First Nations Families of Children with Disabilities Summit

Understanding the Disability Trajectory of First Nations Families of Children with Disabilities: Advancing Jordan’s Principle
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Research Partners

Assembly of Manitoba Chiefs (AMC), Research and Policy Development (RPD) Committee, Kathi Avery Kinew, MSW, PhD; Barb Borton, MSC, Rehabilitation Centre for Children (RCC), and Norway House Cree Nation.

Sponsor: Canadian Institutes of Health Research

This executive summary reports the findings from the project titled, “Understanding the disability trajectory of First Nations families of children with a disability: Advancing Jordan’s Principle.” This summary includes a brief description of the project and the study’s findings. Following the findings, key questions (p. 18) are provided for all summit participants to consider and discuss. These questions are posed to determine the best actions we can make as individuals and groups to ensure that we contribute to a positive difference in the lives of First Nations families and their special children.
The old man said, to have been born imperfect was a sign of specialness...The old man explained carefully that in the old days, if a child came with a hare-shorn lip, it wasn’t a terrible thing or a hurtful thing; it meant the child’s soul was still in touch with the Spirit world.


"... the disability rate among FN children was found to be twice that of the general population."²

Acknowledgements

No project of this size and magnitude is completed alone and without the support and participation of many individuals. Thank you to:

The First Nations families who volunteered their precious time to take part in this study. Your words and ideas were the backbone to this study. Quite simply, we could not have done this work without you.

The family of the late Jordan River Anderson. Jordan was a child from Norway House Cree Nation.

Background

Consistently, the literature supports the finding that the most prominent health disparities in Canada are those existing between First Nations (FN) peoples and the rest of the Canadian population.²⁻⁵

In general, the disability rate among FN children was found to be twice that of the general population.²

The concept of triple jeopardy created by Demas in her description of FN women with disabilities could equally be used to describe FN children with disabilities.⁶ First Nations children live in a situation of extreme disadvantage due to the triple jeopardy of inequities experienced by First Nations people, being a child, and living with a disability.

There are limited studies of the perspectives and experiences of FN peoples living with childhood disability.
What is Jordan’s Principle?

Jordan's Principle is a child-first principle. This principle was created to resolve conflicts and disputes within and between governments about health care services for First Nations children. Under this principle, the agency that is first contacted must pay for the child’s services without delay. Jordan's Principle is one of the most supported children's policy movements in Canadian history. Ernest Anderson (Jordan's father) said that Motion 296 will only be a moral victory unless it is fully adopted and used by all Canadian governments.7,8

"...the agency that is first contacted must pay for the child’s services without delay."

Research Purpose and Design

The primary purpose of this study was to arrive at an increased understanding of the disability trajectory from the perspectives of FN families of children with disabilities in Manitoba.

By understanding how families interpret disability, we focused on detailing the perspectives and experiences of the entire family. The main research objectives were:

1. To describe the meanings FN families of children with disabilities assign to childhood disability.

2. To identify FN families’ needs and experiences of health and social service use and delivery in the context of childhood disability.

3. To examine how FN families of children with disabilities position childhood disability at the individual, family, and community level with attention to describing how childhood disability influences meaningful participation in everyday life.

4. To examine how physical, individual, social, environmental, and cultural conditions contribute to how FN families of children with disabilities participate in everyday life.

Design: Key Features

- Qualitative Research Approach

- Guided by the Life Needs Model as situated within the concept of Therapeutic Landscapes. (9-12)

- Multiple Data Collection Methods (e.g., interviews, photovoice, eco-maps, field notes, document review)

- Four levels of analysis to generate socio-cultural themes and varying profiles of childhood disability
Study Participants

First Nations Families

Included parents, children with disabilities, siblings, and any other members (e.g., grandparents) deemed significant in the children’s lives.

To arrive at a detailed understanding of both the urban southern and rural northern family experience, FN families were recruited from: Winnipeg, Norway House Cree Nation (NHCN), and other southern/northern MB sites.

Key Informants

Service providers, administrators/policy makers, Elders and other FN key informants.

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Findings

This study yielded a detailed and rich description of the disability trajectory from the perspectives of First Nations (FN) families of children with disabilities. Multiple themes from the families’ experiences emerged including:

- Life is Hard
- Child as a Gift
- Intense Parenting
- Harnessing Resources
- Parenting in a Fishbowl
- Disabling Environments
- Missing Out
- It All Depends On What Side of the Road You Live On
- Being Known
- Enabling the Child to Flourish
- Need for a Strength-Based System/Services

“...kind of like one of those things where I bought them thinking that he was just like, going to be like any other kid...”

Findings: Life is Hard

This theme underscores the difficulties, hardships, and losses that come with being a FN family of a child with a disability.

Quote: And um finally when he started walking, it was kind of cool in our house so I try to keep him with his feet covered as much as possible, and I just remember the period of time where he was um just walking until he was maybe four, I think three or four he loves these things, he loves his Barney slippers. He lived in them. I still have them. Obviously I took this picture not that long ago, and I keep them aside cause it’s kind of like one of those things where I bought them thinking that he was just like going to be like any other kid and you know he was going to be interested in Barney and he was going to be interested in all the things that you know little boys are interested in. And that took me through the period of you know finding out that he, he was autistic and uh um and so on, so I think for, for me this photo kind of symbolizes this whole period of time for us and for, for my son. It’s just a, a really, a really strong memory of that particular time, a time that meant it’s kind of like the loss of um the child that I thought that I had. And it just kind of reminds me of the, the grief and loss that we, that we experienced with, and it’s not just me I think of, it’s my, my daughter as well cause she was old enough to know that he’s not going to be like other kids.
Findings: Child as a Gift

Most parents viewed children with disabilities as "special people" who have so much to contribute to their families and society in general. Parents felt that society could learn so much from children with disabilities.

**Quote:** "R's" respite worker took this picture and I think it was for Mother's day. She had him for I think four hours and she took this picture and got it developed and bought a frame and put it in the frame. And for him at that point in his life, to be able to sit and to be able to take a photograph, and he's got this expression on his face where he looks just like the, the Curious George monkey that's sitting in front of him. And I don't know how to put it, it was very surprising when she gave the picture to me. It was like how did you do this? So for me it is a cute picture but, but the behind the scenes, like how this picture got to be made was, it is the reason why I put he has got these people like that keep, that keep changing, there's this ever changing mix of people, respite workers and TA's and resource teachers and doctors and CFS workers and you know, I think everybody that he comes into contact with, he touches them in some particular way.

**Quote from Sibling:** He's just a very happy fourteen year old boy that doesn't, doesn't come off as fourteen but he makes you have a sense of purpose, he makes you feel happy, you just, you love him and he's just good to be around and he's just...I'm just happy he's in my life and I think that he's here to, to teach everyone patience and, and just maybe to stop and to just give a little more care and time and...I think he just teaches everyone a little bit more about themselves.

"...I think everybody that he comes into contact with, he touches them in some particular way."

Findings: Intense Parenting

This theme refers to the extra efforts FN parents must commit to in order to provide a good life for their children.

**Quote:** She'll call me first thing in the morning when she wakes up. I heard her calling me. She gets me to do this and that for her. At home there's only me and her dad too but he doesn't, it's not the same...Um (chuckle) just that I have somebody that I have to look after and give my attention to all the time... If she were normal like maybe things might have been different. I wouldn't have to worry about somebody having to look after her.
Findings: Harnessing Resources

The physical, mental, psychological, and spiritual resources of parents were crucial determinants of the family’s ability to harness resources and involved parents assuming multiple roles. However, the demands placed on parents in harnessing resources constantly challenged the parents’ own resources.

The Student - Learning all you can
The Educator - Teaching others
The Detective - Figuring it out
The Fighter - Fighting battles
The Case Manager - Coordinates and plans
The Guard - Watches over, protects, monitors
The Health Care Provider - Professional caregiver who holds special knowledge
The Lawyer - Making the case
The Advocate - Standing up for your child/family

Findings: Parenting in a Fish Bowl

All parents expressed wanting “the best” for their child and did strive to do their best as parents. Maintaining the role of the “good” parent became more difficult for parents as they struggled with trying to do the right thing for their child while feeling at times judged by others. Parents felt that society in general, watched and judged them more harshly compared to other parents.

Quote: And I made cupcakes, we made cupcakes, I actually messed up on the first batch, so I had to make them all over again. I feel like I am always being judged. They always say that “you are not being judged or not judging you, we’re just trying to help you understand how your daughter learns and what, how she”... Maybe if they would say “we’re concerned or do you know that your daughter has some disabilities...” Um it makes me feel like they think I abused “A,” like I hit her and beat her up and all that, and I haven’t.
Findings: Disabling Environments

This theme refers to the conditions/barriers in the lives of FN families of children with disabilities that prevent families from having a life. There are many different types of barriers including structural (infrastructure, physical environments, transportation), social (e.g., social disruption due to the intergenerational effects of residential schools and colonization, lack of disability awareness, lack of assistance), psychological (e.g., low self-esteem), historical trauma, and economic (underdevelopment and poverty).

“"It’s been a year and it’s still sitting the same as it was when it was first built.”

Quote: The wheelchair, his wheelchair that’s what’s mostly in that washroom. His washroom that’s supposed to be for him to use. More like a storage, the whole place is a storage unit instead of a, a washroom. Well as you see the picture of it that it’s quite roomy, it’s a big space and there’s no shower, there’s no plumbing, there’s no, actually nothing. And it should have been...It should have been up and running already, its, it would have been so convenient, it’s right beside “J’s” room and but its, we’re not even using it it’s more like a storage place. Like it’s been a year and it’s still sitting the same as it was when it was first built. It’s just a waste of space that’s moulding away, it’s just so sad that they couldn’t, we couldn’t, like we can’t use it it’s...

Findings: Missing Out

This theme refers to the many aspects of daily life that contribute to a good life that First Nations families of children with disabilities have minimal or no access to (includes work, education, family time together, playing with peers, services for children with disabilities etc.).

Quote: We enjoy doing, and camping but to date we haven’t taken my son in the boat. I don’t know that he would be able to, to sit and be comfortable or not agitated for any period of time, and to think about taking “R” on a boat and, and you know getting, you know ten kilometres out into nowhere and then have him become agitated. That would be, it would be too much, he’d put everybody else at risk so, I don’t know. We’ve had a discussion about this, my husband and I we’re thinking about maybe next year, cause he’s kind of, he’s settled a little bit.
Findings: Mission Out - Examples of Not Missing Out

**Quote:** Uh, uh cause she likes going in the, in the bush with her dad sometimes, so this is one of the few times in the skidoo, she just really says she likes going up there I guess.

Findings: It All Depends on What Side of the Road You Live On

This theme reinforces the inequities that FN families of children with disabilities experience due to living on reserves. While all FN families of children with disabilities “miss out” on services and programs that contribute to them having a good life, this was especially the case for FN families of children with disabilities who lived on reserves. The majority of the families in the study who lived on reserves lacked in many of the services and programs meant to help their child with a disability.

**Quote:** Compared to living in FN community, living in city is like living in luxury even if you are on welfare. When you run out of money in Norway House, you go hungry.

**Quote:** The government needs to step up! When are they going to bring the resources we need to our reserves, to improve the lives of our children with long term disabilities? When is the funding going to come our ways? We need structures placed on the reserves. When will the resources come to my community? When am I going stop leaving my reserve for better services and health care?
Findings: Being Known

This theme refers to the complexities and the importance of others “really getting to know” FN families of children with disabilities. It is about others:

a) understanding the FN child/family;
b) accepting the FN child/family;
c) listening to the FN child/family; and
d) welcoming/embracing the FN child/family.

It is about not seeing the FN child with a disability as the “other” or “outsider” but instead as a “gift” to the family and to society.

**Quote:** This is my brother’s hockey team. And I think my brother at that point was the same age that “R” is now. And I think for me this is kind of like when “R” was born I kind of thought you know “yes I have a boy, all the thoughts of, all the things that I would do with him and when he, as he was growing up.” My dad was really big into sports with my brothers, I have five brothers, and my dad assisted in coaching and really encouraged my brothers to succeed, and their team did quite well. All these guys are still really close and I think, when I look at this picture I think you know this is where I wish my son was right now. This is, this is what, I wanted for him. You know to have that, that I don’t what’s the word camaraderie. And to have team, um friends, to be able to be part of something, um yeah that’s about it.

**Quote:** And I know that one time she did tell me that “S” was doing this and I finally just, I didn’t get like defensive right away, I kind of just like changed, I was like you know maybe you should do it this way because maybe “S” is um feeling you know a little upset that she does have to get taken out of the room to do braille and it does make her upset right, like she wants to play with her friends and her other friends don’t have to do it.

**Quote:** Yeah, school and then daycare in the afternoon. And then she’s sitting there with her friends eating her cupcake. Yeah, we made the
Findings: Enabling the Child to Flourish

This theme refers to the need for a changing landscape that moves beyond basic survival of FN children with disabilities to one that enables FN children to flourish.

Making sure my child has a future Quote: Well yeah she’ll be at home with me but she’ll be turning 18 in a couple of years, going to school, um I think she’ll be finishing school and getting ready to finish school and graduate and probably go to university or college like she says she wants to do. And then hopefully no boyfriends or you know anything like that... Hopefully in a really stable career and a nice home...uh I don’t know I guess my wish for her is to live a healthy life and not be ashamed of who she is...

Findings: Need for a Strength-Based System

This theme refers to the need to have a system and services that focus on the strengths of FN families of children with disabilities.

Quote: And that’s kind of what I mean by cultural appropriate for service delivery because I know that a lot our people, there are circles out there, there are support services for learning disabilities for children like mine, but um most of our people won’t access them because they come into a room and they’re the only brown face and they don’t know how to cope with that, so they don’t come back. So for us and that’s, so we need our own circle to feel safe in order for our own voice to be heard and our own unique perspective and issues because we don’t have the same perspectives and the same problems that mainstream people have, you know and that’s something that needs to be addressed. And then even the resourcing of any of these support groups, if they’re going to have these support groups they’ve got to have an outreach worker almost that’s going to connect with these parents and make sure these parents you know do have that debriefing after a circle if something happens or you know or if they didn’t get there, well what’s the barrier that’s keeping them from going there, you know how can you address that because those are the things that you know mainstream takes for granted that you know parents can be self-sufficient and independent and show up to do all these things, but you know for our people it’s just not, it’s just not that easy, its life skills that a lot of us don’t have.
Findings:
Key Informants

Themes from the key informants’ perspectives emerged including:
- Disability in the First Nations Context
- Missing-out on Services and Programs
- Marginalization
- Intense Parenting as a Health Risk for Parents

Disability in the First Nations Context
This theme refers to the meanings FN families assign to disabilities. FN people have a unique perspective rooted in their culture, lifestyle, and way of living. They are more focused on what children with disabilities can do and not what they are unable to do.

Quote: I’ve been to some First Nation communities to see if we could advertise our study and there’s been a few people who’ve said, “oh we don’t have any disabilities…” it’s like a cultural difference ... they see them as people with gifts or special talents or whatever, ....So they don’t categorize them the same as we would or diagnose them. Like I know even one mom whose son is like thirteen and they were in the progress of getting diagnosed or whatever, but she really didn’t want to have him diagnosed.

Missing-Out on Services and Programs
This theme addresses the issues with respect to the availability of services/programs for FN families. FN communities are lacking in the appropriate services and programs that would help FN children with disabilities to flourish. Even when services/programs are available, FN families still experience missing-out on services and programs due to the complexities and difficulties in navigating the system.

Quote: If you were in the city or you were living in the city then you would get that resources right away in place, so it’s very hard for a lot of families, they have to relocate and because sometimes it’s not available in their own communities.

Quote: The houses need ramps you know and that costs money, like being able to put a ramp up you know for their wheelchair or even the doorways are not wide enough. There’s a lot of things that homes need, like housing with because there’s so many people living in the home too.
Findings: Key Informants

Themes from the key informants’ perspectives emerged including:

Disability in the First Nations Context

Missing-out on Services and Programs

Marginalization

Intense Parenting as a Health Risk for Parents

Parenting children with disabilities requires a lot of work on the part of parents. The intense parenting can be stressful and can take a toll on the physical and mental health of parents. Lack of appropriate social supports and services can especially contribute to parents experiencing poor health.

Quote: But “A” stayed right in the hospital on one of those little beds and then she started to have her own health issues but “A” is, is a mom and, and she discounts her own health issues. She just has severe, severe back pain and she couldn’t sit down right, she couldn’t lie right...

Quote: And you know having somebody that needs a child to be looked after twenty-four hours is a lot of work and like there’s emotionally, mentally, physically, you know all the, spiritually, all these areas get affected because they’re not, because there’s no time that you can put into your own self when you live with a child, when you have a child that has a disability. It’s like that child has to have all the attention.

Marginalization

This theme details factors that contribute to the risk of isolation for FN families of children with disabilities. Feeling like an “outsider” was identified as a common experience for families.

Quote: I have one little boy who he has Asperger’s and he played hockey all of his life until now and he’s, he’s thirteen and he just couldn’t take the social part of it anymore like just getting ostracized all the time...

Quote: I worked in the school setting too and there’s children with disabilities there and the other kids do not, like a lot of the kids do not go near that person, you know if that person’s in a wheelchair, you know when they, cause they see him different, they see him as different and they have a hard time accepting that disability of that child.
Findings: The Way Forward

This theme details recommendations for improving the services and programs for FN families of children with disabilities that will help them flourish. Recommendations include:

Support Authentic Engagement

◊ FN families of children with disabilities need a continuing voice (includes parents, children with disabilities, siblings, and other significant family members)
◊ Service providers and other professionals, educators, and community members need to recognize each family is unique with distinct needs
◊ Adopt a collaborative approach
◊ Trust and respect

The Need for Services and Programs that Foster Equity

◊ Eradicate jurisdictional barriers that block effective health care and social services delivery on reserves
◊ Address the issue of poverty
◊ Increase resources and funding for FN families
◊ Provide services and programs at each stage of the disability trajectory to ensure a continuous transition of services and programs throughout the life of a FN person living with a disability
◊ Coordinate services and programs across all sectors so as to address the full range of challenges that FN families of children with disabilities must deal with on a daily basis
◊ Provide therapists/services/programs on site (locally available)
Findings: The Way Forward Continued

Promote Awareness

◊ More education/training for all involved
◊ Provide opportunities for educators, service providers/professionals, and community members to listen to the stories of families and children
◊ Need for cultural competence programs for all service providers
◊ More public awareness programs

Promote the Physical and Mental Health of FN Families

◊ Need for sharing circles and other opportunities where families can talk about their experiences
◊ Need for others to also be the advocate for families
◊ Need for coordinators that can help families navigate the multiple systems
◊ Need for out-reach workers to check-in on families to make sure they are doing alright
◊ Need for a toolkit with a “need to know” list that families can refer to
◊ Need to create opportunities that allow families to participate in family and community events
◊ Need for “time-outs” for families→Respite→Offer a lifeline
◊ Need for community resource centers that support FN families of children with disabilities
◊ Need to recognize and support siblings of FN children with disabilities
◊ Need to move beyond minimum standards so that FN families of children with disabilities can flourish

Promote Landscapes that Encourage Meaningful Participation for Families

◊ Homes, schools, and communities and so on, need to be accessible for FN children with disabilities. Places, spaces, activities, and situations have to be easy to move in and out of in order to be considered accessible
◊ Ensure the element of safety within landscapes
◊ The need for understanding and acceptance of families and their children
◊ The need for accommodation and flexibility
◊ Dismantle barriers to inclusion
Summary

Overall, the findings revealed that First Nations families of children with disabilities have many needs that are not adequately addressed.

Parents struggle to provide a good life for their children in environments that are lacking the appropriate resources and services.

“Having a life” for these families required significant physical, mental, psychological, and spiritual work by parents. At times, the personal resources of parents were so taxed that the possibility for meaningful participation in everyday life was something less than what they desired.

This study lends support for further improvements that may enrich the lives of First Nations families with children with disabilities.

As First Nations families of children with disabilities strive to provide a good life for their children, it is clear that they do so with a commitment to family and their children’s human potential. Their efforts benefit society by broadening our collective human experience.

Yet the question remains: Will society be there to assist First Nations families of children with disabilities as they struggle to have a life?

“Parents struggle to provide a good life for their children in environments that are lacking the appropriate resources and services.”
Questions:

1. What do you see are the two key issues affecting the lives of First Nations families of children with disabilities?
2. What currently could (not should) be done to resolve or address each key issue?
3. Based on the findings of the study, where do we go from here and what do we need to with respect to advancing:
   - Programs
   - Services
   - Policy
   - Research

*specific to First Nations families of children with disabilities?

References

The Way Forward: Advancing Jordan’s Principle

Notes