

Research Brief No. 1: Young people's analysis of systemic production of disabled childhoods and research (July 2019)

The Inclusive Early Childhood Service System project (IECSS)

The Inclusive Early Childhood Service System project is a partnership funded by the Social Sciences and Humanities Research Council (SSRHC), Ryerson University, and the project partners. This partnership is led by Ryerson University, working in conjunction with a number of academic, municipal and community partners who have expertise in social policy, disability studies, nursing, social work, and early childhood studies. (A full list is available online www.inclusiveearlychildhood.ca.)

The partnership includes representatives from childcare, early intervention, social service planning, and research, as well as organizations that practice in these domains using Indigenous values. This brief does not represent the viewpoint of any partner organizations but an analysis from the project perspective.

The purpose of the project is to understand experiences of disability in early childhood and to understand how services are delivered in varied geographic and cultural contexts. Our aim is to build theoretical understanding that may inform social policy to have more respectful and responsive supports that recognize the value of disability identities, and the need for universally designed services.

This Research Brief is the first in a series of briefs that communicate findings from our advisory committee groups. Our goal in these briefs is to provide guidance to the researchers, partners, students and staff who work on the IECSS project. Making these guiding reports public allow us to share the wisdom passed on to our research team to the larger research world. They also allow us to cite the Advisory Committees where we draw on their advice in our academic publications.

This is the 1st in a series of research briefs that are prepared as part of the IECSS Project. To view the other briefs in this series please visit www.inclusiveearlychildhood.ca.

Cite brief as:

Underwood, K. & Atwal, A. (2019). Young people's analysis of systemic production of disabled childhoods and research. Inclusive Early Childhood Service System project: Research Brief No. 1. Available online: <http://iecss.blog.ryerson.ca/files/2019/11/Research-brief-1-Young-peoples-views-on-disabled-childhoods.pdf>

Youth Advisory Committee

The Inclusive Early Childhood Service System project (IECSS) is a longitudinal study of how institutions construct childhood disability. The study has been underway for 3 years, and recently was awarded funding for an additional 7 years. Drawing on our experience from the first phase of the project, and in order to facilitate participation of social groups impacted by the research, we have formed three research advisory committees. Our goal is to ensure meaningful community consultation and ethical decision-making throughout the research process. The three Advisory groups who will guide the 7-year partnership include a Youth Advisory Committee, the District of Temiskaming Elders' Council, and an International Advisory Committee. This research brief is part of the ongoing process of communication between the research team and the Youth Advisory Committee. It is also being shared publicly for the benefit of the broader disability and research communities.

The Youth Advisory Committee

Through the summer and fall of 2018, we recruited Youth Advisory committee members to meet. The purpose of the Youth Advisory committee was to inform our analysis, and to provide expertise on our interpretation of the childhood cultural aspects of the IECSS study. The Advisory Committee was established because from both disability and childhood studies perspectives, research about disabled children should not be conducted without active engagement with disabled young people (Charlton, 1998).

The Youth Advisory includes 21 Youth aged 10 to 20 who identify as having a disability or who are deaf. The Youth Advisors are from five provinces: Alberta, Saskatchewan, Ontario, New Brunswick, and Newfoundland, and from a range of disability identity groups, including deaf youth, Indigenous disabled youth, neurodiverse youth, blind youth and youth with physical and intellectual disabilities. Youth were recruited through emails and phone calls to University access centres and networks and through partner organizations, research team networks, as well as other disability and youth specific organizations and programs across the country.

IECSS/Shaking the Movers Event

The first event for our Youth Advisory Committee was a children's rights forum hosted by the Landon Pearson Centre at Carleton University. This event was an opportunity for young people to come together and learn about children's rights and disability rights frameworks. For more details about the event, please refer to the workshop report (Benincasa, St. Dennis, & Caputo, 2018; Xu, 2018). The format of the meeting was a "youth-led and youth-driven" method developed by the Landon Pearson Centre for the Study of Children's Rights and Childhood. The "Shaking the Movers" approach was designed by the Landon Pearson Centre to enable children and young people to present their unique perspectives and experiences, and to provide specific recommendations and input related to children's civil, political and participatory rights. In keeping with the method, adults provided infrastructure support only and were not to be part of the group.

The IECSS/STM event was successful in bringing the Youth together, building relationships and providing an opportunity to them to share their own views on their rights. However, we wanted to follow it with a more direct discussion of the IECSS research project. Our goal for the Youth Advisory Committee from the outset has been to gain perspective from the Youth on both our ongoing findings from the research as well as their perspectives on ongoing development of relevant research questions, design and implementation of new research initiatives. Finally, we were seeking advice on targeted mobilisation of the research. In the months following the IECSS/STM event we had 3 small group video-conference meetings with a maximum of 5 Youth Advisors, as well as one face-to-face meeting specifically for deaf Youth Advisors. The findings from the deaf Youth Advisory meeting are reported in a separate research brief (Snoddon, forthcoming).

Procedures and systems

Our meetings began with us sharing findings from our ongoing research. Appendix 1 shows a map generated by asking a mother about her interactions as she sought services for her young child in Toronto. We asked our Advisory Committee for their reflections on their own early experiences and to interpret our findings from the perspective of the child.

One young person noted that similar to what is represented in the map, “I find there are services it just takes a very long time to get and there’s a very long process (Kalea, meeting 1).

Another Youth noted that,

It’s very, very complicated. And somebody that small would be kind of – I don’t know, confused but kind of like curious/confused. Because they are seeing so many different people for so many different things. And they might not know really what is going on at the time, kind of thing (Youth Advisory Member, meeting 3).

When we asked participants if there was something missing from the map, or if there were too many services on the map, they described a tension between wanting greater access to services through easier procedures. This included being able to access these services through mainstream programs such as childcare and schools, rather than in special settings. Most of the Youth Advisors had participated in special services in their early childhood.

One Youth Advisor said that “her experience was pretty good because I was able to [be] connected to a lot of different programs. So I did swimming and horseback riding and a bunch of recreational activities that helped me to start thinking about what I wanted to do when I got older (Kalea, meeting 1).

Another Youth Advisor, however, said that in these programs “I did learn some things out of that but I found the work they did was repetitive in a way. They kept teaching us

the same things” (Youth Advisory Member, meeting 3). Several Youth Advisors raised this point. This same Advisor noted that Occupational Therapy appeared multiple times on the map, which confirmed one of our findings.

Ultimately, there was a common thread that these services are important. The Youth Advisors note that in all services including in special services and general early childhood education, care, and intervention services. One Youth said, “I did have in school OT and in school physiotherapy. But they only worked with me [for a short time on minimal goal]. It’s almost like they were giving me the bare minimum of what they could do” (Youth Advisory Member, meeting 3). When discussing their experience in school, B.B (meeting 1) said, “I hate my new school because they’re not really supporting me with my adaptive needs.”

The final concern that arose was that participating in these services “really affects you” (Munashe, meeting 1). “You know that your parents are trying to make sure you adjust. And sometimes when you do extra meetings and stuff like that, it takes away your personal time. [...] It could be hard to socialize after because you know you have to do a certain thing, while your other friends are going out and having fun” (Munashe, meeting 1). This concern does not mean that the Youth Advisors did not want special services. One Youth noted that “now that I’m moving on and I’m living with the after effects, I kind of want more support and stuff just to help me live a better life” (MK, meeting 2).

Key Messages from the Youth Advisors:

- The process to get access to services is long and complicated
- There needs to be more access to services through mainstream programs
- Special services and general early childhood, education, care, and intervention services are important
- Participation in services has an effect on children’s participation in other aspects of their lives

The work of families

In the meetings, we asked participants to reflect on the role of families in getting access to services. The Youth Advisors noted that it was important for adults to speak up for young people, particularly if they were being bullied by other children or adults. They thought it was critical for adults to provide intervention in their learning, especially if the adults involved (parents, early childhood educators, teachers or therapists) had particular traits. These included “patience”, “empathy”, “flexibility” and they allowed independence as well as interdependence. This term is introduced here to capture the importance that the Youth Advisors placed on adults who supported them in their lives, including in early childhood and school settings.

One Youth Advisor noted that it is important for parents (and families) to have support for themselves not just their children. The Youth Advisors recommended that for families;

After you've gotten a diagnosis, you shouldn't necessarily just listen to what medical professionals have to say, because everything they say is scientific based on numbers and science. But I think that it's important to talk to other parents of children with cerebral palsy [for example] and other youth and teenagers with cerebral palsy to learn their struggles so you can better know how to help your child when the time comes that they need help. (Kalea, meeting 1)

The same Youth Advisor noted that “if you do more research prior to getting a diagnosis and you don't go see as many people then it helps the diagnosis process be more straightforward and therefore the child's not moving around so much”. Munashe (meeting 1) agreed, saying understanding what your child is going through in their day to day lives is important so, “you can connect more to them [the child] and go to the doctor and say, ‘I think my child is gonna struggle with this and this.’”

Overall, the Youth Advisors acknowledged the critical role of their parents and adults in their lives, but ultimately, they also felt it was important for young people to speak for themselves. Kalea (meeting 1) said, “The only way to truly understand what someone is going to go through, is to ask them directly”. This is central to better understanding what young people need from institutions, but also how they define themselves (in the next section) and how they are represented in research (see below).

Key Messages from the Youth Advisors:

- Important for adults to speak up for young children
- Parents and families need support for themselves
- Parents and families should get to know their child and do their research prior to getting a diagnosis has an effect on children's participation in other aspects of their lives

Disability identity

Based on our research findings, diagnosis and designations of impairment are central to gaining access to services. We asked the Youth Advisors about how people talk to them about disability and whether the right conversations are taking place. We also asked them what information they would have liked to have when they were younger.

Throughout the advisory meetings, we heard that being a disabled person is positive but other people don't see it that way. One Youth Advisor told us, “It's like kind of like a gift almost because it makes you almost more special. And different from everyone else” (Grace, meeting 3).

Across the meetings we heard about the tension between how the Youth Advisors see themselves and how others view them. They noted that teachers often misunderstand

that each child is unique and that their diagnosis does not define them. They also noted that many people, including other children, teachers, and people who do not have experience with disability make assumptions about them. Many Youth Advisors agreed that other young people have a difficult time talking to them about disability. One Youth Advisor said, “I think it is important to allow kids to ask these questions and to not be afraid that it’s rude or disrespectful” (Kalea, meeting 1). She further noted that “it’s more rude or disrespectful for adults to later be staring and really awkward around people with disabilities, than to ask these questions when they are younger so they get an answer and they can understand it better” (Kalea, meeting 1).

Many of the Youth Advisors also noted that few adults had talked to them about disability. Most of the Youth Advisors had spoken to their own parents about disability but they described a discomfort on the part of people outside their families in talking about disability. B.B (meeting 1) said, “my parents told me at a young age that I had autism. My mom did most of the work in telling me but in my experience it was ok because I was just like thinking about how I’m going to have a future with this”.

In addition, several Youth Advisors noted that “a lot of times, adults think it’s only about right now and helping people with disabilities while they’re young, but they don’t really focus on the future or they don’t care much about the future” (Kalea, meeting 1). The implication is that a more positive representation of disability is needed, and that it would be consistent with the Youth’s own positive view of themselves.

The Youth Advisors also acknowledged that disability identity does not stand-alone. They discussed the need for equity across the country and the need for politicians to recognize diversity. The Youth Advisors specifically noted geographical differences in terms of funding and immigration. Our study has also identified differences based on race, gender, and economics.

Key Messages from the Youth Advisors:

- Being a disabled person is positive but a more positive representation of disability is needed
- Many people make assumptions about them
- People outside of their family have a difficult time talking to them about disability

Reflections for current and future research

We finished the meetings by noting that we believe research helps us to find out about things we don’t know. We then asked our Youth Advisors what research questions and approaches we should explore in the future.

One Youth suggested that we make documentaries about specific children so that educators and other adults would understand that each child is unique. They also suggested that this should follow people from early childhood to adulthood, confirming

our view that longitudinal studies are important. We want to note that one of our Youth Advisors has been involved in a documentary (Müller, 2017), as are some of the researchers associated with this project (Enacting autism and inclusion, 2019; Living life to the fullest, 2019). Grace (meeting 3) said that “In the disability community there are more kids who are into writing things like their own kind of stories about the disability or condition so that it’s not just coming from what a professional knows or what the internet or wiki is saying, but something personal”. When considering the audience for our research, the Youth Advisory committee told us that we should share the findings with a number of groups. Munashe (meeting 1) said we should “make it easier to get those services and maybe make it an easier process to get those services. Find help—like the government can maybe help the parents and the family to find support and help”.

Further, a suggestion that we talk to educators and early childhood educators about our findings, and to better understand the “reasons why they approach things the way that they do, and what they’ve been taught? (Kalea, meeting 1).

Finally, the Youth noted that their own perspectives as youth differed from how they felt when they were young. The final suggestion was that we need to talk directly with younger children. The Youth Advisors varied in their views of what age would be appropriate, but the ages ranged from age 6 to 10 and a suggestion was made that Youth would be good interviewers for younger children because they could relate to each other.

Resources

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