tiwšamstawɬšt

(We will teach each other)
Final Report

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VANCOUVER ISLAND UNIVERSITY

TLA'AMIN NATION

Aboriginal Supported Child Development

tiwšamstawɬšt

> "A human rights lens allows us to see injustice as well as possibilities that should exist for citizens who are marginalized." (Lord & Hutchinson, 2007 p. 47).

When families cannot access services, funding, or education to be able to support their child with a disability at home because they live on reserve and must also overcome many barriers like the impact of residential schools, trauma, access to transportation, poverty, and colonization their children end up in the child welfare system, often away from their culture and family. The history of injustice has resulted in a larger representation of Indigenous children with disabilities in care often due to lack of services in their home community. These children are invisible in the system limiting information that could help inform culturally safe services and supports (Ball, 2008; Leitch, 2007). As well, indigenous children, even those who remain in their home, often receive early childhood education from non-Indigenous professionals. Gerlach (2018) noted that perspectives on disability that inform current practice seldom take into account the impacts of colonization on the health and well-being of Indigenous families and children. She documented the profound impact of the related structural inequities and recommended decolonizing research methodologies.

Introduction

tiwšamstawɬšt was developed to generate dialogue about historical and current Indigenous perspectives about children with disabilities so that caregivers and community members could apply their collective wisdom to advance more culturally safe and appropriate ways of providing disability supports. This project hoped to solidify the rights of Indigenous children with disabilities to be supported in culturally safe and appropriate ways in their home communities and within the child welfare system. The project included a workshop for ɬəʔamɛn Elders, child care providers, and caregivers with guest speaker Alison Gerlach, followed several months later by a World Café. The World Café began with a brief summary of key ideas discussed with Alison Gerlach specifically the importance of parent to parent support and advocacy, the experience of assessments as traumatic and racist and how to respond, and the collective use of funding like that provided by the Jordan's Principle to advance community wide changes.

World Café design principles were adapted to the local situation and culture and were congruent with Indigenous research methods and more importantly with the Ta'ow of the ɬəʔamɛn people. By following an Indigenous research agenda, this project sought to build capacity and healing, and bridge community development with reconciliation (Tuhiwai Smith, 2012). This method created generative dialogue, mutual learning, and resulted in the practical recommendations provided in this report. Anchored in respect, relationship building and dialogue, outcomes may emerge beyond the findings and recommendations of this project because of the potential for transformative learning. For more detail about the project methodology, see Appendix A.

tiwšamstawɬšt was developed collaboratively with Rose Adams, ɬəʔamɛn Child Development Resource Center (CDRC) Manager. She informed the project by sharing her teachings and the teachings passed on to her by elders. Rose is a strong advocate for the ɬəʔamɛn culture and language, and a community leader. Bringing forth ɬəʔamɛn Ta'ow and

ideas that can be implemented in daily practice of working with indigenous children matters to her. The guidance of Rose Adams, and other knowledge keepers was invaluable to the development of this project which could not have occurred without them. In addition, the CDRC matched an award from Vancouver Island University's (VIU)'s Research Advisory Committee to fund the project.

What is working?

Participants reflected some of the things they felt are working well earlier on in the day. It was reflected that they are appreciative that the ways that we access professional development are improving by having **guest speakers and experiential learning exercises** to give people an idea of what it's like (to have a disability) as previously there has been less awareness of how different developmental delays show them themselves, now we know different approaches and that there is support out there now. The **rekindling of culture and language** in ɬəʔamɛn is happening now, so having language on walls, singing at CDRC, culture nights in community works really well. At the CDRC, the kids know some words in language, the staff model when they can. As well, **Total Physical Response** training for the staff is helping them teach language. Having cultural coordinators - Sosan Blaney at CDRC, and Drew Blaney in community - and participating in and helping with Tribal Journeys were also identified as things happening now.

What does cultural safety look like?

Identity

The word 'identity' repeatedly surfaced as important during discussions. It is important for ɬəʔamɛn children to know their culture, lineage, and family tree. This can be fostered in many ways such as providing opportunities for youth to stand up and saying prayers at community events: "It lifts you up and makes you proud." Helping youth to stay connected with culture helps everyone feel proud of their identities.

Ta'ow

The ɬəʔamɛn Ta'ow consists of everything: language, culture, and teachings. And from a ɬəʔamɛn perspective, children with intellectual disabilities and developmental delays need to have access to Ta'ow, like every other child, and be acknowledged and embraced for their gifts. Participants at the World Café had many strategies and ideas for how to integrate Ta'ow into daily life and practice for **all** ɬəʔamɛn children:

- Storytelling, language, song, and dance: "**Culture and language should be everywhere**!" Grow the language programs, and revitalize cultural resources (books, CDs, equipment, instruments).
- Cultural activities through **intergenerational** connections (i.e. Hatchery tour; art; Aboriginal Head Start; Elders in the classrooms
- **Centering ɬəʔamɛn** perspectives and presence
- Supporting families to practice culture at **home**; bringing it to the public **school** system; and bringing it into the **community**.
- Teaching the **values** that underlie our practices: respect, patience, empathy, life skills. "We learn these things through doing cultural things together" (ie. Tribal Journeys). The fast pace of modern life can interfere with this learning.
- An elective in the public school system of cultural practices, sweats, drum making, etc.
- "Longhouse is like school for our kids, of all ages." Provide opportunities for **youth to mentor and teach younger children** in the culture.

Relationships

Relationships are central to culturally safe practice, and must take place at every level: Relationships with the child (building healthy social connections between children; creating tools so they can take these skills with them; getting to know the child and their experiences to support them through trauma or difficulties)

- Relationships with the **family** (get to know the family's identity and culture; respect the family as expert)

- Relationships with **Elders** (Elders at CDRC and schools where children can become familiar with them, approach them, and interact with them).
- Relationships with **schools** (Aboriginal Supported Child Development in pre-school, daycare, and kindergarten)
- Relationships with **professionals** (Having an ally to go interpret and advocate; training and hiring more ɬəʔamɛn people to work at the CDRC and in the school system. Role models empower children).

Systemic barriers

While many great ideas surfaced during the discussions, participants identified two major systemic barriers to optimal support for children with intellectual disabilities and developmental delays.

"Red Tape"

The referral process is generally described as a cumbersome and **unwelcoming process**. In addition to having to make (and wait for) many phone calls, there are complicated "rules" and pre-requisites that are limiting. There is also currently the **need to travel** in order to get an assessment which is extremely challenging due to the expense and need for transportation. The wait list can be up to two years, which dramatically decreases the chances of early intervention.

The process of undergoing the interview can **feel judgemental**, particularly if the complicated process described above has not been followed exactly. It often involves repeating answers to the same questions with different professionals, who are most often strangers to the family. Explaining to a professional is quite hard. Doctors sometimes ask questions to which they already have answers, or which can be intrusive. If a family has not successfully navigated this process during the early years, they also often face questions from the schools as to why there has not been an assessment. The **transition to kindergarten** can be extremely challenging.

Furthermore, assessment tools themselves are not culturally appropriate for ɬəʔamɛn children, and most of the professionals administering them are not Indigenous. Families describe feeling shame in "failing" tests or assessments, and ultimately it is the child who bears the burden of a system that is not working well.

Racism

All of this is compounded by the fact that our systems are still designed in such a way that privileges certain children and families over others. Participants noted a lack of cultural knowledge/experience among professionals, and have even witnessed professionals speaking down to community members. This, understandably, leads to a **fear of engaging** with that system. Professionals may not know they are being insensitive, but participants in the World Café shared stories of **stereotyping** and even feeling attacked during an assessment process. Media contributes to some of these ongoing stereotypes.

With the recent history of residential schools and other experiences of state interference in family life, many ɬəʔamɛn people are not comfortable and **do not trust** government workers or other professionals. This history is still not understood and respected by all workers who engage with children and families. Additionally, when it comes to intellectual disabilities and developmental delays, some children and families experience the additional burden of shame and stigma – even bullying - regarding diagnosis.

The school system provides very little support for ɬəʔamɛn children and families in the face of all of this. Participants in the World Café expressed difficulties in finding **culturally appropriate resources**. Children have been historically denied access to culture and language – and the pride that comes with this. There is a strong desire among those who attended this event to provide more support for cultural and language revitalization, and concerns as to why it is not happening to the extent needed. The question was asked: "Is it because of money or people or racism?"

Recommendations: What can be done moving forward?

Centering the child in everything we do

Participants in the World Café had many ideas as to how to ensure children remain at the center of their experiences of care. It is difficult to generalize recommendations in this area, as it is necessarily child-specific and involves **relationship-building** with the child, their family, and the community, and **flexibility** in approach. This can be done through:

- **Visual aids** to assist in transitions (a kind of roadmap for the child, so they know what to expect throughout the day to alleviate anxiety)
- **Arts and crafts** for visual and tactile learners
- **Validation** of various emotions
- Lots of **affection**: "Love fixes so many things!"
- Different tools for communication including **verbal** (songs, stories, rhymes, books) and **non-verbal** (body language, sign language, Total Physical Response)
- Building a **seamless routine** between home and the CDRC for each child
- Honouring the **family as experts** and part of the solution to any challenges a child may face

Support and capacity building for workers and caregivers

Formal caregivers at the CDRC and informal caregivers in the home all need support to build their capacities to **work together** for the wellbeing of each child. The more opportunity for the caregivers to learn, the better the program delivery becomes. This can involve **professional development** for staff to help them a) learn more about intellectual disabilities or developmental delays, and b) learn how to support parents/guardians at "every step of the way" through their journey. Parents should have access to staff for **comfort and debriefing**, and should not be alone through this process. All of this will help **remove the stigma** that sometimes comes with additional needs, and help to keep the child at the center.

Revitalizing language and culture

There was agreement among participants at the World Café that revitalizing the ɬəʔamɛn language and culture are vital in meaningful child-centered care. This is a process that requires a lot of **support from leadership**, as many staff may not have the knowledge and/or

confidence to integrate language and culture into programming. Some strategies for **expanding language programming** at the CDRC include **having Elders and language-speakers present** so that children can approach them, interact with them, hear them speak, and learn teachings from them. This also benefits staff at the center as well. A question was raised as to whether or not there should be a **mandatory competency level** of language and culture for staff, with a recognition of the many barriers to language and culture that exist.

ɬəʔamɛn youth - the next generation of caregivers and leaders

Though the focus of discussions was young children with intellectual disabilities and developmental delays, conversations moved often to recognizing young people as an important part of this equation – now and into the future – given they are the next generation of caregivers, language teachers, cultural practitioners, and leaders in the community. Some suggestions from participants for **building up young people** to fill these important roles include:

- Drawing back home already-trained professionals to work in the community; **role models**
- Offering **high school credits** for Tribal Journeys and other cultural activities
- Providing **cultural classes** in which youth have access to teachings that can equip them to "walk in two worlds"
- Ensuring the **curriculum in the education system is relevant** to them so they stay engaged and continue with their education
- Support development of ɬəʔamɛn youth to professional positions with more **education/training opportunities**.
- If programs are not available at VIU's Powell River campus, send two or three people together to support one another relationally.
- Individual tutors and **personal mentors**

Systemic changes

While many of the recommendations involve change at the level of service, all of this will be facilitated with **meaningful change of the system** as well. Some ways participants would like to see the system adjusted to better support their efforts include:

- ɬəʔamɛn developing its own Educational System by hiring a **curriculum writer** who is knowledgeable of culture, language, and teachings
- Ensuring MCFD, school district, and other outside institutions prioritize **cultural safety** and competency training for their workers (and this training should be tailored so that it is ɬəʔamɛn-specific)
- Considering having a ɬəʔamɛn-run system for **children living in care**.
- Increased access to professionals who can do **developmental assessments in community** (Occupational Therapist and Pediatrician), and ensure they are culturally safe and competent.
- Require all workers to take **cultural and language training**. Increase pay accordingly.

Conclusion

Overall, the tiwšamstawɬšt project brought together a range of people to engage with each other in a meaningful way about how to use collective wisdom and knowledge to plan for and enact social change. Conversations have continued since the cafe, and some participants have taken steps in their personal lives and work practices that reflect what they heard and discussed together. Communicating with one another about work underway and coming together to intentionally implement some of the ideas may amplify individual efforts and accelerate change. This report was written to record and share what was learned for those present and absent. Since it was repeatedly expressed by those who participated that local and provincial policies need to change, the distribution of this report especially is an opportunity for those who did not participate in the World Café, like School District 47, ɬəʔamɛn local leadership, and representatives of the Ministry of Children and Family Development to join this

dialogue and advance changes aligned with the findings and recommendations of tiwšamstawɬšt, we will teach each other. In this way, we can solidify the rights of Indigenous children with disabilities to be supported in culturally safe and appropriate ways in their home communities, at school and within the provincial government system.

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Appendix A: Information about Research Methodology

This project was led by Courtney Harrop (VIU student), working under the supervision of Alison Taplay (VIU instructor) and in collaboration with Rose Adams (community partner) as partial completion of the Disability Studies Diploma. Dr. Janet Newbury joined the research team, providing support with design and implementation. Motivated by her personal and professional interest, Courtney pursued knowledge related to decolonization, indigenous child development, and indigenous practices regarding supporting children within indigenous communities, including reading Alison Gerlach, whose work strongly influenced this project. Courtney's experience as a white person coordinating the Aboriginal Supported Child Development (ASCD) program at the ɬəʔamɛn Child Development Resource Centre (CDRC) made clear to her that change was needed in the delivery of indigenous programs for ID/DD to provide more culturally safe and appropriate services.

Courtney's dual relationships may be perceived through a western lens as a conflict of interest. However, within this particular cultural context these relationships facilitated the research and allowed it to be conducted in a responsible way. Research by outsiders over time has had damaging impacts in ɬəʔamɛn. Doing this work in partnership with the CDRC and in the context of relationships minimizes the potential of this kind of damage.

> How might a greater awareness and understanding of both Settler and Indigenous cultural and historical perspectives on child developmental and intellectual disabilities inform or improve current support to children with these disabilities through a collaboration between ɬəʔamɛn elders and caregivers?

tiwšamstawɬšt began with a workshop for ɬəʔamɛn Elders, child care providers, and caregivers with guest speaker Alison Gerlach in May 2019 which was followed by a World Café in September 2019. The World Café responded to the question, how might a greater awareness and understanding of both Settler and Indigenous cultural and historical perspectives on child developmental and intellectual disabilities inform or improve current support to children with these disabilities through a collaboration between ɬəʔamɛn elders and caregivers?

tiwšamstawɬšt was a qualitative, cross sectional study which used an inductive approach relying on grounded theory (Bryman, Bell and Teevan, 2012). Research participants were

ɬəʔamɛn elders, and caregivers of children with intellectual/developmental disabilities. Data was collected at a World Cafe in the ɬəʔamɛn community. Utilizing the design principles developed by Brown and Isaacs (2005), the method was aligned with Indigenous culture as it provided some structure but not too much. According to Steier, Brown and da Silva (2015), "the practice of the World Café rests on (1) a flexibility for adaptations to local situations and local knowledge, and (2) an ongoing conversation, for researcher-practitioners between design principles and local practices" (p. 214). Design principles included: set the context, create hospitable space, explore questions that matter, encourage everyone's contribution, cross-pollinate and connect diverse perspectives, listen together for patterns, insights and deeper questions, harvest and share collective discoveries. tiwšamstawɬšt emphasized creating safe space with cultural components, such as opening and closing prayer, cedar boughs on tables and providing a brushing at the end of the event.

Qualitative data was collected, with a focus on words, symbols, ideas, oral storytelling and knowledge sharing. Data was recorded on flip charts by table hosts at three different tables. Each table presented to the larger group after each session, and these larger discussions were recorded by graphic recorder, Wayne Hanson. Following the event, a narrative analysis was conducted by the research team. Narrative analysis "examines the stories that people tell about their lives and other events" and "entails sensitivity to the connections to people's past, present, and future events…" (Bryman, Bell & Teevan, 2012, p. 26**)**.