Right-Sizing Children's Healthcare: The Critical Role of Community-Based Developmental Care

SUMMARY KEYWORDS

Children's Healthcare Canada, right sizing, community based healthcare, developmental healthcare, Empowered Kids Ontario, Pathways Health Center, pediatric rehabilitation, child development, integrated healthcare, early intervention, human health resources, data systems, funding challenges, family centered care.

SPEAKERS

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Episode Transcript

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Katharine Smart 00:20
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. This year, SPARK: Conversations is dedicated to right sizing children's healthcare systems. We're grateful to the IWK Health Center for its ongoing sponsorship of SPARK: Conversations podcast right sizing series. I'm Dr. Katharine Smart, host of this podcast series, and today I'm absolutely delighted to be speaking to two amazing women: Jennifer Churchill, President and CEO of Empower Kids Ontario and Alison Morrison, CEO of Pathways Health Centre for Children. So let me tell you a little bit about these amazing ladies and what we're going to be talking about today.

Jennifer is President and the CEO of Empowered Kids Ontario. Jennifer Churchill leads the association through a significant period of growth and change, as the province continues to innovate in its approaches to the delivery of community-based health care in child development and rehabilitation. She is respected as a collaborative partner by colleagues in a sector in which Ontario is known across Canada and around the world as a leader in both developmental health research and clinical care. During her tenure at EKO the association has modernized its governance, expanded its membership, and developed relationships that ensure EKO's voice represents a broad range of diverse stakeholders. Jennifer joined EKO after more than 25 years in the health and government sectors. She has a degree in Social Work, a Master's Certificate in Municipal Management and Executive Leadership Certification.

As CEO of Pathways Health Centre for Children, Alison works with a dedicated team of 200 staff in Sarnia, Ontario to provide exceptional care to over 5,000 children and youth annually, with physical, communication and developmental needs. Pathways is a member of Empowered Kids Ontario, working together to ensure pediatric rehabilitation and child development services are accessible and impactful across the province. Alison is a Registered Nurse and a Registered Speech-Language Pathologist. Her work at Pathways has spanned 27 years, with the last 6 years being in the CEO role. More fulsome bios for Jennifer and Alison can be found on Children's Healthcare Canada's website (childrenshealthcarecanada.ca) under SPARK and then navigate to the Podcast section.

So, as you can tell listeners, we are in for a treat today, learning from these incredible women. I think, as our regular listeners know, Children's Healthcare Canada has been on a mission to discuss how we right size children's healthcare systems across this country. Right sized healthcare systems for children are accessible, equitable and connected healthcare systems designed for the needs of children, youth and their families. From coast to coast to coast and across the continuum of care, children, youth and their families are experiencing long and often costly delays for essential and time sensitive healthcare services. We're exploring what this means in real world contexts across along with the collective action required to change the way systems work, interact and intersect. Today, on this episode, we are focusing on community-based developmental healthcare in right sizing healthcare systems for kids. So Jennifer and Alison, welcome.

Jennifer Churchill 03:34
Thank you.

Alison Morrison 03:36
Thank you, Katharine.

Katharine Smart 03:37
So I wonder you know, many of our listeners may be wondering, like, what is this developmental healthcare that you folks are talking about today? So Jennifer, I'm going to start with you. Tell us a little

bit about EKO, your organization, and what it is you do, and what we're talking about when we're saying developmental healthcare.

Jennifer Churchill 03:53
Sure. So EKO is a member organization that brings together children's developmental health providers from across Ontario, along with associate members from other provinces, as well as equity serving and other sector partners. Our clinicians care for kids with disability and developmental needs, communication, physical or cognitive. We support kids who have experienced illness or injury or have complex care needs, and we're a foundational part of the children's health system, because one in six kids has a developmental need or a disability. So the kind of care that we provide actually, I'm going to let Alison talk a little bit about that, because the joy of coming together today is we get to talk about the system at large through the association lens, but even more importantly, the system on the ground and what type of care is actually provided. So Alison, I'm going to let you take that.

Alison Morrison 04:48
Yeah so developmental healthcare, it is a family centered healthcare delivered by specialized allied health professionals and developmental pediatricians. And it's delivered at a critical moment in a child's development, and importantly, it's delivered in the community, where kids and families grow close to home, so that we can wrap around children and have everybody working together for the child's best. We provide a number of services; Regulated Health Professions, like occupational therapists, physiotherapists, speech language pathologists, audiologists, therapeutic recreation, social worker - the list goes on and on.

Katharine Smart 05:32
It's so incredible to think about all those incredible professionals coming together to work and support kids at these critical moments. And I think you know, part of the reason we're here today is because we know that what kids need and what the system's designed to deliver isn't always matched up. So tell us a little bit about that. What is timely access like? What are you seeing in your system, and what does it mean in terms of developmental health when kids are waiting? Alison, do you maybe want to start and then Jennifer can give us her thoughts as well.

Alison Morrison 06:03
Sure. I mean developmental health supports need to be given at the right time, at the right moment. We know that for kids, there are these critical moments that can set a trajectory for the lifetime. So when we're talking about access to care, we need it when we need it, which means not waiting 3, 6, 9, 12 months or years, to access these services and miss those windows.

Jennifer Churchill 06:28
You know Katharine, we know that developmental health is the foundation for lifelong health. In Ontario, we have a really robust system of community-based organizations, from Windsor in the South to Sioux Lookout First Nations Health Authority in the North, meaning that families can get expert care in their community. But we do have a system that for many many years has been not only underfunded; not funded. For more than a decade in Ontario, there wasn't a single base budget increase for this type of healthcare for kids. As a result of that, we've been playing a lot of catch up. I can tell you, in Ontario right now, we have more than 60,000 kids who are waiting to access speech and language services.

This is really upsetting to us, and really, is really something that keeps me up at night. You know what? We are such an important part of the health system, and a lot of health system conversation is really anchored at the other end of the spectrum in the hospital system. But we actually want conversations around children's healthcare to not be an either-or conversation. It should be access to community-based care, access to hospital care, and the movement back and forth between those two opportunities for care delivery.

Katharine Smart 07:46
Thank you for that. Jennifer, I think what you touched on there is so important, right? I think in a system that's often strained, and when we're sort of in a position of austerity, we get into this mind frame of either-or, rather than both-and. I think what you've highlighted here is so important, those same kids that are served by children's hospitals have needs when they get home. And there's, of course, kids who never need a children's hospital but have developmental health needs in their community that are essential and important. So, tell us a little bit more about your vision for that. I think what you're really I'm hearing you talk about is this idea of integrated healthcare, where we move seamlessly from community to hospital, back to community, and sometimes maybe never leave the community. So what does that look like? What is your systems thinking, planning? How would that be better, in your view?

Jennifer Churchill 08:31
If I was the wizard with the magic wand, honestly, every conversation about children's healthcare should include conversations that include the entire continuum of care. And we've seen real success on that in Ontario, when we had all of the children's health leaders come together that provided every kind of care a child could need, and went together to the government to say, we need a collective investment. And I have to tell you, the Ontario government listened, and it was really remarkable. But I think the opportunity we have when I think down the line is any conversation around health systems planning for children, needs to include community-based developmental healthcare. It needs to include that care that a family receives that helps that our child participate in school. That helps that family stay at work. That prepares that child to not only participate in school, but graduate from school, go on to high school, finish high school, go into the workforce and allow their family to participate in the community.

Katharine Smart 09:33
Thank you, Alison. Do you have any other thoughts?

Alison Morrison 09:38
As we work together, we can accomplish so much more when we are leveraging resources in acute care settings and in the community. Working across partners does so much good for families who once felt alone talk about this new discovery that they aren't alone when their partners come together around a unified care plan. And say, I've discovered that I have capacity, and my child does too, because y’all are working together to make it good for us.

Katharine Smart 10:07
Yeah, incredible. And so important, you know, and certainly something I often reflect on caring for many kids with complexity and developmental challenges, is so much of that burden can be downloaded onto

families to have to try to solve these complex problems on their own. So I think what you're both talking about that wrapping around the family, walking alongside of them. Making it easy or for them to put that team together that their child and family needs for their child to reach their full potential is so important because it can be so isolating to be trying to help your child in a system that often is, you know, sign up for this wait list, sign up for that wait list. And families can be confused about how to move ahead. So that work is so important. You know, you're both talking about some of the successes you've seen in Ontario, which is incredible. I'm definitely hearing the importance of partnership, bringing leaders and teams together across the system you've you obviously both have also created models of care that are working well. So Alison, I'd love to hear you know, what is the model you're working with, with your teams, and what leads to the success that you're having in serving kids and their families?

Alison Morrison 11:08
Well, the model for care certainly is a family-centered, solution focused approach, where we are, you know, talking about what's going to make the biggest impact in this family's life and in the child's life that will set them up for success. So we're working across disciplines and across sectors, even to again, we talk about that wrap around care, to work together to set a course that sets the child and the family up for success.

Katharine Smart 11:34
Jennifer, anything you've learned from sort of your position as overseeing Empowering Kids Ontario, around models that work and lessons that we should be taking when we look across the developmental healthcare system?

Jennifer Churchill 11:46
Absolutely, I've seen the value of community-based centers delivering care in schools, delivering care in community. Also, many of our members are actually based within some Ontario hospitals. So it's a really unique opportunity for some of our hospital based members to actually extend into the community and provide that community care and that continuum of care under the umbrella of them also being a hospital. So having us as part of the health system conversation is actually going to help improve or reduce the fragmentation that families get to experience, and sometimes that fragmentation is is caused because of the way ministries fund programs or ministries identify programs. When in fact, families actually just want help for their kids and they don't understand ministry silos or funding envelopes or or how hard it is to actually move through a system of care that we are working really hard to be far more fluid. And if we can be included in every health system planning conversation, then we actually won't be left out when there are people, policymakers and funders deciding how to embolden that children's health system.

Katharine Smart 13:04
It's so important, you know, obviously the funding piece of this matters a lot, right? It's a critical part of terms of access and being able to meet the need, which is growing, as we know. So, Jennifer, tell us a little bit more about that idea. Like, what does adequate funding look like? Again, if you had your wizard wand, how would you design the system so that the funding made sense in terms of what kids and their families need?

Jennifer Churchill 13:26
Well, it's interesting, because community-based care is delivered, you know, at a fraction of the cost of more institutional care models. We know that. But we've had a history of essentially, at best, some sporadic investment. Welcome always. But if you have a sporadic investment and then a period of flat investment, then any gains you made from that sporadic investment are quickly eroded. So what we're seeing right now in Ontario is for every two children we bring into service, five go on our wait list. We understand the demand for service is great. We also can tie some of that to the COVID period. In Ontario, there were more than 300,000 babies born during COVID and with one in six having a disability or developmental need, just those children that were born during that COVID period are starting school, and many of them aren't ready to start school. So if we could really, you know the the value of early intervention and investment and early intervention, people know it. They see it, they understand it. But actually trying to get governments to action that investment is really hard, is really hard. So, you know, we're constantly trying to help people realize the value of, you know, seeing a child early. And I'm sure Alison has so many examples. If we can see you early, sometimes you only need that light touch of intervention from some of our regulated health professionals. And we can actually set you on a course to feel confident, to participate in your community, for your parents to stay and work, for you to participate in school. Those are the things that we want our decision makers to know and part of our health system partners to recognize as well.

Katharine Smart 15:16
So true and so important. Alison, I'd love to hear from you. You know a bit what you're seeing in that regard, maybe some examples or experiences you've had about how that that early intervention really changes that trajectory, and why it's so important that we are investing in kids when it matters.

Alison Morrison 15:33
Absolutely, I mean equipping families and children to move forward, helping families, help their children at home, helping teachers, helping children means that they're reaching their goals. They're growing confidence, they're growing capacity so that they can live into their everyday. Participate on the playground, participate at birthday parties, be kids, being kids. We do hear stories almost every week, I have a family calling in and saying, I don't know what we would have done without being introduced to Pathways. We're not sure how we would have navigated this, because we were just told off you go and a discharge from a hospital or here's a new diagnosis. But in meeting a Children's Treatment Center, a place that provides community-based care, families and children quickly feel that they're not alone and that together, we're going to problem solve and figure a way forward.

Katharine Smart 16:29
Absolutely, I certainly see that in my work every single day. And you know, just yesterday, I had the experience of a family with a child with a developmental disability, and the occupational therapist working with that family came to the appointment. And it was just so incredible to all be sitting there together having that conversation and just hearing all the work of the therapists that are working with this child and family, occupational therapy, physiotherapy, speech and language pathology, family support worker, and just the impact that's having on the confidence of these new young parents to work with their child who's thriving with the support of this team, and for me as the treating physician, to be able to be there, hear what's happening, and then be able to contribute. You know, it was for me, I just

thought, wow, like this, this is how we should be doing things, but really seeing that, that impact and and the impact on the parents and how you also see them, not only the child's thriving, but they're thriving in their confidence in parenting this child that does have some special needs. So I think what you're describing, you know, I certainly see that, and it's, it's amazing to think that that people can access this care, but it's also, you know, I think part of what we're wanting people to understand today is we should also be concerned about all the people waiting who are not getting that care in an ideal time. So, you know, I think partly what's important when we're talking about right sizing systems is knowing what we're talking about. You know, Jennifer, you shared some statistics and some numbers that I think are quite compelling. For every two kids getting service, you know, five more are on the wait list. So let's talk a little bit about data and data systems, and how what you're doing in that regard, and how that's important in terms of furthering this conversation around developmental healthcare, so that people that make the decisions understand what we're talking about, and why, why this is a compelling case for investment. So, Jennifer, tell us a little bit about that. What's the data look like in this area of work?

Jennifer Churchill 18:18
Katharine I'm so glad you asked about data, because I actually think it's, you know, data has real. Access to data has really been a barrier for us to be included in health system conversations. Historically, there's been little interest and little investment in trying to understand community-based healthcare, and the reason for that is a lack of systems and a lack of interest from, you know, certainly from different ministries in my government, to actually hone in on the care that's delivered in the community. I think because of that, it's been really convenient to leave us out of conversations when you don't have visibility to very easy data sets that help us understand emergency visits or even primary care. So the opportunity that we have to be included is going to be a bit harder, because there's no clear cut data sets that exist that describe the amount of care in the community that's being delivered to children. And I actually don't think that this is the time to use that as an excuse anymore. There are a number of conversations happening in Ontario, and actually we're working really closely with our funding ministry to establish a brand new, essentially data initiative that will consolidate our reporting and partner across sectors for us to understand what care delivery looks like. But really, we've been at a disadvantage because it hasn't been a priority for anybody. And as you know, collecting data and analyzing that data requires investment. Requires investment across the board, not only from the data collectors, but those who are delivering care, and that has been absent from our system, and I think that's slowly changing, but we have a lot of catching up to do in order for us to to be able to contribute in a really timely way. Right now in Ontario, if we want to look at data from our system performance, we are looking back where it's 18 months. Real time data in our world is 18 months ago. So you know that needs to change, and that's why, when you have really timely conversations about health system planning and health system resource planning, we can't give you something that's happening in up to the here and now, and we're working to change that, but it's been such a problem.

Katharine Smart 20:33
Yeah, it's a challenging area, for sure, and I think you're absolutely right. You know, governments, and rightfully so, are wanting more data and hard numbers around decision making, and I think that's important, but like you're talking about, that means that we need to be really thinking about where are sectors that need support to get their data, where it needs to be to actually tell the story of the impactful

work that they're doing, right? Because you know that, but how do we make sure the data is there to tell that story and to support the growth that you're seeing? The other area I think that ties to is the issue around human health resources, right? Because, as we know, the lack of data around human health resources in Canada is part of what's led us to the I'm going to call sort of crisis, or really challenging position we're in now where we're really don't have all the health professionals we need, and certainly in terms of kids, people working with kids, we know these are specialized skills. You know, you might be an occupational therapist, but are you trained to work with children? So Alison, I'd love to hear from you. You know, you're working with a broad array of healthcare professionals that are specialists in a whole range of areas, that then also have to be specialized in working with children. So what does that human health resource landscape look like, and what do we need to be thinking about to make sure that we're training, mentoring and encouraging healthcare professionals with the right skill set to provide developmental healthcare to kids?

Alison Morrison 21:49
Yeah, my goodness, human health resources has been a real challenge, and certainly the pandemic made that even worse. I think certainly we're not alone in Sarnia-Lambton, where we've had ongoing challenges with recruitment of regulated health professionals, particularly because we run into challenges with being being on a level playing field with some of the other sectors that hire these same regulated professionals. So we simply cannot compete with the hospital sector. We cannot compete with the private sector. Our funding is is lacking in an area that helps us recruit and retain those staff. And as you mentioned, it's certainly an investment in in the the onboarding and the ongoing specialization for providing care to a pediatric population and to their family. Certainly at pathways, we've made it a priority to to ensure that we are bringing on students in these regulated health fields so that hopefully they're going to fall in love with our organization and stick around a little longer. And it's been working out fairly well for us. But raising the profile of pediatric rehabilitation and developmental healthcare is certainly something very important. Not enough attention happens in university programs on the pediatric learning side of things, and we'd certainly like to see more of an investment there, too.

Katharine Smart 23:16
Absolutely. Jennifer, do you have any thoughts on the HHR side of this issue and what you're thinking about as you're leading EKO?

Jennifer Churchill 23:23
Yeah, we're starting to do some work in that area, Katharine. And it's interesting, because we've had to take this on because our funding ministry isn't particularly interested in what our HHR pressures are. So we're in the midst of conducting our very first workforce survey to really understand where our gaps are. But anecdotally, I do hear from Alison and her colleagues that when we can recruit those regulated health professionals, which is marvelous, many of them actually have a learning gap around actually pediatric care delivery.

So we're starting to think about, what can we be doing to build that capacity with the staff that our members have in place to help them, essentially, you know, reduce that onboarding time, right? It's great to be an OT or an SLP, but then you actually have to get into the pediatric space. And, I mean, I can think about all of my physician friends who have never worked in pediatrics, and don't really want to

think about that very much, because it's a completely different mindset. Just because you're an OT or a physician, it doesn't mean that you're actually confident to go in and work with kids and families. And I think that's the other really important thing about our entire system, and in fact, the pediatric system as a whole. You've heard this many, many times, it's no one sees that child in isolation. This is about caring for kids and families. And I think that's one of the things Alison was referencing when you have families that come to your center, there's not too many three year olds, Katharine, that come to their own appointments. I'm sure in your office, it's the same. They don't show up on their own. We're caring for that entire family. In fact, we were part we're providing care for that entire community. And often bridging a gap between hospital and home and back into the hospital if required, or the community into the school and back, or the municipal swimming program and back. Like there's so many things that we are doing to help keep families whole and help keep them healthy. And we're really proud of that work, right? But that is a special skill set, to be working in that space and to welcome the chance to work with kids and families. And it's not easy. We know it's not.

Katharine Smart 25:27
No, for sure. And I think that's like what you touched on there so critical. And again, you know, so often, the person and the people doing the intervention with the children on the daily are the parents, you know, and they are trained and supported by these regulated healthcare professionals who give them the skills so that they know how to optimally interact and support their child, and they're there then doing the exercises, doing the programming with their child. So you're absolutely right. The child is not living in isolation. The parents are become an essential part of the team, and they need these experts to help them know what to do. And again, you know, with that support. I think so many parents are just so impactful, but they also feel empowered, because you can imagine how helpless it must feel to see your child who's struggling with language, struggling, you know, interacting with peers unable to be at school or in daycare, and you don't know how to help them. And then in comes this team of people who are able to look at the situation and actually give you suggestions and advice and support and interventions that make that difference, right? And that's what your teams are doing. And then that's that shift in that trajectory for that child and that family. And I so really, you know, your patient is just one person. It's, it's a it's a constellation of people, and it impacts their siblings and their communities and extended family members. You know, the impact is really so far beyond just the child as an individual. And I think that message is so important for people to understand.

Jennifer Churchill 26:47
One of the neat things that EKO has done for more than a decade now is award scholarships to young people who have received care among one of our member sites. And I can tell you that often when any one of these young people is recognized with a scholarship, often, their clinicians are even prouder than the kids themselves. Like honestly, the pride that the staff who helped them reach that place where they could go off to school is, you know, is a personal a piece of personal satisfaction for that clinician, but the investment that many of our clinicians make, and the kids and family that they have come to know as they've watched them grow is really quite remarkable, and I actually think, unique to our system and a real source of pride accomplishment for our clinicians. It's really amazing to see what happens when you get to see those families. And you know, this is some of the feedback that we get. It's awful, awful waiting for service, but oh my gosh, once we got here, it's terrific. And we need to

actually reduce that time where families are feeling so frustrated that they can't access that care that can help their child reach that developmental milestone and be the best person that they can be.

Katharine Smart 27:59
Absolutely. So what I'm really hearing is where our problem is not that we don't know what to do. We know what to do. Your teams are experts. They know how to deliver this care and how to make that impact. The challenge is being able to reach people when they need it in a timely way. And that really is about resources. So we know what we need to do, it's how do we get the funding and the support and the integration into the system to be able to deliver when families need it. Yeah.

Katharine Smart 28:27
So before we conclude, I'd like to ask each of you. What would be your 30 second elevator pitch about why right sizing children's health should be a priority right now amongst all the competing healthcare priorities in the system. So Alison, I'm going to start with you.

Alison Morrison 28:43
Gosh, okay. Investing in children's health isn't just the right thing to do, it's an investment. It's the smartest investment that we can make. The first years of life, shape lifelong learning, shape lifelong health and productivity. And yet, too many children wait months or years for developmental service supports. They miss windows when intervention can make the biggest difference. So by prioritizing community-based pediatric services now, we can catch issues early. We can strengthen families. We can reduce future healthcare costs and social costs every dollar invested in children's health today returns many times over in healthier kids, healthier communities and a better future for all of us.

Katharine Smart 29:29
Thank you. Jennifer, your turn.

Jennifer Churchill 29:30
Wow Alison, that was great! I would say any conversation in any province in this country that's talking about investment in healthcare, especially children's healthcare, must include community-based care. It is hospital and community and mental health and access to diagnostics and access to ambulatory care, all of those things. It's that full continuum of care that need to be considered when we are planning an investment, when we are planning system redesign. When we are planning system strategy. It is hospital *and*. That would be, that would be, I think we would see a real difference if we could always think about that continuum of care for kids and families when we make policy and funding decisions.

Katharine Smart 30:15
Thank you both. I think you both have made such a compelling case today for why developmental healthcare for kids is so essential, how it's part of nation building. That was really what we're talking a lot about in Canada right now, kids are that future, and having them able to reach their full potential is an essential part of building a stronger and better Canada, and we need to not forget about that essential care happening with so many highly trained experts in our communities to support children and families as they move into their lives and into schools and beyond. So I want to thank you both for the incredible work you're doing, for elevating the voices of kids and families that need your services,

for making sure that these voices are heard or at the table, and that we're doing better in terms of delivering to children in these critical periods. So thank you for sharing your vision and your work and your passion with our listeners today.

Jennifer Churchill 31:05
Well, thank you for including this part of the health system in your podcast.

Katharine Smart 31:11
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