



**Supporting the Gifts  
of First Nations  
Adults Living  
with Exceptionalities**



**Research Report  
September 2023**

Community Engagement & Intergovernmental Relations Department





## Acknowledgments

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We wish to also extend our sincere gratitude to the Advisory Circle that provided invaluable guidance throughout this study. We deeply appreciate their time, wisdom, contributions, and unwavering support, which have greatly enhanced the quality and relevance of our research and the recommendations. We wish to thank our partners, namely the team at St. Amant, who helped ground this work and our recommendations with their knowledge of federal and provincial systems and the body of research and established best-practices.

This study truly embodies the spirit of collaboration, highlighting the collective strength and dedication of participants, community members, First Nations and other partners, and all those who contributed to its realization. We are grateful for the opportunity to work together towards a shared goal and are hopeful that this collective effort will have a lasting and positive impact. Last, but certainly not least, we pay tribute to First Nations with exceptionalities who have passed away and those who continue to demonstrate remarkable strength in the face of numerous challenges. We recognize their resilience and honor their enduring spirit. In particular, we wish to honour D'Arcy Linklater. Though no longer with us, his spirit and commitment have left an indelible mark on us all. We remember D'Arcy with deep admiration and gratitude for his enduring legacy.

**“When someone has a special gift, they get named for these gifts. Our exceptional relatives have gifts and terms we use for them are supportive - for them to go ahead to do their healing work.”**

-Knowledge Keeper Wanbdi Wakita, Sioux Valley Dakota Nation

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## Overview



The objective of this study is to provide unique insight into First Nations' understandings of disability and the experience of First Nations persons with disabilities in Manitoba. To do this, we rely on the literature as well as the lived-experiences of First Nations adults with exceptionalities in Manitoba along with those of their families and caregivers. By also sharing the stories of those requiring services or supports living on-reserve, we hope to illuminate the practical applications and impacts of these programs, or conversely, lack thereof.

Over the years, there have been advancements in knowledge and understanding of the important gaps in services for adults with exceptionalities, impacts of jurisdictional issues, the role of self-determination, and the importance of cultural inclusivity/safety in health and social services. However, based on our review of the literature, no research has explored these factors in relation to disability supports from the perspectives of First Nations adults and their families/caregivers living on-reserve who directly utilize, rely or require them. A comprehensive exploration of the lived-experiences of First Nations adults living with exceptionalities and accessing disability services and supports on- and off-reserve gives invaluable insight into avenues for system changes to better meet needs and priorities; reduce gaps and barriers; and foster improved quality of life for these individuals and their families. Consequently, the objective of this qualitative study was to explore the lived-experiences of First Nations adults living with exceptionalities in Manitoba, with a particular focus on their experiences and perspectives around disability services, programs, and supports.

This study was guided by a community-based participatory research (CBPR) approach. The study was framed by Indigenous methodological research design principles and utilized a modified grounded theory approach for thematic analysis and data organization. The research was independently led by FNHSSM, a First Nations organization tasked with coordinating regional health and social development initiatives for First Nations in Manitoba that are founded in the Treaty and inherent right to health and that are culturally appropriate, holistic, and community-based.

Moreover, this study was guided by an Advisory Circle, consisting of FNHSSM researchers, First Nations community-based researchers external to FNHSSM, representatives from partner organizations that service Manitoba First Nations with disabilities, and health professionals (physiotherapists, occupational therapists) experienced in providing care to Manitoba First Nations with disabilities.

A combination of purposeful and snowball sampling methods was utilized to recruit 32 participants. Some participants were members of the same family and participated in interviews alongside family members. A maximum variation approach was utilized to ensure a diversity of perspectives by age, gender, and in particular, regional participation via the five Manitoba First Nation cultural/linguistic groups (Anishinew, Cree, Dakota, Dene and Ojibway) (Patton, 1990). Moreover, this study sought to ensure representation of diverse perspectives and experiences from First Nations living with different types of exceptionalities. Recruitment occurred via service provider networks (e.g. through Jordan's Principle programs), word of mouth, online social media platforms (i.e. the FNHSSM's Facebook and Instagram pages, Tribal Council Facebook pages, and more), and advertisements on the Native Communications Inc. (NCI) FM radio station. Interviews were conducted using a conversational approach with open-ended, semi-structured interview questions to prompt conversation and facilitate participant and researcher co-creation of knowledge. For further details on the methods utilized in this study, please see Appendix D.

The findings are presented through three overarching and intertwining thematic areas that emerged out of analysis of interview field notes. These themes centered around (1) the design, structure, and administration of federal government programs; (2) inadequate resources, services, and supports; and (3) failure to deliver culturally and stigma-safe services/supports. Informed by these themes and in consultation with First Nations health and social service experts on the outcomes of this study, recommendations to improve programs and supports designed to assist First Nations living with disabilities are proposed.

## Recommendations

With these recommendations, we envision a world where First Nations living with exceptionalities can thrive, living full and satisfying lives. It is a world where cultural safety and inclusion is a top priority, and self-determination is upheld at every turn. First Nations have enhanced control over services, supports, and infrastructure as they see fit in their communities. Health and social systems balance high-risk medical and social intervention with wellness promotion and illness prevention. Through this balanced approach, the social determinants of First Nation health are taken into account, with a focus on addressing the root causes of health disparities especially colonization, intergenerational trauma and poverty.

Our recommendations promote the provision of supports across the life course of First Nation adults with exceptionalities with little to no gaps, interruptions, and barriers to care. Essential to this vision, First Nations with exceptionalities can access all the supports and care they need in their home communities. Supports are person-centered to recognize the unique needs and strengths of each person. Caregivers are valued and provided with resources and training to provide high-quality care without detriment to their own wellbeing. Finally, robust research and data collection are prioritized, to guide decision-making and improve outcomes. By implementing these recommendations, we can create a world where First Nations with exceptionalities empowered in their pursuit to live a good life, connected to home, family, community, culture, and the land.

In this report, we detail recommendations that outline approaches to improving and enhancing disability services, programs, and supports for First Nations that are grounded in the lived-experiences of those who depend on them. Notably, all recommendations include reference to ensuring that any resulting activities uphold self-determination and inclusion of First Nations' culture, language, and spirituality. Moreover, recommended options are asserted with accessibility and availability to ALL First Nations persons living with disabilities, regardless of where they reside (on- or off-reserve) but at times we also highlight needs critical for on-reserve contexts in particular. All recommendations are addressed to the Government of Canada, however most require collaboration between different levels of government (provincial, municipal, and First Nations) and other institutions such as universities, public and private continuing care institutions, regional health authorities and more. Thus we also call upon these entities to heed these recommendations and work collaboratively with the aim of ensuring First Nations with exceptionalities empowered in their pursuit to live a good life. Above all, jurisdiction should not be used as an excuse for inaction, and we urge the Government of Canada to wield its spending power to promote action among other jurisdictions and institutions.





## Recommendations

### Culture as Foundation

1. Commit to creating flexible funding allotments within all on-reserve programming and services to enable First Nations to integrate community-determined cultural and land-based activities/supports for First Nations living with exceptionalities.
2. Fund cultural and land-based activities/supports specifically for First Nations with exceptionalities who live on- and off-reserve.
3. Fund the development of a First Nations-led and delivered anti-racism, stigma, and prejudice training that explores First Nations' history, spirituality, languages, worldviews, ways of being and knowing. Mandate that all federal health and social services workers complete the training.
4. Commit to funding a First Nations-led engagement strategy to identify suitable options/mechanisms for First Nations to report experiences of racism or prejudice within health and social services, as well as processes to hold service providers accountable and promote healing.

### Self-Determination

5. Commit to funding the introduction, enhancement, and upholding of processes for self-determination and on-going community engagement at all levels of health and social system planning and decision making.

### Social Determinants of First Nation Health

6. Commit to funding to ensure all First Nations persons living with exceptionalities on-reserve have timely access to suitable, affordable, accessible and supportive housing via investments in community-driven:
  - a. *Single family dwellings;*
  - b. *Community-driven, local collective/cooperative supportive living options; and*
  - c. *Homelessness prevention/interruption strategies including: rent subsidies, rapid re-housing, transitional housing, shelter diversion/respice housing options, and on-reserve to off-reserve migration supports.*

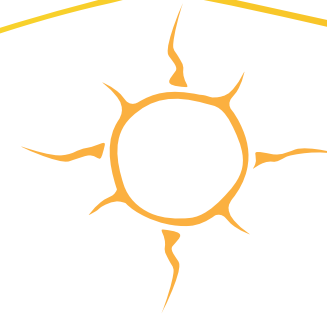
7. Invest in community-driven processes for continuous improvement of housing for First Nations with exceptionalities. Such processes could include:
  - a. *Aids & Assistive Equipment/Technology Loan Program*
  - b. *Community Tool Library*
  - c. *Building Supplies Inventory*
  - d. *Community Housing Renovation, Repair and Renewal Support*
  - e. *Local Pool of Community Helpers with funding for their labour*

8. Implement a Universal Basic Income for First Nations with exceptionalities on- and off-reserve (either via the Canada Disability Benefit or other benefit) with timely adjustments according to the cost of living, inflation, and geographical considerations (i.e., costs of living in northern and remote communities).

9. Fund meaningful engagement and consultation with First Nations in the design and implementation of the Canada Disability Benefit or related benefit.

10. Reduce barriers to accessing existing financial supports for First Nations with exceptionalities, including but not limited to:
  - a. *Extending the Disability Tax Credit to all individuals with a disability diagnosis regardless of place of residence (on/off reserve), provider of social assistance (federal or provincial government), or type of disability;*
  - b. *Provide support to First Nations with disabilities to access all benefits they are entitled to via case manager or other means.*

11. Fund the development of a First Nations-led strategy to comprehensively address the unique challenges related to household food security, including assurance of food sovereignty, with access to lands and resources, for acquiring traditional foods, as well as improved access to more affordable and healthy store-bought/market foods, especially in:
  - a. *Remote, rural, and northern First Nation communities;*
  - b. *Urban contexts;*
  - c. *Community-driven, local collective/cooperative supportive living environments.*



12. Invest in First Nations-led programs to close the education gap between First Nations children with disabilities and all other Canadians, across all stages of the education system, from kindergarten through to post-secondary education, including but not limited to:
  - a. *Funding of ongoing learning and education opportunities for school staff to learn about invisible and visible disabilities to increase the safety for all learners;*
  - b. *Funding of specialized teachers and educational assistants to work with students living with a disability;*
  - c. *Investments for the creation of safe and inclusive learning spaces in First Nation schools for students living with an exceptionality who cannot thrive in the overcrowded, overstimulating classrooms;*
  - d. *Supports for achieving high-school equivalency (e.g. continuing adult educational opportunities, GED).*

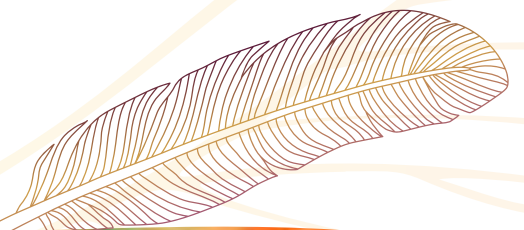
13. Invest in First Nations-led programs to provide financial assistance and education/career guidance support to First Nations persons with exceptionalities pursuing education, training, and/or employment including but not limited to:
  - a. *Post-secondary financial assistance and transition supports;*
  - b. *First Nations bridging programs (i.e., pathways to university education for those who do not meet conventional admission requirements);*
  - c. *Community-driven mentoring and other early exposure programs;*
  - d. *Liaisons to promote admission or recruitment policies/quotas and mission statements demonstrating a commitment to achieving equity in education institutions and among employers;*
  - e. *Life-skills development and supports for capacity in educational/employment settings as well as daily living activities (e.g. acquiring driver's licence, goal setting, coping skills, self-advocating, cooking, budgeting and banking, independent living, healthy relationships, health and wellness, technology and assistive devices, transit training, preparation for schooling and employment, engaging in community, culture, and language, and more);*
  - f. *Employment guidance supports to assist with resume development, job searches, navigating recruitment processes, interview preparation, more; and*
  - g. *Funding for one-on-one supports for First Nations with exceptionalities to work and volunteer.*

### Support Across the Life Course

14. Invest in the creation of a new principle akin to the Jordan's Principle-Child First Initiative specifically for First Nations adults with exceptionalities for the purpose of:
  - a. *Enabling seamless transition of services and supports from Jordan's Principle-Child First Initiative into adulthood and throughout the life course; and*
  - b. *Enabling adult enrollment to support our relatives who did not previously qualify for or access Jordan's Principle-Child First Initiative services.*
15. Invest in enhanced supports to aid First Nations with disabilities in their transition from the care of Child and Family Services to life as independent, empowered adults.

### Person-Centered Care

16. Invest in First Nations-led person-centered case management and coordination supports for First Nations living with exceptionalities, including, but not limited to:
  - a. *Funding for the establishment of individual case managers or client advocates to provide support across the life course with navigating services/supports, referrals, ensuring timely diagnoses and intervention, completing program requirements (applications, assessments, etc.), asserting and advocating with goals/priorities/needs, accessing recreation and cultural activities, discharge or transition planning, accessing supports for informal caregivers and more;*
  - b. *Ensure reasonable caseloads (defined by community) for case managers so that need does not surpass capacity; and*
  - c. *Support the creation of a 'service roadmap' to assist with navigating services/supports.*
17. Establish a regional First Nations with Exceptionalities Advocate Office to lead efforts to improve system-level issues to reduce barriers, improve processes, and enhance continuity/coordination of supports for First Nations with disabilities and their families/caregivers.







## Recommendations

### Caring for Caregivers

18. Invest in resources and supports to all relatives and the families/caregivers living with an exceptionality, including but not limited to the following topics:

- a. *Families/caregivers supporting First Nations living with an exceptionality*
- b. *Educational supports, medical and therapeutic necessities tailored to the specific needs of the care recipient;*
- c. *Educational supports on disability rights and advocacy;*
- d. *psychotherapy and counselling supports for the caregiver;*
- e. *Peer support networks;*
- f. *Problem-solving techniques;*
- g. *Opportunities for experiential learning; and/or*
- h. *Financial assistance for caregivers to participate in a Health Care Aide or similar educational program.*

19. Invest in person-centered, community-driven and local respite services and other burnout prevention supports for informal caregivers of First Nations living with disabilities, particularly in:

- a. *Respite supports that are person-centered and led by the person receiving the supports and their respective caregivers;*
- b. *Respite supports that enable informal caregivers' ability to participate in the workforce or attend personal health priorities (i.e. health problems, supporting other family members, etc.);*
- c. *Respite supports that allow informal caregivers to relieve stress, restore energy, and promote balance in their life; and*
- d. *A variety of respite support options (e.g. in-home and out-of-home respite supports available for varying amounts of time such as a few hours, day programs, to a few days or longer-term stays).*

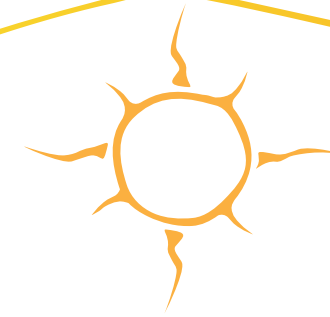
20. Fund the First Nations-led development of livable allowance, benefit, or other mechanism to adequately compensate informal caregivers for their holistic care.

### Health Care & Social Service Systems

21. Initiate extensive engagement processes with First Nations to co-develop suitable, flexible, and responsive approaches to all program and service funding on-reserve, including but not limited to health and social services/supports.

22. Fund a First Nations-led approach to resolving jurisdictional disputes around fiscal responsibility for services for First Nations adults with exceptionalities to prevent denials, delays, or disruption of services.

23. Integrate the principle of "Connection to Home" as a cornerstone for all health and social policy, planning, and programming for First Nations. This means prioritizing supports to remain at home, supporting family/informal caregivers, and fostering connection to family, community, land, culture, and language.



24. Commit to and fund enhanced services on-reserve, namely a transition from the current sole reliance on nursing model of care to a multidisciplinary team-based, community-driven holistic health care model that:

- a. *Ensures timely access (define by community) to an array of health services and professionals regardless of residence (on- or off-reserve);*
- b. *Integrates diverse health care professionals in a team-based model including family physicians, specialists, nurses, mental health therapists, crisis responders, dental health professionals, social workers, dietitians, occupational therapists, physiotherapist, speech language pathologists, massage therapists, traditional healers, knowledge keepers, and Elders work collaboratively to provide integrated care;*
- c. *Ensures access to medical specialists beyond only emergency need to also include health prevention and promotion focus (e.g. dermatology, gerontology, rehabilitation medicine, ophthalmology, genetics, neurology, gynecology, etc.);*
- d. *Incorporates First Nations-led development of palliative or end-of-life care supports utilizing both Western/biomedical and Indigenous approaches;*
- e. *Conducts outreach and/or home visitation services to improve access and reduce barriers to accessing care;*
- f. *Funding for one-on-one supports for First Nation with exceptionalities to support them in activities for daily living.*

25. Establish a Manitoba Adult Assessment and Diagnostic Clinic to aid in "case finding" or identification of previously undiagnosed adults so that they can then access services and supports. Ensure cultural validation of assessment/diagnostic tools in First Nations populations and that tools, services, & supports are available in First Nations languages.

26. Commit to addressing chronic human resource shortages in health and social services on-reserve via targeted training and educational opportunities and supports along with retention incentives for First Nation community members.

27. Compel the Province of Manitoba to review and revise all policies and procedures to ensure there are no exclusions of First Nations adults with exceptionalities on-reserve.



## Recommendations

28. Expand the funding and scope of Non-Insured Health Benefits (NIHB) to:

- a. *Improve timeliness of access to benefits by renewing approval processes;*
- b. *Adapt policy so that provision of supplies and equipment reflect actual client need and not arbitrary quotas and limits that are frequently inadequate and inhumane;*
- c. *Conduct regular policy and program review in partnership with First Nations to ensure alignment with community needs and priorities as well as clinical guidelines/best practices;*
- d. *Introduce balance between Western/biomedical therapies and Indigenous healing approaches by providing financial resources to compensate for traditional medicines as well as knowledge keepers, traditional healers, Elder counsellors, spiritual counsellors, and more;*
- e. *Include coverage for subsidized bus passes to facilitate transportation to access key services in urban centres including school, appointments, recreation, cultural endeavours, socialization, and shopping for essentials;*
- f. *Provide financial assistance for the purchase of or modification of an accessible family vehicle;*
- g. *Create a flex category to allow for person-centred autonomy in selecting therapies not on the formulary (e.g. accessing evidence-based alternative pain management strategies such as meditation, medical cannabis, traditional healing, etc.).*

29. Commit to overhauling the Non-Insured Health Benefits' Medical Transportation Program to ensure equitable financial resources/rates for mileage, accommodation, and meals allocated to First Nations travelling for medical care. We recommend that rates match those allocated to federal government staff.

### Community Infrastructure, Resources, & Capacities

30. Commit to funding community-driven Accessibility Plan development in every First Nation.

31. Commit to providing funding to address on-reserve community infrastructure needs, namely to:

- a. *Achieve universal access to clean drinking water and sewer sanitation for all households;*
- b. *Achieve universal access to high-speed internet and cellular service for all First Nation citizens;*
- c. *Foster interoperability of eHealth applications to ensure seamless access to health information for continuity of timely care between on-reserve and external health care providers;*
- d. *Ensure community-wide accessibility for all;*
- e. *Provide capital funding to support the creation of accessible indoor and outdoor spaces in all First Nations communities to accommodate cultural, spiritual, recreational, and wellness programming and supports;*
- f. *Fund the construction of safe and inclusive play structures and accessible cultural and recreational spaces within all First Nations communities;*
- g. *Establish reliable and accessible community transportation for accessing local and regional cultural, spiritual, and recreational pursuits in addition to health and social services*

### Research And Data

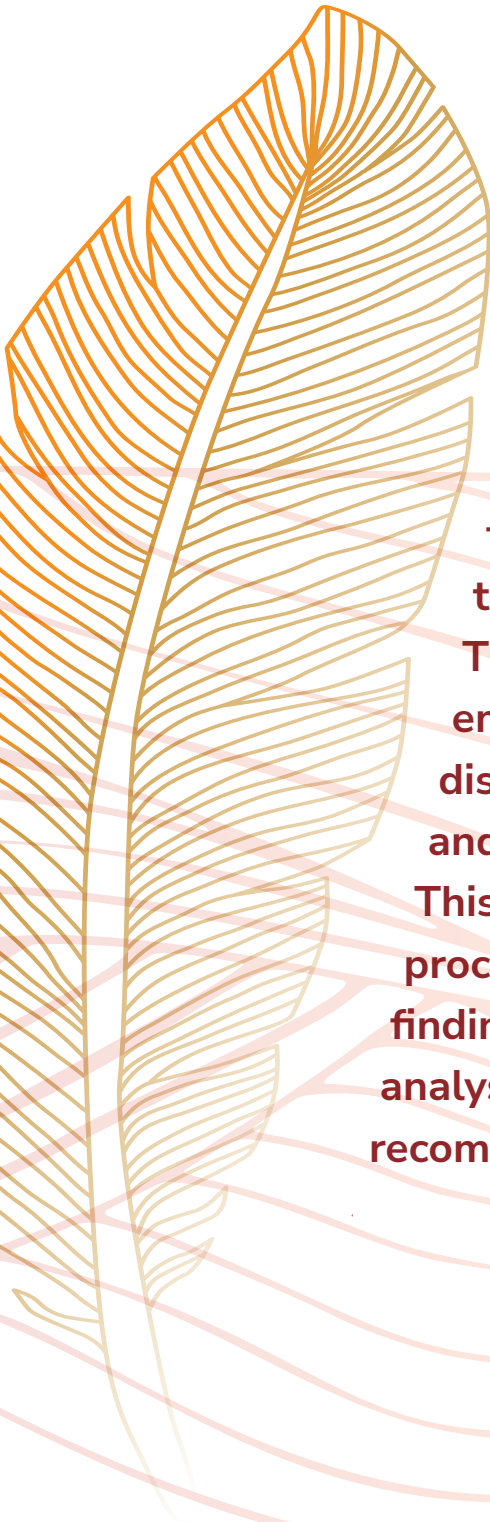
Invest in comprehensive, First Nations-led, and OCAP® compliant research and data collection involving:

- a. *The prevalence and types of disabilities (diagnosed and undiagnosed) among First Nations on-reserve and off-reserve;*
- b. *The circumstances that create and exacerbate disability for the purpose of prevention & intervention (e.g. specific and detailed data pertaining to injuries, accidents, chronic illness, co-morbidities, etc.);* OCAP Socio-demographic data pertinent to future community planning (i.e. projection of children aging out of care/services, etc.);
- d. *In-depth and on-going lived-experiences of First Nations with exceptionalities;*
- e. *More specifically, the impacts of intersecting identities on the lived-experiences of First Nations with exceptionalities (e.g. gender, class, Indian status, skin color, geography, and more);*
- f. *Explicit linkages across systems containing First Nations data (provincial population data repositories across health, justice, child welfare data sets and beyond, regional data sets, census data, etc.).*

### A note on Terminology

Throughout this report, we utilize the terms "Indigenous" and "First Nations." We use the term "Indigenous" to refer more broadly to the peoples who are the original inhabitants of Turtle Island (also known as North America) who have shared ways of knowing, being, relationships to the land and living things, and who have been adversely affected by incursions by industrial economies, displacement, and settlement of their traditional territories by others (University of British Columbia, 2009). Conversely, we utilize the term "First Nations" to refer to bands, reserve-based communities, or larger tribal groupings in Canada that call themselves as "First Nations" and their self-defined membership (which can include First Nations person with status under the Indian Act, non-status First Nations, and more) (University of British Columbia, 2009).






This section (alongside Appendix A which defines disability according to theoretical perspectives in the field of disability studies) reviews the body of academic literature to present a picture of the existing research, theoretical perspectives, and debates relevant to this study design and analysis of outcomes. This section also seeks to summarize the empirical evidence around the prevalence of disabilities among First Nations in Canada and what is known about needs and supports. This information aided to guide the research process/approach, the interpretation of findings by the research team, and pragmatic analysis of findings for practical recommendation.

A

First Nations' Understandings of Disability



“When someone has a special gift, they get named for these gifts. Our exceptional relatives have gifts and terms we use for them are supportive - for them to go ahead to do their healing work.”

-Knowledge Keeper Wanbdi Wakita, Sioux Valley Dakota Nation



## Background - Part 1

Throughout this report, we often utilize the term “First Nations living with OCAP®” instead of using the term disability. We do this to honour First Nations’ understandings of disability, to emphasize that ability is a construct shaped by social processes, and to emphasize the ability is a construct shaped by social processes, and to acknowledge gifts as opposed to obstacles.

First Nations peoples across Turtle Island (North America) have their own unique understandings of disability, which are often deeply connected to cultural beliefs and practices. There are several other ways that First Nations’ understandings around disability are distinct from Western, medical views. While First Nations are culturally and linguistically diverse, the literature has identified some shared cultural understandings and values that are pertinent to consider in developing and implementing disability services and supports.

Firstly, First Nations’ understandings of health and wellness typically aim to focus on strengths and resilience in contrast to the typical focus on deficits and problems. This is embodied in the languages spoken by the inhabitants of Turtle Island, which do not commonly have a word to describe the concept of disability (Ineese-Nash, 2020). During Manitoba-wide First Nations engagement on long-term care strategy, for example, Elders shared that there is no word for “handicap”, and that instead individuals with “disabilities” are just those that require extra care in a culture where we take care of each other (FNHSSM, 2022). As another example, in Anishinaabe (Ojibway) culture, children are named in ceremony and their names reflect the gifts and responsibilities that they hold within their community (Willmott, 2016). Naming ceremonies reflect the understanding that all people are gifts to the community. In this sense, there is a focus on a child’s abilities, strengths, talents, and kinships rather on their perceived limitations or weaknesses (Greenwood, 2006).

Many First Nations’ cultures see disability as a natural aspect of human diversity, rather than as a problem to be fixed. For example, Anishinaabe teachings understand that everyone within a community is kin and not “other,” which comes from the cultural recognition that each individual is a descendant of the original being Nanaboozhoo (or Nanabush) (Simpson, 2014). In another example, a concept known as Mino Bimaadiziwin, or “The Good Path” or

“The Good Life” is a cornerstone of many First Nations’ teachings. This idea is based on the life-long pursuit of following the rightful path by respecting all life and understanding cultural teachings based on honouring oneself, one’s relations, and all of creation (Ineese-Nash, 2020). The Haudenosaunee have a similar concept known as “The Good Mind” (Antoine, 2013). In this way, First Nations’ teachings do not see persons with disabilities as having a medical condition that requires intervention to restore normal functioning, but as a member of the community that maintains their place using their individual and unique gifts as a resource (Bell, 2013). Overall, many First Nations’ traditions hold esteem for people with disabilities for their unique perspectives, their special gifts or talents, the important roles they can take on in the community, and/or for possessing spiritual or supernatural connection.

Secondly, First Nations’ understandings of disability generally tend to be more holistic and inclusive. Good health, what it means to live a good life and to age well – requires a balance between the mind, body, spirit, and emotions (Hillier & Al-Shammaa, 2020). In general, First Nations’ understandings of disability tend to be more holistic and inclusive, more aligned with the social model of disability and less

*<sup>1</sup>The social model of disability is a way of understanding disability that focuses on the ways in which society creates barriers for people with disabilities, rather than focusing on their individual impairments (Shakespeare, 2006). The social model emphasizes the importance of removing societal barriers and creating a more inclusive society (Shakespeare, 2006; Oliver, 2013). It is based on the idea that disability is a socially constructed experience, rather than a medical one. For a more in-depth review of the social model of disability, please see Appendix A.*

focused on the medical model of disability. In contrast, Western medical understandings tend to focus primarily on the physical aspect of wellbeing, with services and supports that centre mainly around tending to physical needs. Spiritual, mental, and emotional wellbeing are often treated as outside of the scope of care or as recreational/optional instead of essential.

To decolonize policy pertaining to notions of disability support resources to First Nations, and to integrate First Nations’ value systems, the incorporation of the Medicine Wheel has been proposed. The Medicine Wheel teachings are founded on a principle of holism, putting forth the importance of a balance between all four domains of humanity, namely the mental, physical, emotional, and spiritual (OCAP®, 2007). For example, the Government of Ontario has developed a network of Aboriginal Health Access Centres (AHAC) that have integrated healing practices that engages Elders, healers, medicine people, helpers and others from a traditional healing background. This model has been endorsed by all major Indigenous Provincial Treaty and Territorial Organizations. With this model they have found that cultural considerations have improved health outcomes (Government of Ontario, 2022).

Lastly, connectedness is a core aspect of First Nations’ understandings of wellbeing, which aligns strongly with an intersectional lens. Interconnectedness often encompasses connection to family, community, the land, culture, and traditions (Balestrery, 2016; Coombes et al., 2018; Gabel & Pace, 2016; Habjan et al., 2012; Waugh & Mackenzie, 2011). Connectedness has also been highlighted as a key factor in what it means to age well among First Nations Elders. Maintaining connections with one’s community despite living away in a long-term care facility, a connection to the land despite mobility challenges, and being able to maintain intergenerational relationships are particularly important (Balestrery, 2016; Baskin & Davey, 2015; Browne & Braun, 2017; Browne et al., 2014; Lewis & Allen, 2017; Owen-Williams, 2012; Wilson et al., 2010). Research outcomes emphasize how First Nations’ culture, knowledge, and language are transferred from Elders to youth and Elders see this as a critical role and cultural obligation. Disability supports thus need to foster these relationships to support Elders’ sense of meaning, belonging, and purpose, which are key components of First Nations’ understandings of mental wellness (Health Canada, 2013; Gabel & Pace, 2016;

*<sup>2</sup>The medical model of disability is often associated with a focus on finding a cure or fixing the individual with the disability, rather than addressing the societal barriers that prevent them from fully participating in society (Meekosha & Shuttleworth, 2009). It also emphasizes the idea that people with disabilities need to be “fixed” in order to be able to live a normal life (Meekosha & Shuttleworth, 2009). In this sense, disability is defined as a limitation or deficit within an individual, and disability programs thus must attempt to provide services that aim to help an individual compensate for perceived deficits in order to allow them to better function in society. For a more in-depth review of the medical model of disability, please see Appendix A.*

Lanting et al., 2011; Lewis & Allen, 2017; Tobias & Richmond, 2016; Waugh & Mackenzie, 2011, Baskin & Davey, 2015; Brooks-Cleator & Giles, 2016; Waugh & Mackenzie, 2011). (Gabel & Pace, 2016; Baskin & Davey, 2015; Brooks-Cleator & Giles, 2016; Health Canada, 2013; Lanting et al., 2011; Lewis & Allen, 2017; Tobias & Richmond, 2016; Waugh & Mackenzie, 2011)

A First Nations’ worldview emphasizes the interconnectedness among all things: individuals, families, organizations, communities, Nations, to the land, and to all of Creation (Lavallee, 2009; Hart, 2010).



Within this belief system, constructs such as culture, history, race, and gender cannot be compartmentalized and separated. In some First Nations' cultures, disability is also understood as being connected to the environment and the community. For example, some believe that a person's disability may be caused or impacted by the land or the community being out of balance, and that restoring balance will help with wellbeing and healing. Moreover, the tangled and compounded impacts of colonization must be central to any examination of health or wellness experience among First Nations peoples.

Supporting connectedness is not commonly prioritized in the provision of disability services and supports that operate from a Western, medical model. Consequently, First Nations Elders and persons with exceptionalities accessing disability supports and services often report a need for improved social support networks (ISC, 2022). Such improvements would ideally be achieved by being able to stay home or at least close to their homelands for as long as possible (ISC, 2022). Research has noted the critical role that family members, peers and social networks have in assisting with the management of care; however, many receiving care expressed concern with burdening their family and community (Government of Ontario, 2017). This is complicated by the noted change in the traditional extended family system, such that family and community networks were breaking down as a result of colonization (Muir & Bohr, 2019). Thus, some studies noted how First Nations individuals receiving disability supports viewed a need for shared responsibility of social support (caregiving) by the family/community and government system (Bonita & Weber-Beads, 2012). It is

suggested that the opportunity for educational interventions be provided to the caregivers to assist with mitigating anxiety and cultivating supportive practices (Schulz et al., 2016). Creating social avenues to enable older adults to connect with both each other, and their culture, through health promoting activities is important.

Related to supporting connectedness and holistic notions of health is the need for preservation and promotion of cultural approaches to living a good life and achieving holistic balance between the spiritual, mental, emotional, and physical dimensions of wellness. Such approaches can include cultural activities on the land (berry picking, tanning hide, medicine picking, gardening, etc.), sharing circles, art-based activities, participation in ceremony, access to traditional foods, participation in community (via special events, volunteering, Elder-youth groups, Elder lodges, storytelling, language groups, drumming and singing groups, etc.), and more (Sjoblom et al., 2022).

## B

### Disability Services & Supports Needs of First Nations



Although disability has been studied widely for the general Canadian population (Arim, 2012; Burlock, 2017; Casey, 2015; Morris et al., 2018), there is a paucity of research that examines disability among Indigenous peoples and First Nations people living on-reserve in particular. In the limited research that is available, Indigenous peoples have been shown to experience a disproportionate burden of disability when compared to the non-Indigenous population that amounts to as high as twice the rate of the national average (Burlock, 2017; Durst et al., 2006). According to the 2012 Canadian Survey on Disability, Indigenous women were more likely to have one or more disabilities than non-Indigenous women, with a similar pattern between Indigenous and non-Indigenous men albeit to a lesser degree. Indigenous women were also more likely to experience greater severity in disability in comparison to the experiences of non-Indigenous women (Burlock, 2017).

According to the Aboriginal Peoples Survey, a study published by Statistics Canada that focused on First Nations living off-reserve, 32% of First Nations people in Canada living off-reserve in 2017 lived with disabilities that limited their daily activities (Statistics Canada, 2019). In this context, disability was defined according to the social model of disability. This takes into account both the persons impairments or task difficulties and the added impact of barriers including environmental barriers, technological barriers and issues caused by prejudice and exclusion. Examples of environmental barriers can include physical obstacles such as stairs; technological barriers such as inaccessible websites; or they can be social barriers, resulting in prejudice and exclusion. This perspective on disability focuses more on barriers to the participation of persons with disabilities in society and the economy and less on the perceived deficits of the individual (Government of Canada, 2019).

Findings from this study also highlighted the following findings:

- Disability increased with age for both men and women among First Nations groups
- Of all severity levels, mild disabilities were most common. The second most common disability type was mental-health related disabilities;
- Women had higher rates of predicated disability than men and these differences were larger than among non-indigenous people
- Pain-related disabilities were the most common disability type (Statistics Canada, 2019)

There is limited research on disability types among First Nations peoples. Much of the research conducted on these populations has approached the topic from the perspective of chronic health issues rather than disability. For instance, according to the 2008/2010 First Nations Regional Health Survey, based on First Nations adults living on reserve and in Northern communities, the most frequently reported chronic health conditions were chronic back pain (16.2%), hearing impairment (8.8%), blindness or vision problems (3.6%), learning disability (3.6%), and cognitive or mental health issues (1.2%). Previous studies on pain among Indigenous peoples in Canada and the United States have found markedly higher rates of reported pain overall and in specific areas of the body. A greater proportion of First Nation people are also likely to suffer from chronic health conditions at a younger age compared to the general Canadian population (First Nations Information Governance Centre [FNIGC], 2012).





## Impacts of Colonization Within the Context of Disability



The colonial legacy has been cited as the primary cause of the intergenerational health and wellness gaps between Canada's First Nations peoples and the general Canadian population (Czyzewski, 2011). The health and wellness of First Nations peoples are strongly influenced by social determinants and, as a result of historical and ongoing colonization and colonialism mechanisms, these factors have intersected a broad array of health capacities and vulnerabilities (Reading & Wein, 2009).

There has been little written about pre-colonial history on Turtle Island. Drawing on historical documents and oral histories, the Royal Commission on Aboriginal Peoples (1996) and the First Nations Health Council (2011), reported that First Nations populations prior to European contact were diverse, complex societies with some estimates suggesting a population size that exceeded 2 million. Oral histories and observations highlighted that First Nations experienced no diabetes or dental cavities and had healthy traditional diets and lifestyles (Hopkinson, Stephenson & Turner, 1995). Societies had complex systems of healing and traditional knowledge which evolved to safeguard collective wellness. The early relationship between First Nations peoples and the British Crown was founded on mutual respect, sharing, and recognition of First Nation sovereignty, as evidenced in the treaty-making process that resulted in what First Nations have considered to be formal agreements between sovereign nations (Royal Commission on Aboriginal Peoples [RCAP], 1996; Rotman, 1996; Aboriginal Justice Implementation Commission, 2001). (Aboriginal Justice Implementation Commission, 2001; Rotman, 1996; Royal Commission on Aboriginal Peoples [RCAP], 1996)

European-introduced epidemics devastated First Nations populations resulting in entire bands disappearing in Manitoba by the early 1700s (Hackett, 2005). Population declines disrupted food harvesting, resulting in widespread malnutrition leading to the introduction of infectious diseases, which further devastated Indigenous populations (RCAP, 1996). This population decline resulted in traditional

knowledge experts perishing and a widespread loss of Indigenous oral knowledge (RCAP, 1996).

Following population collapse, interventions into First Nations societies by governments and churches increased, characterizing First Nations as wards of the Crown (RCAP, 1996). Following the Bagot report of 1844, the Indian Act was introduced in 1876 as a declaration of the paternal role the federal government would take regarding Indigenous affairs (Joseph, 2018). This legislation created a land reserve system, aimed to assimilate and control Indigenous peoples by determining identity, education, healthcare, and political systems (Joseph, 2018). Traditional practices in communities, including methods of traditional healing, spiritual ceremonies, cultural events and gatherings such as pow-wows, were made illegal and sacred places were destroyed (Joseph, 2018).

Residential schools were established to remove children from their families with the intent to "kill the Indian in the child" (Truth and Reconciliation Commission of Canada [TRC], 2015). The residential school system existed from the 1870s to 1996 when the last government-run residential school closed (TRC, 2015). In addition to residential schools, child welfare agencies removed children and placed them with non-First Nations families in what was referred to as the "Sixties Scoop". These actions "deprived children of the information, skills, and resources to address the poverty, disempowerment, multi-generational grief and loss of parenting knowledge", amounting to cultural genocide (Trocmé, Knoke & Blackstock, 2004). The removal of children was a means to remove the future of First Nations culture so it would die off with the older generations.

Inter-generational trauma and community upheaval as a result of colonization led to poor socio-economic conditions on-reserve. This in turn generated a greater burden of health needs due to the lack of infrastructure, social supports, employment, and inclusion programs (Shackel, 2008). In the Ojibway/Saulteaux language the term for reserve, *Ishkonegan*, literally means "leftover land" (Sjoblom, 2018). Poverty places individuals at a much greater risk of acquiring a disability due to the general lack of health care, nutrition, sanitation and safe working conditions (Huntjens & Finlay, 2017). First Nations women experience many barriers to receiving adequate prenatal care which can also lead to increased cases of disability (Jameson, 2021). Historical trauma may contribute to First Nations not seeking colonial run health care services, resulting in a lack of early medical intervention contributing to disability. These issues are further exacerbated by the failure of the government to recognize the unique needs of First Nations based on cultural concepts of wellness and quality of life.

The Truth and Reconciliation Call to action 18 highlights the importance of all levels of government to acknowledge the impacts of colonization on Indigenous peoples in Canada and Call 21 discusses the importance of healing centers to support those who need support healing from this trauma respectively:

We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.

We call upon the federal government to provide sustainable funding for existing and new Aboriginal healing centres to address the physical, mental, emotional, and spiritual harms caused by residential schools, and to ensure that the funding of healing centres in Nunavut and the Northwest Territories is a priority.

Research on disability among First Nations peoples is especially relevant in light of colonization, experienced prejudice, and historic oppression and trauma (Truth and

Reconciliation Commission of Canada, 2018) that are tied to various social and health inequalities (Firestone, Tyndall, & Fischer, 2015). Some scholars have highlighted how the overrepresentation of First Nations among those with disabilities is largely shaped by the impacts of colonization and on-going marginalization which have created elevated risk for injuries, substance use, chronic illness, and other conditions/determinants that are connected to disability (Ineese-Nash, 2020).

Moreover, in considering the social model of disability and intersectionality, First Nations—particularly those living on-reserve—are arguably further impacted by environmental conditions and social determinants that work to shape limitations to activities for daily living and thus exacerbate experiences of disability. Such environmental conditions can include poor housing/living conditions and community infrastructure; inequitable, inaccessible, or inadequate access to disability support services; reduced support from informal social networks (family and community); lower Socio-economic Status (SES) which impacts an individual's ability to access the resources necessary for health and wellbeing (Adler & Newman, 2002; Reading & Wein, 2009). The literature on the disparities experienced by First Nations, relative to the general Canadian population, consistently shows direct and indirect links to a colonial-shaped socio-cultural, political, economic, and environmental context in which First Nations live today.





D

## Gaps or Criticism of Services for First Nations with Exceptionalities



This section aims to summarize known issues highlighted in the literature around the provision of services and supports to First Nations with exceptionalities. For a full catalogue of both federal/on-reserve and provincial, off-reserve services for persons with exceptionalities in Manitoba, please see Appendix B.

### Jurisdiction

The literature highlights a number of notable barriers and gaps in disability services, programs, and supports offered on-reserve that negatively impact First Nations adults living with exceptionalities and their families. The Canadian health system consists of inter-related components that are the responsibility of the federal, territorial, provincial, municipal

governments, First Nation authorities, or the private sector (Wigmore & Conn, 2003). Legislation, policies, relationships and goodwill glue the system together, which in some cases results in a relatively seamless system. In most cases however, the system is at best loosely woven, resulting in gaps and ambiguities (Marchildon, Allin, & Merkur, 2020). The fragmented nature of the healthcare system, to which jurisdictional issues add complexity and confusion, creates a patchwork of policies and programmes for First Nations (Romanow, 2002). Studies have shown that this jurisdictional confusion creates barriers to First Nations accessing services other Canadians can expect (Lavoie et al., 2015).

<sup>3</sup>Intersectional theory is a paradigm that frames how social categories such as gender, ethnicity, class and education interact, intersect, and mutually reinforce each other to produce different health outcomes and experiences of oppression among and between social groups (Reid, Pederson, & Dupere, 2012). The theory aims to understand the multitude of factors that work to influence experiences, how these factors interact, and the social and institutional power structures and systems that produce and perpetuate disparities (Reid, Pederson, & Dupere, 2012). As such, intersectional theory advocates for the examination of the experience of disability beyond just the experience of impairment, but also about the ways in which society views and treats people with disabilities based on their other identities. For a more in-depth review of intersectional theory within the field of disability studies, please see Appendix A.

The Truth and Reconciliation Call to action #20 highlights the importance addressing jurisdictional disputes as part of the health services provided to Indigenous peoples 20.

In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on-reserve, we call upon the federal government to recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples.

First Nations peoples' experiences of disability are shaped by jurisdictional issues and disputes between governments and service providers for the provision of essential services, programs, and supports. First Nations living on-reserve are caught in a complex web of government-based jurisdictional and departmental wrangling, offloading, complexities, and ambiguities, directly impacting the types of services and supports they receive at the community-level (National Collaborating Centre for Indigenous Health, 2019). Decades of complex, ambiguous and fragmented jurisdictional issues continue to result in frustration, confusion, unmet health care needs and, most concerning, higher mortality and morbidity of Indigenous peoples (Greenwood et al., 2018; Lavoie et al., 2015). As stated by Martin and colleagues (2018) "[a] dizzying array of services in the health-care system, including federal programmes, provincially provided services, and highly bureaucratized add-ons together continue to fail to meet the needs and constitutional rights of Indigenous people" (p. 1729).

Provincial policies and procedures can further exacerbate jurisdictional barriers for First Nations with exceptionalities. Province of Manitoba, often have explicit statements that exclude First Nations on-reserve from provincial services or are simply silent on the issue, resulting in jurisdictional ambiguity and gaps in services (Lavoie, 2013).

The case of Jordan River Anderson underscores the inequity of health service provision for First Nations peoples and children living on-reserve. A Cree child from

the Norway House Cree Nation in northern Manitoba, Jordan was born in 1999 with complex health issues. He died in 2005 in a Winnipeg hospital at the age of five after waiting two years for federal and provincial governments to resolve the issue of who should pay for the necessary specialized care in his home community (Chambers & Burnett, 2017; Jordan's Principle Working Group, 2015). On February 26, 2016, a landmark ruling of the Canadian Human Rights Tribunal (CHRT) called on the Government of Canada to end racial discrimination against First Nations children and to provide equitable funding and access to health, education and social services, with a fifth non-compliance order issued in February 2018 (First Nations Child & Family Caring Society of Canada, 2018). The Canadian government has been working to address these inequities under a program named after Jordan called the Jordan's Principle Child-First Initiative (ISC, 2018). Nonetheless, First Nations adults with exceptionalities are ineligible for this program, and thus continue to experience frequent and harmful barriers due to jurisdictional disputes (Assembly of First Nations [AFN], 2017).

Overall, jurisdictional barriers have led to lengthy disputes between various levels of government over who has financial responsibility for particular health services for First Nations peoples. Ultimately, ongoing jurisdictional disputes, funding inequities and structural discrimination raise "questions about where responsibilities [lie] for the 'implicit social contract' guiding Canada's vision of equitable health care," and how this affects the health and well-being of Indigenous peoples (Greenwood et al. 2018, p. 1647). Despite some research being invested into exploring the impacts of jurisdiction issues on the health status of First Nations peoples overall and the impacts on First Nations families and children living with exceptionalities on-reserve, we are not aware of studies that have explored how they impact, from the perspective of those navigating these systems, the lived-experiences of First Nations adults living with exceptionalities on-reserve.



### Inequitable Access

Another commonly experienced challenge involves limited access to required medical and other resources (AFN, 2017). Some of the factors that may affect the delivery of resources to communities include: “demand for services; availability of local expertise based on demand for services and recruitment and retention challenges for care providers; year-round infrastructure for transportation; and weather and climate barriers impacting year-round service” (Canadian Home Care Association, 2016).

As many of communities are remote and small, they lack many essential services such as medical care and homecare due to issues around transport and economies of scale. Moreover, many buildings on-reserve are not accessible to persons with exceptionalities and are not mandated to meet accessibility guidelines like many provincial/territorial and federal government buildings (AFN, 2006). Significantly, the issue of winter-roads affects many northern reserves and communities, creating challenges to accessing services/supplies required year-round (AFN, 2017). This means many must leave their home communities and move to urban centres in order to receive the necessary resources (AFN, 2017).

Long wait lists, difficult diagnostic processes, and limited numbers of practitioners in some regions lead to poor access to intervention for many families (Underwood et al., 2018). First Nations with exceptionalities who must access care in urban settings are also prone to experiencing racism and disability-related prejudice while also being isolated from their communities and cultures (Durst et al., 2001).

Overall, services available to First Nations with exceptionalities depend and vary widely according to:

- How their disability was caused (vehicle or workplace accident, victim of crime, hereditary or congenital);
- When their disability began or was acquired (before or after the age of majority);
- What form of disability they have (physical, intellectual, psychiatric, sensory, acquired brain injury, etc.);
- How old are they are when accessing services (child or adult);
- Whether they are Indigenous and if so, where they live. (on or off-reserve); and
- What types of services they are looking for (residential, health, education, employment). (Fenez & Abilities Manitoba, 2019)

### Poor Cultural Safety

Current disability services and supports available to First Nations on-reserve have been criticized to be culturally unsafe or inappropriate and unable to address the full scope of needs and priorities of First Nations individuals living with exceptionalities across the lifespan (Gionnas et al., 2021). The definition of adequate and appropriate supports and services is inextricably tied to cultural and social values and understandings of aging, disability, and caregiving (Gionnas et al., 2021). Accordingly, Indigenous and specifically First Nations’ cultural values and understandings have important implications for the design and delivery of services, programs and supports. The literature highlights the importance of two concepts that are identified as key to disability service provision to Indigenous peoples: cultural competence and cultural safety. These concepts must be integrated into both the practitioner/worker and organizational levels.

Cultural competence is defined as the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, race, ethnic backgrounds, religions, and other diversity factors in a manner that recognizes, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each. Providing culturally competent care means integrating and respecting Indigenous values into program policy and programming.

Cultural safety incorporates the idea of a changed power structure that carries with it potentially difficult social and political ramifications (Ramsden, 2002; Cooney, 1994). It is defined by the Winnipeg Regional Health Authority as follows:

**Cultural safety expands the concept of cultural understanding to analyze power imbalances, institutional prejudice, colonization and colonial relationships as they apply to, and impact on, service delivery. Cultural safety means providing services that show respect for culture and identity, incorporate a person’s needs and rights, and are free of prejudice. It requires us to examine our history, policies, and processes that create power imbalance and health and social inequities between Indigenous people and all others. Indigenous cultural safety is often seen on a continuum that includes cultural awareness, cultural sensitivity and cultural competence.**





Cultural safety questions and challenges the concept of cultural competence and, by bringing in the notion of safety, it extends the debate by focusing less on the benefits of cross-cultural awareness and sensitivity, and more on the risks associated with their absence (Curtis et al., 2019). Culturally unsafe practices have been defined as “any actions that diminish, demean or disempower the cultural identity and well-being of an individual.” (Kirmayer, 2012) Power imbalances need to be addressed so that Indigenous and non-Indigenous ways of knowing can come together and be equally valued (Blanchet-Cohen & Richardson/Kinewesquao, 2017). The current power structure undermines the role of Indigenous people as partners with healthcare workers in their own care and treatment.

In contrast, culturally safe disability services can be supported through a number of actions. Firstly cultural safety training for all staff is paramount and should be designed and delivered by First Nations organizations. Such training could include topics like:

- Respect for Indigenous views of aging, disability, and of the understandings of care;
- Knowledge of the complexity of the Indigenous determinants of health;
- Understanding the role of the family in care; approaches for relationship development with primary care professionals to help minimize distrust in the health care system;
- Culturally specific coping strategies;
- Knowledge of historical policies that may affect care giving today and of contemporary policies that result in differential access to care;
- Training on appropriate advocacy for Indigenous caregivers; and the development of health promotion and prevention tools that are sensitive to diverse Indigenous peoples' understandings of aging, disability, and care.

Policies and mechanisms to enhance cultural safety could also involve establishing a committee that consists of clients, family members, community leaders and more to guide programming. Such a committee would also support on-going self-determination in disability supports. Programs could also adopt practices to integrate cultural information into the care plan; create constructive mechanisms for dealing with intercultural conflict and encouraging respect; innovative ways to attract and retain Indigenous staff, supervisors, board members; and more (Schill & Caxaj, 2019).

Many institutions in Canada today require some type of cultural awareness or safety training for health care professionals. The Winnipeg Regional Health Authority (WRHA), for example, offers the Manitoba Indigenous Cultural Safety Training (MICST) program as an online program designed for service providers that work directly or indirectly with Indigenous people in Manitoba (WRHA, 2022). The core program takes between 8-10 hours to complete and is supplemented with additional workshops including Indigenous Cultural Awareness, Indigenous Traditional Teachings, Indigenous Sweat Lodge Teaching, Palliative Care: Indigenous Perspectives on End of Life, Indigenous Employee Retention for Managers, Indigenous Health Policy and Circle of Care: Enhancing the Culture of Well-being (WRHA, 2022). Despite these types of programs, First Nations continue to voice concern over the lack of cultural competency among non-Indigenous health care workers and overall lack of inclusion of culture into programming (ISC, 2022).

The Truth and Reconciliation Calls to action 23 and 24 highlight the importance for cultural safety in the health care field through cultural safety training to all healthcare professionals and increasing the number of Aboriginal healthcare providers.

23. We call upon all levels of government to:

- Increase the number of Aboriginal professionals working in the health-care field.**
- Ensure the retention of Aboriginal health-care providers in Aboriginal communities.**
- Provide cultural competency training for all healthcare professionals.**

24. We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism.

### Lack of Self-Determination

First Nations' control over the design, delivery and administration of health and social services is recognized as central to ensuring cultural safety in health care provision in their communities (Cameron et al., 2014; Horrill et al., 2018; Ringer, 2017). Moreover, research has consistently demonstrated that self-determination in health policy and program development, along with incorporation of First Nations culture, language, knowledge, and traditional healing have positive impacts on health and wellness among First Nations. In fact, self-determination is one of the most important determinants of First Nations health and well-being (Reading & Wien, 2013). This is especially true in contexts where dominant biomedical approaches have failed to reverse the course of the growing gap between the health of First Nations and non-First Nations persons in Canada (Angell, 2017; Katz et al., 2019). However, many First Nations leaders and scholars have critiqued current self-governance arrangements—purported to enact self-determination—are in fact mere “self-administration”, where First Nations' control over programs and services is extremely limited and First Nations bands are still subject to federal government control via mechanisms like financial transfers, departmental administrative and accountability require-

ments, the use of third party management, and its ability to override all by-laws (Ladner, 2009; Canada, 1985; Elias, 1991). Ultimately these limitations on self-determination impact a community's ability to address the needs, priorities, aspirations and demands of the community, including the assurance of cultural inclusivity and safety in health and social service programming (Ladner, 2009).

Overall, services available to First Nations with exceptionalities are colonial in nature and are predicated upon Western, medical notions of disability and how to support persons with disabilities. Despite advancements in knowledge and understanding of the important gaps in services, impacts of jurisdictional issues, role of self-determination, and importance and meanings of cultural inclusivity/safety in health and social services in general, no research has explored these factors in relation to disability supports specifically, especially from the perspectives of First Nations adult individuals and their families living on-reserve directly utilizing and relying on them.

In summary, a comprehensive exploration of the lived-experiences of First Nations adults living with exceptionalities and accessing disability services and supports on- and off-reserve would give invaluable insight into avenues for system changes to better meet needs and priorities; reduce gaps and barriers; and foster improved quality of life for these individuals and their families. Consequently, the objective of this qualitative study was to explore the lived-experiences of First Nations adults living with exceptionalities in Manitoba, with a particular focus on their experiences and perspectives around on- and off-reserve disability services, programs, and supports.







A

## Culture as Foundation

“I remember going to [disability service provider] early years in my disability sitting there with a white person was like talking to a stone. They didn’t know who I am, didn’t know me as being native or how to talk to me. Foreign. How many times I thought I wish they had a native working for [disability service provider]. White people don’t understand our ways. When we want to congregate together let us, you took everything else away, let us love one another. That’s the way I feel. We need more people who speak the languages, Cree, Sioux, Ojibway.”

The cultural values, sacred knowledge, language, and practices of First Nations are essential determinants of individual, family, and community health and wellness. Extensive research has demonstrated the relationship between what has been referred to as “cultural continuity” and positive outcomes across many health and wellbeing indicators. Cultural continuity might be described as the degree of social and cultural cohesion within a community. It also involves traditional intergenerational connectedness, which is maintained through intact families and the engagement of Elders and knowledge keepers, who pass traditions and knowledge to subsequent generations. Despite the impacts of colonization, many First Nations people have maintained their cultural knowledge in their ways of living (with the land and with each other) and in their language. These foundations have ensured First Nations people have strength, laughter, and resilience.

Culture is the foundation for a “good life”, and the knowledge contained within culture applies across the life span and addresses all aspects of life. First Nations individuals, families, and communities have a wealth of knowledge from which to draw on to know how to live in balance, to care for themselves and others, and to restore balance when it is lost. Recognizing the healing force of culture and backed by empirical evidence, First Nations leadership, organizations, and health experts continue to assert the importance of the role of culture to reinforce: the role of traditional and cultural approaches to healing and maintenance of wellness; the interconnectedness of community, family, and individual

health and wellness; and the cultural connections to language, land, and ancestry; and how culture must be integrated into all health and social programming and policy targeting First Nations.

All participants in this study spoke to the importance of culture for their wellbeing and highlighted how they wished to see First Nations culture, languages, and spirituality integrated into the supports and services they receive both on- and off-reserve via activities like ceremony, land-based healing, language classes, access to traditional healers and Elders, creative arts, sharing circles, and more. Participants and members of our expert panel noted how accessing cultural activities was often more challenging on-reserve than in urban environments where such activities are more readily offered and organized by different entities such as not-for-profit, charitable, or Indigenous-led organizations. The absence of cultural inclusivity in health and social services has been a longstanding issue. Healthcare systems in Canada were developed on a foundation of systemic racism, which continue to facilitate and force assimilation into “mainstream” healthcare treatment and disregard First Nations practices and perspectives (Giannas et al., 2021).

“Culture is the foundation for a good life”




#### Racism & Prejudice

The 2015 Calls to Action of the Truth and Reconciliation Commission of Canada underscored an urgent need for full health care rights for Indigenous Peoples, the elimination of health disparities, antiracist decolonization of the health sector, and self-determination in use of and access to traditional knowledge, therapies and healing practices (Truth and Reconciliation Commission of Canada, 2015). Indeed, Call to Action 22 states, “We call upon those who

can effect change within the Canadian health care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.” (Truth and Reconciliation Commission of Canada, 2015)

Participants also spoke about how experiences racism and intersectional prejudice (prejudice linked to their disability, class, gender, age, and more) from health and social service providers impacted them in numerous negative ways, creating distress, harm and barriers to accessing essential supports. As noted prior in this report, considerable research has demonstrated the negative impacts of racism and prejudice towards First Nations while engaging with the health and social services systems (Reading & Wein, 2009).

“When [Interviewee 1] was in grade 7 he came home one day and asked his mother if he was stupid. His mother reassured him that he has a learning disability but is not stupid. Interviewee 1 then proceeded to tell his mother an interaction that he had with his teacher that day, his grade 7 teacher folded her arms and told him ‘I can’t wait till you’re out on the streets with the bums like the others.’”



“The pediatrician has been stereotypical/ racist at times and maybe some of his behaviors are chalked up to our culture.”



Many institutions in Canada today require some type of cultural awareness or safety training for health care professionals; however, First Nations continue to voice concern over the lack of cultural competency among non-Indigenous health care workers and overall lack of inclusion of culture into programming (ISC, 2022). In addition, as far as we are aware, there are no formal mechanisms for First Nations to report incidents of racism or prejudice experienced in health and social systems, and thus no means to ensure accountability, learning, and healing from such occurrences.

Consequently, we put forth the following recommendations, with the note that recommended options are asserted with accessibility and availability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):

1

1. Commit to creating flexible funding allotments within both on-reserve & off reserve programming and service to enable First Nations to integrate community-determined cultural activities/supports for First Nations living with exceptionalities.



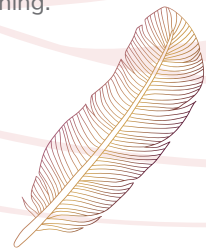
2

2. Fund cultural and land-based activities/supports specifically for First Nations with exceptionalities who live both on-reserve & off reserve.



3

3. Fund the development of a First Nations-led and delivered anti-racism, stigma, and prejudice training that explores First Nations' history, spirituality, languages, worldviews, ways of being and knowing. Mandate that all federal health and social services workers complete the training.



4

4. Commit to funding a First Nations-led engagement strategy to identify suitable options/mechanisms for First Nations to report experiences of racism or prejudice within health and social services, as well as processes to hold service providers accountable and promote healing.



B

## Self-Determination

“Every person has a human right to be taken care of regardless of age. I see in society people who are not taken care of, their needs not met and they suffer. For our First Nations, we need funding to provide care because we know how to care for our relatives.”

-Knowledge Keeper Sarah Samuel, Lac Brochet First Nation



As noted prior, self-determination has been cited as the most important determinant of health for First Nations peoples. Self-determination includes equal participation in political decision-making, as well as possession of control over governance structures, lands, economies, education systems, and social and health services (Reading & Wein, 2009). A growing body of evidence has highlighted the importance of self-determination on health outcomes (Chandler & Lalonde, 1998; Anderson & Kowal, 2012; Mead et al., 2010; Reading & Wein, 2009). The First Nations Mental Wellness Continuum Framework and the Honouring Our Strengths: A Renewed Framework to Address Substance Use Issues among First Nations in Canada stresses the importance of self-determination of communities in identifying effectively and culturally appropriate means to

address First Nation-specific health care needs (Assembly of First Nations & Health Canada, 2015; Health Canada, Assembly of First Nations & The National Native Addictions Partnership Foundation Inc., 2011).

This right to self-determination is a cornerstone of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), which underscores how it is a foundation of meaningful integration of First Nations culture, knowledge, language, and healing practices into health and social systems and is achieved by increased local control including funding of programs:

### Article 3

Indigenous peoples have the right to self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.

### Article 4

Indigenous peoples, in exercising their right to self-determination, have the right to autonomy or self-government in matters relating to their internal and local affairs, as well as ways and means for financing their autonomous functions.

(UNDRIP, 2007)

Self-determination is especially important in contexts where dominant biomedical approaches have failed to reverse the course of the growing gap between the health of First Nations and non-First Nations persons in Canada (Angell, 2017; Katz et al., 2019). However, many First Nations leaders and scholars have critiqued current self-governance arrangements—purported to enact self-determination—are in fact mere “self-administration”, where First Nations’ control over programs and services is extremely limited and First Nations bands are still subject to federal government

control via mechanisms like financial transfers, departmental administrative and accountability requirements, the use of third party management, and its ability to override all by-laws (Ladner, 2009; Indian Act, 1985; Elias, 1991). Ultimately these limitations on self-determination impact a community’s ability to address the needs, priorities, aspirations and demands of the community, including the assurance of cultural inclusivity and safety in health and social service programming (Ladner, 2009).

“We have home care, but they don’t approve anything. They wanted us to sign up for home care – they don’t have flexibility to meet the needs i.e., start at 8:00 am to help but they don’t open till 8:30 am. Had to sign up for home care before getting OT/PT, can come sweep your floor once a week, help bathe on Wednesday, but [Interviewee 15] doesn’t want a stranger bathing her.”

Participants in this study along with the expert panel highlighted the need to support First Nations’ efforts toward self-determination in local programs and services as well as in the wider political decision-making processes that impact them. This can be achieved through bolstering local control over programs and policies as well as funding structures. In the wider political context, effective and meaningful engagement is needed to ensure First Nations’ voices are included at decision-making tables, particularly in the systems that First Nations with exceptionalities rely on (e.g. provincial health and social systems). Consequently, all recommendations put forth in this report should be

understood as calls to enhance and uphold the self-determination of First Nations, even if not explicitly stated. Moreover, we put forth the following recommendation, with the note that recommended options are asserted with accessibility and availability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):

5. Commit to funding the introduction, enhancement, and upholding of processes for self-determination and on-going community engagement at all levels of health and social system planning and decision making.



C

## Social Determinants of First Nations Health

Social determinants of health reflect the circumstances, conditions, and contexts of peoples' lives, and the effect these have on health and wellbeing (Wilkinson & Marmot, 2003; WHO Commission on Social Determinants of Health, 2008). As noted earlier, First Nations view health as a holistic concept—balance between the mind, body, spirit, and emotion—that extends beyond Western notions that tend to focus on individual behaviours and genetics (de Leeuw, Lindsay, & Greenwood, 2015). Social determinants of health in a First Nations' context also include unique structural determinants, such as history, colonization, political climate, economics, and social contexts. These determinants are premised on the importance of relationships, interconnectivity, and community (Reading & Wein, 2009). While all social determinants of First Nations health are pertinent (including the ones we address above and below such as culture, self-determination, systems, etc.), in this section we chose to highlight the determinants particularly pertinent to participants.

### Physical Environments

Physical environments play a primary role in determining health and wellbeing. Among First Nations, physical environments that are largely detrimental to health have been imposed through historic dispossession of traditional territories, as well as current reserve or settlement systems (Reading & Wein, 2009). The most pervasive outcomes of these systems include substantial housing shortages and poor quality of existing homes (Reading & Wein, 2009). Many on-reserve homes are overcrowded; require major structural repair or pest control; lack appropriate ventilation contributing to excessive mold; and lack basic amenities such as clean, running water, functioning showers and/or toilets, intact plumbing or electrical wiring (Reading & Wein, 2009). These poor conditions significantly impact health problems or create unnecessary risk to health and life, especially for persons with disabilities who typically have heightened vulnerability (Krahn, Hammond & Turner, 2006; Ouellette-Kuntz, 2005; Sutherland, Couch & Iacono, 2002).

Housing and access to essential needs was an important concern for participants in this study who frequently spoke about how overcrowded, substandard, unstable, and inaccessible housing conditions on-reserve negatively impacted their health, wellness, and quality of life. Participants highlighted how poor housing conditions frequently created dangerous situations for them, would force them to relocate to less desirable housing options (i.e. institutionalization away from home community), and impeded their ability to participate in family and community life. Moreover, when people have a lack of access to appropriate services, they have difficulty outfitting their homes to be suitably accessible so are often denied the chance of experiencing functional independence (Croxall, 2017).

While there are several existing programs to fund and finance on-reserve housing renovation, repair and renewal including for individual households and for community-level housing initiatives (CMHC, 2023; ISC, 2023), awareness of such supports may be limited and the application process can be onerous and thus additional supports are warranted, namely to assist individuals, families, and communities in navigating eligibility, applying, developing proposals, and more. Moreover, a notable challenge for some communities, especially rural and remote First Nations, is the procurement of tools, supplies, and tradespeople needed to repair or renovate housing.

In this study, we heard from participants about their experiences of relocation or migration from reserve to urban centres to access essential services and supports. This phenomenon is highlighted in much of the research around the issue of migration and homelessness among First Nations (Mental Health Commission of Canada, 2013; Lange, Skelton, & Meade, 2010; End Homelessness Winnipeg, 2014). This body of research highlights that people move away from their homes on the reserve or rural and northern communities for a variety of reasons — to be closer to family and friends who moved before them; in search of greater employment and education opportunities; or to be within close proximity to medical and other services, among many other reasons (End Homelessness Winnipeg, 2014). Research (Lange, Skelton, & Meade, 2010) also suggests that the transition from rural reserve to urban life is often not easy. Persons with physical or developmental disabilities are already at elevated risk for homelessness overall (End Homelessness Winnipeg, 2014; Calgary Homeless Foundation, 2008). Further research has noted that those looking to access services are the group most vulnerable to housing instability and outright homelessness (Distasio, Sylvestre, & Wall-Wieler, 2013). Attempting to find a home and access services can be laced with racism and prejudice, compounding barriers to basic needs for First Nations with exceptionalities (End Homelessness Winnipeg, 2014). This is further exacerbated by the overall and increasing lack of available accessible and affordable housing in Winnipeg and other urban areas (Randle & Thurston, 2022). These factors, and economic instability, often force First Nations into homelessness or transient residency situations (Statistics Canada, 2006).

“[Interviewee 3] sleeps in basement. He lives in a 3-bedroom home where there are 8 people living. As an adult he should qualify for own independent living.”

“[Interviewee 4] answered that having a good quality of life means having a decent income, something she can live on and provide more food for my kids and things they need. She stated that after school programs are not even achievable for her family. Her home is currently lacking furniture and she has had to make layaway payments at Surplus to try to get furniture where she lives.”

“[Interviewee 14 and 18] also raised concerns about the current state of their housing. [Interviewee 18] mentioned that what she currently receives from the government is not enough even with relying on social services such as social assistance and food banks.”

The National Housing Strategy Act (2019) declared that “the right to adequate housing is a fundamental human right affirmed in international law.” Adequate housing is understood in international law as housing that provides secure tenure; is affordable; is habitable; provides access to basic infrastructure; is located close to employment, services and amenities; is accessible for persons of all abilities; and is culturally appropriate (National Housing Strategy Act, 2019). The United Nations Convention on the Rights of Persons with Disabilities (CRPD) also includes specific rights related to housing for persons with disabilities. For instance, the CRPD requires states to provide an adequate standard of living for persons with disabilities and their families, including the right to adequate and accessible housing and to the continuous improvement of living conditions.

The outcomes of this study indicate that First Nations living with exceptionalities living on-reserve do not have access to adequate and accessible housing and calls attention to the need for improving living conditions to promote independence, dignity, health, wellbeing, and overall quality of life. Consequently, we put forth the following recommendations, with the note that recommended options are asserted with accessibility and availability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):

6. Commit funding to ensure all First Nations persons living with exceptionalities on-reserve have timely access to suitable, affordable, accessible and supportive housing via investments in community-driven:

- a) Single family dwellings; and
- b) Community-driven, local collective/cooperative supportive living options; and
- c) Homelessness prevention/interruption strategies including: rent subsidies, rapid re-housing, transitional housing, shelter diversion/respite housing options, and on-reserve to off-reserve migration supports.

7. Invest in community-driven processes for continuous improvement of housing for First Nations with exceptionalities. Such processes could include:

**a) Aids & Assistive Equipment/Technology Loan Program**  
This could constitute, for example, a local or regional program to maintain and distribute or loan essential aids and assistive equipment/technology that ensure home accessibility. A key feature would include assessment support to aid households and/or allied health (occupational therapy) in determining suitable equipment. Such a program could also be extended to improve community accessibility at public facilities (i.e. band offices, schools, recreational centres, etc.). Equipment/technology might include access to orthotics, ramps, clamp-ons, canes, walk-in baths or showers, lift devices or elevators, lowered counters, automatic doors, voice activated devices, breath/sip activated wheelchairs, smart home technology, assistive technology such as screen readers, software, and more.

**b) Community Tool Library**  
Lending libraries are becoming increasingly popular, offering community members no-cost or low-cost access to home tools that, for a variety of reasons, may not be practical for a household to buy and maintain. Shared ownership of tools may lead to an absolute reduction in the amount of tools purchased and eventually entering the waste stream. Tool libraries make it easier for community members with limited resources to maintain their homes, which helps to provide for

housing security. Additionally, tool libraries may serve as a gateway to other types of borrowing and sharing opportunities and initiatives such as kitchen, garden, craft tool shares, skill shares, and game/toy shares among other sharing activities. Such a library could be particularly beneficial in rural/remote First Nations where even those with the financial means to purchase tools must still face geographical barriers to access.

**c) Building Supplies Inventory**  
Access to lumber and other building materials may present a notable barrier to the ability of households and communities to renovate, repair and renew housing, especially for emergency needs and among First Nations that have winter road access only. Supporting communities to establish and maintain a basic building supplies inventory would ensure year-round accessibility to materials for timely renovations and repairs.

**d) Community Housing Renovation, Repair and Renewal Support**  
This could constitute, for example, a local or regional program to awareness of funding and financing options for on-reserve housing renovation, repair and renewal and support individuals, families, and communities in navigating eligibility, applying, developing proposals, and more.

**e) Local Pool of Community Helpers with funding for their labour**  
This could constitute providing funding and training to establish a pool of community helpers assigned to assist individuals with handywork and household tasks they cannot complete on their own due to diverse abilities. Funding will be required to support their labour, with flexible remuneration mechanisms to support both regular and casual labour.

## Addressing Poverty

When [Interviewee 2] was asked what having a good quality of life meant to him, he answered that it was to have enough money to survive and that he can not achieve this with current situation because he is living in poverty, in unsecure housing. He currently receives assistance with housing from Doorways and Stepping forward. Disability is not sufficient to live in a safe home or have food security. During the interview he stated: “My disability doesn’t define me but there are inadequate services for me to thrive. It would be nice to live in a place that was safe, my stuff is at risk of being stolen everyday. This stress adds to my disability.”





The results from this study highlight the impacts of poverty on First Nations persons living with exceptionalities. Participants stressed how a lack of access to necessities including access to adequate housing, nutritious food, health supplies, and more, contributed to significant harm to their health and wellbeing. Participants spoke to how the harms they experience in association to their disability are exacerbated by poverty and put them at further risk for injury, harm, more severe disability, as poverty created additional barriers that limited access to health care and preventive services and increased the likelihood of living in conditions that may adversely affect their health. Persons with disabilities are significantly overrepresented in the low-income population (41%) (Statistics Canada, 2017). This is especially true for First Nations with exceptionalities; the 2016 Census found an estimated 80% of First Nations in Canada have a median income that falls under the poverty line (Statistics Canada, 2018). Barriers to access essential basic needs for First Nations with exceptionalities are further compounded by intersecting issues of prejudice/racism, lack of culturally-safe services, jurisdictional barriers, geographic barriers, and social determinants of poor health (AFN, 2017; National Association of Friendship Centres, 2006; Statistics Canada, 2012). The social determinants of health have a compounding effect: the greater the number of social determinants of poor health that off-reserve First Nations people experience, the more likely they are to report poor health outcomes (Statistics Canada, 2012; Siltanen & Doucet, 2008).

*Participants stressed how a lack of access to necessities including access to adequate housing, nutritious food, health supplies, and more, contributed to significant harm to their health and wellbeing.*

Other barriers also play a significant role in limiting access to financial supports for First Nations with exceptionalities. For instance, advocacy groups such as the BC Aboriginal Network on Disability Society and Disability Alliance of BC have noted the lack of participation in programs such as the Disability Tax Credit (DTC) and the Registered Disability Savings Plan (RDSP) among First Nations. They note that the focus, for many First Nations people, is on surviving one day at a time, rather than planning for the future (Eragoda, 2021). Applying for the DTC and opening an RDSP may not be a high priority for individuals whose immediate financial need is great. Often, there is just no money left at the end of the day to save for tomorrow (Ergoda, 2021). Moreover, the application process can be a barrier. People need to be aware of the credit, be able to access a healthcare professional to fill out the long application, and be able to pay a fee which is often not set as fees are not regulated (Ergoda, 2021).

Anti-poverty advocates around the world have long promoted a Universal Basic Income as an effective, efficient, transparent and non-paternalistic form of direct income support (Ruckert, Huynh, & Labonté, 2018). Many countries have already implemented Universal Basic Income strategies in various forms, including in Canada/Manitoba, where research has demonstrated its effectiveness (Stevens & Simpson, 2017). In a 2020 Throne Speech, the federal government acknowledged that COVID-19 has not only disproportionately affected Canadians with disabilities but laid bare long-standing challenges for persons with disabilities to access adequate programs and benefits (Privy Council Office, 2020). The government's response to what the community has long known is a commitment to establish a Canadian Disability Benefit via Bill C-22 (Canada Disability Benefit Act), which as of February 2, 2023, had passed the third reading in the House of Commons and was at the second reading in the Senate (Parliament of Canada, 2023).

While the details have not yet been released, the government has stated the Disability Benefit will be modelled after the Guaranteed Income Supplement for Seniors (Employment and Social Development Canada, 2022). This means the Disability Benefit will not be a simple one-time payout or top-up but provide a regular long-term supplement to other (provincial) supports and will act like a Universal Basic Income (Employment and Social Development Canada, 2022). The federal government also indicates that, "in the spirit and principle of 'Nothing Without Us', the proposed [Canada Disability Benefit] will be informed through further engagement with the disability community as well as other stakeholders, including Indigenous organizations, and academics." (Employment and Social Development Canada, 2022).

The outcomes of this study highlight a dire need to address poverty as a root cause of harm and suffering experienced by First Nations with exceptionalities and that existing financial supports are both insufficient and come with significant barriers to access. Consequently, we put forth the following recommendations, with the note that recommended options

are asserted with accessibility and availability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):

8. Implement a Universal Basic Income for First Nations with exceptionalities on- and off-reserve (either via the Canada Disability Benefit or other benefit) with timely adjustments according to the cost of living, inflation, and geographical considerations (i.e. costs of living in northern and remote communities)
9. Fund meaningful engagement and consultation with First Nations in the design and implementation of the Canada Disability Benefit or other benefit.
10. Reduce barriers to accessing existing financial supports for First Nations with exceptionalities, including but not limited to:
  - a. Extending the Disability Tax Credit to all individuals with a disability diagnosis regardless of place of residence (on/off reserve), provider of social assistance (federal or provincial government), or type of disability;
  - b. Provide support to First Nations with exceptionalities to access all benefits they are entitled to via case manager or other means.

## Food Sovereignty

“[Interviewee 19] also raised issues about food security stating that in order to make his budget work he must eat frozen dinners which is not healthy for his diabetes: ‘I’m in a no-win situation right now. I want fresh food in my house I can’t get that with my budget that I have.’”

Food insecurity, which is linked to physical environments and poverty, was an important issue impacting participants in this study. First Nations, especially those with exceptionalities, living in remote, rural and reserve communities face considerable food insecurity related to challenges acquiring both market and traditional foods (Reading & Wein, 2009). The cost of transporting market foods to remote communities means that healthy, nutritious food is not affordable to most. Poverty not only limits the extent to which individuals and families can access market foods, but also makes the costs associated with contemporary hunting out of reach for many (Reading & Wein, 2009). With respect to poverty specifically, the most widely discussed impact is a lack of access to material resources such as nutrient dense food, which leads to high rates of chronic conditions, obesity, diabetes, distress and depression (Reading & Wein, 2009). First Nations living with exceptionalities face compounded vulnerability to the consequences of food insecurity which can in turn exacerbate health problems and harms linked to their disability (Reading & Wein, 2009).

**Addressing poverty among First Nations with exceptionalities will do much to alleviate food insecurity;** however, scholars and advocates indicate that more must be done to adequately interrupt the disproportionately high rates of food insecurity that has resulted from settler-colonial activities (Reading & Wein, 2009). Colonization and on-going colonial practices have contributed to long-standing and pervasive diet-related disparities that have seen limited improvement from Western interventions aimed at improving individual dietary intake (Reading & Wein, 2009). For instance, food assistance programs developed to assist people with food insecurity by providing them additional resources to purchase fruits, vegetables, and other healthy foods do little to impact systemic barriers that many First Nations face around access to foods especially in remote, rural, northern, reserve communities (Reading & Wein, 2009). Such programs were developed to augment household food supplies, not serve as the primary source of food for a household. Thus, households that experience more acute food insecurity, characterized by disrupted eating patterns and reduced food intake, are unlikely to receive enough food from these programs to become food secure (United States Department of Agriculture, 2006). In addition, these programs do not

adequately address the root causes of food insecurity and may not be highly utilized in Indigenous and First Nations communities (McLaury et al., 2016; Jernigan et al., 2017; O’Connell et al., 2011; Kelli et al., 2017). Such programs aimed at persons with disabilities also largely view “disability” from a medical model as a deficit or a problem inherent in the individual to be addressed via neo-liberal intervention on the individual and not changes to systems or environments (Hiranandani, 2009).

Many First Nations communities have worked to revitalize their local food systems by pursuing food sovereignty. Supporting First Nations’ community capacity for food sovereignty has been shown to have positive impacts on the food security of individuals and families and vulnerable persons including those living with disabilities (Dieticians of Canada, 2016; Cidro et al., 2018; Hiranandani, 2009). Consequently, we recommend the following, **again with the note that recommended options are asserted with accessibility and availability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):**

11. Fund the development of a First Nations-led strategy to comprehensively address the unique challenges related to household food security, including assurance of food sovereignty, with access to lands and resources, for acquiring traditional foods, as well as improved access to more affordable and healthy store-bought/market foods, especially in:
  - a. **Remote, rural, and northern First Nation communities;**
  - b. **Urban contexts;**
  - c. **Community-driven, local collective/cooperative supportive living environments.**



## Education & Employment

"[Interviewee 19] has not been able to find employment due to his disability. Before he had his legs amputated, he worked at a job that required him to drive. Since he lost his drivers licence, he has not been able to secure new work because there is a lack of supports for him in his community."

"The caregivers to [Interviewee 6] said that those with special needs should have an option to continue their learning. They stated: 'There's no reasons why just because they have exceptionalities, they don't deserve their schooling, [Interviewee 6] loves to be in society and work. She needs people. People need her.'"

“[Interviewee 2] wants to be an Ojibway language interpreter and help his people. To do this effectively he must finish his schooling at Red River College. This has been difficult with no financial means. Interviewee 2 stated: ‘My disability doesn’t define me but there are inadequate services for me to thrive.’”

Most of the participants in this study spoke to how poor access to education and employment opportunities negatively impacted not only their finances but also their mental wellbeing. The evidence is clear about the role of various dimensions of socioeconomic status (SES) in determining health and wellbeing. Such dimensions include educational attainment and economic opportunities and employment. Through colonization, on-going colonialism, and systemic racism and prejudice, First Nations have been denied access to the resources and conditions necessary to maximize SES (Reading & Wein, 2009). This is especially true for First Nations persons living with exceptionalities who face compounded barriers to educational attainment and economic opportunities. This disadvantage is manifested in high rates of unemployment, low income, high rates of poverty, and low literacy and educational attainment (Reading & Wein, 2009) which in turn contributes to poor mental health, substance use, increased vulnerability to health problems, low self-esteem, feelings of hopelessness, and more (Reading & Wein, 2009). In contrast, access to meaningful employment and educational opportunities is recognized as a core aspect of First Nations mental wellness, contributing to a sense of purpose and hope for the future (Assembly of First Nations & Health Canada, 2015). Inadequate or insufficient education can affect literacy and one’s ability to acquire information and resources or access the labour market (Reading & Wein, 2009). There is clear evidence of inequities in the distribution of education resources and opportunities for First Nations. Inadequate educational opportunities for most adults manifest early as a lack of capacity to promote education among their children

(Reading & Wein, 2009). First Nations youth drop out or are “pushed out” of high schools at a disproportionate rate, resulting in diminished literacy and employment, and increased poverty for themselves and their families as well as for future generations (Reading & Wein, 2009). First Nations are thus very underrepresented in higher education (postsecondary certificates, diplomas, and degrees).

These educational disparities are added compounded among First Nations living with exceptionalities who face added barriers to accessing resources and opportunities. For example, in remote First Nation communities, due to the small population size and location it is challenging to recruit teachers and teacher aids which results in critical shortages in supports for children with exceptionalities in schools (Huot et al., 2019; Mew et al. 2017; Oosterveer & Young, 2015). This problem continues into adulthood with the availability of adult educational programs where services are not always available.

Advocacy groups echo the concerns voiced by participants in this study that existing programs to support those with exceptionalities to work or access education (e.g. federal Disability Vocational Rehabilitation Program or the Opportunities fund; provincial Employability Assistance for People with Disabilities Program) are not often accessible to those living on-reserve or that programs are not often suitable for implementation in First Nations communities (Fenez & Abilities Manitoba, 2019). A disproportionate number of people with disabilities are unemployed or underemployed which forces them to access income support to meet their basic needs if they are eligible. Employment and Income Assistance (EIA) is designed to meet the needs of people who are between jobs and are not likely to have life long, persistent needs for assistance (Fenez & Abilities Manitoba, 2019). EIA rates on- and off-reserve are low to encourage those accessing it to seek employment and leave the program (Fenez & Abilities Manitoba, 2019). For those living with disabilities that face pervasive and significant barriers to employment, this leaves them living in poverty for much of their lives (Fenez & Abilities Manitoba, 2019).

Findings from this study also highlight the need to invest in supports for accessing education and training to increase the participation of First Nations with exceptionalities in health and social service jobs. Many participants noted how a lack of representation among the health and social services workforce was at times problematic and created barriers to access them. They noted the benefits to recipients of care that would come with being served by those who know their culture, language, community, and the experience of living with a disability. Training and hiring local community

members could also combat chronic human resource issues around recruitment and retention to First Nations communities that currently contributes to the erosion of services that those with exceptionalities rely on. There have been a number of successful programs to increase First Nations representation in the workforce, components of which can be applied to all industries and typically comprise of:

- **Early exposure activities** encourage students to achieve success in appropriate school subjects, address deficiencies in careers advice and offer tertiary enrichment opportunities.
- **Support to transition into and within programmes** is required including bridging/foundation programmes, admission policies/quotas and institutional mission statements demonstrating a commitment to achieving equity.
- **Retention/completion support** includes academic and pastoral interventions and institutional changes to ensure safer environments for indigenous students. (Curtis et al., 2012)

Accordingly, we put forth the following recommendations to begin to address educational and employment needs of First Nations living with exceptionalities, **with the note that recommended options are asserted with accessibility and availability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):**



12. Invest in First Nations-led programs to close the education gap between First Nations children with exceptionalities and all other Canadians, across all stages of the education system, from kindergarten through to post-secondary education, including but not limited to:

- a. *Funding of ongoing learning and education opportunities for school staff to learn about invisible and visible disabilities to increase the safety for all learners;*
- b. *Funding of specialized teachers and educational assistants to work with students living with a disability;*
- c. *Investments for the creation of safe and inclusive learning spaces in First Nation schools for students living with an exceptionality who cannot thrive in the overcrowded, overstimulating classrooms;*
- d. *Supports for achieving high-school equivalency (e.g. continuing adult educational opportunities, GED).*

13. Invest in First Nations-led programs to provide financial assistance and education/career guidance support to First Nations persons with exceptionalities pursuing education, training, and/or employment including but not limited to:

- a. *Post-secondary financial assistance and transition supports;*
- b. *First Nations bridging programs (i.e. pathways to university education for those who do not meet conventional admission requirements);*
- c. *Community-driven mentoring and other early exposure programs;*
- d. *Liaisons to promote admission or recruitment policies/quotas and mission statements demonstrating a commitment to achieving equity in education institutions and among employers; and*

- e. *Life-skills development and supports for capacity in educational/employment settings as well as daily living activities (e.g. acquiring driver's licence, goal setting, coping skills, self-advocating, cooking, budgeting and banking, independent living, healthy relationships, health and wellness, technology and assistive devices, transit training, preparation for schooling and employment, engaging in community, culture, and language, and more);*
- f. *Employment guidance supports to assist with resume development, job searches, navigating recruitment processes, interview preparation, and more; and*
- g. *Funding for one-on-one supports for people with exceptionalities to work and volunteer.*

D

### Support Across the Life Course

“[Interviewee 1] just aged out of Jordan’s Principle, and there was no transition process. The family stated that the services should not end as disabilities are usually for life.

“[Interviewee 3] at age 12 received Jordans Principle for 1-2 years. The family saw a huge improvement for both the Interviewee and the [Interviewee’s] mother who was the primary caregiver. Jordan’s Principle gave the Interviewee healthy interaction with others and allowed him to attend the fitness centre which improved his fitness. This service was cut off once he aged out and his mother had to become full time caregiver again without any respite services.”

Health and wellbeing are not only experienced across the physical, spiritual, mental, and emotional dimensions, but also experienced across the life course from gestation to elderhood (Reading & Wein, 2009). **Barriers to participation in society and to living a good life do not suddenly disappear when an individual turns 18 years of age.**

As noted by Cooke & McWhirter. (2011), understanding the continuing and widening health disparities that First Nations experience and the policies and programs required to address them necessitates a life course perspective. A life-course perspective can highlight how events in earlier life can affect well-being in later life (Cooke & McWhirter, 2011). This was indeed a sentiment expressed by participants in this study. All participants spoke to how their experiences, opportunities, ability to access supports or lack thereof earlier in life had impacts on their health and wellbeing throughout their life and their experience living with a disability. Of note were experiences of disruption of services across the life course, which occurred with “aging out” of services in the transition from childhood to adulthood.

Concerns about the care of young people as they transition to adulthood was a strong theme in the literature as well (Gosek et al., 2007; Obomsawin, 2019; Vives & Sinha, 2019; Woodgate, 2013). The lack of post-majority support (i.e. “aging out”) was a prominent theme in the stories of lived-experiences shared by participants in this study. **This abrupt termination of essential services and supports caused much harm to adults with exceptionalities and their families, especially in consideration that disability services for First Nations adults are extremely limited in comparison to those for children.** Comparable harms are also well documented in the academic literature. First Nations children and youth make up approximately 80% of the number of children in care in Manitoba (Trocme, Knoke, & Blackstock, 2004).

**With the lack of existing supports, the reality is that many First Nations children aging out of care are at risk of becoming homeless and/or becoming involved with the justice system.** This is documented most recently in the Manitoba Centre for Health Policy (MCHP) report, *The Overlap Between the Child Welfare and Youth Criminal Justice Systems: Documenting “Cross-Over Kids” in Manitoba*, which found significant evidence that involvement in the CFS system is a strong risk factor for contact with the youth criminal justice system and suggests that the process of aging out of care can contribute to this risk (Brownell et al., 2020). Young women who have aged out of care of CFS are also identified as being more vulnerable to being assaulted, murdered, or going missing (Assembly of Manitoba Chiefs, 2021). Overall, there is broad recognition that youth in care of CFS require a more gradual transition to independence and support in doing so. Interestingly, no participants in this study spoke about issues with aging out of child welfare services. This may have been a result of an issue with participant sampling and further research should be conducted to understand the lived-experience of First Nations with exceptionalities with a history of involvement in the child welfare system.

The lack of post-majority support is a major concern about Canada’s implementation of the Jordan’s Principle-Child First Initiative (see First Nations Child & Family Caring Society of Canada, 2020), and this abrupt stop of supports is felt particularly harshly by persons with exceptionalities. Jordan’s Principle is a child-first principle to resolving jurisdictional disputes within and between federal and provincial/territorial governments within Canada. The Jordan’s Principle – Child First Initiative Program provides supports to families with children with complex needs living on-reserve, and to help enhance the child’s life and facilitate health care interventions and developmental stimulation. The goal of the program is to contribute to quality of life ensuring that children, young people and their families are enabled to experience a life that is as full and as normal as possible. Supports and Services may include Respite Care and Support Groups, Child Development Program (Preschool), American Sign Language (ASL), Therapy, Intervention Programs, Socialization Activities, and Land-Based Activities.

Children and their families are eligible for the Jordan’s Principle – Child First Initiative Program up to the age of 18. However, the needs of young people and their right to a good life do not suddenly disappear when they reach the age of majority. Moreover, many First Nations living with exceptionalities were over the age of 18 before the program even began, or were wrongly turned away from the program and never received any supports as children, which has impacted them and their experience of disability into their adulthood (ISC, 2022). Some remedies have been proposed for these issues, including an agreement to provide funding to First Nations

children and families on-reserve and in the Yukon as compensation for the harm they suffered due to Canada’s discriminatory provision of child and family services and failure to properly apply Jordan’s Principle (ISC, 2022). This funding may also be used to support First Nations who are aging out of the child welfare system and develop prevention services to help children and families stay together (ISC, 2022). Canada also recently initiated a program to support First Nations persons aging out of care in addition to prevention services (ISC, 2022). Called “Post-majority care services for First Nations youth and young adults,” the program allows First Nations authorized service providers to submit claims for the reimbursement of costs related to such post-majority services to ISC through the existing First Nations Child and Family Services claims process until March 31, 2023, or such a time that the fully reformed program is implemented (ISC, 2022).

While this is a step in the right direction, it relies on existing programs—which are already overstretched—to cash-manage costs of extending services that are not specifically designed to aid in helping children and youth smoothly transition out of care. Broader reform of the First Nations Child and Family Services (FNCFS) Program and the proposed renewed approach to Jordan’s Principle must involve supporting the development of a self-determined service via extensive community engagement that specifically focuses on aiding children and youth to smoothly transition out of CFS care and the Jordan’s Principle-Child First Initiative into other services and supports that will reduce the likelihood of harm as they move into adulthood.





It is clear that the Jordan's Principle-Child First Initiative has quickly become known as a benchmark for services and supports for First Nations children with exceptionalities and special needs. This sentiment was also reiterated frequently by participants and their families in this study. Comparable services for First Nations adults with exceptionalities on-reserve do not exist, and as noted, the services currently employed for this group are extremely limited and are overall failing to meet need. The supports needed to assist those with disabilities do not end once adulthood is reached. Supports are necessary for the patients lifetime and in many cases patients require more support as they age.

Another notable concern voiced by participants was the lack of services and supports for First Nations with disabilities in their adulthood, especially if they were unable access key supports in their childhood (e.g. diagnosis, early intervention, and more). Participants spoke to how inability to access diagnostic services in childhood contributed to poor access to services they should have been eligible for as adults and the consequences of that poor access (housing and income insecurity, education attainment, etc.). This was compounded by even poorer access to diagnosis services for adults. It is clear that the Jordan's Principle-Child First Initiative has quickly become known as a benchmark for services and supports for First Nations children with exceptionalities and special needs. This sentiment was also reiterated frequently by participants and their families in this study. Comparable services for First Nations adults with exceptionalities on-reserve do not exist, and, as noted, the services currently employed for this group are extremely limited and are overall failing to meet need.

Lastly, the life course perspective is pertinent in the experiences of First Nations living with exceptionalities because it aims to consider how disability changes overtime and as a person ages (Jeppsson et al., 2012). Impairments are not static conditions, where individuals learn to cope with them using available resources—once and for all (Jeppsson et al., 2012). Instead, disability, the persons

experiencing them, and the capacity of their families/ caregivers evolve and change over time or as one ages, and supports and services should be able to adapt to meet ever-changing needs (Jeppsson et al., 2012).

Accordingly, we put forth the following recommendations to support First Nations living with exceptionalities and their families/caregivers across the life course, **again with the note that recommended options are asserted with accessibility and availability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):**

14. Invest in the creation of a new principle akin to the Jordan's Principle-Child First Initiative specifically for First Nations adults with exceptionalities for the purpose of:
  - a. *Enabling seamless transition of services and supports from Jordan's Principle-Child First Initiative into adulthood and throughout the life course; and*
  - b. *Enabling adult enrollment to support our relatives who did not previously qualify for or access Jordan's Principle-Child First Initiative services.*
15. Invest in enhanced supports to aid First Nations with exceptionalities in their transition from the care of Child and Family Services to life as independent, empowered adults.



E

## Person-Centered Care

“[Interviewee 11] has expressed concern that for pain management she is only supported for pharmaceutical options when she knows that she would benefit from massage and physio but does not have access to funds for non-pharmaceutical options.”

“Currently Home and Community care has suggested [Interviewee 5] move into a care home, but he doesn't want to go there because care homes are designed for the elderly and do not have services for people of his age and longer-term residence.”

One central theme of the life course perspective is human agency, recognizing that people actively shape their own lives in the context of various constraints and with the aid of various resources (Cooke & McWhirter, 2011). Human agency or autonomy is also a core principle person-centered care, which has become known as best practice in the provision of health and social services (Cooke & McWhirter, 2011). Person-centered care refers to a philosophy and approach to care that places the person receiving care at the center of all decision-making and care processes. It is based on the principles of respect, dignity, and choice and focuses on the individual's needs, preferences, and goals. In person-centered care, the person receiving care is seen as a whole person, with unique strengths, abilities, and experiences, rather than simply as a medical condition or diagnosis. This means that care is tailored to the individual's needs, preferences, and goals, and that their experiences and perspectives are valued and incorporated into the care process.

Person-centered care also involves collaboration and partnership between the person receiving care and their care team, including healthcare providers, family members, and support staff. This allows for open communication, shared decision-making, and a focus on outcomes that are important to the person receiving care.

Person-centered care has been shown to improve outcomes for people receiving care, including increased satisfaction with care, improved health and well-being, and greater autonomy and independence. It also has the potential to reduce healthcare costs by promoting effective, efficient, coordinated, and individualized care that is aligned with the person's goals and needs. It is also an important means to mitigate harms connected with the fragmentation of services.

Person-centered care comprises attributes of care that participants in this study expressed hopes for supports and services for First Nations with exceptionalities. Participants often spoke about a need for support navigating across fragmented services, supported care across the life course, supported decision-making, and emphasized their right and freedom for self-determination in their overall life and an end to institutional guardianship.

Instead of designing support around a particular health or social service and the needs/priorities of that service provider, a person-centred model supports a person and their family/caregivers in achieving their needs and priorities in accessing services. In person-centred care, an individual's specific health needs and desired health outcomes are the driving force behind all decisions, and an individual is supported along their journey across the various services they need.

As such, we put forth the following recommendations, **with the note that recommended options are asserted with accessibility and availability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):**

16. Invest in First Nations-led person-centered case management and coordination supports for First Nations living with exceptionalities, including, but not limited to:

- a. Funding for the establishment of individual case managers or client advocates to provide support across the life course with navigating services/supports, referrals, ensuring timely diagnoses and intervention, completing program requirements (applications, assessments, etc.), asserting and advocating with goals/priorities/needs, accessing recreation and cultural activities, discharge or transition planning, accessing supports for informal caregivers and more;*
- b. Ensure reasonable caseloads (defined by community) for case managers so that need does not surpass capacity; and*
- c. Support the creation of a 'service roadmap' to assist with navigating services/supports.*

17. Establish a regional First Nations with Exceptionalities Advocate Office to lead efforts to improve system-level issues to reduce barriers, improve processes, and enhance continuity/coordination of supports for First Nations with exceptionalities and their families/caregivers.

## F

### Caring for Caregivers

“The mother and primary caregiver of [Interviewee 3] has had to be on welfare for her whole life because her son requires around the clock care and cannot be left unattended. In the interview she stated: ‘Who would take care of my sick baby if it wasn’t for me.’”

“[Interviewee 15’s] primary caregiver doesn’t have a steady alternate caregiver and cannot leave [Interviewee 15] alone for the entire day. The primary caregiver had to get a job to support the family and is now working half days. Finding someone to watch over [Interviewee 15] is both difficult to arrange and must be paid for out of the money for the part time job. There is zero care for adults and this family is in desperate need of respite.”





In this report, we refer to caregivers as someone who assists a family member or friend with challenges resulting in disability. In this sense, we are referring to informal caregiving, where care is provided to someone in their immediate circle who is not a typical paid health or social services professional. This was also an issue expressed in the interviews undertaken for this study. Informal caregivers are particularly invested in advocating for the wellbeing of the person they care for, help persons with disabilities remain in their homes for longer, can provide supports (mental, emotional, spiritual, and physical) that health and social systems may otherwise neglect, and overall contribute to reduced demands on health and social systems (Stall, 2019). While caregiving for persons with exceptionalities can be rewarding, it is increasingly demanding, complex and stressful.

Despite little to no training, caregivers are expected to provide medical and nursing care in the home, navigate complicated health and long-term care systems, and serve as substitute decision makers (National Academies of Science Engineering and Medicine, 2016). Many Canadian caregivers report distress, including 26% of those caring for older adults and 45% of those caring for people with dementia (Canadian Institute for Health Information, 2018). Distressed caregivers experience a myriad of adverse outcomes, including deteriorations in mental and physical health, disruptions in social and family relationships, and increased risk of death (National Academies of Science Engineering and Medicine, 2016). The stressors of informal caregiving by First Nations are even further compounded, as they must also deal with the collective, cumulative and intergenerational impacts of colonization that impact

a multitude of pertinent issues including socioeconomic status, mental wellness, family structure, unity/cohesion, and quality of family life (Lavallee & Poole, 2009; Gone, 2013; Mignone & O'Neil, 2005; Lafrance & Collins, 2003; Wesley-Esquimaux & Smolewski, 2004; Sarche & Whitesell, 2012; BraveHeart, 1999).

The stressors of informal caregiving were a prominent concern expressed in all interviews undertaken for this study. Participants noted how further supports for caregivers are essential, especially in the face of lack of access to or non-existence of services to meet the basic needs of First Nations persons living with exceptionalities on-reserve. They highlighted that not only is the bolstering home care and respite care essential for supporting both caregivers and care recipients, most informal caregivers of First Nations living with exceptionalities do not have access to caregiver-specific education and supports despite evidence that these can improve their well-being and that of the care recipient (National Academies of Science Engineering and Medicine, 2016). Effective supports for informal caregivers must be multidimensional and involve assessment of caregivers' risks and needs, education and skills training, counselling and self-care. Moreover, just like the care recipients' needs and capacities evolve across the life course, so do those of their caregivers, thus supports need to be organized to be able to meet evolving needs.



Supporting informal caregivers also means protecting them from economic and retirement insecurity. To supplement limited publicly funded home and community care services, many caregivers incur substantial costs for transportation, equipment, and professional help. Caregivers may forgo wages and benefits, with many reducing their hours, missing work, turning down advancement opportunities or exiting the workforce altogether. Such economic costs further compound the poverty many First Nations with exceptionalities and their families experience.

As such, we provide the following recommendations to support the informal caregivers of First Nations living with exceptionalities, with the note that recommended options are asserted with accessibility and availability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):

18. Invest in resources and supports to all relatives and the families/caregivers living with an exceptionality, including but not limited to the following topics:

- a. Educational supports, medical and therapeutic necessities tailored to the specific needs of the care recipient;
- b. Educational supports on disability rights and advocacy;
- c. Psychotherapy and counselling supports for the caregiver;
- d. Peer support networks;
- e. Problem-solving techniques;
- f. Opportunities for experiential learning; and
- g. Financial assistance for caregivers to participate in a Health Care Aide or similar educational program.

19. Invest in person-centered, community-driven and local

respite services and other burnout prevention supports for informal caregivers of First Nations living with exceptionalities, particularly in:

- a. Respite supports that are person-centered and led by the person receiving the supports and their respective caregivers;
- b. Respite supports that enable informal caregivers' ability to participate in the workforce or attend to other critical matters (i.e. supporting personal health priorities, other family responsibilities etc.);
- c. Respite supports that allow informal caregivers to relieve stress, restore energy, and promote balance in their life; and
- d. A variety of respite support options (e.g. in-home and out-of-home respite supports available for varying amounts of time such as a few hours, day programs, to a few days or longer-term stays).

20. Fund the First Nations-led development of a livable allowance, benefit or other mechanism to adequately compensate informal caregivers for their holistic support.

G

## Health Care & Social Services Systems

### Services & Supports On-Reserve

“I always see nurses. I want to see the doctor. I’m a patient at the Aboriginal Centre. I am promised to see a doctor, and when I get there it’s usually a nurse and my doctor isn’t even in the building. I have complex needs that aren’t being tended to effectively. It’s been 1.5 years since I have seen a doctor face to face.”

Starting when she was 12 years old [Interviewee 20’s] ankles, knees would get swollen. She would go to the nursing station, and they would tell her it was growing pains. This happened for a long time and finally after doing some bloodwork she was referred to a rheumatologist who eventually diagnosed her. It took a long time from start of the process to getting the diagnosis, Interviewee 20 estimates 8 years from when she first sought medical help for her condition.

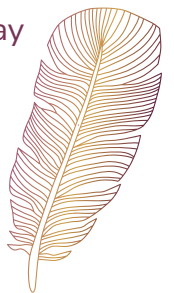
A prominent theme that emerged from this study was the impact of the overwhelming absence of services and supports for First Nations living with exceptionalities, especially on-reserve. This absence of services and supports on-reserve causes considerable harm including neglect of basic care (that is otherwise afforded to persons off-reserve) or forced relocation to access services off-reserve leading to isolation and disconnection from home, family, community, culture, and language. Participants also cited jurisdictional ambiguities as an important contributor to poor access to supports and services.

Participants noted how existing services/supports on-reserve are substantially underfunded, under resourced, and understaffed, meaning participants chronically lacked sufficient support especially outside of regular business hours. Also of note was the lack of access to supports to adequately meet basic needs such as housing, transportation, medical care and supplies, and mental health supports. Poor community infrastructure and a lack of accessibility at the community-level drastically limited participants’ ability to participate in community life, cultural activities, and recreation. Overall, participants felt that these circumstances can acutely put their life and health at risk and chronically impact their wellness and quality of life.



[Interviewee 5’s] wheelchair broke, and he was stuck in bed for six months while he waited for a new wheelchair.

“[Interviewee 15’s] primary caretaker was forced to get a part time job to pay for [incontinence product] for [Interviewee 15]. They have a prescription for them so the [incontinence product] should be covered by NIHB however through this system it takes a month to receive them and when they arrive the supply is inadequate to cover their needs. Sometimes the pharmacist loans her out of the kindness of her heart but it’s not enough. They have found that NIHB is usually about 3-weeks behind.”



“[Interviewee 2] stated that his general practitioner prescribes him medication for mental health, but no other services have been available. He further discussed how group activities, stable counselling and stable living environments are a necessary service that is lacking and that dealing with mental illness in an emergency room instead of providing stable housing or stable care with healthier options that’s where it’s lacking.”





“[Interviewee 17] moved back to Winnipeg a few months after he was born because there was not adequate access to medical services on-reserve. When [Interviewee 17] was more stable at age 5 the family tried to move back home to the reserve but eventually had to return to Winnipeg as it was too difficult due to the lack of services. Each time the family was cut off provincial services and they found that the community did not have the proper funding to support the interviewee’s needs. The caregiver stated in the interview: ‘Having anything that is disability specific services is lacking, CLDS [Community Living disABILITY Services] provides on the provincial side is not available on the federal.’”

Funding and support are required for the expansion of on-reserve programs to meet the needs of First Nations persons living on-reserve so their needs can be met, they can receive equitable care, and are not forced to relocate to cities to gain access to provincial/off-reserve supports. The current resources cannot meet the growing need and are often not equitable to those provided by the provincial government off-reserve. Note that when participants spoke to equity, they did not merely mean equal access to the services offered off-reserve, even though many noted this would be a considerable improvement given the current state of supports on-reserve. Many of the services offered

provincially/off-reserve are not suitable for First Nations, are antiquated, and do not even align with recognized best practices for care in the body of disability research (McColl et al., 2017; Smith-Carrier et al., 2017; Stienstra, 2018). Equity is created when individuals have the fair opportunity to reach their fullest potential. A health equity approach encompasses “upstream” efforts—those that address people’s access to the social determinants of health—to the individual-, community-, and population-levels, with interventions tailored to the needs, priorities, and assets of individuals, families, and communities (Government of Ontario, 2018).

## Funding for Services & Supports

Participants as well as the expert panel convened to formulate recommendations noted problems with current funding structures to services/supports offered on-reserve that contributed to downstream problems within services/supports themselves. Currently, the normative approach to funding is based on demand, where a Nation must submit funding requests for special programs/projects or communities are allocated funds for more permanent programs according to federal criteria (Health Canada, 2013). The resulting funding allocation is typically limited on a basis of population estimates (e.g. Modified Berger Formula, using the Indian Registration System population counts of on- and off -reserve) with little consideration for actual need or aspirations within communities (Health Canada, 2013).

First Nations must request funding, and they must do so with very little access to information about what has been funded in other Nations, or what types of services can be funded through current programs. Many participants, when asked about programs stated that they did not exist in their communities, were unavailable due to strict eligibility criteria, and there was often little awareness around the programs that do exist and what supports they as clients were entitled to under various programs.

Our expert panel highlighted a number of key issues they would like to see implemented around the provision of funding for disability supports and services on-reserve.

Firstly, every First Nation should be ensured equitable, flexible, long-term funding for a common baseline of services that is dependent on the level of need within communities and considers their right to self-determine the design and implementation of services.

Secondly, funding should thus allow for flexibility in service design and delivery to allow the incorporation of culture, language, and spirituality as communities see fit.

Thirdly, First Nations must have consistent, ongoing access to clear and transparent information about the scope of funding that is available. They must have ongoing access to supports for visioning and making sense of the ways in which the full scope of this funding can be utilized in their Nations.

Fourth, they must also have access to ongoing supports for revising/adapting funding as service capacities or contexts change or to support innovation and adaptation of services. Such supports include access to data for informed planning to meet community need.

Similar calls for transforming funding approaches for First Nations have also been made by First Nations organizations and leaders. For example, the Assembly of First Nations Chiefs in Assembly have frequently called for the development for renewed funding models for numerous program areas including First Nations Early Learning and Child Care (AFN, 2019a), First Nations languages funding (AFN, 2022), and education (AFN, 2019b). The Chiefs cite the same issues identified by participants in this study, namely how current approaches fail to account for high costs of service delivery in northern locales or small communities, historical underfunding, infrastructure and human resource needs, costs of language and culture programming, and reliance on an inadequate population dataset (AFN, 2019).

## Transportation

“When patients must travel for medical services it is a ridiculous experience. Wait times and travelling is a huge barrier. There should be a way to make medical transportation from the reserve to the city better. Riding an 8-hour bus to get to an appointment and then there are wait times for subsequent appointments. For medical results you are sometimes left waiting for an answer for 6 or more months.”

This study particularly highlighted programs intended to ensure basic needs are met, transportation services, medical services, and medical supplies. Non-Insured Health Benefits (NIHB) provides insurance coverage for eligible First Nations for medical transportation. Factors that complicate medical transport include remoteness, attrition of local service providers, limited access to local specialized services, under-equipped medical providers, and limited cultural safety across service provision. Participants in this study along with our expert panel also noted that the paperwork and approval processes for medical transportation were complicated and restrictive.

Claims for medical transportation benefits are processed by the NIHB Program through Indigenous Services Canada's regional offices. The medical transportation client reimbursement form is submitted at the NIHB regional office. Prior to July 1, 2022, the NIHB kilometric rates when using a privately owned vehicle to access health services was 21.5 cents per kilometre (from April 1-June 30, 2022). For trips July 1, 2022 and onward, NIHB's kilometric rates will be 24.5 cents per kilometre (MKO, 2022). This is much lower than the CRA Kilometric Rates that the Government of Canada uses for employees for the use of privately owned vehicles driven on business travel which ranges from 48.5-61.5 cents per kilometre depending on the province or territory and is 49.5 in Manitoba (CRA, 2021). The meal

allowance rate are also much lower for NIHB medical transport than the Government of Canada with NIHB's daily allowance allocating \$60/day while the Government of Canada rate is \$94.85/day in all provinces and higher for the territories (CRA, 2021; MKO, 2022).

In addition to issues with medical transport, there are also no programs to support non-medical transportation and private options (taxis, ride share, volunteer transport groups) that would typically be available in urban centres and even small towns. The lack of accessible transportation infrastructure and systems means that people with exceptionalities have added barriers to getting around their community. This leaves those living with exceptionalities on-reserve with no supports for transporting themselves to meet their basic needs or to participate in community life. Both medical and non-medical transportation are imperative for quality of life and participation in communities.

## Accessing Services & Supports Off-Reserve

There are significant challenges for those accessing medical services both in cities and rural/remote communities. Some of these issues include transportation to and from medical appointments as well as long wait times to see health care providers and specialized medical professionals. These issues can result in late diagnosis and impede continuity of care, which result in reduced effectiveness of the health care system (Horrill et al., 2018; Huot et al., 2019).

Problems with accessibility to medical services are exacerbated in rural, remote and northern communities (National Collaborating Centre for Indigenous Health, 2019). Due to the small community size and location of communities it is challenging to recruit and retain health professionals which results in smaller communities with critical shortages in medical personnel (Huot et al., 2019; Mew et al., 2017; Oosterveer & Young, 2015). The result of the lack of in-community medical professionals is that many

communities rely on non-resident health professionals. These health care professionals fly into communities for short durations to see patients (Nelson & Wilson, 2018; Oosterveer & Young, 2015; Wallace, 2014). As a result many individuals are transported to urban centers for medical emergencies, hospitalization, appointments with medical specialists, diagnosis and treatments, often leaving behind families and support networks for extended periods of time (Huot et al., 2019; Mew et al., 2017; Oosterveer & Young, 2015; Patterson, Finn, & Barker, 2018; Wallace, 2014).



“Some of our relatives never made it home. The health care system has done the same thing to us as the Indian Residential School system. Our history of mistrust with these systems is long because of the harms they continue to inflict.”

-Knowledge Keeper Simon Samuel,  
Lac Brochet First Nation



“They should give amputees automatically electric wheelchairs. It is so hard to get around in the snow in the wheelchairs. We are isolated. If there is snow you can’t go anywhere for at least 4 days. It takes sometimes longer to get sidewalks plowed. When it is plowed its not even passable in my wheelchair. Most of the time I make the path to the street, and this is difficult, and I get help to push me to the bus stop. To get where I need to go at my bus stop, I’m alone and in a more difficult situation because I don’t have help.”

Following these concerns around on-reserve supports, infrastructure, resources, and capacity, we put forth the following recommendations, with the note that recommended options are asserted with accessibility and availability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):

21. Initiate extensive engagement processes with First Nations to co-develop more suitable, flexible, and responsive approaches to all program and service funding on-reserve, including but not limited to health and social services/supports.

22. Fund a First Nations-led approach to resolving jurisdictional disputes around fiscal responsibility for services for First Nations adults with exceptionalities to prevent denials, delays, or disruption of services.

23. Integrate the principle of “Connection to Home” as a cornerstone for all health and social policy, planning, and programming for First Nations. This means prioritizing supports to remain at home, supporting family/informal caregivers, and fostering connection to family, community, land, culture, and language.

24. Commit to and fund enhanced services on-reserve, namely a transition from the current sole reliance on nursing model of care to a multidisciplinary team-based, community-driven holistic health care model that:

- a. Ensures timely access (defined by community) to an array of health services and professionals regardless of residence (on- or off-reserve);**
- b. Integrates diverse health care professionals in a team-based model including family physicians, specialists, nurses, mental health therapists, crisis responders, dental health professionals, social workers, dietitians, occupational therapists, physiotherapist, speech language pathologists, massage therapists, traditional healers, knowledge keepers, and Elders work collaboratively to provide integrated care;**
- c. Ensures access to medical specialists beyond only emergency need to also include health prevention and promotion focus (e.g. dermatology, gerontology, rehabilitation medicine, ophthalmology, genetics, neurology, gynecology, etc.);**

- d. Incorporates First Nations-led development of palliative or end-of-life care supports utilizing both Western/biomedical and Indigenous approaches;**
- e. Conducts outreach and/or home visitation services to improve access and reduce barriers to accessing care;**
- f. Funding for one-on-one supports for First Nation with exceptionalities to support them in activities for daily living.**

25. Establish a Manitoba Adult Assessment and Diagnostic Clinic to aid in “case finding” or identification of previously undiagnosed adults so that they can then access services and supports. Ensure cultural validation of assessment/diagnostic tools in First Nations populations and that tools, services, & supports are available in First Nations languages.

26. Commit to addressing chronic human resource shortages in health and social services on-reserve via targeted training and educational opportunities and supports along with retention incentives for First Nation community members.

27. Compel the Province of Manitoba to review and revise all policies and procedures to ensure there are no exclusions of First Nations adults with exceptionalities on-reserve.

28. Expand the funding and scope of Non-Insured Health Benefits (NIHB) to:

- a. Improve timeliness of access to benefits by renewing approval processes;**
- b. Adapt policy so that provision of supplies and equipment reflect actual client need and not arbitrary quotas and limits that are frequently inadequate and inhumane;**
- c. Conduct regular policy and program review in partnership with First Nations to ensure alignment with community needs and priorities as well as clinical guidelines/best practices;**

- d. Introduce balance between Western/biomedical therapies and Indigenous healing approaches by providing financial resources to compensate for traditional medicines as well as knowledge keepers, traditional healers, Elder counsellors, spiritual counsellors, and more;**
- e. Include coverage for subsidized bus passes to facilitate transportation to access key services in urban centres including school, appointments, recreation, cultural endeavours, socialization, and shopping for essentials;**
- f. Provide financial assistance to help offset a portion of the costs for the purchase of or modification of an accessible family vehicle;**
- g. Create a flex category to allow for person-centred autonomy in selecting therapies not on the formulary (e.g. accessing evidence-based alternative pain management strategies such as meditation, medical cannabis, traditional healing, etc.).**

29. Commit to overhauling the Non-Insured Health Benefits’ Medical Transportation Program to ensure equitable financial resources/rates for mileage, accommodation and meals allocated to First Nations travelling for medical care. We recommend that rates match those allocated to federal government staff.

H

## Community Infrastructure, Resources, & Capacities

For [Interviewee 15], the size of the home is wheelchair accessible, but she received a wheelchair that is too wide for the home, so she must scoot everywhere. Her quality of life is impacted due to her grandma's small home. She does not have access to the bathroom, so she hasn't bathed in 2 years. She sponge bathes everyday and must poop on a pad in her room."

This study particularly highlighted how on-reserve infrastructure, resources, and capacities beyond health and social services are inequitable and contribute to harms experienced by First Nations with exceptionalities. While we have already identified housing as an important issue above, participants also spoke to how a lack of access to clean, running water and poor wastewater infrastructure impacted their safety and health. Investigations by human rights organizations have found contaminants in drinking water on First Nations reserves, included coliform, *Escherichia coli* (*E. coli*), cancer-causing Trihalomethanes, and uranium (Human Rights Watch, 2016). The daily hardship of living under a water advisory for years means that some people become frustrated and drink it without boiling or otherwise treating it—risking exposure to contaminants (Human Rights Watch, 2016). Dealing with water advisories is an even greater challenge for First Nations living with exceptionalities who may struggle to boil water or access bottled water. Some may use tainted water for bathing or for household tasks, which increases health risk with many households without clean water reporting problems related to skin infections, eczema, psoriasis, or other skin problems (Human Rights Watch, 2016). Some avoid the water at all costs, but do not have sufficient safe water to meet their daily needs (Human Rights Watch, 2016). Many report changing hygiene habits, including limiting baths or showers for children, based on

concerns about water quality (Human Rights Watch, 2016). Overall, the water crisis decreases the quality and quantity of water available for hygiene which puts First Nations living with exceptionalities at greater risk to physical and mental health and well-being.

Participants also spoke to how poor internet and wireless connectivity impacted their ability to work, study, connect with friends/families, or access other services such as virtual appointments. The impact of poor connectivity was felt especially among those with exceptionalities that impact their mobility. This is reflected in the recent efforts of the federal government for "High-Speed Access for All: Canada's Connectivity Strategy" which notes the unique challenges many First Nations communities face (Innovation, Science and Economic Development Canada, 2019). They note that First Nations "shouldn't have to move elsewhere because of the lack of basic infrastructure and services to pursue education, undergo training or find employment." (Innovation, Science and Economic Development Canada, 2019) We must therefore ensure that investments are made effectively so that the youngest and fastest growing sector of our population can uncap the full potential of the Internet. The Government of Canada will continue to work with Indigenous communities to implement connectivity projects and meet their unique needs.

"There should be a program where families can get accessible ramps – we are close with our families, but we have no way to get in their houses. The only time we can go to family gatherings is in the summer as we sit outside but get eaten by mosquitos."



Participants often spoke to how much of the community was inaccessible to them due to poor road infrastructure, absence of sidewalks, and no wheelchair doors, ramps or accessible bathrooms in public spaces like schools, band offices, cultural sites, or recreation areas. Similar issues around accessible infrastructure on-reserve is echoed in the literature, which also notes issues around access to key documents (treaty documents, by-laws, community notices, etc.) in plain language, no access to sign language interpretation of important meetings like council meetings, poor lighting and no visual markers for those with sight impairments, the impacts of harsh winters and heavy snowfall, barriers to using wheeled mobility equipment to negotiate terrain, no accessible transportation, and attitudinal and knowledge barriers among fellow community members (Kiedrowski, 2021; Wearmount & Wilandt, 2009; Elias & Demas, 2001; AFN, n.d.).

Following these concerns around on-reserve infrastructure, resources, and capacity, we put forth the following recommendations, with the note that recommended options are asserted with applicability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):

30. Commit to funding community-driven Accessibility Plan development in every First Nation.
31. Commit to addressing on-reserve community infrastructure needs, namely:
  - a. *Achieving universal access to clean drinking water and sewer sanitation for all households;*
  - b. *Achieving universal access to high-speed internet and cellular service for all First Nation citizens;*
  - c. *Foster interoperability of eHealth applications to ensure seamless access to health information for continuity of timely care between on-reserve and external health care providers;*
  - d. *Ensuring community-wide accessibility for all;*
  - e. *Provide capital funding to fund and support the creation of accessible indoor and outdoor spaces in all First Nations communities to accommodate cultural, spiritual, recreational, and wellness programming and supports;*
  - f. *Funding the construction of safe and inclusive play structures and accessible cultural and recreational spaces within all First Nations communities;*
  - g. *Establishing reliable and accessible community transportation for accessing cultural and recreational pursuits in addition to health and social services.*





## Research and Data

Currently there is no systematic or national data available to understand the number or type of disabilities for First Nations on- and off-reserve. This lack of data impedes Nations' ability to effectively plan and budget to meet the needs of their community members living with exceptionalities. Moreover, there is paucity of research on the experiences of First Nations living with exceptionalities and their support needs and priorities.

The Truth and Reconciliation Call to action 19 highlights the importance of data collection as part of the health services provided to Aboriginal peoples.

19. We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.

A high-quality health information base is the cornerstone for health research and for evidence-based public policy (Reading & Wein, 2009) including for persons with exceptionalities, and this we put forth the following recommendation, once more with the note that recommended options are asserted with applicability to all First Nations persons living with exceptionalities, regardless of where they reside (on- or off-reserve):

32. Invest in comprehensive, First Nations-led, and OCAP® compliant research and data collection on:

- a. *The prevalence and types of disabilities (diagnosed and undiagnosed) among First Nations on-reserve and off-reserve;*
- b. *The circumstances that create and exacerbate disability for the purpose of prevention & intervention (e.g. specific and detailed data pertaining to injuries, accidents, chronic illness, co-morbidities, etc.);*
- c. *Socio-demographic data pertinent to future community planning (i.e. projection of children aging out of care/services, etc.);*
- d. *In-depth and on-going the lived-experiences of First Nations with exceptionalities;*
- e. *More specifically, the impacts of intersecting identities on the lived-experiences of First Nations with exceptionalities (e.g. how gender, class, Indian status, skin color, geography, and more);*
- f. *Explicit linkages across systems containing First Nations data (provincial population data repositories across health, justice, child welfare data sets and beyond, regional data sets, census data, etc.).*

## Conclusion

This study demonstrates the multitude of challenges that First Nations adults living with exceptionalities face, particularly while living on-reserve. The findings are presented through three overarching and intertwining thematic areas that emerged out of analysis of the interview field notes. These themes centered around (1) the design, structure, and administration of federal government programs; (2) inadequate resources, services, and supports; and (3) failure to deliver culturally and stigma-safe services/supports to First Nation persons with

exceptionalities on-reserve. Within these themes, participants often identified major challenges they face that negatively impact their daily life, quality of life, and overall wellness, alongside discussions of the things that promote their wellness. This report offers concrete recommendations to Canada grounded in the experiences of participants to inform a strategy for systemic changes to improve the wellbeing and quality of life of First Nations adults living with exceptionalities.

**We wish to also highlight how the results from this study reflect outcomes of our recent endeavour to engage First Nations in Manitoba in their vision for a long-term/continuing care strategy to better serve aging First Nations and those living with exceptionalities. Outcomes of this engagement process highlighted the following:**

- **A need for equitable services and supports between on-reserve and off-reserve as well as between First Nations and all other Manitobans;**
- **Reformation of funding approaches & funding formulas to better meet actual need in communities and to allow flexibility so communities can direct funds to meet evolving needs;**
- **Calls to involve First Nations/families/individuals in design & implementation and uphold community self-determination;**
- **Improved efforts to integrate Indigenous culture, language, & spirituality;**
- **Enhanced access to holistic wellness approaches;**
- **Enhanced continuity of care across the lifespan;**
- **Accessibility (namely accessibly infrastructure and accessibility to land-based activities, culture, recreation, health/social services);**
- **Investments in infrastructure, capital funding including operation & maintenance;**
- **Local capacity building;**
- **Tackling challenges around human resources;**
- **Home & Community Care Program transformation to improve the program's access and impact;**
- **A focus on support to remain in the home community;**
- **Improved supports for families and caregivers including respite and counselling; and**
- **Concrete mechanisms to resolve jurisdictional disputes/quagmires.**

## Appendix A: Defining Disability: Theoretical Perspectives

This section has four primary components. First, by way of background, the entry articulates and explores disability theory's origin and evolution. Then, it introduces different key aspects of disability theory, including the social model of disability and the use of the new language of "critical disability theory" to highlight critical approaches against traditional "disability studies".

Disability studies emerged out of the disability civil rights movement in the late twentieth century (Meekosha & Shuttleworth, 2009). It is an interdisciplinary field that examines the social, cultural, political, and economic aspects of disability (Meekosha & Shuttleworth, 2009). This academic field encompasses a wide range of disciplines, including sociology, philosophy, psychology, history, and political science (Meekosha & Shuttleworth, 2009). The discipline has evolved over time to incorporate new theoretical perspectives. Early scholarship in the field distinguishes the medical model of disability, which locates physical and mental impairments within individual bodies, from the social model, which understands the world as disabling people.

### Medical Model of Disability

The medical model of disability is often associated with a focus on finding a cure or fixing the individual with the disability, rather than addressing the societal barriers that prevent them from fully participating in society (Meekosha & Shuttleworth, 2009). It also emphasizes the idea that people with disabilities need to be "fixed" in order to be able to live a normal life (Meekosha & Shuttleworth, 2009). For instance, the medical model is reflected in Canada's Disability Reference Guide, which puts forth disability "as a medical or health problem that prevents or reduces a person's ability to participate fully in society" (Human Resources and Skills Development Canada, 2013). In this sense, disability is defined as a limitation or deficit within an individual, and disability programs thus must attempt to provide services that aim to help an individual compensate for perceived deficits in order to allow them to better function in society.

This model has been critiqued for many reasons. First, its perpetuation of "ableism," which refers to the societal belief in the superiority of able-bodied people and the discrimination and marginalization that people with disabilities experience as a result (Shyman, 2016). This model also tends to focus on the impairment and the physical or mental condition

specifically, instead of considering the person as a whole (Shyman, 2016). In addition, the medical model of disability has contributed to the institutionalization of people with disabilities in various ways. The focus on medical diagnosis and treatment of the individual can lead to people with disabilities being seen as passive recipients of care, rather than as active agents in their own lives (Meekosha & Shuttleworth, 2009; Haegele & Hodge, 2016). This can result in people with disabilities being placed in institutions, such as nursing homes or mental health facilities, where they receive care primarily from medical professionals (i.e. physicians, nurses, etc.) who tend to focus support and services on physical or bodily needs and not emotional, spiritual, or mental wellbeing. This orientation contributes to a focus on medical treatments and interventions aiming to fix or support a perceived deficit in the individual, rather than addressing the societal barriers that prevent people with disabilities from fully participating in society (Haegele & Hodge, 2016). Institutionalization can also perpetuate ableism by reinforcing negative stereotypes and societal barriers that people with disabilities face (Haegele & Hodge, 2016). People with disabilities who are institutionalized often less able to participate in community, are seen as "different" or "other," and their experiences and perspectives can consequently be ignored or dismissed (Haegele & Hodge, 2016). Overall, institutionalization creates barriers to participating in everyday life, contributes to isolation from family and social networks, impedes involvement in meaningful activities, and can contribute to a loss of independence, autonomy, and dignity (Haegele & Hodge, 2016).

### Social Model of Disability

As a challenge to the medical model, the contemporary field of disability studies has been largely informed by the social model of disability. The social model of disability is a way of understanding disability that focuses on the ways in which society creates barriers for people with disabilities, rather than focusing on their individual impairments (Shakespeare, 2006). The Canadian Disability Reference Guide also cites a social approach view of disability, stating that disability is "a natural part of society, where attitudes, stigma and prejudices present barriers to people with disabilities, and prevent or hinder their participation in mainstream society" (Government of Canada, 2019). The social model emphasizes the importance of removing societal barriers and creating a more inclusive society (Shakespeare, 2006; Oliver, 2013). It is based on the idea that disability is a socially constructed experience, rather than a medical one.

Notably, some scholars caution that there is a tendency within some academic fields, notably those in the health professions, to refer to themselves as "disability studies" by virtue of taking disabled people as objects of study (Linton, 1998; p. 526). However, the discipline aims to take the opposite approach, seeking leadership by people with disabilities and investigation into social environments and circumstances. Along similar lines, it is important to note that the language of disability studies has been coopted, for example, by rehabilitation and special education disciplines that remain tied to the medical model (Meekosha & Shuttleworth, 2009; p. 49). Disability studies, working in tandem with the disability rights movement, shifts the focus from the medical model and correlational intervention on disabled people to increase "fit" in society to instead focus on the "rigidity, faultiness, deficits, and pathological structures" in society itself that construct disability (Linton, 2005; p. 518). For example, Linton writes:

**"Disability studies' project is to weave disabled people back into the fabric of society...as full citizens whose rights and privileges are intact, whose history and contributions are recorded, and whose often distorted representations in art, literature, film, theater, and other forms of artistic expression are fully analyzed." (Linton, 2005; p 518).**

### Critical Disability Theory

Disability studies has more recently evolved to incorporate a critical theoretical lens. Broadly understood, critical theory identifies, describes, and analyzes the subsumed or hidden origins of social and political culture, discourses, and institutions (Hall, 2019). In these ways, critical theory also exposes the contingency of ideas or circumstances often presumed natural or unchangeable (Hall, 2019). It also aims to examine underlying structures of power and meaning that organize relationships, institutions, and knowledge production (Foucault, Davidson, & Burchell, 2008).

Critical disability theory thus responds to the traditional disability studies project by pointing to its limits, including its exclusions and framing. Critical disability theory helps to interrogate not so much "whether the disability inheres in a particular person, but what is society's response to a particular person's circumstances?" (Pothier & Devlin, 2006; p.5). Critiques of traditional disability studies include its largely liberal approach (Sleeter, 2010), narrow consideration of physical disability, focus on the global North (Meekosha & Shuttleworth, 2009), independent living (Sleeter, 2009; Fritsch, 2010), downplay of pain and suffering (Mollow, 2017), ties to or investment in class elitism (Erevelles & Kafer, 2010), neoliberalism (Sleeter, 2010), masculinism (Fritsch, 2010), materialism (Vehmas & Watson 2014), and white supremacy (Bell, 2006; Erevelles & Kafer, 2010; Moore, Lewis, & Brown, 2018).

Scholars have also highlighted traditional disability studies' lack of focus on the body/embodiment of disability (i.e. somatophobia), overlooking of pain, erasure of bodies of color, reinforcement of hierarchies, policing of points of view, and moments of careerism over coalition (Fox, 2017; Goodley, Liddiard, & Runswick Cole 2018; Snyder & Mitchell 2001). They also note that the social and structural analysis focus of the social model of disability tends to overlook the embodiment of disability, leading to inattention to the physical, lived-experiences of those with disability especially around experiences of pain (Shakespeare & Erikson, 2001; Mollow, 2017; Tremain, 2017). Prominent disability theorists Tom Shakespeare and Mark Erickson, for example, do not deny that society causes many problems, but they also feel that their bodies may cause difficulties and they don't want any theory of disability to take account of the physical dimension to their lives. They suggest that in developing a social and structural analysis, the disability movement has omitted a key facet of their experience (Shakespeare & Erikson, 2001).



## Intersectionality

Another important aspect of disability theory includes consideration of intersectionality. Intersectional theory is a paradigm that frames how social categories such as gender, ethnicity, class and education interact, intersect, and mutually reinforce each other to produce different health outcomes and experiences of oppression among and between social groups (Reid, Pederson, & Dupere, 2012). The theory aims to understand the multitude of factors that work to influence experiences, how these factors interact, and the social and institutional power structures and systems that produce and perpetuate disparities (Reid, Pederson, & Dupere, 2012). As such, intersectional theory advocates for the examination of the experience of disability beyond just the experience of impairment, but also about the ways in which society views and treats people with disabilities based on their other identities.

Intersectionality highlights that disability is not just a personal experience, but also a social one, and that people with disabilities can be affected by multiple forms of prejudice and oppression. It also emphasizes the importance of understanding and addressing the ways in which different forms of oppression interact and compound each other (Reid, Pederson, & Dupere, 2012). It helps to provide a more complete and nuanced understanding of the experiences of people with disabilities and highlights the importance of addressing multiple forms of oppression in order to create a more inclusive and equitable society (Reid, Pederson, & Dupere, 2012).

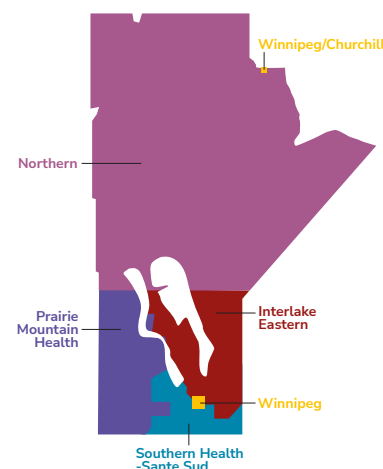
## Appendix B: Federal, On-Reserve And Provincial, Off-Reserve Services For Persons With Disabilities In Manitoba

### Long-Term Care In Manitoba: Provincial Services, Off-Reserve

In Manitoba, the responsibility for long-term care for First Nations is shared between provincial and federal governments. Different services and supports that fall under the long-term care continuum are provided across several different provincial ministries and health service providers. Manitoba Health funds many long-term care services via the five regional health authorities including home care, supportive housing, personal care homes, and palliative/end-of-life care supports and services. There are five Regional Health Authority offices including the Interlake-Eastern Regional Health Authority, Prairie Mountain Health, Winnipeg Regional Health Authority, Northern Regional Health Authority, and

Southern Health-Santé Sud offices. These provincial services are available to all eligible Manitobans in their respective regional health authorities, including First Nations. However, provincial programs operate off-reserve only, with the exception of some costs paid for adult care in long-term care facilities on-reserve. Manitoba Department of Families funds and delivers income supports for Elders/seniors and persons with disabilities as well as the Community Living disABILITY Services and Children's disABILITY Services programs.

### Map of Manitoba Regional Health Authorities



[http://www.ltcam.mv.ca/options\\_map.htm](http://www.ltcam.mv.ca/options_map.htm)

### Manitoba Home Care Program

The Manitoba Home Care Program, established in September 1974 and provides a continuum of services including home-based care planning and provision, liaising with other care providers, and managing Personal Care Home placement. In 2004, Manitoba Health announced Aging in Place as an alternative to PCH care for some individuals. This in effect expands Manitoba's continuum of home and PCH care to include supportive housing.

Home Care is provided to Manitobans of all ages based on assessed need and taking into account other resources available to the individual, including families, community resources and other programs. The Home Care program was established to help people live at home and remain independent for as long as possible, thereby avoiding or delaying the need for individuals to go into long term care facilities.

The mandate of the program is to provide effective, reliable and responsive community health care services to support independent living, develop appropriate care options with clients and/or family, and facilitate admission into long term care facilities when living in the community is no longer possible.

Typical home care services under the program may include:

- Personal Care Assistance (bathing, dressing, toileting)
- Home Support (meal preparation, light house keeping and laundry)
- Health Professional Services (example nursing)
- Assistance with taking medications
- Respite Care
- Other specialty services and clinics

Individuals seeking home care services must access the program via their respective regional health authority. Individuals looking to access other provincial supports such as home care, supportive housing or a personal care home must start with their respective regional health authority home care access point as well.

Some regional health authorities are also looking to provide enhanced transitional care under their home care programs. These "Transitional Care Environments" will aim to benefit patients who have completed the acute care portion of a hospital stay but who need some transitional support before returning home. The goal of separating transitional care from an acute care environment is to improve the quality of care and reduce unnecessary hospital burden and costs. Clients using transitional care will be medically stable and ready to be discharged from hospital, but still need time to make long-term arrangements for their care. Following a short term (30-90 day) transitional care stay in an acute care setting, clients may be able to return home with home care supports, be eligible for a supportive housing environment or, receive care in a personal care home. In a transitional care environment, the care team will assess and determine the level of care and support necessary for each client.

Transitional care will eventually be offered out of community hospitals once the WRHA's Healing our Health System consolidation plan is fully implemented. In the interim, this transitional care environment will provide additional capacity to establish and implement an enhanced home care system – called Priority Home – which will help many clients return straight home with robust home care supports.

Another planned strategy called a "Priority Home" may be available as part of the home care program in the future. The new service is anticipated to provide intensive home care to clients for up to 90 days as an alternative to a transitional care stay in a hospital or acute care setting. Following the 90 days, it is anticipated that most clients will be able to remain in their homes with regular, ongoing home care, and not require immediate paneling for a personal care home.

Being able to recover at home, among familiar surroundings and comforts, can have a profound effect on recovery and also reduce the potential for injury. It is a much healthier option for those clients who don't need to be in hospital. This intensive service will also help reduce the length of time clients spend in hospital, and may help some avoid placement in a personal care home altogether.

### Supportive Housing

Supportive Housing is designed for individuals who require access to 24 hour supervision and some assistance managing with physical limitations, or ongoing health conditions such as dementia. In Supportive Housing, people live in their own apartment within a group community setting. Meals are provided and people share a common kitchen and living area. Laundry and housekeeping services are available, as well as social and recreational activities. Residents receive some support and cueing with activities of daily living such as bathing, dressing, and medication reminders.

Individuals seeking to access Supportive Housing must do so via their respective regional health authority's home care contact. Rent and services are paid by the resident, while the support component is funded through the Regional Health Authorities of Manitoba. The cost of living in a supportive housing unit average between \$1695-\$3195 per month. Both the Disability Tax Credit and the Primary Caregiver Tax Credit can be used to offset some of the costs of Supportive Housing.

### Personal Care Homes

A Personal Care Home (PCH), also known as a "Nursing Home" or "long term care home," provides personal care services to individuals who can no longer manage independently at home with family support and community services.

The insured personal care services provided throughout Manitoba's 125 licensed personal care homes include the following:

- meals (including meals for special diets)
- assistance with daily living activities such as bathing, getting dressed and using the bathroom
- necessary nursing care
- routine medical and surgical supplies
- prescription drugs eligible under Manitoba's Personal Care Home Program
- physiotherapy and occupational therapy, if the facility is approved to provide these services
- routine laundry, linen and housekeeping services

Access to a personal care home is provided through regional health authority's Home Care program. The provincial government (Manitoba Health) and the client or resident who needs the services share the cost of personal care home services. Manitoba Health pays the majority of the cost through the regional health authorities. The personal care home resident pays the other portion of the cost, called a Residential Charge.

A classification system for PCH residents is used to define the extent of their dependence, to approximate the amount of daily nursing care they may require, and thus determine which facilities may be best suited to meet the resident's level of care needed. All nursing home (PCH) residents are assessed at one of four levels of care based on the Dependency Assessment Supplement (DAS). This assesses the residents' abilities to complete activities of daily living tasks, on their need for professional interventions, and their degree of behavioral problems. This leads to a determination of the number of nursing hours they require per day.

Assessments occur as part of the panelling process for admission to a personal care home (PCH) and at regular intervals during the residents' stay in a PCH. All residents are assigned a level of care based on their assessed dependence in six areas:

1. Bathing and dressing,
2. Assistance with meals including feeding,
3. Ambulation/mobility/transfers,
4. Elimination,
5. Professional intervention (such as oxygen therapy, skin care, recording of vital signs, and treatments/medications), and
6. Behaviour management/support and supervision required.

In each of the six areas of care, people receive a score ranging from:

- Independent (score of X) - requires no supervision or assistance
- Minimum dependence (score of A) - requires some supervision/encouragement and/or intermittent assistance
- Partial dependence (score of B) - requires ongoing supervision and/or assistance
- Maximum dependence (score of C) - completely dependent and/or requires ongoing supervision
- Chronic care indicator (score of D) - as 'score C' but requires ongoing attention by medical staff and/or multiple people to provide assistance.

Individuals that are assigned a score of 'chronic care indicator' in any of the six areas of care may be considered for placement into a chronic care facility in Manitoba, such as Deer Lodge or Riverview located within the Winnipeg Regional Health Authority (WRHA).

The assessment is currently done using a standardized tool called the Dependency Assessment Supplement (DAS). Based on the scores in each of the six areas, an algorithm is used to assign people to one of four levels of care.

Based on the individual area scores, the level of care is defined using the following rules:

- Level of Care I : Score of 'independent' or 'minimal dependence' in all six items.
- Level of Care IV : Score of 'maximum dependence' in four or more items.
- Level of Care III :
  - a) Score of 'maximum dependence' in two or three areas of care plus a score of 'independent' or 'minimal dependence' in all other items OR
  - b) Score of 'maximum dependence' in the behavioral management item plus a score of 'partial dependence' in at least two other items.
- Level of Care II : All remaining combinations.

Hours of nursing care in a PCH have been estimated for residents assigned to different levels of care. Residents assigned to Level of Care I are estimated to require 0.5 hours of care in a 24-hour period. Residents assigned to Level of Care II are estimated to require 2.0 hours of care in a 24-hour period, while those assigned to Level of Care III or IV are estimated to require at least 3.5 hours of nursing care during a 24-hour period.

#### Aging In Place Community

An "Aging in Place Community" sometimes known as a "Campus of Care" model, can be described as a residence or group of residences, where more than one type of living and/or care option is offered on the same property. As more "Aging in Place Communities" are developed, individuals may choose to live in a community such as this in order to accommodate future service and care requirements should they arise. The options within an Aging in Place Community could include two or more of the following settings:

- Independent Living with Services (also known as Assisted Living)
- Supportive Housing Residence
- Personal Care Home

Aging in Place communities are designed to improve the continuum in care and reduce the potential detrimental impact of moving an individual from their established community (circle of friends, familiar staff, familiar setting, close to family, etc.) or away from their spouse should they require a higher level of care. In situations involving spouses, such communities would aim to alleviate the caregiver burden, while providing an environment where the couple can still be together.

#### Palliative/End-Of-Life Care

Palliative or end-of-life care is an approach to care that improves the quality of living and dying for the patient and their families. The palliative approach provides exceptional care to alleviate suffering and provides important physical, psychological, social, spiritual and practical supports. Palliative/end-of-life care is available in many care settings in Manitoba, including the home, in a palliative care unit (in a hospital or acute care setting) or in a hospice, a personal care home (PCH) or other health care facilities. The Winnipeg Regional Health Authority (WRHA) Palliative Care program provides access to care 24 hours a day to people registered with the WRHA program. The program also provides consultative services to patients and health care professionals across Manitoba. Direct palliative care services in the community are provided through home care in some regional health authorities.

End-of-life care delivered at a hospice facility is intended for individuals who have symptoms that are relatively well-controlled and who do not require specialized treatments in an acute care facility. In general, hospice is considered if a patient has a prognosis of one to three months and cannot or do not wish to receive care at home.

The Palliative Care Drug Access Program (PCDAP) provides deductible-free drug coverage for individuals who choose to remain at home for the final days of their life. Manitoba Health already covers the costs of drugs for individuals who are in hospital or a personal care home, so the PCDAP ensures that the same cost-free coverage is available to those who reside at home in their final days. The PCDAP is administered through Manitoba Health, and includes the costs of all eligible drugs prescribed by an eligible health care provider. Individuals enrolled in the program will not be charged for their prescribed medication when filling their prescriptions at the pharmacy of their choice.

The program is open to residents of Manitoba with a current Manitoba Health registration number. When an eligible health care provider makes a palliative diagnosis, an

application form must be completed and signed by the patient (or guardian) and their health care provider. The health care provider will then send the completed application form to the palliative care coordinator in the local regional health authority. If the patient is eligible for coverage, the form will be forwarded to Manitoba Health for registration.

#### Children's Disability Services Program

Children's disABILITY Services offers a variety of resources and supports to parents to assist them to care for their children at home in their own communities, where children grow and thrive. This program, provided through Manitoba Department of Families, supports families who are raising a child (or children) with developmental and physical disabilities, to meet some of the additional needs they may have. Children under the age of 18, who live in Manitoba with their birth, adoptive or extended families, are eligible. Eligible children must also have a medical diagnosis confirming one or more of the following conditions:

- Intellectual disability
- Developmental delay
- Autism spectrum disorder
- Lifelong physical disability
- High probability of developmental delay due to a pre-existing condition

Eligible families can be referred to Children's disABILITY Services by medical professionals, schools, and day cares. Families may also apply to the program directly by completing the Referral and Intake Application form (PDF) and submitting it, along with diagnostic assessment or medical report, to the regional Children's disABILITY Services office in their region. Services are not available on-reserve.

#### Community Living Disability Services Program

Community Living disABILITY Services aims to support eligible Manitoban adults (18 years of age or older) with significantly impaired intellectual functioning with impaired adaptive behaviour, existing prior to the age of 18. The program, provided through Manitoba Department of Families, aims to assist individuals with intellectual disabilities in Manitoba to live good and satisfying lives in their communities and empowers clients to make their own decisions regarding their life and care. Namely, the program aims to work with clients to provide client-driven supports and service via development of a "person-centred plan" that aims to empower clients to;



- Make decisions about their own life, including what services they may want
- Have the right amount of support needed to be happy and healthy
- Do things in the community that are important to them
- Stay connected with family and friends, and other important relationships
- Meet new people in their community

Potential services and supports provided through the program include:

- Supports to People Living at Home with Family: respite, in-home services support to family (person-centred and family focused planning, problem solving, before and after school/day service support, recreational activities, training or learning opportunities) or via outreach services (assistance with moving, help with developing skills that align with client goals, learning opportunities for the client or family)
- School In-Service and Summer Programming (for those 18-21 years of age)
- Day Services (employment, job training, or accessing a day service operated by an agency or recreational activity in community)
- Residential Services (supported independent living, rent top-up, home share, staffed home/group home)
- Clinical Services (assistance with clinical needs including specialized diets, therapy, etc.)
- Crisis Intervention (short-term crisis intervention services, establishing and accessing safe living arrangements)

You can apply to Community Living disABILITY Services by contacting their closest office. Referrals can also be made via the individual's school, family, an agency, a doctor, or other person in their support network with consent of the prospective client. The program is available to First Nations, but they must have an established permanent residence off-reserve in Manitoba prior to referral or request for services.

#### Disability And Health Supports Unit

Disability and Health Supports Unit (DHSU) assists with obtaining health-related supplies, equipment, and nutritional or diet supplements required based on medical need. In order to qualify for DHSU the individual must be enrolled in the Employment and Income Assistance Program, the Children's disABILITY Services Program or the Community Living disABILITY Services Program. All requests for health related products must be made by an approved health care professional and can include: specialized medical equipment; medical supplies; and nutritional supplements and diets to support a diagnosed medical condition.

Medical equipment can include assistive devices; mobility aids; support stockings; hearing aids and batteries; customized seating for wheelchairs, and wheelchair lifts, or ramps. Medical supplies can include diabetic supplies; feeding supplies; incontinence supplies for medical conditions; and oxygen. Eligible items may be delivered to an applicant's home.

#### Crisis Stabilization Units

Crisis Stabilization Units provide short-term, community-based supportive care and treatment for individuals in psychiatric or psychosocial crisis who may be at risk of hospitalization. Referrals are welcome from mental health-care professionals working in crisis services, community (Shared Health Manitoba, 2022).

The Crisis Stabilization Unit offers the following services:

- Short Term Crisis intervention
- Mental health assessment and psychosocial assessment
- Supportive place for an individual who is in crisis
- Therapeutic group programming
- Management of medications
- Health education regarding mental illness, coping strategies, wellness recovery planning and preventative techniques
- Liaison and referral to community resources
- Support to family members and others concerned
- Psychiatric consultation and assessment

#### Mobile Crisis Services

The Mobile Crisis Service assists individuals experiencing a mental health or psychosocial crisis, including persons with a co-occurring mental health/substance use disorder. Calls or referrals are welcome from anyone who is concerned about a person experiencing a mental health or psychosocial crisis, including self-referrals and referrals from family members. A mental health professional will take your call and work with you to decide on an appropriate course of action, based on the best interests of the individual who is in crisis (WRHA, 2022b).

The Mobile Crisis Service offers the following services:

- Crisis Intervention
- Mental health assessment and psychosocial assessment
- Telephone consultation and support
- Health education on mental illness, medication, coping strategies and preventative techniques
- Liaison and referral to community resources
- Support to family members and other concerned individuals
- Psychiatric consultation and assessment
- Short term follow-up

#### Hospital-Based Mental Health Services

Hospital-based services include both inpatient and outpatient services. Inpatient services are those where an individual is admitted to the hospital for at least an overnight stay. Outpatient services are located in hospitals and provided to individuals who are living in the community and not admitted to the hospital. Outpatient services are organized around specific mental health concerns and focus primarily on treatment of illness and reducing symptoms. Referrals to Outpatient Services are made by treating psychiatrists or primary care providers (WHRA, 2022c). The WRHA has adult mental health beds located in three hospitals across the city. Location of admission is determined by bed availability in one of the three hospitals:

- Health Sciences Centre
- St. Boniface Hospital
- Victoria General Hospital

The Selkirk Mental Health Centre is a 252-bed facility that provides specialized inpatient mental health and acquired brain injury treatment and rehabilitation services to residents of Manitoba whose challenging needs cannot be met elsewhere in the provincial health care system (Government of Manitoba, 2022).

#### Transportation

A number of services exist in Manitoba to support access to subsidized and specialized transportation for Seniors/Elders and those with disabilities; however, these services are typically limited to the urban setting of Winnipeg alone. These services include the following:

- Canadian Cancer Society Volunteer Driver Program: Provides transportation to ambulatory cancer patients receiving active cancer treatments who have no other options. Fees are applied monthly.
- Ring-a-Ride Program: Assists older adults in the community get to appointments, social outings and more with the help of a volunteer driver. All volunteers are screened to ensure client safety. Clients accessing this program must be independently mobile (ambulatory). Program users must live independently and live within the postal codes R3L, R3M, R3N, R3P, and R3T. Donations are requested to help support this program.
- Winnipeg Transit Plus: Winnipeg Transit Plus is a service of Winnipeg's public transit system that provides door-to-door transportation for people who are unable to regularly use the City's fixed route transit system because they are legally blind or have a disability that significantly impairs their mobility.

#### Financial Supports

Financial assistance for those requiring care and/or services is available depending on the individual's need. There are a variety of provincial tax credits, benefits, subsidies, and supplements to assist persons requiring long-term care, depending on their specific situation. Financial assistance supports specifically for Seniors/Elders and those with disabilities include:

- 55 PLUS Program, a Manitoba Income Supplement which provides quarterly benefits to lower-income Manitobans who are 55 years of age and over, and whose incomes are within certain levels
- Employment and Income Assistance (EIA) through the "Persons with Disabilities" category that provides financial help to Manitobans in need, supports for clients to meet their health needs, supports and referrals to help clients gain employment and achieve financial independence, and is available to all Manitobans living off-reserve. EIA is a program that is not specifically geared to First Nations, despite First Nations being disproportionately represented among EIA clientele. There are many different categories of assistance with a subcategory for those who have a mental or physical disability that prevents them from earning enough money to meet individual and/or families basic needs. The disability must be likely to last more than 90 days and a financial need must be demonstrated. Financial need is based on basic need and shelter costs. Financial resources are based on assets and income. Basic needs are calculated according to family size and cost of ongoing medical needs. Rent assistance may also be applied to offset the cost of shelter, utilities and fuel and is calculated at 80% of Median Market Rent according to household size. Unlike for those in other categories of the program, EIA for those with disabilities does not require individuals to look for work to qualify.
- A new income support program for Manitobans with severe and prolonged disabilities, separate from EIA, is currently in development. Design of new program is being informed by community feedback that urged for a service navigation component that provides information and referrals, case management, employment and training supports, enhanced communication with clients, and transition support.
- Rent Assist is a financial benefit for people who receive Employment and Income Assistance (EIA) and have housing costs to cover. It is also available to other low-income private renters. The amount paid from Rent Assist depends on the number of people in the household especially dependent children, the total household income, age of applicant (55 years or older), and disability status of applicant. This program is available to First Nations, but they must not live on-reserve or in Manitoba Housing, a personal care home, supportive living, student housing, or receive any other housing benefit or subsidy.

## Independent/Assisted Living (Private)

Independent/Assisted Living is an uninsured service that is not associated with the provincial government. Private senior living buildings are rented by individuals and different support services are offered depending on different service packages offered at different residences. The residence may offer various services such as housekeeping, meals, recreation, and more. Individuals who require financial assistance may qualify for Rent Assist to supplement the cost of Independent/Assisted Living. Home Care services can be used by individuals living in an Independent/Assisted Living residence.

## Other Services/Supports

### Allied Health Services

Within Manitoba, the Regional Health Authorities (RHA's) also offer therapy services that include physiotherapy, occupational therapy, speech language pathology and audiology. Therapy is delivered by RHA and service providers in hospital and community settings. Hospital-based therapy services are funded by Manitoba Health as an insured health benefit. Many community-based therapy services are also fully funded. A referral from a physician or other health professional may be required for community-based services. Services that are offered by the provincial government are accessible to First Nations persons but not offered on-reserve.

### Not-For-Profit/Charitable Services

Indigenous Friendship Centres in Manitoba typically offer a number of different programs to support Indigenous seniors in the local community. Such programs can include cultural/spiritual activities and supports, recreation, assistance with programs, and other lifestyle choices and needs.

The Indigenous Senior Resource Centre is a non-profit, charitable organization that utilizes a holistic approach to ensure the respect and well-being of Indigenous Seniors in Winnipeg. Their goal is to help improve the health and well-being of Indigenous Seniors in Winnipeg by:

- Increasing access to information, resources, and supports for Indigenous Seniors.
- Creating opportunities for active involvement within the community as a means of achieving physical, emotional, mental, and spiritual balance.
- Providing opportunities for Indigenous Seniors to pass on their traditional values and historical knowledge to younger generations.
- Create an environment where Indigenous Seniors can celebrate their uniqueness and build strong community friendships.

**Manitoba Senior Centres** are health promoting, capacity building, and community focal points on aging where older

persons can come together for services and activities that enhance their dignity, support their independence and encourage their involvement in and with the community. Open to all individuals 55 years and older, or retired, senior communities provide programs that offer core health services, are governed by a community-based Board of Directors, respond to diverse needs of older persons, hire professionals, provide education, develop innovative programming approaches, and are a community resource for information on aging.

**A & O: Support Services for Older Adults** is a not-for-profit organization that provides specialized services for older Manitobans across the province. The goal of these programs is to empower and support older adults in the community. The Agency aims to improve the quality of life for older adults in Manitoba through advocacy, education and service delivery and involve older adults in decision-making.

**Community Respite Service Inc.** provides quality respite in parts of southern Manitoba, especially Winnipeg and the Westman regions, for the caregivers of and to individuals with physical and/or intellectual disabilities. Community Respite Service (CRS) provides parents and caregivers of people with intellectual and/or physical disabilities the opportunity to take a much-deserved break. Also provide support, companionship and assistance to people with disabilities whether they are living independently in their communities or with their caregivers.

**St. Amant** is a not-for-profit organization for Manitobans with developmental disabilities, and autism that offers a wide range of programs and services to support individuals and their families. St. Amant programs include a large residence for complex-care with more than 100 community sites and homes. They are a member of the Catholic Health Network and offer programs for children with autism and also for families who care for an individual with a developmental disability at home.

### Long-Term Care In Manitoba: Federal Services, On-Reserve

The Canada Health Act (CHA) sets out criteria and conditions that a province's health care insurance plan must meet to receive the full cash contribution to which it is entitled under the Canada Health Transfer. However, there is no requirement that provincial health insurance plans cover extended health care services. "Extended health services" are defined in section 2 of the CHA and include the following: (a) nursing home intermediate care service; (b) adult residential care service; (c) home care service; and (d) ambulatory health care service. As continuing care is not an insured service under the CHA, "provinces deliver it in different ways even within provinces there are variations".

The federal government is involved in continuing care on-reserve and in providing home care or funding through the following programs: the First Nations and Inuit Home and Community Care Program (Home Care Program), the Assisted Living Program, the First Nation Basic Foot Care Program (unique to Manitoba), Elders' Lodges, First Nations Personal Care Homes, Jordan's Principle-Child First Initiative

### First Nations And Inuit Home And Community Care Program

The First Nations and Inuit Home and Community Care program supports the delivery of a continuum of basic home care services. This suite of services is based on a case management approach that includes client assessment and reassessment, which can involve the client, family caregivers or service providers, and help determine a client's needs and the services required. Home care nursing includes direct service delivery, personal care services and support to family caregivers. The basic home care services also encompass home support (e.g., bathing and grooming, home management assistance, etc.), as well as in-home respite benefiting clients, families and caregivers. The program also entails access to medical equipment and supplies, management and supervision, data collection and record-keeping, as well as linkages and referral, as needed, to other health and social services. Depending on community needs, priorities, infrastructures and resources, the Program may also incorporate supportive services: rehabilitation and other therapies; adult day programs; meal programs; in home mental health; in home palliative care; and, specialized health promotion, wellness, and fitness services. On-reserve First Nations, of all ages, with disabilities, chronic or acute illnesses and the elderly, as well as those who require continuing care on-reserve, are eligible for the program.

While the Home Care Program has authority to provide supportive services such as palliative care, mental health home-based care and therapies, it does not directly fund them. According to the most recent internal audit of the Home Care Program, "These services can only be provided once essential service elements are provided and if there are remaining funds." In her appearance before the Committee, an ISC representative noted that the Home Care Program had gaps, such as limited hours of service and limited types of services (i.e., physiotherapy and occupational therapy).

### Assisted Living Program

The Assisted Living Program provides funding for non-medical, social support services to seniors, adults with chronic illness, and children and adults with disabilities (mental and physical) on-reserve to help them maintain their

independence. It includes in-home care, adult foster care, and institutional care (for those needing personal non-medical 24-hour care). The services are available for people who live on-reserve and do not maintain a primary residence off-reserve. Funding is approved through a band appointed assisted living coordinator or band managers.

Services included home care, institutional care, adult foster care and disability initiative. The program does not offer nursing or medical care. However, eligible individuals can receive light housekeeping services and supervision as part of an in-home care or adult foster care service. The in-home care incorporates funding for assistance for daily living including but not limited to housekeeping, meal preparation and laundry services. Adult foster care provides management for adults in family settings that are unable to live on their own but do not require 24-hour supervision. For institutional care, the program helps to subsidize the facility copayment fees related to room and board for those within an institutional environment, long-term care facility, or personal care home, either on or off-reserve.

The scope of the Assisted Living Program is limited and functions like an income support program, available to those individuals who cannot pay for institutional care or in-home care supports themselves and who do not have any available family members who can provide the service for them. In addition, the financial support for institutional care (on or off-reserve) is provided only for people requiring Types I and II care. The responsibility to provide funding for delivering care in institutions (on or off-reserve) for Types III, IV and V care falls to the provinces and territories.

### First Nation Basic Foot Care Program

First Nation Basic Foot Care Program aims to help Manitoba First Nations lower their risks of diabetes-related foot complications and will see services provided by certified foot care nurses through Tribal Councils or directly by community health services. The Foot Care Program was developed to ensure access to Basic Foot Care Service in all Manitoba First Nation communities with an overall goal of reducing diabetes related foot complications and the rate of lower limb amputations. Basic Foot Care services are provided by a nurse (LPN/RN) with basic foot care certification and services are often provided alongside the Home and Community Care Program. The Foot Care Program is jointly led by the FNHSSM/Diabetes Integration Project (DIP) and the Manitoba First Nations Diabetes Leadership Council (MFNDLC). The program also provides professional development and capacity development opportunities in communities.



Sipi Personal Care Home (32 beds); George M. Guimond Care Centre (30 beds); Peguis Senior Centre (22 beds), Dakota Oyate Lodge (26 beds); Rod McGillivray Memorial Care Home (40 beds); and George Colon Memorial Home (34 beds). Those that are license by the province are: Nisichawayasihk Personal Care Home (24 beds) and Pinaow Wachi Personal Care Home (26 beds).

#### Elder's Lodges

Elders' Lodges are community-based live-in residences that provide collective housing, social, dietary and cultural activities. The Elders' Lodges operate through the Home & Community Care Program or by Assisted Living program funding. There are currently 7 Elders' Lodges in Manitoba: Kasayak Centre (16 units), Ginew Elders Lodge (12 units); Poplar River Elders Lodge (12 units); Private Matthew Sinclair Elders Lodge; Pine Creek Elders Lodge; Gods Lake Elders Lodge; and Tataskweyak Elders Lodge.

#### Jordan's Principle-Child First Initiative

Jordan's Principle is a child-first principle to resolving jurisdictional disputes within and between federal and provincial/territorial governments within Canada. It was named in memory of Jordan River Anderson, a young boy from Norway House Cree Nation, who spent more than two years unnecessarily in hospital while Canada and Manitoba argued over payment for his at-home care.

Under the Jordan's Principle – Child First Initiative, Niniijaanis Nide “My Child, My Heart” Program provides supports to families with children with complex needs and to help enhance the child's life and facilitate health care interventions and developmental stimulation. The program engages families and the community in working together to improve services. The goal is to contribute to quality of life ensuring that children, young people and their families are enabled to experience a life that is as full and as normal as possible. Children living on and off reserve with complex needs are eligible under the program.

Supports and Services may include Respite Care and Support Groups, Child Development Program (Preschool), American Sign Language (ASL), Therapy, Intervention Programs, Socialization Activities, and Land-Based Activities.

#### Non-Insured Health Benefits

The Non-Insured Health Benefits (NIHB) program provides eligible First Nations with coverage for a range of health

on-reserve with disabilities, chronic illness, or other challenges associated with aging including vision, dental, mental health counseling, medical supplies and equipment, prescription and over-the-counter medications, and medical transportation. Medical transportation includes transportation to enable access to health services that are not available on-reserve or in the community of residence. In order to qualify for NIHB you must be a First Nations person registered under the Indian Act (Status Indian) or a child less than 18 months old of a parent that is eligible.

#### Financial Supports

On-Reserve Income Assistance is delivered by Indigenous Services Canada and administered locally by community-based Social Assistance Administrators. The program intends to alleviate poverty in First Nations by providing families and individuals the means to meet their basic needs and typically matches payment amounts and policies delivered by comparable provincial/territorial programs.

- An additional monthly allowance called a disability allowance is payable to a recipient or adult dependent who has been medically assessed as having a disability (a physical or mental illness, incapacity or disorder that is likely to continue for more than 90 days) and who is residing in the community.
- A benefit payable on behalf of an eligible physically and/or mentally disabled adult who requires assistance in activities of daily living and who is residing with his or her family or in a private boarding home is available called a special care room and board allowance or a special care allowance.
- There are also two Social Categories that pertain to adults (age 18 or older) and who lack sufficient financial resources to provide for basic needs due to family responsibilities or circumstances. These responsibilities include:
  - Parents of a child with special needs (severe disability) who requires extensive parental care;
  - Persons who are providing full-time unpaid care for an elderly or disabled relative residing in their household.

Other Federal Financial Supports:

- OAS, CPP, Guaranteed Income Supplement
- Primary Caregiver Tax Benefit
- Disability Tax Credit
- Employment Insurance sickness & caregiving benefits

Canada Mortgage and Housing Corporation On-Reserve Program:

- Residential Rehabilitation Assistance Program for Persons with Disabilities
- Home Adaptations for Seniors Independence (HASI) Program

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- Ben Adaman, Director of Clinical Services, St. Amant

## Appendix D: Methods

### Methodology

A mixed qualitative methodology was employed, combining an Indigenous methodological research design, with a modified grounded theory method for organization of qualitative data. An Indigenous research methodology necessitates a modified grounded theory approach in order to allow for Indigenous epistemologies and theory to guide the research process and interpretations; an integrationist and inductive approach, enabling the integration of the researcher team's knowledge as well as past research on the subject area; pragmatic analysis that can provide space for practical recommendation on top of theory development; and interpretation of findings that are consistent with Indigenous perspectives (Kovach, 2011).

The study was also founded in the principles of community-based participatory research (CBPR). In utilizing a CBPR approach, community partners were equitably involved throughout the research process, drawing on their knowledge and experience, and sharing decision-making responsibilities throughout. While traditional research typically seeks to explore social structures, individual experiences, and relationships between phenomena, the overarching goals of CBPR is to “equalize power differences, build trust, and create a sense of ownership in an effort to bring about social justice and change.” This study also adhered to the ethical principles of Ownership, Control, Access and Possession (OCAP®), and TCPS-II, chapter 9. The principles of OCAP were designed to address issues of power imbalance

The research was independently led by FNHSSM, a First Nations organization tasked with coordinating regional health and social development initiatives for First Nations in Manitoba that are founded in the Treaty and inherent right to health and that are culturally appropriate, holistic, and community-based. Moreover, this study was guided by an Advisory Circle, consisting of FNHSSM researchers, First Nations community-based researchers external to FNHSSM, representatives from partner organizations that service Manitoba First Nations with disabilities, and health professionals (physiotherapists, occupational therapists) experienced in providing care to Manitoba First Nations with disabilities. Appendix C details the members of the study's Advisory Circle, who were selected for their experience in conducting research in this field and/or experience in clinical service provision to First Nations living with disabilities. The Advisory Circle was tasked with providing on-going guidance to the research process, inclusive of: determining methodology, development of participant interview guide, determining participant inclusion/exclusion criteria and the recruitment strategy, as well as with data analysis and interpretation.

### Sampling and Participants

Consistent with CBPR and OCAP principles, the research team with guidance from the Advisory Circle identified and invited/recruited key interviewees, established participant inclusion and exclusion criteria, and determined when an adequate sample was reached. A combination of purposeful and snowball sampling methods was utilized to recruit 32 participants. Some participants were members of the same family and participated in interviews alongside family members. A maximum variation approach was utilized to ensure a diversity of perspectives by age, gender, and in particular, regional participation via the five Manitoba First Nation cultural/linguistic groups (Anishinew, Cree, Dakota, Dene and Ojibway) (Patton, 1990). Recruitment occurred via service provider networks (e.g. through Jordan's Principle programs), word of mouth, online social media platforms (i.e. the FNHSSM's Facebook and Instagram pages, Tribal Council Facebook pages, and more), and advertisements on the Native Communications Inc. (NCI) FM radio station.

Moreover, this study sought to ensure representation of diverse perspectives and experiences of First Nations living with disabilities. Self-identified disability status included, but was not limited to, disabilities involving:

1. Seeing
2. Hearing
3. Mobility
4. Flexibility
5. Dexterity
6. Pain-related
7. Learning
8. Developmental
9. Mental health-related
10. Memory
11. Communication

Overall, the focus of sampling was placed less on size and generalizability, and more on sample adequacy so that depth and breadth of information and perspectives was achieved (Bowen, 2009). Consequently, this phase sought to recruit status First Nations youth, adults and Elders (aged 18 years and older); men, women, 2-spirited or gender diverse persons; traditional knowledge keepers and traditional healers; and those living in urban settings, rural, northern and remote communities with one or more self-identified disability. Potential participants were screened by the research team over the phone to ensure they met inclusion criteria and to determine if interpretative services would be needed for the interview. Recruitment continued until the research questions were sufficiently answered, as determined by the Advisory Circle.

#### Qualitative Methods and Data Collection

Interviews were conducted to elicit the lived-experience of First Nations adults with exceptionalities in Manitoba using a conversational method. Conversational method is a method that elicits “story, through conversation, as a culturally organic means to gather knowledge.” (Kovach, 2010, p. 42) This method is congruent with an Indigenous paradigm and Indigenous methodologies as it is inherently relational (Kovach, 2010; Wilson, 2001). According to Māori researcher Bishop (1999), the story and conversation approach can be dialogic and collaborative, where the researcher is positioned as participant and both parties become engaged in collaborative storytelling, contributing

to the building, and deepening of relationships. This approach is capable of incorporating decolonizing methods that break down the power hierarchy between researcher and participant and enable both parties to engage in examining their storied experiences in the context of life, culture, society, and institutions in ways that challenge dominant perspectives of wellness, disability, and health and social services. In accordance with CBPR and OCAP® principles, the Advisory Circle was engaged in developing an open-ended, non-directive interview guide (see Appendix E) that was used to prompt conversation and facilitate participant and researcher co-creation of knowledge. Interviews were conducted face-to-face where possible and preferable or otherwise over the phone or a video conferencing program across a three-month period, with additional time allocated to revisit questions and reach a reciprocal understanding.

Moreover, as part of this study, the research team presented the results to a panel of First Nations health and social service experts/professionals with many years of experience working in service provision on- and off-reserve as well as in health and social policy planning and implementation in First Nations contexts. Thus, recommendations from this report are informed by guidance from this panel.

#### Data Analysis

This study utilized a modified grounded theory approach for thematically organizing the qualitative data for analysis. Interviews were audio recorded if the participant gave consent; however, most declined to be recorded thus the interviewer took extensive field notes during the interview to attempt to document verbatim responses from participants where possible. Field notes were imported into the qualitative data analysis software Dedoose Version 8.1 (2018). These were then coded into core themes using the participants’ language wherever possible.

A draft thematic summary was generated and discussed with participants approximately 1 month following their interview to ensure validity and accuracy in understanding the participants’ responses and to enable participants to have another opportunity to add information that was not discussed in the initial interview. Moreover, draft recommendations were presented to participants to elicit their feedback and input, which was then incorporated into the final recommendations presented in this report. In addition, the research team provided draft recommendations to senior staff at St. Amant who provided feedback that was incorporated into the final report. Finally, the research team presented the results and recommendations to a panel of First Nations Knowledge Keepers, who provided additional input. We quote some of their wisdom throughout this report to support the recommendations presented.

#### Ethical Considerations

Ethical consent, project approval and permission to conduct this research was received from the Manitoba First Nations Health Research Information Governance Committee. Interview participants were given full disclosure of the nature and objectives of the research project, both verbally and in writing, and each was asked to give explicit free and informed consent to the interview. Participants were provided with an information package on the project, including an introduction and welcome cover page that introduced the researchers and community partners, the project, how participants were selected, what the data would be utilized for, and also indicated that participation is optional and confidential. Each participant was given the option to sign a consent form, or to indicate consent orally. Oral consent is recognized as a culturally appropriate alternative to written consent for research with Indigenous peoples (Canadian Institute of Health Research, 2013).

The safety, privacy, anonymity, and confidentiality of research participants was conserved and protected throughout this study. Interviews were completed in a discrete and confidential location to ensure participants were comfortable and to ensure confidentiality. When reporting participants’ experiences, direct quotations that may identify a participant were not used. Participants’ statements were reported using randomly assigned numbers to further protect the study participants’ anonymity. To ensure confidentiality, no identifying information from participants was attached to field notes. All interviewee digital information (email correspondence, audio recordings, and interview transcripts) was stored on a password-protected computer. Audio-recorded interviews were deleted once transcribed and

any printed documents and consent forms were safeguarded within a locked file cabinet at FNHSSM office. While traveling, all paper documents were stored and transported in a locked briefcase. Any documents that needed to be disposed at study-end were destroyed using ethics approved confidential shredding.

An anticipated risk of participation for the study participants was emotional distress during the interview process. In following CBPR principles, the Advisory Circle was consulted to determine appropriate, on-going support for participants who may have required it. Appendix F outlines participant consent documents and support information.

At the end of the data collection, a total of 21 interviews were conducted involving 32 participants. Approximately two-thirds of participants chose not to be audio recorded, and thus, as noted above, analysis was conducted on field notes taken during and after that interview.

*St. Amant is a not-for-profit organization that supports over 2,200 people (including First Nations) in Manitoba with developmental disabilities, autism and acquired brain injury.*



# Appendix E: Semi-structured Interview Guide

## Supporting the Gifts of First Nation Adults with Disabilities Research Study Interview for Adults with Disabilities

### Participant Profile

Survey Commenced: \_\_\_\_ Survey Ended: \_\_\_\_

a. Name:
b. First Nation:
c. DOB:
d. 9 Digit PHIN:
e. Mailing Address:
f. Telephone:
g. Email:
h. Disability Diagnosis:
i. Marital Status:
j. Caregiver Name and Relation (if applicable):
k. First Language:
l. How many people reside in your home:
m. What is your highest level of education?
n. What is your monthly income?
o. Do you receive or have difficulty receiving the Disability Tax Credit?
1. Do you have difficulties with any of the following while at home? <input type="checkbox"/> getting dressed <input type="checkbox"/> bathing <input type="checkbox"/> eating <input type="checkbox"/> moving around <input type="checkbox"/> getting in and out of bed <input type="checkbox"/> cleaning <input type="checkbox"/> taking medicine <input type="checkbox"/> preparing meals <input type="checkbox"/> housework <input type="checkbox"/> going outside to enjoy the outdoors <input type="checkbox"/> Other, please explain
Notes:
2. What challenges, if any, do you encounter outside your home? <input type="checkbox"/> being able to take care of yourself <input type="checkbox"/> having to ask other people for help <input type="checkbox"/> shopping <input type="checkbox"/> not being able to get out to take part in community life <input type="checkbox"/> not able to work <input type="checkbox"/> paying bills <input type="checkbox"/> receiving medical care <input type="checkbox"/> getting to medical appointments <input type="checkbox"/> getting medication <input type="checkbox"/> receiving medication education <input type="checkbox"/> socializing <input type="checkbox"/> going to community events <input type="checkbox"/> vision difficulties and need assistance <input type="checkbox"/> hearing difficulties and need assistance <input type="checkbox"/> social anxiety/mental health conditions/psychological/emotional
Notes:

3. When were you diagnosed/how long have you lived with this condition(s)?

4. What does having a good quality of life mean to you? Are you able to achieve this with your current living situation?

## Supporting the Gifts of First Nation Adults with Disabilities Research Study Interview for Adults with Disabilities

5. Do you feel that you are included in programs and services in your home community? Please explain.

6. What disability medical care, programs and services are you currently receiving?

7. Are there programs and services that you received previously that you found beneficial to your wellbeing? Please explain.

8. Can you access advocacy services to support your rights from within your community?

9. Is your home fully accessible to you and do you have the equipment you require on a daily basis? (i.e. ramp to the home, lifts, bathing chair, standing frame, visual aids, hearing devices etc.)

10. What activities do you take part in outside your home?

Interview for Adults with Disabilities

11. Do you have access to and participate in traditional/cultural/church activities in your home community? Please explain.

12. What supports do you need to live life more independently? (i.e. programs, equipment, services, medical care etc.)

13. In your home community, in your opinion what services are lacking for people with disabilities?

14. Do you have a positive patient/doctor/specialist relationship? Please explain.

15. Have you encountered racism or other forms of discrimination while seeking medical care? Please explain.

16. What are your goals, dreams and aspirations? How can an improvement in medical care, programs and services affect your life goals?

Interview for Adults with Disabilities

Notes:



## Appendix F: Participant Consent Documents & Support Information

### Supporting the Gifts of Adults with Disabilities Research Project Consent Form



#### Background

The First Nations Health and Social Secretariat of Manitoba (FNHSSM) was created in 2014 and functions under the direction of the FNHSSM Board of Directors (Manitoba First Nation Chiefs) and the FNHSSM Membership (Manitoba First Nations) to carry out business in the areas of health and social development that are founded in the treaty and inherent right to health that are culturally appropriate, holistic and community-based. FNHSSM has developed wellbeing measurement tools for on-reserve communities, which has the potential to be adapted for use in urban contexts.

The *Supporting the Gifts of Adults with Disabilities Project* is a research project inclusive of 5 language groups (Anishinew, Cree, Dakota, Dene, and Ojibway) working alongside 63 Manitoba First Nations to uncover the specific medical care challenges, gaps in services and lack of coordination that people living on-reserve face in seeking relevant programs and services. There may be instances where a survey participant has had to relocate off-reserve to be a closer proximity to necessary services that were not afforded/available to them on-reserve.

This study will also bring forward the individuals' strengths, aspirations and how programs and services can benefit access and improve their outcomes body, mind and spirit.

#### Who can participate?

Interviews will be conducted for:

- Current Jordan's Principle clients and families who will be aging out of care within 2-years;
- Individual adults living with a disability on-reserve; and,
- Caregivers of current Jordan's Principle clients or individual adults living with a disability.

#### Consent to Participate

Any data obtained will be kept strictly private and confidential. All identifying information such as name and date of birth will be replaced by a unique identifier in order to ensure confidentiality of the interview participants. Interview responses will be kept on a secure server to ensure the safe storage of personal information.

### Supporting the Gifts of Adults with Disabilities Research Project Consent Form



#### Adult Participant:

First Name: \_\_\_\_\_

Last Name: \_\_\_\_\_

I consent to participate in the study

Signature of Adult Participant: \_\_\_\_\_

Date: \_\_\_\_\_

If applicable, child under the age of 18 in my care who I give permission to participate in this study:

First Name: \_\_\_\_\_

Last Name: \_\_\_\_\_ DOB: \_\_\_\_\_

I consent for my child to participate in the study

Legal guardian signature: \_\_\_\_\_

#### For Internal Use:

Data Collector Name: \_\_\_\_\_

Date of Interview: \_\_\_\_\_

## Appendix G: Results

### Demographics of Participants

This study resulted in the collection of 21 interviews. Many of the interviews included more than one participant living with a disability in attendance, as well as their caregivers giving feedback which resulted in a sample of 32 participants. The age of participants ranged from 19 years old to 72 years old as of January 1st, 2023.

Participants had lived-experience with a number of different types of disabilities. Moreover, 14 participants reported living with multiple disabilities. The types of disabilities are as follows:

#### Developmental/Learning Disability

- Bi-Polar Disorder
- Autism Spectrum Disorder
- Attention-Deficit/Hyperactivity Disorder
- Attention-Deficit Disorder
- Fetal Alcohol Spectrum Disorder
- Dyslexia
- Developmental Delay
- Global Development Delay
- Psychiatric Schizophrenia with Delusional Disorder
- Oppositional Defiance Disorder
- Depression
- Trauma Induced Anxiety
- Post Traumatic Stress Disorder
- Social Anxiety Disorder

#### Physical

- Rheumatoid Arthritis
- Osteoarthritis
- (C4 and C5,6)
- Fusion Surgery of L5,6,7
- Spina Bifida
- Mobility Issues due to Amputation
- Mobility Issues due to Stroke Complications
- Various Other Mobility issues

#### Neurological

- Epilepsy
- Chronic Pain
- Seizure Disorder

Other disabilities due to chronic illness, congenital abnormalities, or hearing or vision deficits

- Horseshoe Kidney
- Diabetes
- Hydrocephalus
- Salla Disease

- Hypopituitarism
- Congenital Heart Disease
- Speech and Hearing Deficits
- Vision Deficits

Nine of the participants and families lived on-reserve and nine moved off-reserve including seven living in Winnipeg and two in Dauphin. Of the participants that lived on-reserve, three lived in Opaskwayak Cree Nation, 5 lived in Fisher River Cree Nation, three lived in Nisichawayasihk Cree Nation and one lived in Dakota Tipi First Nation. Of the participants that lived in Winnipeg, two were from Rolling River First Nation, two were from Fisher River First Nation; two were from Peguis First Nation, and one was from Lake-Cross Band of Indians.

### Themes

The findings are presented through three overarching and intertwining thematic areas that emerged out of analysis of the interview field notes. These themes centered around (1) the design, structure, and administration of federal government programs; (2) inadequate resources, services, and supports; and (3) failure to deliver culturally and stigma-safe services/supports to First Nation persons with disabilities on-reserve. Included in this section are examples and quotations that exemplify each theme. Table 1 summarizes themes, subthemes, and corresponding interviews.

Table 1: Themes, subthemes, and Corresponding Interviews

Themes	Subthemes	Interviews
Design, Structure, Delivery, and Administration	Failure to meet needs / inadequate resources / forced relocation	[2, 4, 6, 9, 10, 17, 19, 20]
	Insufficient support in existing on-reserve programs	[4, 5, 7, 8, 9, 11, 15, 19, 20, 21]
	Lack of service coordination	[1, 2, 4, 5, 6, 7, 11, 15, 17, 19]
	Challenging bureaucratic processes	[1, 2, 3, 5, 7, 11, 12, 13, 16, 19, 20, 21]
	Aging out	[1, 3, 6, 7, 12, 13, 15, 17]
Inadequate parallel resources	Lack of self-determination in care	[1, 2, 4, 5, 6, 7, 8, 11, 15, 17, 19, 21]
	Impact of jurisdictional issues on access	[1, 2, 6, 8, 14, 15, 17, 18, 19, 20, 21]
	Lack of mental health services	[1, 2, 8, 9, 14, 15, 18, 19, 20, 21]
	Lack of support for basic needs	[2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 18, 19, 20, 21]
	Lack of medical services in community	All participants
	Late diagnosis	[7, 16, 18, 20]
	Lack of necessary medical supplies	[3, 5, 6, 11, 15, 19]
	Lack of accessibility in community	[3, 4, 5, 7, 8, 9, 10, 15, 19]
	Lack of accessibility in home	[3, 5, 6, 8, 15]
	Overcrowding and substandard housing	[3, 4, 10, 14, 18]
Failure to deliver culturally-safe services/supports	Lack of supports for transportation	[2, 3, 5, 11, 12, 14, 15, 17, 18, 19]
	Lack of education opportunities and educational supports	All participants
	Lack of employment opportunities and supports	All participants
	Lack of caregiver supports	[3, 15, 17]
	Lack of respite care	[3, 15, 17]
	Prejudice, stigma and racism	All participants
	Medical professionals / pharmacists	All participants
Teachers	All participants	
Failure to consider Indigenous history, languages, worldviews, ways of being and knowing	Failure to consider Indigenous history, languages, worldviews, ways of being and knowing	All participants
	Failure to incorporate cultural activities	All participants





Figure 1: Sunburst chart of results, arranged according to theme frequency (number of interviewees citing a theme)

**Design, Structure, Delivery, and Administration**

The development, structure, delivery and administration of federal, on-reserve disability programs emerged as an important theme for almost all participants except two [14, 18]. Generally, participants highlighted how the ways in which federal, on-reserve programs are developed, structured, and administered forced them to relocate; created significant barriers to access such as the aging out process and challenging bureaucratic processes; contributed to lack of service coordination; and failed to uphold self-determination at the individual-level.

**Failure to Meet Needs / Inadequate Resources**

**Forced Relocation**  
 Participants often referred to how federal programs on-reserve have failed to adequately meet their needs, resulting in many families being forced to relocate off-reserve into major cities where sufficient supports may be more available. Unmet needs highlighted by participants primarily concerned access to basic medical services that are necessary to support the health of the person living with a disability as well as unmet needs concerning support for families in the form of respite care. Relocation to major cities means they could utilize more comprehensive provincial programs as well as have access to private services. In eight of the twenty-one interviews, families and individuals discussed how they were forced to relocate into the city due to the barriers they faced in society as people with exceptionalities [2, 4, 6, 9, 10, 17, 19, 20].

**Interviewee 6** and their family was forced to relocate off-reserve as there were no safe and healthy day-services available on-reserve. Having access to day-services that provided care for the Interviewee during business hours allowed both parents of the Interviewee to continue working, which allowed the family to maintain enough funds to support the family.

**Interviewee 17** moved back to Winnipeg a few months after he was born because there was not adequate access to medical services on-reserve. When interviewee 17 was more stable at age 5 the family tried to move back home to the reserve but eventually had to return to Winnipeg as it was too difficult due to the lack of services. Each time the family was cut off provincial services and they found that the community did not have the proper funding to support the interviewee’s needs. The caregiver stated in the interview: “Having anything that is disability specific services is lacking, what CLDS provides on the provincial side is not available on the federal.”

The caregiver of **Interviewee 17** also shared the stories of extended family members who had similar stories to them:

My cousin who was 2 years younger passed away couple years ago and was born with congenital heart disease and cerebral palsy. She was registered as Fisher River, but she could never live out there because of her needs. Up until the day she passed away she was never able to return home in her lifetime. She always yearned to be home. She spent her years away from her family, community and didn’t have the resources to visit home. Her cousin on the other side of the family had severe epilepsy, as he got older, he was moved into supported living. There are a lot of people with stories like ours off-reserve who never got the opportunity to go home. They didn’t choose to live away and were not able to go home.

**Interviewee 9** stated that if she had the ability to go home, she would. If she had the care she receives in the city she would immediately go home.

The truth is there is no home care service that you get on-reserve that you get in the city. That’s completely unfair as there’s dollars that are allocated for this. We need more services for people to be trained on-reserve – HCAs are who care for me in the city why can’t they do that on-reserve?

**Insufficient Support in Existing On-Reserve Programs**  
 Federal, on-reserve programs have also failed to meet needs of First Nations persons with disabilities by not allocating enough time for those who require continuing care on-

reserve through their Home and Community Care program and not offering adequate supports for those living on-reserve. For example, many noted how the program does not fund home care services in the evenings or on weekends, and because funding is limited, allocated hours for supporting people varies by available capacity and overall demand, with many not receiving enough support even within regular business hours. Out of the twenty-one families interviewed, ten of the participants specifically mentioned the lack of support from Home and Community care presenting a major issue [4, 5, 7, 8, 9, 11, 15, 19, 20, 21]. This created notable harms and impacted the quality of life of participants, with many citing how it impacted their personal hygiene, overall health status, daily living, and safety.

**Interviewee 5** stated that their disability requires them to have 24-hour care. This person is only allocated 4 hours per day for home and community care.

**Interviewee 8** has serious mobility issues and is wheelchair bound but is only approved for home and community care to come once a month. He finds it very difficult to get services, and because of this, he is only able to bathe once a week. He also requires foot care but this is not available in his community so he must travel one hour to the nearest city to receive this necessary service.

**Interviewee 15** “We have home care, but they don’t approve anything. They wanted us to sign up for home care – they don’t have flexibility to meet the needs i.e., start at 8:00 to help but they don’t open till 8:30. Had to sign up for home-care before getting OT/PT, I can come sweep your floor once a week, help bathe on Wednesday, but [participant] doesn’t want a stranger bathing her.”

### Lack of Service Coordination

Participants also noted how programs designed to assist those with disabilities are administered without sufficient coordination between them, despite often serving the same clients. This disconnect can often create duplication of services in some contexts and gaps in others. Another issue that arises from the lack of service coordination is the large discrepancy between what services are provided based on geographical location. This was particularly an issue when navigating jurisdictional boundaries between federal and provincial programs. For example, many noted how they did not understand why they would be ineligible for near by provincial programs just because they lived on-reserve or how being enrolled in one program made them ineligible for accessing other supports. Some noted how there were also significant incongruencies in program policies, eligibility criteria and more among federal and provincial programs that are purported to be equivalent. Programs for financial support (i.e. on-reserve Income Assistance versus provincial Employment and Income Assistance) were commonly cited as examples. Ten of the twenty-one participants cited issues that they encountered due to lack of services coordination [1, 2, 4, 5, 6, 7, 11, 15, 17, 19].

**Interviewee 1** experienced issues due to the lack of communication between Jordans Principle and the education systems on-reserve. He was labelled a troubled student and his psychological assessments appeared word for word copied and pasted from others. So he never was properly assessed according to the mother. Jordans Principle was ineffective in getting him classroom supports for his adapted education plan.

**Interviewee 6** had issues trying to get data from Manitoba First Nations Education Resource Centre (MFNERC) when clinicians didn't transfer files from MFNERC to their new clinicians. They expressed concerns that the MFNERC has data on every single community how many students are referred to therapy, how many were assessed, how many were discharged and that this program does not share its data with other institutions and is not accredited. The family of Interviewee 6 is concerned that there is very little data on what their communities' needs are and a lack of this data creates issues with accountability.

### Challenging Bureaucratic Processes

Participants frequently noted how the application process for accessing services is complex and challenging to navigate. For instance, barriers to accessing required information and documentation for one program can then create challenges with one's application to a different program. Moreover, issues can arise when a person with a mental disability is forced to be officially diagnosed to gain access to supports, but this diagnosis can in turn limit future opportunities. This can create hesitancy to accessing much needed programs for some. Of the twenty-one interviews, twelve experienced issues navigating the application process [1, 2, 3, 5, 7, 11, 12, 13, 16, 19, 20, 21].

**Interviewee 16** received forms for disability tax credit but hasn't received it because the process to receive a letter from a doctor to confirm the disability was daunting because he does not have a consistent family doctor.

**Interviewee 12** and Interviewee 13 also tried to apply for disability tax credit, but it was too difficult, when they tried to seek help in the application process, they were denied assistance in the application process.

**Interviewee 11** was diagnosed in 1980 with chronic pain but did not receive disability payments until 2000 because they fell through the cracks and didn't know what services were available to them.

**Interviewee 4** receives EI and child tax but has issues with accessing disability tax credit because she does not qualify for it when she is on social assistance.

**Interviewee 20** received the disability tax credit previously when she worked for the City of Winnipeg, but when she began to work for an indigenous organization, she was cut off because of the organizations tax free status.

**Interviewee 15** receives disability tax credit but when they applied for the caregivers benefit through the province, they did not receive it because they live on-reserve.

**Interviewee 4** stated: "JP and FNIHB is so complicated to deal with, I have to advocate for myself and my children and I feel sorry for them, I want something better for them so they don't have to advocate for themselves constantly. There needs to be a more case managed process"

**Interviewee 1** was offered the Disability Tax Credit through their speech pathologists but didn't claim it because his caregiver was scared it would follow Interviewee 1 into adulthood. The caregiver was worried that if her children wanted to get employment in the trucking industry or other employment they would be stigmatized once diagnosed. The caregiver to Interviewee 1 also worries about the stigma involved in receiving money for respite. All the caregivers' children are ADHD and she gets \$200 per month for respite "I don't want to get the children diagnosed and then people thinking I want the respite."

Another challenging bureaucratic process cited by many participants was the process of establishing a Power of Attorney. Sometimes due to the nature of a person's disability, it is necessary to grant a caregiver the Power of Attorney in order to make complex medical decisions. This allows the caregiver to be legally empowered to make decisions "on behalf" of the person living with a disability. The Province of Manitoba has an Office of the Vulnerable Persons' Commissioner that conducts preliminary investigations of applications for substitute decision makers. The process of transferring Power of Attorney is lengthy, complex, usually done through a lawyer located in the city, and can therefore be a significant barrier to timely access of services. It also impedes on the ability of multiple caregivers to be involved in supporting the individual, as almost all interactions with service providers of all kinds require the designated Power of Attorney's direct involvement. This can be a heavy burden for that individual. Of the twenty-one interviews, three discussed issues over Power of Attorney [3, 6, 15].

**Interviewee 3** has received Disability Tax Credit as a minor but has not applied as an adult this is due to his mother, having difficulty becoming power of attorney.

**Interviewee 6** had to go to legal aid in order to become the signing legal authority and is still waiting for the judge to approve their application.

The process of assigning a Power of Attorney for **Interviewee 15** took 3-4 years to complete. The process was complicated due to the Interviewee's grandmother being her Power of Attorney instead of her parents.

### Aging Out

Part of the rationale for implementing the Jordan's Principle-Child First Initiative was to support First Nations youth who lived on-reserve or who were forced to relocate to an urban setting for medical reasons. This

support was originally available to youth up to age 21, but in 2019 the eligibility age was changed to 18. Support has resulted in service improvements for youth, however; there is no transition program once one turns 18, which results in necessary supports abruptly ending. All study participants have chronic conditions, where issues are lifelong and, in some cases, become more serious over time. This abrupt end in service was noted as a major issue and participants often questioned the reasoning why services provided by the Jordan's Principle-Child First Initiative are halted at an arbitrary age. Of the twenty-one interviews, six participants had experience with Jordan's Principle supports and lost necessary services upon entering adulthood [1, 3, 6, 7, 15, 17]. Two of the interviews never received Jordan's Principle supports — even though they qualified for it — due to issues with the application process [12, 13].

**Interviewee 1** just aged out of Jordans Principle, and there was no transition process. The family stated that the services should not end as disabilities are usually for life. The Caregiver/mother to Interviewee 1 also mentioned that one of the issues with receiving Jordans Principle is that the children must be diagnosed and labelled which can hurt future work opportunities. For this reason, Caregiver/mother to Interviewee 1 has not enrolled her other children who are 13 and 10 years old who qualify for Jordans Principle. She does not want to hurt their future work prospects.

**Interviewee 3** at age 12 received Jordans Principle for 1-2 years. The family saw a huge improvement for both the Interviewee and the Interviewee's mother who was the primary caregiver. Jordans Principle gave the Interviewee healthy interaction with others and allowed him to attend the fitness centre which improved his fitness. This service was cut off once he aged out and his mother had to become full time caregiver again without any respite services.

**Interviewee 7** found that the services for Jordans Principle through St. Amant was beneficial, and that the therapist helped with anxiety and identifying anxiety triggers. Unfortunately, there was no warning that services were going to end once the Interviewee turned 18 and there was no attempt to transfer her file to a clinician for adults. Interviewee 7 also expressed that they did not understand why these services did not continue into adulthood.



**Interviewee 15** benefited from the Children's Rehab program where she had specialists to assist her. She also used the special needs activity program where she was able to use the pool in town that is equipped with a lift that allows her to swim which is an excellent strengthening activity. Now that she has aged out of Jordans Principle she no longer has access to these services.

**Interviewee 17** found that Jordans Principle helped in a variety of ways. It allowed access to a variety of programs and workshops that were geared towards Interviewee 17's sensory issues. These programs helped his mother/primary caregiver identify Interviewee 17's triggers which improved his behavior. The programs also helped the caregiver manage expectations when it came to Interviewee 17's abilities. Now that Interviewee 17 has aged out, he is no longer eligible for day programs, school-based programs, and supported employment programming.

**Interviewee 6** experienced issues with the Jordan's Principle program. Jordan's Principle programs assessed their home and identified improvements that had to be made to make it wheelchair accessible. Renovations were proposed for the stairs, hallway and the installation of a lift and accessible bathroom was recommended. During this process, Jordans Principle did not ensure their contractor was properly installing things which resulted in major plumbing issues in the house. The family found that the renovations caused more grief than the issues it was resolving. The family is also concerned that they have no idea where they are going to get Interviewee's next wheelchair once she has aged out of Jordans Principle.

**Interviewee 13** and Interviewee 12 tried to get on Jordans Principle in Winnipeg but were unable to access the program due to the complex application process.

#### **Lack of Self-Determination at the Individual-Level:**

Self-determination in care is important for a patient/client to have control over their life and to be satisfied with the services that they are getting. Participants noted how it should ultimately be up to them to decide whether to accept a suggested treatment or service, and that they to have more control over the type of treatment they are able to seek. Many noted how available services and supports in Canada are set up to focus on treatment of issues and symptom management instead of preventive care and

traditional supports and that resources and efforts are often paternalistically directed toward services and supports prioritized by those who are not recipients of the care. Many expressed how they felt that their wishes were not often taken into consideration at multiple levels including which services they should be personally accessing and how the system of services/supports is designed overall. Twelve of the twenty-one interviews discussed issues with their care where their wishes were not taken into consideration with the current system [1, 2, 4, 5, 6, 7, 8, 11, 15, 17, 19, 21].

**Interviewee 4** has expressed the desire to access traditional on the land supports but doesn't have access to them.

**Interviewee 11** has expressed concern that for pain management she is only supported for pharmaceutical options when she knows that she would benefit from massage and physio but does not have access to funds for non-pharmaceutical options.

Many also voiced a need for more creative solutions for those who require support in daily living but still wish to maintain independence and avoid living in a facility.

**Interviewee 5** would like to return to [Independent Living Housing Location/Program] or as similar instead of receiving Home Care services. They have stated that they lived life much more independently there and received much better care. Living in [Independent Living Housing Location/Program] also allowed Interviewee 5 to live closer to their kids, but they have been unsuccessful in moving back to [Independent Living Housing Location/Program] due to lack of availability. Currently Home and Community care has suggested Interviewee 5 move into a care home, but he doesn't want to go there because care homes are designed for the elderly and do not have services for people of his age and longer-term residence.

**Interviewee 7** wishes she could have an independent apartment beside her mother – she would have independence and practice her life skills but still be supported by mom.

#### **Inadequate Parallel Resources**

##### *Impact of Jurisdictional Issues on Access*

Due to the complex colonial structure of services for First Nation people, jurisdictional disputes are common between government departments regarding services available. Typically, the federal government is responsible for funding services on-reserve and the provincial government is responsible for services off-reserve. This system results in jurisdictional ambiguity and disputes over responsibility for services that leaves large gaps and delays in services and complications when obtaining supports. All the participants are impacted by jurisdictional issues or disputes between federal and provincial governments in some way, either directly or indirectly through the discrepancy of services and supports provided on- and off-reserve. Eleven of the twenty-one Interviewees specifically mentioned that jurisdictional issues had directly affected them [1, 2, 6, 8, 14, 15, 17, 18, 19, 20, 21].

**Interviewee 17** said "We have a Manitoba health card, why can't we get the services?"

**Interviewee 18** stated:

"Our community is seeing urban Jordans Principle and First Nation Jordans Principle and we are a community divided by a bridge and one of the things we spoke to Jordans Principle on our First Nation about is I had said I want to see more programming, take teachers into a workshop and teach them what ADHD is, teacher said problem is that some Jordans Principle recipients live in town side and they go to our school and we have some of our OCN members who go to town school so there is a mixture there and having a hard time defining it within our department, providing workshop but only to OCN or town and not being fair, hard time generating a program that helps everyone but stay within guidelines is not in another jurisdictional issue."

**Interviewee 6's** caregiver said that she was forced to live in town because she cannot access necessary services on-reserve. The Province states that services must be accessed through Treaty, and the Federal government states that they must access services through the province. The jurisdictional issues eventually delay services for so long that she would end up just getting tired of it and paying for it herself.

#### **Lack of Mental Health Care**

Participants with mental health-related disabilities discussed how their disability is an "invisible" illness and

thus very hard to diagnose and get treatment for. Of the twenty-one interviews conducted, ten involved participants with mental health-related disabilities [1, 2, 4, 10, 12, 13, 14, 16, 17, 18]. Moreover, several participants who did not have a disability related to mental health described their need for mental health supports [8, 9, 15, 19, 20, 21]. Many participants expressed how they felt that mental health-specific services are non-existent on-reserve. Participants discussed how they would see general practitioners to access medication for mental health concerns without any counselling services and in crisis situations, some would seek help from emergency departments. They expressed how this process was highly reactionary instead of preventative and felt that instead of getting the proper tools to manage, cope, and heal their mental health, they were forced to seek ways to alleviate crisis or temporarily treat symptoms on their own without support to address root causes of mental health concerns.

**Interviewee 2** stated that his general practitioner prescribes him medication for mental health, but no other services have been available. He further discussed how group activities, stable counselling and stable living environments are a necessary service that is lacking and that dealing with mental illness in an emergency room instead of providing stable housing or stable care with healthier options that's where it's lacking. He also speaks to the harm reduction programs that he has experienced.

Harm reduction is still a dangerous environment when it comes to substance abuse. Allowing potential predators/offenders to still do what they want to do. I have a hard time with that aspect of it. I understand they want to house people and put people in harm reduction, but it would be better to put us in environments that suit our mental health. I live with people who are mentally ill and don't use substances we'd be better suited in an environment where our mental health is addressed. They try to use harm reduction as a catch all thing. They need to do a better job of addressing populations within our categories and tailor to your individual needs. All I see them building is public restrooms by salvation army. Three railcars on top of each other. There's enough land there to build a social housing unit, but they are just building rest rooms for street people.

**Interviewee 1's caretaker** discussed how proper mental health supports will help with her son's self-esteem. She sees that being able to stay on task is important for his self worth: "He wants to learn but knows it's impossible for him."

**Interviewee 15** does not have a mental health related disability, but her caregiver discussed how mental health challenges are rarely talked about. She goes on to say that there are no tools to deal with the emotional part of living with a disability and that both patients and caregivers need to be given the tools to cope with these emotions.

#### Lack of Support for Basic Needs

Food and housing insecurity as well as poverty was a major issue for participants. Of the twenty-one interviews that were conducted, eighteen involved discussions around food insecurity [2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 18, 19, 20, 21]. Many of the participants talked about utilizing the food bank to meet their basic food needs. It was also noted by some that the experience of food insecurity can be especially damaging to those with diabetes or other special dietary needs that are linked to their disability. Many participants also spoke about their experiences living with housing insecurity or living in homes with poor conditions (i.e. overcrowded, in desperate need of repairs, no running water). The stress of not having basic needs met created dangerous situations for many participants both mentally and physically. Some have had to reach out to housing programs to secure housing.

When **Interviewee 2** was asked what having a good quality of life meant to him, he answered that it was to have enough money to survive and that he can not achieve this with current situation because he is living in poverty, in unsecure housing. He currently receives assistance with housing from Doorways and Stepping forward. Disability is not sufficient to live in a safe home or have food security. During the interview he stated: "My disability doesn't define me but there are inadequate services for me to thrive. It would be nice to live in a place that was safe, my stuff is at risk of being stolen everyday. This stress adds to my disability."

**Interviewee 4** answered that having a good quality of life means having a decent income, something she can live on and provide more food for my kids and things they need. She stated that after school programs are not even achievable for her family. Her home is currently lacking furniture and she has had to make layaway payments at Surplus to try to get furniture where she lives.

**Interviewee 10, 14, 16, and 18** all discussed their use of the foodbank. Interviewee 10 filled out a diabetic nutrition form

for the food bank but is concerned about getting enough healthy food.

**Interviewee 14 and 18** also raised concerns about the current state of their housing. Interviewee 18 mentioned that what she currently receives from the government is not enough even with relying on social services such as social assistance and food banks.

**Interviewee 19** also raised issues about food security stating that in order to make his budget work he must eat frozen dinners which is not healthy for his diabetes: "I'm in a no-win situation right now. I want fresh food in my house I can't get that with my budget that I have."

#### Lack of Medical Services in Community

All the participants experienced issues with lack of medical services in their communities [1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21]. As a result of this poor access to essential medical care, many described having to relocate, travel, or go without care at times. This poor access created notable harms for participants, causing distress. Many spoke about how failure to access care to intervene early resulted in exacerbated and/or worsened medical conditions, requiring more invasive or intensive care later.

**Interviewee 1** stated that up north they constantly have different doctors rotating in and out which can make consistent service hard. Interviewee 3 has struggled to find a family doctor as they do not want to take on his significant issues. Interviewee 16 goes to the health centre to receive medication and injections and every now and then a mental health therapist but does not have a regular doctor.

**Interviewees 8 and 19** have both identified their concern over their lack of doctor care. Both rarely see their doctors but are instead treated by nurses. Interviewee 19 stated: "I always see nurses. I want to see the doctor. I'm a patient at the Aboriginal Centre. I am promised to see a doctor, and when I get there it's usually a nurse and my doctor isn't even in the building. I complex needs that aren't being tended to effectively. It's been 1.5 years since I have seen a doctor face to face."

He on many occasions has had to wait for 8+ hours for care waiting to see a doctor.

For services beyond basic health care needs Interviewees 4 and 7 have both stated that there are no adult services in their communities.

**Interviewee 3's** caretaker says that he would benefit from Assisted living home on-reserve as he has been isolated socially and this would improve his circumstance. This is not available in their community

**Interviewee 20** wishes there was access to physiotherapy or occupational therapy, this would greatly benefit her mobility. Her rheumatoid arthritis could have been more managed with proper medical services. She stated that traveling to attain these services is also a large barrier:

When patients must travel for medical services it is a ridiculous experience. Wait times and travelling is a huge barrier. There should be a way to make medical transportation from the reserve to the city better. Riding an 8-hour bus to get to an appointment and then there are wait times for subsequent appointments. For medical results you are sometimes left waiting for an answer for 6 or more months.

#### Late Diagnosis

A notable consequence of the lack of access to assessments of needs in community was late diagnoses. Many participants discussed how they did not have access to the same physician across their care and that this created significant gaps and delays. They discussed how important and complex medical information was not shared across health service providers. They also spoke about how access to a physician was a challenge often due to nursing stations role as gatekeepers to telehealth physician services or medical transport to a city centre for emergent or specialty care. Another significant barrier that was noted was the lack of testing equipment for conditions. This results in patients being required to travel to get testing in order to receive diagnosis which can lead to a long and arduous process for many participants. All of these factors contributed to what participants perceived as a late diagnoses for issues related to their disability, some delays would amount to years and had significant negative impacts on wellbeing and quality of life. Of the twenty-one interviews, four involved mention of late diagnosis [7, 16, 18, 20].

It took 7 years to diagnose **Interviewee 7's** hypopituitarism that was caused due to a cyst on her pituitary gland. This diagnosis could have been found sooner but the doctor refused to do a CT scan because he did not believe she was experiencing her symptoms.

**Interviewee 16** had shown signs of Schizophrenia for two to three years before being diagnosed at age 17. His mother checked him into the Health Sciences Center where she had to advocate for him to get services. It was very hard to get diagnosed as the doctors didn't believe his symptoms and he felt like they thought he was making it up. He stayed at the hospital, did a CT scan and proper tests where they determined that he was chemically imbalanced. He was diagnosed with anxiety and depression at the same time.

Starting when she was 12 years old **Interviewee 20's** ankles, knees would get swollen. She would go to the nursing station, and they would tell her it was growing pains. This happened for a long time and finally after doing some bloodwork she was referred to a rheumatologist who eventually diagnosed her. It took a long time from start of the process to getting the diagnosis, Interviewee 20 estimates 8 years from when she first sought medical help for her condition.

**Interviewee 2** lived a long time with his conditions without diagnosis, He was diagnosed with depression at age 23, bi-polar at the age of 30 and schizophrenia at age 47.

**Interviewee 18** has never been officially diagnosed with FASD. She has recognized issues in her learning and behaviours but due to a lack of adult diagnostics is unable to be assessed or properly diagnosed. Family members have confirmed that she is probably living with FASD, she is trying to nurture the relationship with her mother to self disclose alcohol use during pregnancy, but she has not been forthcoming. Since Interviewee 18 is undiagnosed she is unable to receive specialized services. This is a definite gap as currently the only FASD adult diagnostics done in Manitoba is for incarcerated individuals who are in prison.

#### Lack of Necessary Medical Supplies

For many of the participants interviewed, medical supplies are expensive and a necessary expense for safe, everyday living. NIHB supplies prescriptions and over the counter medications as well as medical supplies and equipment but for many of the participants, the program does not supply all or enough medical supplies required. There is also significant delays in getting necessary items that results in the participant purchasing items themselves. Participants experienced that equipment repairs to medical equipment can take a very long time to fix with the current system. Of the twenty-one interviews, six mentioned issues with the lack of necessary medical supplies [3, 5, 6, 11, 15, 19].



**Interviewee 5's** wheelchair broke, and he was stuck in bed for six months while he waited for a new wheelchair.

Interviewee 5 says that NIHB supplies are lacking. He only gets 4 bottles of blue pads every 4 months, 4 drainage bags every 2 months, 1 box of gloves a month which is not nearly enough so he must supplement these supplies with his own funds.

**Interviewee 15's** primary caretaker was forced to get a part time job to pay for Tenas for Interviewee 15. They have a prescription for them so the Tenas should be covered by NIHB however through this system it takes a month to receive them and when they arrive the supply is inadequate to cover their needs. Sometimes the pharmacist loans her out of the kindness of her heart but it's not enough. They have found that NIHB is usually about 3-weeks behind.

**Interviewee 6** also has issues with NIHB supplying Tenas (incontinence product). The local pharmacy only gives the amount that the government approves. Tenas are \$26 a bag, and a bag only lasts a couple of days. A large chunk of Interviewee 6's money goes to the Tenas.

**Interviewee 3** had three blood hemorrhages by the time he was 3 years old. Mom checks his blood pressure with her own cuff and had to purchase a pulse meter at her own expense to monitor his blood because they were unable to get this equipment through NIHB. Interviewee 19 had to purchase mobility scooter with his own funds because he does not have access to an electric wheelchair. He also mentioned that sometimes he had to purchase his own medical health items because NIHB doesn't cover everything that he required.

**Interviewee 11** finds that pharmaceuticals covered by NIHB are easy to obtain, however prescribed cannabis THC or CBD is expensive and often unattainable. Interviewee 11 has found that medical cannabis is very impactful with her chronic pain. It turns extreme pain that feels like she's on fire, to a duller sensation. CBD oil under the tongue is most effective. Better control of the pain would allow me to have a healthy quality of life. Being able to get out and do more things, not be a prisoner of my home.

**Interviewee 18's** caregiver stated: My experience with these is challenging. Sure there is coverage there but sometimes you have to wait so long because they are so far behind and

you have to wait over a month to get them approved. Equipment we need needs their blessing before we get them. More pressure needs to be on them because I don't accept having to wait for 6 weeks for essential items. They have to be more realistic and our leadership should be putting pressure on them.

#### **Lack of Accessibility in Community**

Participants emphasized how accessibility is key to their ability to fully participate within their communities. They specifically spoke to accessibility measures they found important including wheelchair ramps, sidewalks, pathways, or roads that are paved and wide enough for a wheelchair, and accessible toilets in community gathering places. For many of the participants with physical disabilities, accessibility has proven to be a major barrier and has resulted in the person being unable to attend events or perform certain jobs. Of the twenty-one interviews, 15 involved discussions around mobility issues on-reserve due to disability and lack of accessibility in their community. For many, this impacted their quality of life greatly, contributing to a sense of social isolation and impeding their access to recreational and cultural/spiritual activities. Lack of accessibility in the community also impacted ability to access necessary care, as many local buildings to community-based programs or services including health centres, band offices, and recreational facilities do not have accessible ways to enter for those in a wheel chair or who cannot climb stairs. Nine interviews specifically involved discussions around issues of lack of accessibility within their community [3, 4, 5, 7, 8, 9, 10, 15, 19].

**Interviewee 15's** wheelchair is barely accessible in the clinic and cannot enter the patient room. The doctor as a result sees her in the hallway. The doctor provides good care, it's an infrastructure problem. The dentist office is also very challenging to access.

**Interviewee 8** stated that community infrastructure is lacking. He mentioned that in his community they hire youth to take care of the elders and that if it snows the elders are unable to leave their homes and the youth cannot get to them. **Interviewee 19** talked about the snow being a problem as well stating that:

"they should give amputees automatically electric wheelchairs. It is so hard to get around in the snow in the wheelchairs. We are isolated. If there is snow you can't go anywhere for at least 4 days. It takes sometimes longer to get sidewalks plowed. When it is plowed its not even passable in my wheelchair. Most of the time I make the path to the street, and this is difficult, and I get help to push me to the bus stop. To get where I need to go at my bus stop, I'm alone and in a more difficult situation because I don't have help. "

A challenge in the community is lack of accessibility for family gatherings.

For family gatherings and birthdays **Interviewee 5** sometimes has to get carried up, this doesn't make him feel bad because it makes him feel loved, but this should not be necessary.

**Interviewee 15** has faced similar issues stating: "There should be a program where families can get accessible ramps – we are close with our families, but we have no way to get in their houses. The only time we can go to family gatherings is in the summer as we sit outside but get eaten by mosquitos."

#### **Lack of Accessibility in Home**

Several participants with mobility issues noted that their homes required modifications to become fully accessible for them. Such modifications were notably pretty major, requiring extensive renovations to, for example, widen door ways to fit wheelchairs or install accessible shower or bathing features. Lack of accessibility within the home had a considerable negative impact on participants' daily living activities which also meant detriments to their health and quality of life. Of the twenty-one interviews, five talked about issues with accessibility in their homes [3, 5, 6, 8, 15].

For **Interviewee 15**, the size of the home is wheelchair accessible, but she received a wheelchair that is too wide for the home, so she must scoot everywhere. Her quality of life is impacted due to her grandma's small home. She does not have access to the bathroom, so she hasn't bathed in 2 years. She sponge bathes everyday and must poop on a pad in her room.

**Interviewee 8's** bathtub is not accessible as it needs ramp to the water and specialized safety equipment such as a cane.

**Interviewee 6** is in the process of getting an elevator lift but it's not yet complete.

**Interviewee 3** has a younger sister who needs a wheelchair accessible house. The home does not have any bedrooms that are wheelchair accessible but have been unable to make arrangements for this.

#### **Overcrowding and Substandard Housing**

Overcrowding was highlighted as a major problem for participants living on-reserve. Substandard housing conditions discussed by participants included moisture build up and mould contamination, poor construction of houses not suited for local conditions, inappropriate layouts to support those with disabilities (i.e. narrow hallways, stairs to entryways, etc.), and more. This can lead to poorer health and conditions that are not suited to the person living with disabilities needs. Of the twenty-one people interviewed, five discussed overcrowding as a significant issue [3, 4, 10, 14, 18].

**Interviewee 3** sleeps in basement. He lives in a 3-bedroom home where there are 8 people living. As an adult he should qualify for own independent living.

#### **Lack of Supports for Transportation**

Transportation creates a serious barrier for the participants. Lack of transportation has caused issues that range from feelings of isolation to not being able to obtain necessities or attend medical appointments. Out of the twenty-one interviews conducted, ten cited issues from lack of supports for transportation [2, 3, 5, 11, 12, 14, 15, 17, 18, 19].

**Interviewee 2** requires a subsidized bus pass or means for transportation. This is not available, so it makes it difficult to take part in activities outside of his home. Interviewee 11 feels isolated due to mobility issues and the lack of access to transportation. NIHB formularies only offers transportation during business hours which is not adequate to support needs. Interviewee 12 is unable to drive while he is awaiting surgery on his driving leg which creates transportation issues.

Transportation to medical appointments is a huge barrier for **Interviewee 3**. Interviewee 3's caretaker noticed while she was sitting outside of the hospital, she could see the vans from Fisher River that were there to transport people from their reserve. Her band does not supply travel cheques, so she had to pay for a taxi out of pocket.

**Interviewee 15** requires transportation that can accommodate a wheelchair. During her school experience there was no wheelchair bus, so the family utilized the medical transport which was hinderance on that program. On days when Interviewee 15 was attending an after-school program, she would have to wait for the bus drivers to finish their run before getting a ride home. Her primary caregiver is 66 and can no longer help Interviewee 15 to the vehicle without assistance anymore. During one incident, the handy van took her to a funeral reception, but she had to find her own ride back.

#### **Lack of Education Opportunities and Educational Supports**

Many of the participants learning about disabilities require educational supports to effectively learn in a classroom environment. Those we interviewed with mobility issues, in the past, also had difficulty accessing educational opportunities due to lack of accessibility in classrooms and learning environments. We were told that schools are now equipped for visible disabilities i.e. wheelchair ramps, accessible washrooms, desks, wider doorways etc. however children with invisible disabilities needs can be forgotten. Often times someone diagnosed with FASD, ADHD, anxiety, PTSD as an example, benefit from a stimuli free environment. Yet we were told by participants that if you go to any classroom in any school and there are bright colours, fluorescent lights, posters and art work on the walls, disorganized work spaces - that can be overwhelming to an individual and result in their inability to adapt to the learning environment.

Most of our participants discussed in the interviews their motivation to learn but they lacked the resources that would effectively allow them to succeed in a classroom environment. Many also did not have access to education opportunities due to lack of availability in their communities. All participants in the interviews had experienced barriers to learning through the lack of education opportunities and supports.

The caregivers to **Interviewee 6** said that those with special needs should have an option to continue their learning. They stated: "There's no reasons why just because they have exceptionalities, they don't deserve their schooling, [Interviewee 6] loves to be in society and work. She needs people. People need her."

**Interviewee 1's caregiver** is a strong advocate for the school experience:

**[Interviewee 1]** has common sense and he wants to learn and go to school and go to work. It's impossible for him, he knows he cannot sit in a classroom and learn. Everything stems from education. Jordans Principle didn't offer speech pathology to him during the 1-year he was in that program. The EAs are not trained to help people with a disability. With the right tools my kids can be contributing members of this community. They're lucky to have me at home to teach them common sense and instill in them right and wrong.

When the caregiver to **Interviewee 1** was asked what services were lacking for people with disabilities in her home community, she responded:

How to educate the teachers to benefit the students. From **[Interviewee 1]'s** file they'd want him to be placed in a resource/intellectual room, but he can learn. The school segregating the "difficult" children negatively impacts their self-esteem. Her son has been beaten down through the years. Mom spends a lot of time educating the teachers. Mom refuses to hinder children's career paths with the label of disabled. Through school they didn't get the proper tools.

**Interviewee 2** wants to be an Ojibway language interpreter and help his people. To do this effectively he must finish his schooling at Red River College. This has been difficult with no financial means. Interviewee 2 stated: "My disability doesn't define me but there are inadequate services for me to thrive."

Educational opportunities and educational supports are directly linked to future job prospects and in turn the person's ability to provide for themselves in the future.

#### **Lack of Employment Opportunities and Supports**

Like education opportunities and supports, many of our participants require job supports to effectively work. In some cases the accommodations that would be required are straight forward to implement, but the resources aren't available to accommodate them. Most of our participants discussed in the interviews their motivation to work but they lacked the resources that would effectively allow them to find and keep employment. All participants in the interviews had experienced barriers to working through the lack of training opportunities and supports as well as lack of job opportunities and supports.

**Interviewee 2, 6, 10, 15, 16, 17** have all expressed a desire to work but are unable to work without supports in the workplace that are unavailable in their communities.

**Interviewee 7** lost her job because of complications that occurred due to her disability. When the first COVID-19 case was recorded in Winnipeg, she took a month off work on stress leave and was reconsidering her career because of her health. Interviewee 7 also had specialist appointments in Winnipeg which required her to isolate for 48 hours. All of this resulted in her missing a lot of work. Interviewee 7 was called into a meeting to discuss all her missed work, and this caused her to have an anxiety attack over the stress of the situation. She was mistreated due to her uncontrollable absences from work and is now filing a human rights complaint. Working is very important to Interviewee 7, but she needs a supportive environment that can help her thrive in her role.

**Interviewee 18** could use a case manager/advocate, someone checking in periodically and to work on her goals. It's difficult to self-manage the household in her current situation, Interviewee 18 is open to an advocate assisting her. She would like to have increased employability and social opportunities to not be so isolated at home.

**Interviewee 19** has not been able to find employment due to his disability. Before he had his legs amputated, he worked at a job that required him to drive. Since he lost his drivers licence, he has not been able to secure new work because there is a lack of supports for him in his community.

#### **Lack of Caregiver Supports**

##### *Lack of Respite Care*

Many of the caregivers that were interviewed stated that respite care is necessary for the health and wellness of both the caregiver and the participant. Lack of respite care has resulted in many of the caregivers being unable to work, as

the person they are caring for requires 24/hour supervision. Many participants have found that the cost of respite care is more than what the caretaker would make at their job, and the level of care and when they do find respite care, the service that the participant receives, is not to the level that the participant needs. Some of the interviews stated that the lack of respite care also had serious consequences for the entire family. This is because when the caregiver is unable to work, they are forced to rely on government programs to support them which does not provide enough support to cover basic needs for the family. Out of the twenty-one interviews, three mentioned the consequences that arose out of the lack of respite care [3, 15, 17].

**Interviewee 15's** primary caregiver doesn't have a steady alternate caregiver and cannot leave Interviewee 15 alone for the entire day. The primary caregiver had to get a job to support the family and is now working half days. Finding someone to watch over Interviewee 15 is both difficult to arrange and must be paid for out of the money for the part time job. There is zero care for adults and this family is in desperate need of respite

The mother and primary caregiver of **Interviewee 3** has had to be on welfare for her whole life because her son requires around the clock care and cannot be left unattended. In the interview she stated: "Who would take care of my sick baby if it wasn't for me."

**Interviewee 17** received respite services off-reserve, and it has been beneficial, but these services were never accessible on-reserve. One of the issues is that this respite care available off-reserve is only available Monday to Friday during business hours. This is helpful however the system is relying on family as caregivers to care for loved ones outside of business hours and not everyone has this type of family support.

#### **Failure to Deliver Culturally-Safe Services/Supports**

##### *Prejudice, Stigma and Racism from Medical Professionals/ Pharmacists*

Every person interviewed in this study has encountered some form of racism from doctors, nurses, pharmacists and other medical support workers at the hospital or nursing stations. Many also reported good relationships with medical professionals which shows that work has been done for cultural safety training, but the negative encounters show that there is still a lot of work to be done to address racism in the medical field. Participants found that when they experienced prejudice, stigma and racism, it resulted in poor patient care, late diagnosis and mistrust of the system which leads to poor medical outcomes.



**Interviewee 3's** caregiver stated that racism in the system has been shown by the lack of care that the medical field has shown her son. The caregiver had to learn the patterns of Interviewee 3's seizures through trial and error and was finally able to find a pattern at age 16. "Has to be well fed, well slept, not hot or cold, not hungry, or else it would trigger a seizure". There was no assistance or guidance from the medical professionals on how to manage Interviewee 3's seizures. Interviewee 7's late diagnosis despite her mothers' pleas for a subsequent CT scan is a blatant example of prejudice.

**Interviewee 17** stated "the pediatrician has been stereotypical/racist at times and maybe some of his behaviors are chalked up to our culture." Drug pushing from pediatrician instead of trying to manage care plan he would be prescribed – he almost passed away twice due to medications. Interviewee 8 has experienced racism from his pharmacists stating: "some of them ask and act like we are abusing drugs."

At times the Interviewees have felt judged by their doctors. **Interviewee 10's** doctor of 20 years left her on the backburner after he found out she had a former addiction. "He didn't care. I was coming off an addiction and he gave me a 7-day prescription despite the fact that I was asking for referrals and help" She didn't want to be on pills and the doctor didn't show any empathy towards the situation.

**Interviewee 18** feels shunned from seeking medical care at times. She feels judged and shamed because her son lives with FASD. It was very brave for her to admit alcohol use during pregnancy with all the stigma. Unfortunately, some care providers still provide judgemental care that is a barrier to accessing services.

There are many stories of racism being experienced in the emergency rooms of hospitals. **Interviewee 11** experienced racism at the St. Boniface emergency room several times. In one incident she was sick and throwing up for over 24hrs couldn't keep her medication down, she was in massive pain and was not treated well: "They treated her like she was seeking drugs and an addict."

**Interviewee 20** broke her arm, and her husband took her to the emergency room. The doctor there was rude and treated her husband like it was his fault that her arm was broken. The doctor spoke to Interviewee 20 and her husband wasn't

giving them quality compassionate care.

**Interviewee 10** was coming off crack cocaine and the emergency room doctor said to her "this isn't a place for you to come to sleep". It was winter and she almost fell asleep in the snowbank outside of the hospital. Her withdrawal from the drug and the way that the doctor made her feel she didn't feel welcome. "This deterred me. It hurt my integrity when I went to go and ask for help and I was looked at like I was rubbish. My kid's dad let me in at that time. Went to a shelter in Winkler and picked myself up."

In the Emergency room November 2019 at HSC a nurse was racist to **Interviewee 7's** while trying to use the washroom. In January 2018 at Percy E Moore the doctor put her into shock by cauterizing her thumb 3 times and was not sensitive.

Racism has also been experienced by our Interviewees once admitted into hospitals. After **Interviewee 4** had her last daughter, while she was at the hospital, she received a lot of negativity and felt that she was being questioned on being capable of watching kids because of her disability. When she had her gallbladder removed, she was treated horribly and never wanted to go back to the hospital. When she was leaving the hospital, she tried to get pain medication and she was treated like a drug addict by the doctor. She filled out a form to report this incident. In her experience she has experienced more prejudice at St. Boniface as opposed to the Woman's Hospital.

**Interviewee 5** had issues with nurses being rough with him. "They'd complain about having 15 other patients meanwhile he was sweating and suffering dizzy spells. The night nurses were mean."

#### Prejudice, Stigma and Racism from Teachers

Teachers have had a significant, lifelong impact on the participants coping skills, problem solving skills, and countless other life skills. Every person who we interviewed had experienced some form of racism in the school system or from teachers in their lives which has created lasting damage to our participants in both their self worth and future employability prospects.

One of the most impactful stories of racism that was mentioned in our interviews was from Interviewee 1. When **Interviewee 1** was in grade 7 he came home one day and asked his mother if he was stupid. His mother reassured him that he has a learning disability but is not stupid. Interviewee 1 then proceeded to tell his mother an interaction that he had with his teacher that day, his grade 7 teacher folded her arms and told him "I can't wait till you're out on the streets with the bums like the others."

**Interviewee 1's** mom emailed the teacher, the education director, principals directors and received no response. His mom then took him to a counsellor in town. The counsellor confirmed her son was verbally abused. They emailed the school again and received no response.

They then elevated the issue to a complaint to the Canadian Human Rights Commission completing a big essay and submitting it. His mother still doubts that anything will happen. They still have had no response from the school. At a community meeting for education **Interviewee 1's** mother stood up on the mic and asked the committee how they deal with teachers bullying students and presented all the emails that she had sent to the school. At this point the school tried to buy her and wanted to rectify the issue.

**Interviewee 1's** mother stated in the interview: "There have never been resources in the school. The assessments of her sons appear to be copied and pasted by the psychologists at KIM. Before JP was taking all assessments to the school, teachers wouldn't even read the file."

#### Failure to Consider Indigenous History, Languages, Worldviews, Ways of Being and Knowing.

According to participants, many of the healthcare workers and program designers who create disability programs come from a western, colonial background and do not take into consideration the unique history, languages, worldviews, ways of being and knowing in Indigenous communities. This has created a disconnect between the people running the programs and the people using the services. All participants have been affected by this disconnect in one way or another during the process of utilizing these services.

**Interviewee 9** stated in her interview:

"I remember going to [disability service support provider] early years in my disability sitting there with a white person was like talking to a stone. They didn't know who I am, didn't know me as being native or how to talk to me. Foreign. How

many times I thought I wish they had a native working for [disability service support provider]. White people don't understand our ways. When we want to congregate together let us, you took everything else away, let us love one another. That's the way I feel. We need more people who speak the languages, Cree, Sioux, Ojibway."

**Interviewee 6's** father discussed how in his culture, people living with disabilities are closest to the creator. They can see spirits. They are interim. They are pure. They are angels. If you look at Norway House the term defined in Cree is precious. People first. He believes that Interviewee 6 is a gift brought here and that they were chosen.

**Interviewee 10** believes the medical system needs more information sessions to ensure that health care providers are knowledgeable, have more empathy, and understand the health issues of her community.

**Interviewee 4:** 3rd generation survivor of IRS, Single parent who survived domestic violence, raising two children who are diagnosed with ADHD. Suffered childhood bullying and as a result had a very low self esteem.

#### Failure to Incorporate Cultural Activities

According to participants, the current medical system does not take into account indigenous peoples ways of knowing or conceptions of wellness. For many of the participants, traditional and cultural activities are linked to wellness and are essential to live a good life. According to the interviews, the current system doesn't incorporate these activities in health care planning and does not provide supports that would allow people to access these services on their own. All participants have been affected by the lack of access to traditional/cultural activities which leads to a disconnect from community, family, identity, the land, and spirituality.

The current healthcare system is rooted in colonial conceptions of wellness.

**Interviewee 2** said there were Programs in Toronto urban sweat lodges, men's groups, and drumming groups. Not many opportunities here in Winnipeg.

**Interviewee 7** wishes she could participate in traditional/cultural activities in her home community. Attends Zoom meetings for church and attended a sweat where she received her name (Swimming Turtle Woman). Cultural activities are not available, they have tried accessing but couldn't.

**Interviewee 8** discusses the need for Elder gatherings available:

“They need to use our ceremonial people especially at the medicine lodge and programs. They have an Elder from Cross Lake come for teachings, but our community has different teachings. My father used to follow moose in springtime and now we don’t practice some of the teachings anymore. Most of the rocks are gone because of sweats. Sometimes we must get rocks from the water, but you’re not supposed to.”

**Interviewee 8’s** father was a storyteller, but he didn’t give tobacco, so he doesn’t remember all the stories.

**Interviewee 11** is not able to leave home or travel more than 2 hours by car without being in critical pain, a lot of things I miss because of my back pain – holidays and family gatherings, cultural events – pow wows, sweats. She has no funds to attend and there are no cultural activities that take place within a 2-hour radius.

**Interviewee 15** would love to participate in community life. She used to attend the sweat lodges but was a challenge to get her out there. She’s gone to Sundance’s outside of the community.

**Interviewee 17** was able to have access to cultural activities through the school in Peguis, however, these opportunities were limited because he needed additional support that he didn’t always have. Access to land-based activities he would have needed someone to shadow him and work with him.

**Interviewee 18** wishes there were more traditional opportunities. She is interested in sweats, ceremonies, and learning crafts but has not had access living off-reserve. She occasionally gets the opportunity to see an Elder at the friendship centre.

**Interviewee 19** stated that he has no access whatsoever to traditional activities. He would like to go to the Peguis pow wow and other events but can never get a ride from Winnipeg and has no access to other, closer traditional activities.

**Interviewee 5** wishes there were accessible traditional/ cultural activities in the community, if he had the opportunity to go to the bush or camp, he would go.

### **Ceremony Accommodations for People Living with Disabilities**

To get a perspective on ceremony accommodations for people living with disabilities, we conducted an interview with David and Sheryl Blacksmith. David Blacksmith is an Elder from Pimicikamak Cree Nation in Manitoba Canada. The Blacksmith Sundance accommodates all individuals, whether they are living with a visible or invisible disability. The Knowledge Keepers recognize that ‘disabled’ is a non-First Nation term that is used to label individuals and can impose a limit on their abilities. All children are gifts from the Creator, we don’t label anyone, and our children are perfectly designed when they arrive on Mother Earth. All participants privacy and confidentiality are adhered to by the ceremony family.

The Blacksmiths are open to all disabilities however that’s not how it is in other circles: “We always seek out professional help for the most respect for the individual. We’ve had amputees, they participate fully even chopping wood. People are dealt with fairly and equally. We accommodate people to be comfortable in the lodge and that they feel welcome.”

### **Hearing Impairment**

During a recent Sundance ceremony, David recognized that there were 3 hearing impaired/deaf dancers in attendance. The caregiver/mother assisted with interpretation in American Sign Language (ASL) and translated all the lodge teachings. Since then, David and Sheryl are learning how to communicate in ASL and hire interpreters when needed to better accommodate the deaf community.

### **Vision Impairment**

Blind Sundancer’s participate in ceremony with helpful intervention by David or an assigned helper. An individual with vision loss can participate fully in all aspects of the ceremony. An example of a modification made by the Elders is to place a stick perpendicular in the group between the individual and a tree that is used as a marker. The individual can use the stick and the tree to determine which way to face i.e., east or west in their prayers and dancing. The vision impaired dancers appreciate being able to self-guide their direction with the use of this simple modification.

### **Mental Health Concerns**

Individuals with mental health concerns may require different accommodations within a ceremony context. In ceremony not everyone understands the unique needs of a person living with an invisible disability. The Blacksmith family maintains a proactive approach to prevent episodes during ceremony. They assign helpers for people who need assistance such as a nurse to maintain the medication needs; a mental health therapist to observe for psychosis and other helpers utilized in the past include physicians, psychologists and other professionals. David Blacksmith stated:

“If an individual can be hungry, can be thirsty and can pray – by all means they can participate in ceremony. Our ceremony family is happy to make modifications to improve access for all.”

### **Accessibility**

Wheelchair accessibility can be difficult in the lodge – typically an individual and their caregivers help the person get to a certain point inside and ceremony helpers assist with bringing their chair or device further. When the dancers dance, all are invited to participate in their own way – differences are celebrated whether they be able to only move their hands or their feet. Recently a Sundancer who is paralyzed from the waist down was pierced in the same manner as other volunteers but when it came to hang from the tree the ceremony family made safety modifications by placing his wheelchair beneath him as a safety guard if his piercings broke. This young man, otherwise healthy, insisted on not being treated differently from other Sundancers, when it came to drag the buffalo skull, he dragged the skull – he wouldn’t take no for an answer, so the Blacksmiths adapted to ensure his needs were met.



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