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Opening a Wider Door: Access to Services for Children with Neurodevelopmental Disabilities

In this Complex Care Journal Club podcast episode, Dr. Patricia Basualto discusses a qualitative study of service provider perspectives on access to disability services for children with neurodevelopmental disabilities in British Columbia, Canada. She describes the importance of cross-sectoral collaboration, actionable policy and program recommendations, and next steps from this work.

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Katie Huth *00:04*

Hello and welcome to the Complex Care Journal Club Podcast. My name is Kathleen Huth, I am a pediatrician at Boston Children's Hospital, and your host for this episode. In this podcast series, we seek to discuss emerging evidence in the care of children with medical complexity and its implications for practice. I'm delighted to have Patricia Basualto from University of Calgary, joining me today. She is the lead author of the article "Improving Equitable Access to Disability Services and Support for Children with Neurodevelopmental Disabilities: Service Provider and Decision Maker Perspectives" published online in Child: Care, Health and Development in December 2025. Patricia thank you so much for being here.

Patricia Basualto *00:45*
Thank you for having me, Katie.

Katie Huth *00: 48*
I was wondering, just for listeners who may not be familiar, could you start with a brief lay of the land of disability services and supports in Canada, in British Columbia, in particular, and what about it prompted this study?

Patricia Basualto *01:03*
Canada is actually like a federal country, so the policy context for arranging disability services will be connected to the federal legislation that Canada has, but also its provinces and territory in Canada can design autonomously how they can implement those federal legislation. So that means that even though there's like a pan-Canadian approach for disability, due to this autonomy from provinces, it ends up with a very varied landscape of disability services across provinces, which means that there are some provinces that are doing probably a better job of providing services for people, and specifically children with disability. Some other provinces maybe are not so successful in providing services. And this scenario in Canada has been documented as a siloed, fragmented disability services system for children, which is pan-Canadian, but also, when you look into provinces that also cures happens within each province.

Katie Huth *02:16*
So what was your study aim, and how did you approach it?

Patricia Basualto *02:20*
Because this policy scenario and disability services scenario. There's disparity in access for services and support for children, and in this study which specifically focused on children with neurodevelopmental disabilities, and because it is well known that access to services for children with disability is a modifiable barrier to improve health and functional outcomes to then support families for the most desirable social participation for their children. And we also know that there are some reports about where the most common barriers or facilitators are that you can find to access services, most peer review literature that you can see as of today comes from the perspective of families, which is very important. You should go that way to actually know what's going on out in the system. But this little information about service providers and decision maker perspective, so like insider knowledge is not so well reported in the literature, and the few literature that's out there is focused on a very specific program or a very specific type of barrier or challenge that the family face. So, we wanted to actually know a more cross sectoral approach, so tackling the entire system, not just one level of care or one type of service, but the entire system of services that's out there for children and from the policy, the service delivery perspective, and decision makers perspective. So, the overall aim is to actually have very good information to design policy and bridge that gap that we know there exists between how policy is designed, but then how it's implemented. There's the implementation gap, and insider knowledge from the system could actually help to bridge that gap.

Katie Huth *04:27*
Yeah, I thought that was an interesting methodologic choice, focusing on the perspectives of service providers and decision makers, and really wanting to have that focus on policy and program implementation gaps. And I think what I loved about this paper is that it didn't aim to just describe what the barriers are but or to frame them

as problems that families are struggling to navigate. It was asking, what is it about the current system that produces inequities or that makes navigation itself difficult, and what are the actionable things that can improve access for everyone? Can you tell us a bit about what was your method and what were some of your key findings?

Patricia Basualto *05:08*
Yeah, so because we actually wanted to know the like, quote, unquote, true inside knowledge from the system, we chose a qualitative, descriptive methodology, which is very well used in health research as a qualitative method, because it's helps you to actually describe what's out there without putting too much theoretical layers on it. And also, this is informed by a pragmatic epistemological approach. That means that we chose the methods that lead us or enable us to actually have the better direct perspective of our interviewees, okay, without having or transforming their perspective through a more theoretical approach. So that's what we wanted to avoid and have a very clear, system perspective of what's going on that in their, in their views, that is tampering access. And then for analysis in the same logic, we chose inductive thematic analysis, to actually identify themes. And then the one decision that we made is that, and this is something that we a decision that we took while we were conducting the analysis, that we noticed that when people were answering us our questions, they were, of course, very contextualized. So, they would mentioned a barrier or facilitator or challenge or recommendation within a process in the system. So we had a lot of information on how the system works, which was not aim, we decided, okay, let's just use that information, plus what is the public information that is out there from the Ministry of British Columbia, and map those barriers and facilitators across the entire process that the family has to go through in the system. So, we chose an axis of the navigation process, from the awareness of the services to the actual delivery of the service, but also the cross sectoral approach across ministry. So, we mapped barriers and facilitators other than the recommendations in that system perspective that we each is one that like the main figure that you can see in there,

Katie Huth *07:27*
Yeah.

Patricia Basualto *07:28*
That is valid.

Katie Huth *07:28*
Yeah. Figure two, that's what you're referencing, right? It's really sobering. It really captures the complexity of service delivery across health, education, social service sectors, and all the places where things can get stuck.

Patricia Basualto *07:41*
Yeah, and I can say that is the simplified version that we have to make it readable for the article. Yeah, but it's very complex, yeah.

Katie Huth *07:51*
I liked how thoughtful all your methodologic choices were, in this sense of qualitative description and trying to stick to the original language or intent and the practical implications of it. And you mentioned the main recommendations in the paper relate to this idea of a wider door for policy and a system that works for everyone, and it seems like those exact words were drawn from the participants. Is that correct?

Patricia Basualto *08:14*
100%, we had tons of wonderful quotes that actually depict the system very clearly and the challenges and also what people in the system what they want, like the recommendation for the system to change. So yeah, we chose

those two because they capture very well, like the overall approach our interviewees had, I think it's a good frame for the recommendation.

Katie Huth *08:43*
Are there any of the findings that you wanted to highlight or call out in particular, either because they were their aha moments? Or something that you thought was particularly impactful?

Patricia Basualto *08:54*
So, there are a few and, but the first one that I could mention is that the barriers and facilitators that you would find in this system, particularly in British Columbia, they are in the system before the family approaches the system. So, it's a system issue. So that's and they also these barriers and facilitators are interacting between each other at all time. Probably because we chose the cross-sector approach, we were able to see that, that how some, let's say a barrier that is probably identified in the educational sector for a family, that same barrier when the family goes to, let's say the health sector is not actually a barrier. It is probably is a facilitator, right? So, when you go into the system, not necessarily a barrier is put in a system is going to be the same across the entire jurisdiction and across sectors. So, I think that's something that is stood out to me very clearly while doing the interviews, not even going into the analysis. So how complex that was, the interaction between barriers and facilitators.

Katie Huth *10:06*
Could you give me one specific example of that difference?

Patricia Basualto *10:10*
Yeah. So, for instance, there's a well-documented thing about urban and rural, right? So that the assumption and what is being reported out there is that families living in rural communities probably has worse access because of geographical distance, or probably because the system has fewer staff there, or there's not some specialized staff there, which is true in British Columbia, is true for some communities, but other communities, or our rural communities, the service delivery organizations, acknowledging that, put some improvements to their practices in order to, to surpass that. Okay, and in that particular rural community, collaboration becomes very important to surpass that. So, then the geographical aspect, it's not a barrier there anymore.

Katie Huth *11:10*
I see becoming a more close-knit community where there's maybe more collaborative relationships or connections that actually then facilitate access. Is that right?

Patricia Basualto *11:19*
Yes.

Katie Huth *11:20*
That's interesting.

Patricia Basualto *11:22*
Yeah.

Katie Huth *11:23*
One of the main focuses of this podcast is the implications for clinical practice and what you would recommend for members of interprofessional care teams for children with medical complexity based on your findings?

Patricia Basualto *11:37*

So here I can see two, two aspects of implications or recommendations. First from the finding itself is what we were just talking about, so collaboration. People in the system value working collaboratively, right? I myself am a pediatric physiotherapist. So that's one my one of my hats, right? But also, people in the system want a system that is designed to support them working collaboratively. So, in the case of British Columbia, in my view, as a researcher, there's a drive to collaborate that is out there. That is important when we are thinking of designing or changing a system in not necessarily, we need to tackle the barriers, but we can actually foster what's the strength that system has. So, there's a drive to collaborate out there, and that is an opportunity in many ways. From the research perspective, it's an open door for implementation research and implementation practices where you could identify what those collaboration practices that are out there are. How can you probably scale them right to other organizations or within a design organization, even cross-sectorally or even more ambitiously, like, how do you kind of scale them across a province or the entire system? So that's something that if you are in a clinical setting, I think it's very important to see, because maybe the good practice that you have could be a benchmarking for your colleagues in a different organization that, but you're working with the same families, right? So that's one thing, and the other, the other thing about collaboration is that in British Columbia, collaboration do exist in policy. I've read their policy, it says cross collaboration in many of their mandates, ministry and mandates, but there's no clear implementation mechanisms on how to put that into practice. So, it's like sitting in a office that's very high in the system, but not necessarily with a clear path of action. So, bringing down those types of policies into actionable protocols for practice is very important. So, so the collaboration is not based on the goodwill of the frontline staff.

Katie Huth *14:06*
Yeah, I love that distinction.

Patricia Basualto *14:08*
Yes, because that is, I mean, policy could be anything in a, in a more theoretical way, and actually it's also a policy. But when the policy, actionable policies just based on the goodwill you have, the risk of burdening people in the system, which is something that our interviewee mentioned. So, it's very important to have that top-down approach where you actually have a very thoughtful implementation of the policies that you intend to achieve and do. And that means also thinking why we are collaborating, if we're thinking from a implementation perspective. So why the why. that's what I mean by clear, actionable protocols for collaboration is, why we are collaborating? Who in the system is doing what to actually make this collaboration effort a really good tool to improve the lives of families and children? So, if any system achieves to pursue health equity for the population they are serving, collaboration should be a foundational work in the system.

Katie Huth *15:19*
Yeah, I think you've laid out such a valuable distinction between, like, the willingness and interest for people to work collaboratively, and the system that is designed to support that collaboration, and moving it from like a policy buzz word to translating that to in practice.

Patricia Basualto *15:35*
Yeah, and the other things that I would highlight and can also become a recommendation is that, in terms of the methodologies that we use as a research team, we conducted our research with the support of an advisory council. And that was a great opportunity to keep our research in check at every stage, right. We were advised by people in that council, who are people with lived experience as service providers in the very same system. Also, some of them were parents of children with some disabilities, so they also had that shared lived experience. So, they provided feedback for the research plan, then the interview guide, then they provided advice on the recruitment process that we had with the type of sample that we needed, because we actually wanted to reach the best people, in the sense that those who could provide the best information. So that became very relevant to actually make sure that the thematic analysis was not only reliable and valid in terms of the findings, but also meaningful.

Katie Huth *16:51*
Yeah, I saw you had mentioned in the paper about the Advisory Council, and I was curious how you engaged that group and the role that they played?

Patricia Basualto *16:59*
100%, I could say this just as an example, because maybe we could use an entire podcast to only talk about engagement in research. The interview based on a previous project that we had in the same team. So, this group is the Disability Policy Research, which is based on the School of Public Policy in the University of Calgary. So, in a previous study interviewing parents of children, so we knew the questions that we needed or we wanted in the interview guide for the service providers and decision makers, based on that previous learnings, right? But then we tested that when we had our interview guide, we just sent it to the advisory council and then give it back with any sort of comments and feedback they were thinking it was useful and relevant to us to consider before the implementation of the actual interview. So, then we adjust, like, when you go in for a colleague ask for recommendation. That's what we did. So, our advisory colleagues gave us recommendation. We included that in the interview guide, that, for instance, we added a question that was about quality of life that we didn't have in the original version.

Katie Huth *18:18*
And it ended up being an important finding too. I think in your paper suggested that family quality of life and well-being should really be a part of how we evaluate whether these systems and supports are working or being delivered as intended.

Patricia Basualto *18:32*
100%, 100% and it ended up being a very important topic to actually discuss with our interviewees, and that went into the analysis.

Katie Huth *18:42*
How do you think that clinicians should be thinking differently about their own role after reading this paper? What does it mean to care for a child who has neurodevelopmental disabilities?

Patricia Basualto *18:55*
Yeah, so I'm going to bring this back to the children with medical complexity, which are different conditions, that family and the children will come to the system to knock the door many times in their lifetime at different doors also in the system. So, this is a family that will navigate and transition a system between different levels of care and different type of services, they are constantly doing that, constantly. So, when we are service providers, we just see them in that interaction. So, it can be easy to forget the entire patient. So that's the first thing. It's not just your contact as a service provider; it's their contact with the system asking for services to support the child. So regardless of the child health condition, the children will change. The family will have also different needs. So, it's going to be like an ever-changing set of needs that the system will need to support. That means that having that this life course perspective, when thinking how you're providing the services is crucial, right? It's not just about collaborating or coordinating. Our job is to better support the family, because they will be needing different services, at different stages of the lifetime. We know that, right, but I think maybe we have to know a little bit better actually put it as the first thing that's leading our actions. So, the system is very well prepared to actually serve the family from that life course perspective, because it's going to demand a cross sectoral collaboration. It's not just one organization who's responsible, but it's a system.

Katie Huth *20:48*
I love that I think that I saw that a number of participants also were describing gaps, and even just service provider knowledge about the system itself, and it seems like that should be part of our workforce development,

like thinking about how we teach and assess a basic understanding of our systems and navigation support and what families are encountering each day.

Patricia Basualto *21:10*
Yes, totally that life course perspective across a system, strengthens your patient centered care approach that you have as an organization. It makes it flourish, that patient centered care. But also, what I want to add it's also that is good for every actor in the system at every level to be aware of what are the values and principles that's behind the system. So, let's say Canada is for the disability policy, the provincial policy is based on equity, because Canada is a signatory of the United Nations convention of the rights of people with disability. So that's a principle that spreads out of the system okay, is going to shape how the policies and therefore how the action are, and how, what type of services you will provide for whom, by which mechanisms is going to shape everything. So, being aware what is the actual value or principle that your system have, is very important so because then that collaboration and coordination can be aligned, right? That why that I mentioned before. Why are we collaborating? Yeah, to serve a family, but also maybe we're doing it from a very clear value or principle that is nested in that particular jurisdiction. I'm going to say again that when you are a frontline professional, probably you're so engaged in the daily work and that person has a face, right? The family has a face, has a story. You are in first contact with that story that it could be easily for us to forget that, but it's important to have it in mind, because it's shaping our actions indeed, yes.

Katie Huth *23:05*
What do you think are the messages for patients and families from your study?

Patricia Basualto *23:12*
This is to me, this is a very sensitive topic because, for a variety of reasons, but first of all, because our study does not include the voices or the perspective of families directly, right, I cannot say that what service providers and decision makers told us is representative of the families. So, I want to acknowledge that, first, having said that, I want to acknowledge also that beyond what our study is showing in these findings, there could be many other challenges that are not in that practical that will come clear and come across with the voices of the family. Having said that, I think it's important and as a message for the families, that it's like a reassuring message that there's people out in the system, clinical practitioners, educators, social workers, decision makers, policy makers, researchers, clinical researchers, that are very committed, like highly committed, to actually improve the lives of children with disability. They're doing their best they can do to improve the system to get equitable access. And that's something that I was very impressed, because I come from the Chilean, my clinical expertise is in the Chilean system. But I was curious how was in the Canadian system. Also, this interview, I conducted these interviews when I was probably two or three months arrived to my PhD, so I was very new to the system. Now looking backwards. We share across countries, probably we share the same ideals and principles as service providers. In Canada, there are many initiatives, and there's a very active effort to include the voices of different partners in research, not just as a participant respond in a survey or participant in an interview, but as an actual partner in research. That probably is a good opportunity for families that might have the time, the motivation to actually advocate it a different way for the children, their child to probably engage in research.

Katie Huth *25:44*
That's a wonderful message. Just hearing about you clearly have such also a valuable perspective from, I think, spanning health systems and with your research and work that you're doing. And I'm curious if the Canadian health system, or if any health system could implement just one of the recommendations from your findings in the next year. What do you think would have the biggest impact?

Patricia Basualto *26:10*
Well, currently, the government of British Columbia is doing some changes to the system, and they are targeting two aspects which I think they they're very important. First, the Canadian system in British Columbia is very

diagnostic based, the eligibility criteria. Okay, so you have to grant access in some way, but choosing diagnostic criteria risks to leave some people out of the system for different models. They are changing from transitioning from a diagnostic based to a functional type of approach, which is challenging in itself. We know how difficult it is to do a functional assessment that is somewhat standardized, which is kind of contradictory to think, okay, but there's they need to go into a need-based assessment, more functional based assessment to grant access. And the second is something that we talk about here a lot is about collaboration. So, the cross sectoral collaboration needs to be built in the system. Because you're an educator, you don't have to be an expert in health, but at least you should know what your health colleague is doing. So, if that parent goes to you to ask for information in the system because he's having trouble, to actually find the more clear information on how, where and which type of services are out there, so you are at least a little bit informed, so you can support that family, right? So little things like that could be at the front line or even higher in the system.

Katie Huth *27:59*
I know I've peppered you with a lot of big questions. I'm curious what you think are the next steps from this work?

Patricia Basualto *28:08*
So currently, I'm preparing a second manuscript with this analysis, the qualitative, focus on the recommendations. Also with a more policy analysis focus, so very contextualized to the context of British Columbia. It's going to be a publication speaking to them, probably not so much general as the first one that we are discussing now. Also, I'm currently running a quantitative analysis based on administrative data from British Columbia as well. It's going to be the same perspective. So, it's a system perspective. I'm looking educational, social and health support for the same group of population. I'll describe in a year by year the access rates for those services, and then hopefully I'll do a time to an event analysis to see what happens with the time between the children is born to the actual receive of the first service in those ministry, particularly education and social supports and, or from the time the children is diagnosed until they get the services and see how different diagnosis might have different time to access potentially and what confounders or modifiers could be out there from the system, but it's going to be highly system perspective again.

Katie Huth *29:39*
Yeah, I'm really looking forward to seeing more of your work. Do you have any advice or lessons learned to share with other researchers in the field?

Patricia Basualto *29:50*
What I'll, what I would recommend or encourage people is to think about the system you're working in. When you're a clinical practitioner, you can partner with researchers to build a research community that has like different type of partnering in it, so that research can be better well informed with different perspectives. So that's one thing, try to engage with your families. Include them, not just as participants in research, right, but also as partners in research.

Katie Huth *30:24*
Thank you so much for your time, Patricia, and thank you to you and your team for advancing the field of complex care.

Patricia Basualto *30:31*
Thank you, Katie, for the invitation, to for us it's an amazing opportunity to talk to your audience and share a little bit of more like the backstage of the study that there's so, always so much to say, but a paper just have so many words where you can say something. So, thank you for the invitation again.

Katie Huth *30:52*

Of course, we're looking forward to hearing more from you and your team, and thank you for reminding us about the story behind every interaction and within every system. And thank you everyone for listening to the Complex Care Journal Club Podcast. We aim to highlight research that has the potential to be practice-changing, that values patient and family engagement, is relevant across disciplines and diagnoses and uses high quality or novel research methods. We invite you to join the conversation by suggesting an article that you would like to see discussed in this podcast using the form provided on the OPENPediatrics YouTube channel. Thank you for joining us.

Journal Club Article

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