

Research Brief No. 2: Analysis from young deaf people of IECSS findings (September 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 and deaf studies, nursing, social work, health 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 create an empirical record of experiences of young children and their families in order 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 and deaf identities, and full participation in family and community. We are working from the assumption that we all need universally designed services – but we are open to being challenged on our assumptions.

This Research Brief is the second 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 and authority 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.

To view the other research and policy briefs in this series please visit
www.inclusiveearlychildhood.ca.

Cite this brief as:

Snoddon, K. & Underwood, K. (2019). Analysis from young deaf people on IECSS findings. Inclusive Early Childhood Service System project: Research Brief No. 2. Available online: <http://iecss.blog.ryerson.ca/files/2019/11/Research-brief-2-Analysis-from-young-deaf-people-ofIECSS-findings.pdf>

ASL version:

Snoddon, K. [Kristin Snoddon]. (2019, October, 31). IECSS Brief [video file]. Retrieved from: <https://www.youtube.com/watch?v=GeQFVMEPbDs>.

Youth Advisory Committee

This research brief is a companion to Research Brief No. 1, which presents views of the Youth Advisory Committee for the Inclusive Early Childhood Service System project (IECSS). The IECSS is an ongoing partnership that has been underway since 2014. The project has engaged with over 120 families who have accessed early childhood disability services. The IECSS is a longitudinal study, with interviews from families conducted annually for up to 6 years, starting prior to school entry.

Since 2018, the partnership has invited young people who identify as deaf and/or disabled to participate on the project through a Youth Advisory Committee (YAC). This YAC is a complement to two other advisory committees: the District of Temiskaming Knowledge Keepers who support our work on Indigenous Experiences, and an International Advisory Committee who are considering IECSS findings from the standpoint of global interests in inclusive education.

Research Brief No.2 takes up the particular viewpoint of deaf youth from a small midwestern Canadian community. Some of these youth were part of our first Youth Advisory Committee meeting held in Ottawa, Ontario in 2018. That meeting, in partnership with the Landon Pearson Center, used the Shaking the Movers (STM) method to learn from young people about Children's Rights and Disability Rights (Benincasa, St. Dennis, & Caputo, 2018; Underwood & Atwal, 2019; Xu, 2018). Following the event in Ottawa, we held smaller group meetings with interested youth to ask our Youth Advisors to more specifically comment on the analysis of our research findings. Our goal in these meetings was to gain analytical insights from young people who might be affected by, or have been affected by early childhood service delivery planning. One of our goals was to more actively engage with deaf youth, because have several families who have participated in the IECSS study who describe limited interaction with American Sign Language (ASL) and deaf communities. Several of the children in the study are deaf or have a hearing loss, but none of them described engagement with deaf communities or having had opportunities to learn ASL. This research brief is the result of a face-to-face meeting with 9 deaf Youth Advisors that took place in June 2019.

Procedures and Systems

The meeting with deaf Youth Advisors was conducted in ASL with a deaf facilitator and a deaf interpreter present to support communication. However, the youth also supported each other with facilitating their own understanding of the research project and questions. Findings from the IECSS project's ongoing research were shared with the deaf youth in the form of a map of one family's experience (see Appendix 1). This map was generated from one mother's interactions with disability services in the first 6 years of her child's life. In this case, the child was accessing many disability services but very

few services related to ASL, despite his early use of ASL due to a hearing loss. The Youth Advisors were asked to give their impressions of the map from their perspective as deaf young people.

One young deaf person noted that many deaf youth have trauma related to early childhood. The same participant commented that she hated the map: “For deaf children, not doing well is part of the whole process. My cochlear implant didn’t work, and this was a waste of time. I needed to go far away [to another province] to access an education.” (M1).

Several deaf youth discussed their early childhood experiences in various Canadian provinces (in the case of Canadian-born youth), or in their home countries (in the case of migrant youth). Another youth who assisted with his peers’ comprehension of the map and research questions noted that, “All of us grew up without signing. There was just speech. I wish parents learned ASL from deaf teachers.” (M2).

We asked the young people if the map was missing something that they thought should be offered. They felt that many families experience an information gap about sign language for parents of young deaf and hard of hearing children and the restrictions these parents may face in accessing early childhood ASL services since parents who choose a cochlear implant may not receive support with learning ASL (confirmed in research by Murray, Hall, and Snoddon, 2019). This may be why this family did not have services related to ASL despite the many services they had accessed. In fact, this mother had noted the lack of access to ASL. This finding is in some ways similar to comments from the District of Temiskaming Elders Council who have noted the lack of language programming in other maps.

One Youth Advisor said, “Sometimes parents have limited education for sign language. They are presented with 2 options [i.e., learning either a spoken or signed language], and there is not enough support.” (A).

Key Messages from the Youth Advisors:

- There is limited access to information about ASL and other natural sign languages for parents of deaf and hard of hearing children.
- There needs to be more access to sign language services.
- Communication with parents and caregivers has a lifelong effect on children’s participation in other aspects of their lives.

The work of families

At the meeting the deaf Youth Advisors were asked about the role of families in accessing services. The Youth Advisors noted “parents do most of the work of the system” (A).

They also emphasized the need for parents and caregivers to do additional research: "It's not the parents' fault. Doctors can give wrong information. Parents need to do research online about disability" (M2). The deaf Youth Advisors emphasized the need for information and support for parents with deaf and hard of hearing children. Youth Advisors noted the role of professionals in counselling parents of deaf children (Humphries et al., 2012). The Youth Advisors recommended that "Doctors must be honest about ASL and that it is a language. They should not confuse or mislead parents. There is a natural deaf culture and language" (M1).

The deaf Youth Advisors felt "People should listen to deaf and disabled people." The Advisors felt parents, caregivers, and other professionals should take a holistic view of deaf children: "The goal for parents is for how deaf children can succeed. Parents want their children to be successful. They should think about that, not audiology." (M1) This comment addresses the need for services to be directed at the identity of young deaf youth and to avoid services being organized around rehabilitation or assimilation.

Key Messages from the Youth Advisors:

- Parents and families should learn sign language and do more research prior to getting a cochlear implant.

Deaf identity

The maps generated from the IECSS study show evidence of the central role of diagnosis and designations of impairment as an organizing factor in early childhood services. The deaf Youth Advisors did not always view these services or diagnoses as appropriate.

The deaf Youth Advisors told us that there was a lack of acknowledgment on other people's part of participants' identities as deaf children. Youth Advisors described how parents and professionals labeled them as hearing or hard of hearing, not as deaf. As a consequence, some youth grew up not understanding they were deaf or how this could be a positive identity.

One Youth Advisor said, "I grew up in a mainstream school and when I was 15 years old, I found the deaf community. I felt happy to find out who I am." (S).

Another Advisor commented, "Be proud of your kid. They are human. Listen to people who have experience of disability. Disability is everywhere. Take ASL first." (M1)

The implication is that a more positive representation of deaf identity is needed, and that it would be consistent with the Youth's own positive view of themselves.

Deaf futures

The advice from deaf youth points to the importance of families having access to services that are supportive not only of ASL learning and a deaf identity but also the life chances of deaf young people. As one Youth Advisor stated, due to lack of access to these services in her home province, “When I try to figure out the future, I feel depressed.” (S) Another participant noted, “There are not enough interpreters. How can I reach my goals without access?” (F) These messages point to the need for current and future research and advocacy that supports early intervention services which are informed by deaf youth’s own experiences.

Key Messages from the Youth Advisors:

- Being a deaf person is positive but a more positive understanding of deaf people is needed.
- Many people deny deaf children their identity.

References

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