you know, I'm really trying to kind of spread the word and help raise awareness. Most people have heard of NIH, even Canadians have heard of NIH. So, I often say, well, you know, if you don't know what CIHR is, we're, we're the Canadian version of that. So, I think there's a lot we need to do around raising awareness, around, you know, our national health research funding organization, but when you compare, just on a per person kind of basis, how much Canada invests in health research, versus, say, how much the United States invests, in Canada, roughly about \$30 per person is invested annually in health research versus, you know, say, I think it's about \$140 US dollars per person in the United States. So, if you just look at that simple comparison between, you know, per person CIHR funding and per person, you know, American NIH funding, we're definitely falling behind where we should be. And I think that's often a surprise for people, just like it's often a surprise that we don't perform as well on the UNICEF report card that as we expect children in Canada would. I think that we often think that we're doing a great job here, and there's many things that we're doing well, but at the end of the day, the overall funding level just isn't, you know, comparing to other countries where health research is just as important.

**Katharine:** I think that is so important for our listeners, and I love how you've broken it down per capita, right? Because I think that is the challenge sometimes in these conversations, is, you know, for people that understand, like, where do we situate relative to others. And that so that per capita dollar investment, and I would really think of it as an investment in our future, I think, is so important, and that's also why I love you bringing up the UNICEF report card, because I agree. You know, we're ranking 30 out of 36 comparable countries. You know, that number helps people go like, Okay, wow. You know, just what you said, we need to challenge our assumption that we're a country that's really invested and focused on children in their future. You know, the data doesn't actually really tell us that that's how we're making our decisions. So, I think that's an important fact for citizens to understand.

So, you know, kind of holding that in our minds, where do you think we need to make greater investments and take more action to make a difference in the lives of children, youth and their families? Like, where specifically are we falling behind? Where would you like to see more investments and more focus?

**Christine:** Yeah, I mean, it's such a fascinating question, right? And in the role of Scientific Director, you're kind of trying to task with predicting or identifying the major gaps, and I think it's really hard to do in science, because what we know about the way science works is that most of our major discoveries and innovations are often by accident. People are studying one thing and then they discover the cure for something else, right? And so, I'm a believer that we need, you know, broad and sort of sustained funding across the board. Because, you know, many of those innovations will happen in well supported labs who aren't struggling for finances.

I think for me, you know, where I've tried to concentrate my efforts have been around making sure that people are linked and connected. So, I think an area that we can improve upon is making sure that people are funded in their individual labs, but they also have opportunities to participate in different networks or different platforms. And we're really proud within our Institute and also at CIHR, to be

funding a program called the HRTPs, the Health Research Training Platforms, and there's a number of these that have been funded across different areas. There's one in pediatrics called ENRICH, which includes perinatal health as well. And these types of networks, these types of training platforms, bring people together, because often, you know, the ideas, the innovations that are necessary to make transformative advancements happen in the collective and so I think creating spaces and opportunities for people to share ideas and learn from one another. But yeah, in general, I think we just need to make sure we have more good ideas and more great people than we have enough funding to support and of course, you know, it's part of being a scientist, writing grants, getting rejected, you know, revising, resubmitting. So not everyone, you know, needs to get every grant every time, but we do need to be in an environment where there's, you know, a decent level of funding, where scientists can be free to create and to think and to discover and to take chances and to fail. I mean, failure is a big part of science, and that can only really happen in a robustly funded environment.

**Katharine:** Yeah, I think that makes so much sense what you're saying. You know, another topic that we've been talking a lot about, and I think that's sort of on the minds of people is the issues around equity, diversity, inclusion and health systems and healthcare. I think this is probably something that's really important in research as well, especially when you look at the diversity of the people that populate a country like Canada, our country. So where does that factor in for you? And is that important? And how should we be thinking about that when it comes to research?

**Christine:** Yeah, I mean, promoting equity, diversity and inclusion in health research is really important at a couple levels. One is just at the level of the type of researcher who's doing the research. And you know, there have been a number of studies that have shown that you know the bias, gender bias, you know, the racial bias that we see in healthcare, you know, also exists within the research funding ecosystem, and I'm really proud that CIHR has taken a number of steps over the years to try to address those equity issues, to make sure that the proportion of women who are applying for grants matches the proportion of women who receive grants right and addressing an equalizing among a number of different parameters. So that's really important, not just because I think it's the right thing to do, but also we know that, you know, women scientists are more likely to study women's health issues, so the inequity kind of gets passed along when you're not creating a more equal playing field for the types of people that you're funding.

And I think we also pay careful attention to what areas are being funded, and you know how we can address that. And one of the major initiatives that we've been working on within our Institute, in collaboration with the Institute of Aging and others at CIHR, including colleagues at NIH, is working towards a Lifespan Inclusion Policy and Research. And we're really pleased that CIHR has made a public commitment as part of its research excellence implementation framework to adopt an organization wide lifespan policy, or Lifespan Inclusion Policy. And what this means, what we know is that you know, certain populations, like children, are often systemically omitted from research. You know, same with pregnant women, same with older adults. So, it means that knowledge lags behind for those more vulnerable populations. And so, moving towards policies that require researchers to justify, for example, when they're submitting a grant on, you know, a scientific or ethical ground, why they're not including that population helps to put pressure on making sure that again, there's that all of the areas and all the vulnerable populations who deserve to have new knowledge or have the opportunity to gain it.

**Katharine:** I think that's fantastic. I love that angle. And I also think, you know, we hear so much about the aging populations, the pressure that's putting on our healthcare system, and I think that's obviously a huge challenge for Canada, but I think we need to also think of aging as something that starts across the lifespan, because we know very much your childhood, what happens to you in those early years impacts how you age and how healthy and well you are as an adult, and that has probably one of the most dramatic impacts on our healthcare system. So, I think, you know, I love that we're thinking, starting to think differently about this, and that we're also seeing that in research, and that we're applying a different lens to recognize, like, who's maybe missing, right?

And that that brings to mind, for me, another thing, you know, we're hearing a lot about AI, Artificial Intelligence. We know that Artificial Intelligence is based on large language models. We know that it can only really access the data that's there to generate ideas and output. So how do you see that interacting with Child Health Research? How is this important, sort of from an equity lens? Because I think it's here. I don't think it's going anywhere. It's powerful. But what should we be thinking about in that space?

**Christine:** Yeah, it's such a great point, and it's fascinating, and really, can only imagine how we're going to see this progress over the next 10 years, but I think you've really hit on a key point, and again, it relates to that inequity being baked in, right? So, you know, if we don't have sufficient data on, you know, a particular health issue or intervention in children, youth, you know, then what happens is, when we're doing synthesis right, which essentially is what AI is doing, right? It's synthesizing information that exists. You're omitted from the synthesis because the information doesn't exist. And so, I think that's even more, you know, puts more weight on why it's so important to ensure we have inclusion and representation, because otherwise you get missed at the recommendation level. And we see this often, right when people are doing knowledge syntheses, and particular health areas, there's just no data on children or pregnant women, for example. And so, they say, well, there's no information available. And then, you know, people end up having to try to make their own decisions based on insufficient information. And so, I think it's even more of an argument as to why we need to make sure that we are, as you know, right sizing, right, that that the needs of children and families are visible, that they're there as part of the knowledge, so that we're not left out.

**Katharine:** Yeah, absolutely. And you know, that's the problem, right? When you start getting left behind, that that gap just augments over time as these things, you know, develop. So, I think that's such an important point.

I want to talk a little bit with you about COVID. You know, we're coming on the other end of the pandemic. Obviously, COVID is still in our communities. It's still having an impact. But that was a really unique experience. I think for many of us in our lifetime. It was an incredible example of science working at speed and pace to save millions of lives. But of course, you know, science also has had to think about "what did we learn from that?" So, what have we you know, what did that look like for children and youth? What have we learned? How has research been impactful in terms of where we're at right now and understanding the impacts of the pandemic and the legacy, really, of it?

**Christine:** Yeah, I mean, it's such a you're right, like, just incredible moment in time. And was really an example of how, you know, a crisis can impact different groups of people in very different ways. And, you know, really, that's been a large part of our conversation around the need for Lifespan Inclusion Policy is that COVID impacted children and older adults in completely different ways. But you know, none of them in a positive way, right? Like these were groups that already had, were left out and had inequities, and then, you know, looking at the impact on their health and impact on policy decisions. So, our work within IHDCYH has really been to try to support pandemic response and covid response in two different ways.

So, we worked with CIHR to create funding for a large platform called POPCORN, which is focused on improving coordination around pandemic response and research in children. And really impressed with the group the work that this group is doing around learning from what happened, but also positioning themselves to be able to respond, you know, to future, you know, events like this in a more coordinated way, and really bringing a pediatric, child focused lens of perspective, because the needs of children weren't always actively considered in a lot of the policy decisions that needed to be made.

We also were able to secure an additional ten million dollar investment from the Government of Canada to look at the impact of the pandemic restrictions on children, youth and families. And so, we funded over 70 research teams through this initiative, and we joined, actually, together with our colleagues at the American version of IHDCYH at NICHD last October for a webinar in which we brought together our Canadian and American funded researchers. They had launched a very similar parallel call. And one of the big themes that came out from our discussions with NICHD was just exactly around equity, diversity, inclusion. So, some of the presentations were focused on black children, children with disabilities. We also had an incredible discussion around indigenous children and families and unique impacts there, and our colleagues in the states were very interested in learning from us around what were the sort of unique contributors. So, I think the data is still rolling in from those studies. You know, eating disorders was another area that received a lot of focus and attention due to sort of a dramatic increase in the number of children presenting with eating disorders during COVID.

So, we're still, you know, watching these data, these studies come in. But what it's doing is creating that knowledge base of where were the areas that children were struggling the most in the future. How can we, you know, adopt interventions or prevention strategies, but we're really pleased that we had such a strong research response in that particular area, and hopefully we can use all of that experience, you know, in ways that will benefit children. And we know children are still experiencing learning loss, disruption to their lives as a result, even though it was nearly five plus, you know, years ago, you know, there's still long-term effects that we'll be continuing to study and continuing to grow from.

**Katharine:** Yeah, absolutely. And, you know, and another thing I've thought a lot about, and I think for me, really started to have awareness of during the pandemic, and I think it's important for your field too, is misinformation and how that just also amplified so dramatically during the pandemic and had, like, such a massive impact on people's health. And I think now we're seeing the ongoing perpetuation of misinformation, of course, fueled by AI, fueled by changes in media, fueled by social media, and it's a real threat to health and a threat to science.

So, I'm curious, you know what are your thoughts on that? How important do you think misinformation is as a threat and how can research be important in addressing the impact misinformation is having, I think, not only on us, from a scientific lens in our communities, but also from a social cohesion lens.

**Christine:** Yeah, I'm so fascinated by this, to be honest, like as someone who's been a scientist for 30 years now, who you know, lives and kind of breathes in an evidence informed ecosystem, the level of misinformation and mistrust that we saw, and, you know, I think I had seen data just before COVID that, you know, Canadians trust in science was at an all-time low, like just before COVID, right? And, you know, it's fascinating that we could find our way through a crisis with, you know, science guiding the way the rapid, you know, generation of effective vaccines that, you know, misinformation would be such a problem. And I think what I often reflect on is just how we haven't done a good enough job as scientists in, you know, building trust. And you know, how is trust built? It's built through relationships. But where does our science sit? You know, you mentioned the ivory tower at the beginning of our interview, like it sits, people feel it sits in an ivory tower. It certainly sits in academic journals that people don't have easy access to. It sits at conferences that not everyone attends. And so, we've made scientific knowledge kind of a hidden, you know, hidden thing at times. And so, I think that lack of accessibility, and also just the lack of building relationships. And, you know, scientists are good at doing science, and that's what we need them to do, but I think there are roles within our ecosystem for people who can bridge that science, who are like sort of knowledge brokers, right, who can help build the relationships.

So, I think, you know, we know how to do good science. We don't know how to do good mobilization and kind of awareness raising and building trust. And, you know, many of the technological things that you mentioned, you know, AI, social media, but all of that, I don't know that we figured out how to harness that in the way that's going to be effective. So, I, you know, I remember seeing Francis Collins, who was the director of NIH retire, and he gave an interview, and someone asked him, like, what one of his biggest regrets was around covid. And he said, like, "if you had told me we would rapidly develop vaccines that people wouldn't take, I never would have believed you." And he sort of said, I think we haven't paid enough attention to the behavioral aspects of health. And, you know, as a psychologist, I certainly agree. And so, I think that human side and that the behavioral aspect of health and delivering health interventions, you know, under a broader umbrella of knowledge mobilization, needs to be a major area of focus, because I do think it is an incredible threat, as we see declining vaccine rates, I mean, it's such a concern in kids.

**Katharine:** Yeah, I totally agree with everything you've said. And the other thing that really worries me is how it's fueling polarization, you know, and there's so much science showing that people's views are becoming very aligned with different political perspectives, and then that's leading to, you know, more polarization across our society, which is leading to distrust and major impacts, I think, even on our democracy. So, I think it's fascinating how something that sort of started around science and questions around these things has sort of spreading out into our culture, really, and, you know, and I read a quote once, it was saying, you know, social media is really an experiment, a mass experiment that's happening in real time. And I think it's true, right? This is something that's new. The impact of it is massive. It's expanding exponentially, particularly with children and youth. You know, here's a



generation that's really growing up for the first time in this ecosystem, and I think what we're seeing is just these impacts that we don't really know what what's going to happen. So, I, you know, I love that people that are sitting where you are, people that are leading us in research work that's so important, are also thinking more broadly about the human piece of it, the communications piece of it.

As you said, you know, what's the most basic thing about being a human being? It's relationships. And you've touched on that, I think, through so many things you've said, both the importance of relationships for science, building connections, but also the relationships that we have with people when we're trying to communicate. And I think sometimes that's when we lose track of that. That's sort of when things go a little bit off the rails. But I think it's a really big challenge that we're facing, and I'm not sure we know exactly what to do, but I think we're learning about it. And I think that's really what you've reminded all of our listeners, right? Is we need to be curious, asking questions. You know, learning in real time as we move ahead.

So, Christine, you know, we're our time together is coming to a close, but before we end, you know, sitting where you are, I think you have such an incredible perspective on the system. And what we like to hear always from our guests is what would be your 30 second elevator pitch right now for why right sizing children's healthcare should be a priority?

**Christine:** Yeah, I mean, right sizing children's healthcare needs to be a priority. And research is such an incredible part of that. Our kids deserve our best knowledge, our, you know, most innovative discoveries, and they also deserve us making sure that this research is really going to make a difference for them, that it's put into practice and put into policy. So yeah, kids, we don't want to wait. We have a lot of knowledge that we can put into practice now and there's still a lot of gaps we need to fill.

**Katharine:** Yeah, absolutely. Thank you.

So, thank you so much, Dr. Chambers, I so appreciate you coming on today, and also thank you for your incredible work. You have shown so much leadership in this space, and I think you've changed the landscape for children, youth and families in so many ways and that impact that you and your team are having is felt by all of us, and it's ongoing. So, I really appreciate you coming on our show today and taking the time to share your incredible work with us.

**Christine:** Thank you. That's so kind. Thank you so much.

**Katharine:** So, thanks again to our listeners and to our SPARK Conversations podcast sponsor, the IWK Health Center, for their ongoing support. That's it for today. Thanks for listening to SPARK Conversations.

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