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Complicating 'Choice' in the Early Child Development and Intervention Sector in BC

Presenter:

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Alison Gerlach: So, welcome everyone to my presentation on Complicating Choice in the Early Child Development and Intervention Sector in British Columbia in western Canada. I'm Alison Gerlach, an associate professor in the School of Child and Youth Care at the University of Victoria, which is located on Vancouver Island on the west coast of Canada. I'm a white settler with blonde hair. I'm wearing glasses and a light gray sweater and presenting to you today for my home office on the traditional and unseated territory of the Squamish Nation. Next slide please. So, this presentation is based on research undertaken here in British Columbia with a focus on the findings related to parents' choices in how they access early child development and intervention services that include community-based speech language, occupational therapy, physiotherapy, and other early child development programs and services. Next slide please. So galvanized by the rapid uptake of technology in this sector in BC and beyond, as a result of the COVID-19 pandemic, I was asked to co-lead a community driven mixed methods participatory study that aims to generate community voices on the long-term integration of information and communication technologies with the goal of addressing primarily longstanding challenges for northern and rural families in our province to access early child development and intervention services and supports.

Next slide please. This research involved and was informed by diverse parents, guardians, early child development and intervention providers from a wide range of different programs, and community-based nonprofit organizations across the province that host and administer these programs with funding primarily from our provincial government. A community council that you can see here was formed specifically for this project and was a guiding force in the research process and decisions that we made during the research. Next slide, please. Briefly, these were the data collection methods used over a two-year period. Tools were co-developed with research community members and by the guiding council, and in total we were able to engage with 110 parents of preschool aged children with disabilities and/or medical complexity and with 147 service providers from different early intervention programs. Next slide please. So I wonder how many of you have considered the notion of choice in your work and research in the disability and rehab sector? In a previous life I was an occupational therapist before getting into research totaling 35 years, and I've never actually thought about the notion of choice. However, it was a really early and recurring theme in this

research, particularly from parent researchers who called for choices to be driven by parents and not by top-down government decisions, which was kind of the case during the pandemic. Next slide please.

So structural analysis of the interview data was informed by these two critical post-colonial feminist perspectives. I'm not sure how familiar you are with using some of these theories, but post-colonial theorizing basically focuses attention on the historical and ongoing forms and impacts of colonial authority and violence. So in settled colonial states such as Canada and the United States, the removal of choices and life opportunities was and continues to be systematically removed as government authority and control continue to be asserted. Intersectionality, as you've already noted, is helpful in better understanding how gender, racialization, ability, socioeconomic status, and so forth intersect with broader structural forces such as ableism, racism, colonialism to create and sustain social injustices and health inequities among certain populations.

Next slide please. So choice is often an assumed, taken for granted notion embedded in neoliberal systems of care for children with disabilities and their parents, caregivers and families. It is rooted in the notion of autonomy, which assumes that everyone has the power and freedom to make rational choices regardless of one's context or circumstances. Individual autonomy, including the freedom to make choices, is also a key principle in the UN convention on the rights of persons with disabilities. In this slide, I've attempted to show the complex and nuanced nature of choices in service access that were identified in our analysis of the data. As you can see, parents' choices in service access in this study did not take place in a vacuum, and they were not experienced the same by all communities and families. In the following slides, I hope to highlight findings that show how geography, weather, poverty and the longstanding under-resourcing of this sector in this province, and the history of colonialism in this province in Canada created non-choices, such that access for historically underserved northern and rural communities and families were likely to remain in place. Next slide please.

Some of the parents in this study describe making strategic choices about when to connect in person or virtually, choosing virtual options for checkups or progress updates with specialists in order to reduce the stress on their children and their families, but also on the demands on their time as parents and caregivers. However, most of the data focused on parents having non-choices. For example, there was a large amount of data on how parents, primarily mothers and providers' choices for in-person visits, were constrained in large geographical, northern and rural service delivery areas by significant driving distances and treacherous driving conditions. For up to six months of the year, weather and road conditions in these communities had a significant impact on the ease and frequency of access to in-person services. In addition, these same large geographical service delivery areas in BC and also in many other parts of Canada also tend to have less access to affordable high speed internet. So both in person and virtual ways of staying connected and accessing services were being compromised. Next slide please. Concerns were raised by providers and parents in the study that there were families who could not afford the gas or other costs to travel to in-person services and

also could not afford the technology to access services virtually. In some cases, choices were further shaped by caregivers' print and digital literacy and their comfort levels.

Next slide please. Non-choices were also created by - sorry, did we move slides? I've lost track there. Okay. Non-Choices were also created by community-based nonprofit organizations who administer early child development and intervention services and programs, not having the financial resources and processes in routine care to offer parents access options or supports in using technology to connect with service providers virtually. There was also a wide variability in tech know-how between providers, between programs, and organizations. Some providers were also reluctant to offer parents a virtual option to connect, as they preferred to be in-person and hands-on. Thus a lack of tech funding and infrastructure, digital literacy and attitudes towards using technology within organizations hindered what choices some parents were offered, creating regional and provincial variations in how parents are expected to fit into a pre-determined menu of available service options that meet organizational rather than parents' preferences and priorities. Next slide please.

Choices fundamentally take place in relationships and are dynamic, influenced by person, place, time, and nature of the choice. There was a lot of data on the capacity of providers in shifting away from an expert model of early intervention, in which power implicitly lies with the provider, to a coaching approach that is tailored with and for each parent and builds on their agency in decision-making and making choices about their child and their family's priorities and preferences, shifting power towards parents. There was also data on how choices made by indigenous families about whether to and how to engage in early child development and intervention were shaped by broader colonial relations of power between indigenous populations and the Canadian state, and indigenous families, histories and ongoing experiences of colonial violence and their justified fears of having their children removed by the child workforce system. Choice in this context is a complicated process that needs to be explored carefully and compassionately.

Next slide please. So the big critical question, so what? Structural analysis of the data on choice highlights the complex situated nature of choice and disrupts the seeming neutrality of claims to being family centered, which assume all families experience choices evenly. As these findings show, choice in service access is an illusion that rests on multiple forms of privilege and is structured by intersectional forces that are often beyond families' immediate environment or their control and have potentially significant impacts on their sense of self, parent's sense of self-efficacy, autonomy, and ultimately their children's health and developmental outcomes. Moreover, constrained choices in this sector contribute to maintaining a sense of un-belonging and inequities in these services for historically underserved populations, including northern and rural families. So how can this nuanced analysis of choice help to inform changes? At a micro level, findings point to the prioritization of a relationship-focused approach in which providers shift away from power-laden expert roles and towards being facilitators, collaborators, and coaches, and who understand how choices can be influenced by broader social and structural factors. Aligned with findings from the larger study, there is also a need in this province to upscale coaching skills in the early child development

and intervention sector, so that choices are discussed in a relational space of non-judgment and safety.

At a meso, or program organizational level, findings call for programs, agencies, organizations to examine how routine and taken-for-granted policies, expectations, and quality standards support or constrain what choices are being offered to families and also how they are being offered. And how they are being offered was really stressed as being critical, particularly for indigenous and racialized families who also experience racism and discrimination and when they're accessing mainstream services. At a macro level, government funding agencies need to provide community organizations with the operational resources to provide access options, including upscaling technology resources as well as knowledge. Also, the government also who are the main funding agency for these programs needs to understand that access to technology is central to a continuity in relationships and a continuity in care for northern and rural families in BC and other parts of Canada. So I hope this brief presentation has piqued your interest in thinking about how your work engages with the notion of choices and the notion of non-choices. Next slide please. Final slide. Thank you so much for listening. I look forward to your questions. Please reach out. But here's our project website on my email and I would like to thank the ASL interpreter. I hope I didn't go too fast, and it's my pleasure to hand over to Nour. Thank you so much for listening.