

HOMECARE:

A key element
of right-sized
health systems

With Special Guest:

**Maureen
Charlebois**



Transcript:

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

Dr. Katharine Smart: 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 2024-2025 fiscal year, SPARK Conversations is dedicated to the topic of how we're Right-sizing Children's Healthcare Systems. Thanks to our SPARK Conversations podcast Right-sizing series sponsor, the IWK Health Center for their ongoing support. I'm Dr. Katherine smart, and today I'm delighted to be speaking with Maureen Charlebois. Maureen, welcome to the podcast, and please tell our listeners a little bit about yourself.

Maureen Charlebois: Thank you, Dr. Smart. As mentioned, I am Maureen Charlebois, and I am a registered nurse, and have been in the healthcare sector for just over 30 years, and I've had the honor of working with children and youth across the spectrum, in home care as well in hospital based care, and it has really been a privilege now to be a board member on Children's Healthcare Canada.

Dr. Katharine Smart: Wonderful. We're so excited to have you today and to talk about a topic that I think often people don't necessarily think about when it comes to children, but talking about home care and why that's important.

As our listeners know, Children's Healthcare Canada is on a mission to right-size children's healthcare systems. Right-sized healthcare systems for children are accessible, equitable, connected healthcare systems designed for 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 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, interact and intersect. Through this episode, we will focus on the role of home care, primary care in right sizing healthcare systems for children, youth and their families.

And Maureen, that's why I'm really excited to have you today. Because again, I think when we think about right sizing systems and thinking about how we can create that continuity experience for children and families, often one of the things that people don't think enough about, I think, is care in the community and home care is clearly a really important part for people with medical complexity.

So, I'd love to hear from you. Can you tell our listeners a little bit more about what does home care for kids and youth look like, what services are provided, and how does it add value in our efforts to right size children's healthcare systems across that continuum of care?

Maureen Charlebois: Yeah, well, it's really amazing what is available beyond the four walls of the hospital, and so home care or care outside of the hospital can be provided in the comfort of the child and family's home care environment, as well as in a clinic setting and in the school health setting. So, at so I'm the, actually the Chief Nursing and Clinical Officer at Bayshore Healthcare, and we provide care for children and youth in all of those type of settings. We have, for example, in British Columbia, a respite program where our nurses go in to help relieve some of the burden from the families, from the parents, so that they can go on to other things, and our nurses would be in there to continue to do what the parents do. So, such as you know, with these medically fragile kids, our nurses would, many of the kids are, let's say, on ventilators. They have tracheotomy care. They are G tube fed, and this is what our parents across Canada are dealing with, and now our nurses can go in and provide that respite.

Similarly in our school health program, and this is not just in Bayshore, but many of our home care organizations, provide school health supports services. So, it would mean, you know, going into the schools to enable these children to live a normal life. But let's say they're, they have advanced diabetes, our nurse could go in and they are there to either provide sort of a nursing interventions, such as administering insulin and/or some of these kids, if they have

other complexities as an example, they may even do a full sort of shift in the school. And that is a great way, that that, you know, it still is a normal kind of process for the child to go to school but be safe and know that their medical needs are being met, and it certainly takes that burden and gives that parent peace of mind.

Dr. Katharine Smart: Absolutely, and I think what's so amazing about the services you're talking about are really two things, right, how we support these families that do such an incredible job. I know that's my, certainly, my experience caring for some families who have children with medical complexity, of caring for their kids 24 hours a day in their own home and, and that nursing support to go in and provide some relief and respite and support to those families is so important in preventing caregiver burnout and making sure those children can thrive at home. And then that beautiful piece of helping children with medical complexity be able to go to school, and trying to integrate them into their communities, with their friends as much as possible, right? And that's so important, right? Because schools can't do that without the support of nurses.

Maureen Charlebois: Exactly, exactly. And that's where it's really that partnership with the school and with the school, I think it's like the team assistant, and just as we're taking the burden off of the parents, we're also providing that peace of mind for the teacher as well, because it's difficult enough to provide, you know, the teaching, let alone when you have additional, you know, care needs for kids that have medical complexities and or even some cognitive behaviors, right? So that can also as a resource that we can, we can provide.

Dr. Katharine Smart: Yeah, absolutely. And I think you know, really, what we're talking about here is, integration, right? How we integrate services between the four walls of the hospital, the home, the school, the community.

So, what are some of the challenges you've seen with the integration of home care, community care, and hospital based care in your work?

Maureen Charlebois: Yeah, I would say on a before I go with some of the challenges. I just want to make a, you know, state that years ago, when I was a home care nurse, there wasn't a lot of resources in home care. Fast forward to today, it's just amazing, the partnerships that we have made, Home Care has made with some of the children's hospitals, so Sick Kids, for example, and CHEO, they have so many resources now to provide support to our nurses in the home, like our home care nurses. And this can span from, you know, education, as well as just, you know, a bit of a peer support if they have any questions or concerns, which it really makes a huge difference for, to achieve, you know, the best possible care for that child in their home.

One of the big challenges, I would say, that existed 20 years ago, when I was, you know, a Director at the Community Care Access Center overseeing children and health services is the same that exists today, is that, you know, everyone has the best intentions in mind, but the reality is, we still work very much in a siloed system, in the sense like there is services that are provided, let's say, through the Ministry of Health Long Term Care. Then there's different services for the provided through the Ministry of Education and then the Ministry of Community Social Services and others. And that's just in Ontario, but I know for a fact that's prevalent in every other jurisdiction across Canada, so that makes it very difficult for our parents and kids to navigate the system, and it also makes it very fragmented, because our healthcare providers don't always know which way to go, and so when Children's Healthcare Canada did these round tables where they brought together, you know, professionals and patient and parents to hear from them, that became really top of mind in all of the discussions. And how do we, you know, consolidate all of these services, funding to make it much more coordinated for those that are trying to navigate the system. So, I think that's where we really need to focus on. How do we make it more seamless? You know, for that, for the client, the child and the family, because they shouldn't have to worry about navigating this on their own, we should be there, and that should be sort of seamless to them, behind the scenes, behind the scenes that we have, let's say, our nurse coordinator that could be, you know, coordinating the services and really understanding. So, we have, let's say, one case manager that is doing that coordination, and they are that key connection with the patient and family. I keep saying, patient, client, child, but really the family, I think that would be make a huge difference, and that's what we heard at the round tables as well.

Dr. Katharine Smart: Yeah, I, you know, I couldn't agree with you more. That's certainly been my experience as a pediatrician. You know, I think people would be shocked just how challenging it is for families to navigate all the different funding sources and resources that they need to care for their children, and the barriers that are there and how sometimes to the programs, the things just don't always make a lot of sense, right, the steps they have to go through. You know, it's just a deluge of paperwork, and it's very overwhelming. And these are families who already are dealing with children that are often 24-hour care. And you know, I've been fortunate in my own clinic, we do have a social worker who works in that role of Patient Navigator, and it's been an absolute game changer for our families, because that's a designated person who can go and help them with the care coordination, make those linkages, make sure they're getting all the resources they're eligible for. Because sometimes people don't know that. It's tricky to find that out, right? So, I think that that piece you're talking about, that care coordination, it really can't be overstated how important that is. And the other piece I find challenging, I'm curious what your experience has been, has just been, often, basic communication, right? Like how that health information flows between providers, between, you know, the hospital, the community, the home, the family.

What are you seeing in your work around sort of sharing of information and what's working, and what are some of the challenges and getting that medical information flowing where it needs to be?

Maureen Charlebois: Yeah, and that's, you know, that was the whole notion of why. You know, at the early days, Canada Health Infoway was brought to brought to life. And the vision there was to have, you know, one integrated electronic health record, so that regardless of where you were practicing, right, that it was really wrapped around that person, family centered care, and that each of our disciplines, you know, our physicians, our nurses, our social workers, could access that record. So, there was one, one integrated care plan and one integrated record with the, as I said, with the client in mind. We're not quite there yet. I worked at Canada Health Infoway many years ago as the Chief Nurse there, and we have made huge progress. And I think we saw, you know, obviously, with the pandemic, we really accelerated the use of digital health. And look at here we are today, doing, you know, a virtual kind of podcast. So, we can do a lot more, but I think, you know, we have to move from, you know, siloed documentation, communications to much more that, again, that integrated so that it's about the client and the family, not so much, I have my records because in, you know, as a nurse in my in my little area, you're the physician. You have it in your office. It has to be part of the child's health record and digital is enabling that.

Dr. Katharine Smart: Yeah, I totally agree. And then I would add on to that, you know, also the patient and the family's access to their own medical records. And Canada's really trailing behind in that way. And I think, you know, so many, in my experience, these families that that have children with complexity, they are the experts in their child, right? They often know much more about their child's underlying diagnosis and all the intricacies of their care, really, than the rest of us that are kind of, I would say, members of their team, but they're really the ones that have that expertise. So, I think that's the other piece, is, you know. What about their ability to access that information, and how that might help with coordination and just making sure that things don't get missed. Because inevitably, that's one of the challenges when information's held all over the place and it's not coordinated, as sometimes, you know, pieces of that that puzzle don't end up where they're supposed to be. So, it's great to hear that people are working on that. And I'm curious, you know, what are your thoughts on patients being able to access their own information? And do you think that's important in home care?

Maureen Charlebois: Oh, yes, absolutely, absolutely. One of the challenges, though, is then, when you are that nurse in the home, even, let's say, we had integrated, like not integrated, if we had a digital system, we have that information. But because, going back to our earlier discussion, is that, you know, the notes that are being held in the school health system is not accessible, right? Or the notes that are in the Ministry of Community Social Services because of that area, it's not totally accessible. And so not only does the nurse, every nurse or member of that circle of care need to have access, so do the client in the family, absolutely, because at

the end of the day, it's about them and it's their it's their health information and their life, their care that's required, and they should be the ones in charge and leading that and that we are there to support their care journey, really, and they need to have that access to their information.

Dr. Katharine Smart: No, I totally agree with you. You know, we're talking right now a lot about integration and integrated systems involving home care, which I think is so important, we've talked about some of the key pieces. Is there anything else that you think is a key component to making sure home care systems are well integrated for patients and families that we haven't touched on?

Maureen Charlebois: Yeah, and I, I wouldn't, and perhaps it's not sort of the system, but I think it's also recognizing, you know where, when you are delivering home care services in the home, you know you're not just caring for the client, the child, you're also caring for the family, the parents and the extended family, because you're there, and that is really where the whole notion of, you know, person and family centered care takes place. But you know, we can't just be driven by a visit, because we need to care for more than the client. It's that whole nucleus of the family to really provide that whole holistic care. So, I think we need to, you know, re-look at how the whole, you know, reimbursement for the family, but also just, how do we make that model of care successful? Because it is complex, and you're delivering and supporting the whole family when you're in the home.

Dr. Katharine Smart: Yes, it's so true. And you also, I think, get such a unique window into the family and their challenges and their strengths when you're in that environment that you probably also have so much to share. Back to the other providers, right about how they can be doing their job best for that family, because you're really uniquely positioned to know them in a way that most of us don't have the privilege to get people at that intimate level right. Being in someone's home is really very unique privilege.

So, you know, you're working, I think, in this really incredible space, and you've described this sort of beautiful blossoming of the role of home care integration with children's hospitals, how you're sort of being able to extend the care partner with those pediatric experts to ensure that quality. What do you think are some of the effective and innovative, but maybe not yet fully tested strategies that would ensure integration across the continuum of care and help us link that hospital care more to the community?

Maureen Charlebois: Yeah, I think that's a, you know, that's a great question, and I don't have, you know, the magic answer however, you know, I think if we could remove all the sort of the layers of bureaucracy, or, you know, policy driven or organizational policy, and remove that, so that we can able, enable, really that one care team for that client, regardless of where

the funding is coming from, regardless of where they may be practicing, so that we can really wrap around the services for that child and the family. And so, what would that look like, right? So, that would mean we would have, you know, if I was that nurse working in the home care, I could and not, you know, that child was, you know, all of a sudden, got an infection and had to be hospitalized, I could then go and go into the hospital and still continue to provide that care and support, you know, the hospital team, but that, that primary care team still kind of follows them, and similarly, you know, going into the school because, we right now don't always have the same nurse providing who's going in providing care in the home, the same nurse going to provide care in the school. So how ideal would that be? So that really is about having that one primary care team that follows the client, the child, regardless of the care setting. And I know that's one of the advocacy strategies that Children's Healthcare Canada is really asking for as well that one primary care team.

Dr. Katharine Smart: Yeah, no, it makes so much sense. And you know what I think is so interesting is sort of a theme throughout our podcast series is we're talking about how to right-size care for children, youth and their families, is what you're talking about, which is really about relationships, right? Like, despite technology, despite digital health, despite electronic medical records, really at the core of what provides a quality experience for people is the relationships they have with the people that work with them. And that's really what you're talking about, right? How do we strengthen and develop longitudinal relationships so that that face that shows up is familiar, that the team that cares for you is known to you, you're not having to retell your story over and over, and people get to know what your unique needs are. And I think this is a theme that I've picked up, really, from all our guests, is, at the core of innovation is really what things drive us towards better relationships.

Maureen Charlebois: Exactly, exactly. I love how you put that and certainly, you know, we've all, I've always said, you know, technology is just an enabler, right? So, if you don't have that core team or those core relationships, as you're saying, you know, it technology's not going to solve that, right? It has to start there. So, yeah, I like how you said that.

Dr. Katharine Smart: Yeah. I think that's so important.

So, you know, you're on the board of Children's Healthcare Canada, which is fantastic. It's wonderful, I think, to have that perspective sitting there knowing that a lot of the members work in hospitals. I think to have that perspective of community home care is so important. To round that perspective out. What do you see as the role of organizations like Children's Healthcare Canada in terms of making these things we've been talking about a reality?

Maureen Charlebois: Yeah, I think you know what they are doing. I've been, you know, privileged to sit on a number of boards, and I have to say, and I'm not just saying it because

I'm on the board, but Children's Healthcare Canada are fantastic. You know, they have a fantastic team, and they are doing exactly what they should be doing. So, if you haven't, you should actually go and even visit their website just to get a flavor of who they are, because they are there and driven, are passionate about right-sizing, children's health, because they know we have to, we know the system is not where it should be, and we have to come together to make this a reality, to provide that best, you know, possible care and support to our clients and our families and that we then, as they, you know, they grow up, then there's a wonderful transition into adulthood, and that is another advocacy area that CHC are working on. So, I would say that is, you know, that is, they exemplify what an organization should be doing.

Dr. Katharine Smart: I couldn't agree with you more, and I think they've really driven the conversation and brought people, stakeholders across the spectrum of children's healthcare, together on a mission. And I think the way they're describing it, what they're pushing towards, is exactly what's needed.

So thank you, Maureen. I really appreciate your time today, but before I let you go, I want you to ask you to give our listeners your 30 second elevator pitch on why right-sizing children's healthcare should be a priority now.

Maureen Charlebois: Sure. Right-sizing is necessary now so that we ensure our children, which are the future of our generations, the future of our future, have the right services in the right care setting to really make them best they can be, and to have them live their life to the fullest. And that can't happen if they're in the hospital where and they really should be in home care and vice versa, and that they're supported throughout all of aspects of their life, and that the families are supported as well, so that they can care for their children and be the parents that they can feel proud and feel they've done everything to provide the best for their children and work together with their healthcare providers.

Dr. Katharine Smart: Wonderful. That's such a beautiful vision. And Maureen, I really want to thank you both for your work. I mean, you are a leader and an innovator in this field, and I think it's essential to this mission of right-sizing healthcare that care in the home and care in the community is optimized. So, I just really want to thank you for your vision and your leadership and for sharing your experience and your wisdom with us today.

Maureen Charlebois: Yes, and likewise, thank you for your leadership and the difference you're making, not just with the kids and the families that you care for, but also across the impact of Canada and especially with the Canadian Medical Association. So we're lucky to have you as well.

Dr. Katharine Smart: Thank you so much. I appreciate that.

So, thanks again 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. Stay up to date on all our SPARK offerings, including the upcoming podcast episodes. Visit our website at ChildrensHealthcareCanada.ca, and subscribe to our SPARK News bi-weekly e bulletin, if you haven't already. If you like this podcast, show us some love by leaving us a review and telling your colleagues about us. We'll see you again next month.