Inclusive Beginnings

Episode 1: Youth Perspectives

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Kevin:

The [Inclusive] Early Childhood Service System (IECSS) is a research project working to better understand programs for children with disabilities. The project uses interviews with families to better understand processes and procedures to access activities and accessibility in daily lives. For disabled children, this can lead to recommendations for educators and governments to make changes that are based on experience of children and families [sic].

The IECSS project is a 9-year partnership between university researchers, community organizations and governments. The partners are working together to better understand disability in early childhood. From the outset, the research partners wanted to hear from Indigenous families, families living with low-income, Black families, families of colour, as well as families living in different geographical locations including rural, remote and Indigenous communities. Grounding their work in everyday decisions and activities of children and families helped the research team better understand how disability is accounted for in children’s identities, participation, and exclusion from early childhood environments.

The partners who started this project decided which researchers they wanted to work with. They also chose to have three advisory committees: The Youth Advisory committee, the Indigenous Elders’ Council and the International Advisory Committee. The partners also planned for specific analysis of the interaction of disability and race – as a result, the project now has a Black Experiences Advisory committee – which I am a part of!

Currently, the project communities consist of: The County of Wellington (Ontario), the District of Temiskaming (Ontario), the Cities of Toronto and Hamilton (Ontario), the Region of Peel (Ontario), Constance Lake First Nation/Hearst (Ontario), Brandon (Manitoba), Comox Valley/Powell River (British Columbia), and Yellowknife (Northwest Territories).

This podcast series is a collaboration between IECSS and the Let's Have this Conversation podcast. The series will present different conversations inspired by different analytical threads emerging from the everyday lives of disabled children and their families documented through the IECSS project. For a full list of IECSS research team members and those involved in the podcast, please see the show notes.

Episode one features discussions with IECSS Youth Advisory committee members, IECSS project coordinator, Abneet Atwal. They discuss what they’ve learned while working on the advisory committee and advice for families, educators, and other professionals.

Abneet Atwal is one of the project coordinators for the project and she says that by engaging with the youth, it provides an opportunity to really get to the heartbeat of the matter.

Abneet:

I think I have been a part of a lot of the interviews with the families and learning from families, so the focus of our research project is the early years, so those very little children. When families start the project, the children are two, three, four years old. They might not be able to talk to us about all the processes that are required to engage with services-- all those application forms, meetings with professionals. When we talk to families it gives us a different perspective. We get to learn about those processes that families are required to engage in with different institutions and services, in order to get access for their child and to get the supports that they require for their child. So, the families give us a very unique perspective on access to services within the early years sector.

Kevin:

Gregory Doucet, Munashe Nyenya, Grace Sweetman and Kalea Davies are all members of the youth advisory committee for the project. And I had a chance to sit down with all of them to reflect upon why they got involved in a project in the first place, the need for education amongst the child service sector and the people they are intending the service, and the messages they hope this project provides on a grander scale. I begin our discussion by asking all of them why it was essentially important to all of them to get involved in this endeavor.

And tell me, Gregory, tell me about the project that you are embarking on and what sort of purpose you hope that the project we are talking about today in this podcast serves other people.

Gregory:

We are hoping that it's going to be a resource for parents of children with disability, young children especially with disabilities, to be able to look at or to be able to obtain– to better understand the services that are available to them. Especially in the school system because the school system is the hardest to navigate, and I have for much first-hand experience with that.

Munashe:

I think it was really important for me to be part of this project because as a person with disabilities I really wanted to help other kids with disabilities experiencing the same kind of struggles. And, I thought it was a really great opportunity to share concerns of the community as a person with disability, as a person with albinism, and share because I know that there are going to be a lot more kids just like me that are going to face the same struggles. I want to make sure that they have the best possibility to succeed, and so that's why– one of the main reasons I really wanted to because I knew if it didn't really change it would still have the same kind of problem. So, that is what kind of motivated me to like I want to help the next person coming through the door.

Kalea:

I have really seen the benefits of knowing how to advocate for yourself in systems because of the way that I grew up and the way my parents helped me learn about these things. I think it's really important that all people with disabilities have the same opportunities that I had.

Grace:

Well, I started working with the IECSS I think it was the fall of grade 10. It was at a conference in Ottawa at Carleton University. I don't know, I think my mom just wanted to get me involved in the disability community and after that conference, I really, really started getting more and more passionate about disability rights and inclusion. And, since then I feel like it's just become my focus and it's something that I see myself continuing to do into the future.

Kevin:

Absolutely and tell me, what are some of the more interesting tidbits of information or findings that families have shared with you so far.

Abneet:

A lot of the families talk about the amount of work that is required in order to access services. So again, filling out all those applications, going to meetings, engaging with all these professionals. Families do a lot of work in order to get access for their young children and I think another thing that's been coming out of our research is intersectionality. So, different families and different children do have different experiences based on their identities, so whether it be class, race, citizenship status, geographic location. If we're thinking about rural Ontario versus urban places in Ontario, the experiences differ quite a bit. We do have a diverse group of families that participate in the study and it gives us insights into how intersectionality plays a role in families’ experiences.

Kevin:

Yeah, absolutely. Let’s talk a bit about the education, in terms of services. Doing these interviews with the youth myself, a lot of them have shared with me that they are excited to be a part of this project because they feel that being a part of this project brings to life the importance of the collaboration of services and working with the service sector. So tell me, how important do you think the youth perspective is when it comes to navigating the service sector as well?

Abneet:

I think the youth perspective is really important, so that's why we started to work with the young people. As we've been talking about, the families have given us a lot of information and we've learned a lot about that navigation to services. But, because we haven't been able to talk to very young children in our research-- talking to the youth, because they are a little bit older when we started working with them many of them were between 12 and 18, it's been 4 years now, so a lot of them are in high school or gone off into other post-secondary education or after adult opportunities. So because they’re a little bit older, they're able to now reflect on those early experiences that they had and provide advice to educators, professionals, and also provide advice to families and young children. In our work with them in the different activities that we've engaged with, we've been talking to them a lot about our research findings and what they think is important from those findings, and how we should be sharing them. You know, we wrote an article with a few of them last year, specifically about the education system. Some of the key ideas that came out of that is that they really want educators to be talking to them directly about what they require, and they discussed if educators and professionals want to understand the experiences of disabled young children-- the only way really to do that is to directly speak to them. This isn't only important for educators, but for all professionals. They also highlighted some of their early experiences within the education system-- people stared at them, would ask odd questions or they would see, like, people talking about them. They highlight that when we think about the early years and education when children are really young, there's this fear that adults sometimes have about talking about disability in general. So, talking to children about disability and the young people have really highlighted that it's really important for educators and professionals to talk to all the children about disability and the classroom, I think provides great space for this. One thing that we've been working with them on is creating this website to share research findings and putting our research findings in child friendly language. So that's one resource that educators could use to start having those conversations with young children. I think that's one of the greatest things that we've learned from them-- that importance of engaging in these conversations and not being scared to have these conversations with children. They also talked a little bit in some of our earlier meetings about how educators and professionals sometimes really focus on the here and now, like what do we need right now. But, a lot of them talked about how they also want educators and professionals to consider their futures, so as they get older-- what are the opportunities? what does the world look like after school? This also connects to the idea like fostering a positive disability identity, and that's something that's been highlighted by our young people. They say that again, that educators play an important role in that.

Kevin:

For this group of talented panelists, one message they wanted to convey with the strongest sense of conviction was the importance of building a strong sense of community and inclusion, within a community of support, in order to successfully navigate the early years with a disability.

Kalea:

I would say that it's ok to speak up for yourself. A lot of people are going to try and tell you what you can and cannot do, but only you know what you can and cannot do. Only you have that power over yourself, so just remember that you are the ultimate decider of how your life will go. Even though you may face extra barriers, you can always overcome them if you're willing to try and willing to ask for help.

Kevin:

And tell me, what advice do you have for young parents who are just beginning their journey with a young child with a disability?

Kalea:

So, what I learned from my parents is that you just kind of have to keep searching. You might not always get the answers that you want, but you just have to keep searching because there's always something out there, something more that you can do to help your child. Another opinion. Another doctor. And, that's difficult. It's not always easy, but there are possibilities. And also it's very important to help your child learn how to advocate for themselves because when you're no longer there, then they'll have the tools to be able to help themselves in the future.

Gregory:

I would say that don't be worried, everything is going to be all fine. Also, continue to look for opportunities to connect with the community and always make sure that the child will have like this community and a group of peers just like them, so they don't really feel isolated but rather feel like they have a community with other people like them. Don't be afraid to let them do different activities and extracurriculars. I'm sure the community will have some for your child and just encourage them to do their best in everything they do and in whatever they do.

Kevin:

Munashe, tell me what sort of advice would you have for early childhood professionals who are entering this field and working with young disabled children?

Munashe:

I would say listen a lot to their needs, listen a lot to what they want and what they think they want. Also, be very willing to look into new technologies, look into new methods and always be open to new solutions. And, always collaborate with the parents and the teachers and the children together to make a great team I would say.

Gregory:

Just that you're not alone and there are lots and lots of other people just like you and we all have the same struggles. It might not feel like there's always someone with you, but we're always thinking about you and there's never a time at which you're experiencing something that no one else has ever experienced. And that other person has always been able to fight through it and so can you.

Kevin:

Yeah and tell me in terms of parents of young disabled children, what advice do you have for parents during the early years as they try to navigate this new experience that they are embarking on?

Gregory:

Check to make sure that your child has all the supports that they need. Make sure that you are not holding their hand the whole way through, so that they learn to cope by themselves as well. But when they were younger, of course, you need to help them and you need to help them grow and learn and overcome their challenges. But their challenges do not stop them from being a child. Do not make it so that their whole life is focused on their challenges-- Let kids be kids as is the most important thing that I can say.

Grace:

I would say don't let others put you down, like if they say you can't do something, don't listen to them. It's not about what you can't do, it's what you can do and you don't know what you can and can't do until you try. So always try, work hard and you might be surprised with what you can accomplish.

Kevin:

Yes, absolutely. What advice would you give to young parents of disabled children about how to navigate having young children with disabilities.

Grace:

Don't be afraid to ask for help. Like even my mom she is part of different groups-- I think she's in Facebook groups and she talks to other parents who also have disabled children. I think that kind of connection and community is really important and yeah.

Kevin:

Yes, absolutely. Tell me, what sort of advice would you have for anyone that wants to pursue working with young children with disabilities? What sort of advice would you give to professionals that want to enter the early childhood space with disabilities?

Grace:

Well, I'd say that it definitely takes a lot of patience. You have to understand that these children they might not act like your typical kid, but they're definitely not stupid. There's a lot going on. It's hard for us to understand because we're not in their shoes and you kind of just need to come from a point of understanding I guess. Listen to them-- to what they're saying and what they want and just sort of get down on their level.

Kevin:

There's so much more we would like to explore during our conversation on Inclusive Beginnings, including a more in-depth dive on the project itself, the panelists' definition of what it truly means to be inclusive and how we can all work together to close the gaps of service, understanding and education. I'm Kevin McShan, I thank you for joining us on our first initial episode exploring this important endeavor and I look forward to seeing you next time.