

IECSS Inclusive Beginnings Podcast, Episode 2 (Inclusive Beginning: Community Partnerships) transcript

Date of transcription: March 3, 2023

Length of Podcast: 29 minutes and 48 seconds

Speakers:

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Kevin McShan: The connectivity of partnerships really elevates a project's potential to maximize its impact. In this episode of Inclusive Beginnings, we'll take a deeper dive and a closer look at two of the essential partnerships within the community which makes the IECSS project one that prominent community partners want to get behind. Nancy Hendy is a Program Manager at Toronto Children's Services. Meanwhile, Arlene Haché is the former Executive Director of Keepers of the Circle. They both join me in this episode to discuss why it was so intricately important for their respective organizations to become involved in this transformational project. Nancy, I want to take a moment to welcome you to our conversation about this inclusive and most important project and I want to thank you for being here this morning. It's most appreciated!

Nancy Hendy: You're very welcome. Thank you for saying that Kevin.

Kevin: Absolutely, now Nancy I'm curious if we can start our conversation by you simply telling me your connection to the project and why you think it's so important.

Nancy: That's a great question. So, in phase one of this project Toronto Children's Services was one of-part of this wonderful group of partners that have been part of it from the get go, from across the country and we've been an active and engaged partner through that entire period. I became aware of this project when I first began at Toronto Children's Services back in 2015 and that's when I came in to the city as the Program Manager for the Every Child Belongs Unit. For those listeners who may not be aware of what Every Child Belongs is, at Toronto Children's Services we provide services for children with extra support needs in child care and in EarlyON programs, through the Every Child Belongs model. So, I just wanted to give you a little synopsis of when I started with the City and uh, that's actually when I became aware of the project itself. So, we've been an active partner from the start through both financial and in-kind supports. What does in-kind mean? Well, that means we help with recruitment, participated in disseminating materials, there was key informant interviews, disseminate the briefings-the policy briefs I should say and articles, and other important information that came out of that, of the mapping itself. Part of the work that we do also is with the

partners in terms of governance and advisory committees and that type of work with the project. So, in a nutshell, really Kevin, that's what I've been participating in since I became part of this project.

Kevin: And tell me. How do you think your participation in the project has been influential to you, your organization, and the Toronto community.

Nancy: Right. Um, so the understanding of how a service system, from the perspective of families who have a child with a disability, and the children and youth themselves is so important. That's the most influential part of this work that-from my perspective. So, the journey mapping itself through institutional ethnography of the journey of families helps to demonstrate that complexity and the nuance that is shouldered by families. They're doing the heavy lifting out there when it comes to getting the support they need for their children and their family through the service system. They really are the ones who are doing that work to get services for their child.

Kevin: Yes-

Nancy: Those stories and the mapping of those stories for an individual child and a family-it also tells the story of a community and how different services can be influenced by where you live and your cultural group. That cross section of different cultural groups and different communities really tells different stories. Their journey mapping is very different depending on where they are living and the cultural group they come from. In the past there's been very little data to tell those stories and so this project actually does that. It gives data to these stories and that data can help to inform policies and decisions that impact on service delivery. That sort of thing is really, *really* influential.

Kevin: Yeah, absolutely and you touched on my next question at the tail end of your last answer, but I will ask you from a more broader perspective, what is it that the strengths are of the project specifically?

Nancy: Well, I think it's really clear that the most important aspect of the project are the voices of the children with disabilities and their families that are coming through this research through the findings and the data. That has been, once again, the most influential and important piece. Listening to and hearing the journey of the children and their families' throughs service systems it really helps to deepen our understanding of each unique and personal story. Gathering that together in a cross-cultural sample provides a lens on that lived experience and helps to inform strategic directions that lead to better outcomes for children with disabilities. Built on that, you know what we already know from Human Rights legislation and the Ontario Human Rights commission information that we have for-that already informs us. So, it really builds off of that as well. Um, I also think that the visual representation, Kevin, is so important because when you see a map and how many different places a journey can go and how many different directions a family goes in to get the services that they need, that visual representation it really is striking. It really-what's the word I'm looking for. It's a very strong influence on how you receive the information.

Kevin: Yeah, and going forward I'm curious to ask you what are you-what are your greatest hopes for your organization and this partnership?

Nancy: Well, I think-you know, sort of in a nutshell I really want people to know about this. I really want them to see the maps and understand the journey of children and families. I really want this to be able to inform policy direction. We can use and have been using this information to modify and develop models of support and interaction. That has been really important. It has helped us to improve customer experience by letting our front-line caseworkers and consultants and even front line ECEs know and understand the journey of families. It has been an influence to customer experience through that-through being able to do that and um, just helped to inform so that it can improve the cultural competency of our front-line staff and ourselves. I think we're all on a learning journey at all times and the information that we gather through different sources including this one helps us to understand how to improve on the journey of children and families. Not only through the lens of disability but also through the lens of culture.

Kevin: Yeah, and Nancy I'm wondering what thoughts are-how do you hope this project sort of helps to guide the government in making decisions about policy moving forward in the best interest of children?

Nancy: Thanks, Kevin. That's a really great question as well. These policy briefs and the information, the maps that have come out of the project help to inform how to deliver inclusive programs, how to deliver inclusive language and it gives recommendations on even things around system transformation and that has helped to inform our resource consultation model and as I said in the last question also, in regards to service delivery even on the front line. So, you know, how do we do that? Well, we really took these-the information and did a broad range of presentations to different groups to help them understand the information and really hear the voices of families and children and youth. Um, and um, we know that addressing challenges in learning pathways for those on the margins helps reduce barriers for all children and families. So, although we are talking about children with extra support needs, children with special gifts, uh, children with disabilities, we do understand that when we make improvements for that group of children, we are making improvements for everyone. So, I think that is also a cornerstone to the importance of this information.

Kevin: Yeah, absolutely. Nancy, my final question for you this morning is how do you think you define an inclusive future for children with disabilities across the province and the country?

Nancy: Kevin, um, what I would say is this. That um, there really should not be a map that tells a story of a family that needs to be told-thanks, so much Kevin, that's a great question and a really important one because I think we all envision a place-a world where all children participate equally and in a way that is supportive to their ability without differentiation, okay? The fact that we have to put a lens to something that is

um, a journey for families and have to help others understand how to make that journey better tells us that we have a lot more work to do. That, in terms of the family maps and their journey, it's important. If we get to a place where we don't need that map anymore then we know we've come to a place where equity and inclusion are just a part of our everyday existence and our everyday work with all children. That's the place I hope we can get to.

Kevin: So, Nancy tell me. Why was it important for your organization to decide to be a part of this partnership?

Nancy: So, my predecessor, Dick Winters, was the original Program Manager from Toronto Children's Services involved in this project. Dick really saw the value of the service-understanding the service journey of families and children and when approached by Dr. Underwood to be a part of the project we were really eager to support and at that time, it was a three year project and then expanded to an additional seven years through further grants and I think in terms of a 10 year longitudinal- sorry- in terms of a 10 year longitudinal study, this provides very important evidence informed information and data. In the second phase, adding the voice of children and youth has been a very dramatic influencer. So, in the first part of the three-year study, we're just looking at the journey mapping of families and now adding on the Youth Advisory in the second phase has been really, *really* important. I know there was recently the launch of an online web resource by the Youth Advisory, which we're really looking forward to diving into a little bit more deeply. So, one more thing I wanted to mention is how grateful we are to be a part of a really dedicated group of partners and when the project first started there was a financial contribution from the partners at that point because at that time the project didn't receive the grant money that had been applied for and so the partners actually funded the first year of the project in order to ensure that it would happen. So, that in itself tells you how strongly the partners feel about this project and how important the work is in informing our policies and decisions and just helping to improve the lives of children and families.

Kevin: Well, Nancy I want to thank you for your involvement in this ground-breaking project and for joining me this morning to share your thoughts and insights. It's most appreciated.

Nancy: Thank you so much, Kevin. I really appreciate this opportunity to speak about the project and the important work.

Kevin: For her part, Haché began her remarks by reflecting on her personal connection to the project and why it was so meaningful for her.

Arlene: The connection I have is that I have been a sort of, part of homelessness. I was homeless and sort of in places where there was a lot of exclusion and not inclusion for a lot of different reasons. So, I'm always really focused on making sure there's inclusion of people regardless of their abilities or ways of being, ways of doing and you know, exclusion particularly impacted Indigenous children in the work that I do and especially

Indigenous children that are considered to be disabled or considered to be you know, not behaving in a way that they need to be in a group and that kind of thing. So, over the years-many years- I've been kind of struck by the numbers of small children and children that are kicked out of daycares and kicked out of schools and that sort of thing. To just end up at home with no help and no resources just because they think in a different way, and they're used to being the world a different way that doesn't match how services are provided.

Kevin: Yeah, and tell me, Arlene. Tell me why you think this partnership is an important one and why your organization decided to be a part of it?

Arlene: We were excited about this partnership for two reasons. It was led by Kathryn Underwood and she is a particularly-in my view, a very unusual person in that she breathes the work that she's doing. It's not a job to her. That's part of her life and that's part of her personal experience and she breathes the work and that matters to me because we're going- I work from a position of lived expertise in the work that I do. So, we kind of meshed in terms of how we both are really dedicated to the communities we serve. Then the other thing-the other reason I was excited about the project is because it wasn't focused on service providers. It was focused on hearing directly from youth with disabilities and from parents who had children with disabilities, and it was about documenting their experience. I find that's unusual and important because [clears throat] service providers are not the same thing as the people who use the service and I find that service providers often think they know and represent that they know what lived experience is like and they don't. So, I think that it's important to kind of being engaged in projects where people with lived experience of disability, or homelessness, or you know these services-it's important to hear directly from those people.

Kevin: Yeah, absolutely and tell me how do you suppose this project will be influential on behalf of your organization, community, and yourself personally?

Arlene: Well, when you pull all of the information together and when you see it in such a visual way, in the way that this project has kind of captured that voice-it's really clear-clearly laid out and shocking about how difficult it is and how much energy it takes, and how challenging it is for people to access any services. Then when you-it kind of shows that the services that are available in a city are not the same thing as services that are available in rural areas. Or no services are available in rural areas. So, it really paints a clear picture from the perspective of parents with children with disabilities or youth with disabilities about what their supports really look like and how hard they actually have to work to find them, how hard they have to work to actually access those services and stay in those services. So, it's a really visual way of telling a story that you rarely hear.

Kevin: Yeah, absolutely and Arlene tell me what do you view as the strength of this project in particular?

Arlene: Well, I would say the strength is that it really connects with the people that are most impacted by the services that they're getting and then you can't diminish the

importance of a great leader. Again, Kathryn Underwood-and I've been on a lot of research teams-Kathryn Underwood is a rare individual who really listens and really hears what you're saying and helps you kind of question it and really be what do you call it? Balanced and wise in how you're understanding the work.

Kevin: And Arlene tell me, what do you hope or results in terms of your ongoing partnership with the organization and the partnership?

Arlene: Well, what I really hope is that the work that we do really changes systems. I hope that the work that we do really helps systems or service providers understand that they have to change the way they do things. I hope it helps decision makers know that they have to make sure that the voices of lived expertise are leading services, not the other way around. So, I hope that the work we're doing is really transformative of the way the world looks at people with disabilities and the family members that support them.

Kevin: And Arlene tell me how do you hope this project positively impacts governmental policy and the way we really uh, promote inclusion from a societal perspective?

Arlene: Well, the most frustrating thing for me over many decades dealing with governments and decision-makers in governments is they never quite really grasp what I'm talking about. So, I used to get really frustrated because they would always say 'paint me a picture of who these people are, paint me a picture of who these people with disabilities are, paint me a picture of these people who are homeless are,' and I said, "well, you're looking at one." Like what are you talking about? It's like they don't even see you when they're talking to you. You're totally invisible kind of-you're totally invisible to them if they haven't had that experience themselves and I think that if people with lived experience don't partner with researchers who really understand how to help you paint that picture to that government audience or to that particular room of decision-makers then you will never get the change you need. You'll never get the resources you need because it's like speaking two different languages.

Kevin: Yeah, and Arlene my final question for you this afternoon has to do with how do you define an inclusive future for children with disabilities?

Arlene: I define inclusiveness as you know, it might not be the most 'researchy' way to put it, but I find inclusiveness is around embracing every person in the way that they want to be. I have a grandson who has been diagnosed with autism and to me he's the most wonderful, different, unique kind of person in the world and you know as a child-as a young person I was raised to be a certain way and we weren't allowed to even look at accommodating differences or tolerating differences really and so, you know in this world I learned because I was marginalized and in a shelter and homeless and treated like I didn't count and treated like you know that I was valueless. So, I want every person no matter who to realize they are a valued human being. They are valued, they are loved, they are important, and they contribute. They literally contribute to the well-being of society. So, to me that's an inclusive society.

Kevin: Arlene, I want to thank you for your tremendous insight and perspective on this important project and I want to thank you for your commitment to diversity, equity, and inclusion and for joining me this afternoon. It's most appreciated.

Arlene: Thanks very much, Kevin. Thank you.

Kevin: In future episodes of Inclusive Beginnings, we'll examine and take a deeper dive into the experiences of Indigenous and Black families and get their firsthand account of raising children with disabilities. We'll also have a conversation with senior researchers from the City of Hamilton and their division of Children and Community Services and discover why the city has also made this project something they are intentionally and intently focused on. I'm Kevin McShan and I'll see you next time.

END: 29:48