

DISABILITY RESEARCH PROJECT 2018-19 FINAL REPORT



March 2019

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Partners and Collaborators

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Project Funder

This research was funded by the *Disabilities Initiative* of Indigenous Services Canada (ISC, formerly Indigenous and Northern Affairs Canada). The opinions, interpretations, and recommendations put forth in this report do not necessarily represent those of the Government of Canada or ISC.

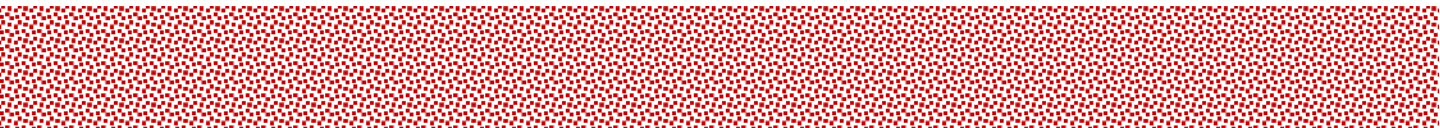
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EXECUTIVE SUMMARY

The Disability Research Partnership is a yearlong community-based research project funded through the *Disabilities Initiative* of the Department of Indigenous Services Canada (DISC) and undertaken as partnerships between Saskatchewan First Nations Family and Community Institute (SFNFCI) and self-selected First Nations child and family service (FNCFS) agencies. The 2018-19 project involved two agencies: QBOW Child and Family Services and Nechapanuk Centre Child and Family Services.

The goals of the project are to:

- Engage First Nations Child and Family Services in the research project
- Utilize culturally relevant practices and resources to engage stakeholders
- Learn more about the ways in which disability is defined and conceptualized in distinct communities
- Better understand service availability, gaps, and needs
- Explore means of integrating or adapting the developed tool with FNCFS agency data information systems and practices
- Have information shared in ways that respect the OCAP principles

Information was collected through multiple methods informed by SFNFCI's Indigenous Research Paradigm and Disability Concept Model: a Disability Information Tool (DIT), focus groups, and one-on-one interviews. Statistical and thematic analyses are presented along with information on the actions resulting from stakeholder engagement.

The conclusions of the project highlight the need for building a stronger continuum of care for families and children/youth with special needs. The core recommendation is that agencies focus on programming, partnerships, and capacity building before, during, and after a child comes into care.



PROJECT

Funder

The Disability Research Partnership is part of a series of yearlong community-based research projects which began in 2016/17. These projects are funded through the *Disabilities Initiative* of the Department of Indigenous Services Canada (DISC) and undertaken as partnerships between Saskatchewan First Nations Family and Community Institute (SFNFCI) and self-selected First Nations child and family service (FNCFS) agencies. This initiative provides funding for projects and activities that increase awareness of disability issues and available supports; and/or improve the coordination and accessibility to these programs and supports among individuals with disabilities living on reserve.

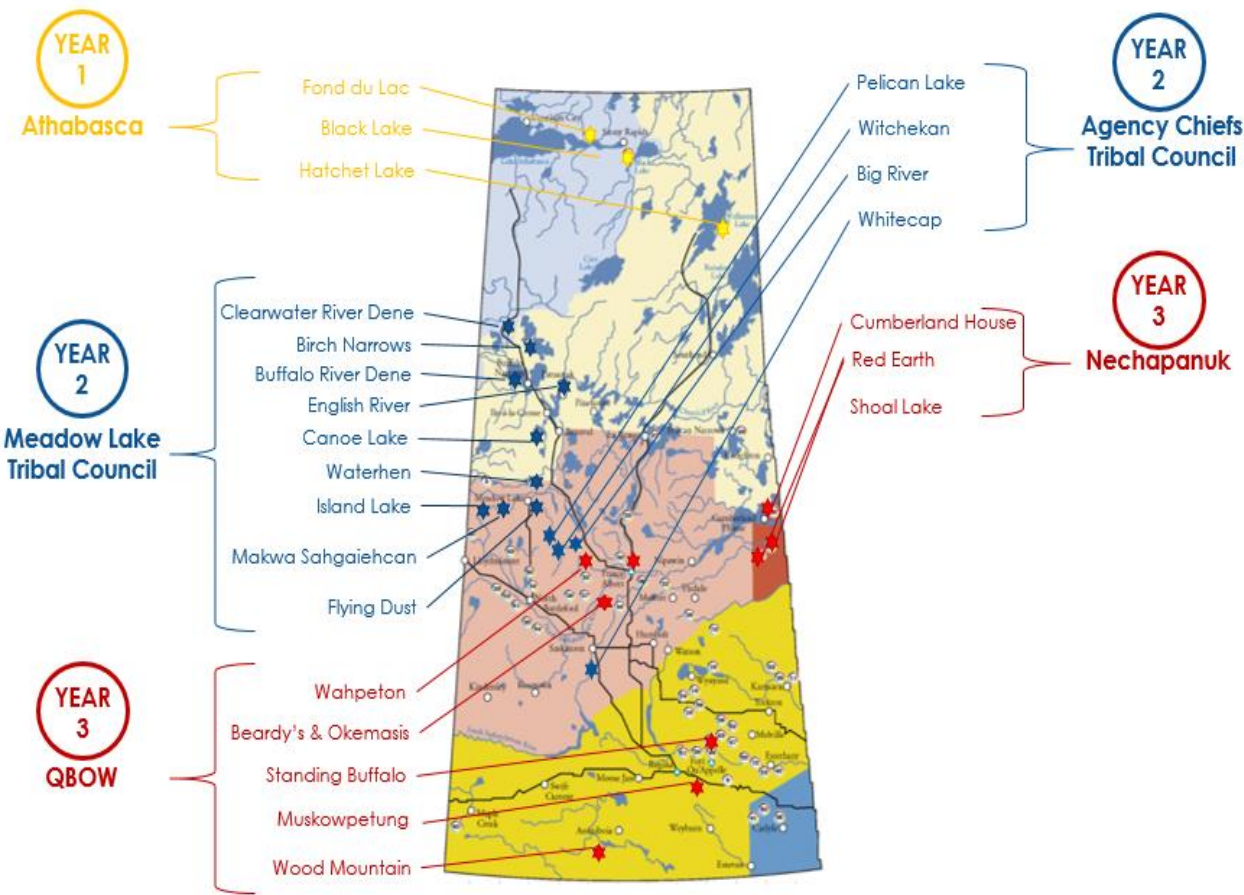
SFNFCI

SFNFCI is a non-profit organization located in Saskatoon, SK that offers research, policy development, training and supports to First Nations child welfare organizations across the province. Its mission is to *build capacity within organizations serving children, youth and families based on First Nation values*. In keeping with this mission, SFNFCI coordinates the disability project in partnership with self-selected FNCFS agencies, working together in ways which meaningfully engage agency staff and stakeholders, providing opportunities for knowledge and skills development.

Past Projects & Research History

As mentioned above, SFNFCI has been engaged in disability research since 2016, with this current project being the third Disability Partnership Project completed to date.

The diagrams below provide an overview of these projects – providing information on the numbers of agencies and communities engaged, as well as the data collection methods completed.



When taken as a whole, the work SFNFCI and its agency partners have done in the Disability Project over the years has been inspired and shaped by several larger contextual factors.

The first of these is the over representation of First Nations children and youth in the child welfare system. This over-representations is a major challenge at both the provincial and federal level (Kirmayer, Sheiner, & Geoffroy, 2016; Fallon et al., 2015; Barker, Alred, & Kerr, 2014). As of 2011, only 0.3 percent among non-First Nations children 14 years or younger were in foster care in Canada, whereas that percent jumped to 3.6 for First Nations children (Statistics Canada, 2013). This is particularly troubling given that, in 2011, Aboriginal children of this age represent 7% of all children in Canada, yet account for 48% of all foster children in the country (Statistics Canada, 2016).

A second important background fact shaping our work is that children/youth with disabilities are more likely to experience neglect and abuse. Substantial research shows that the risk of being maltreated is much greater for children with special needs. Jones and colleagues report that the risk is 4.3 times greater among children with intellectual disabilities than among children without any disability (Jones et al., 2012)). This fact is even more relevant to the work being done here given that studies have noted an “overrepresentation of children with ID involved with child protection agencies for all cases of child maltreatment” (Dion et al., 2018, p. 183). Others have made similar findings, identifying childhood maltreatment as an important issue for children and youth with disabilities (Sullivan & Knutson, 2000; Wissink et al., 2015).

One final broad factor inspiring this research is the lack of specific, reliable data on prevalence rates, functional impacts, and other key information related to disabilities among Indigenous communities in Saskatchewan, but also in Canada and around the world. The First Nations Regional Health Survey (FNRHS, or RHS for short) is the only First Nations-governed, national health

survey in Canada. It has been noted that “with the exception of the 2002/3 RHS, which provides some discussion on the prevalence of disabilities among Canada’s First Nation population, few data exist for other groups of Aboriginal people” (National Collaborating Centre for Aboriginal Health, 2012, p. 23). While various disparities in terms of the health of Canada’s First Nations are well documented, very little comprehensive information is available on Indigenous children and youth with disabilities. This lack of information is even more glaring for children and youth in care with disabilities:

Currently, there is little data nationally that addresses the incidence and prevalence of learning and/or behavioural disabilities among Aboriginal children in care, and there is little research on best practice with this population. It is clear that there is a necessity to systematically examine issues surrounding Aboriginal children and youth with learning and/or behavioural disabilities in the care of Aboriginal child welfare organizations across Canada. (Wright, Hiebert-Murphy, and Gosek, 2005, p.7-8)

Despite being written over ten years ago, the need for more systematic research and reporting continues to be a pressing issue, for “decision-making that is responsive to the needs of child welfare-involved children and families is dependent upon quality data, research evidence, and an organizational culture and climate that supports evidence to inform decisions” (Cram et al., 2015, p. 171). This project then, takes up the call for more quality research and attempts to fill gaps specific to the First Nations children and youth with disabilities in Saskatchewan.

Purpose, Goals, Objectives

Purpose: In partnership, develop a research project that furthers the understanding of the needs of children and youth with disabilities and their families with intent to better serve.

Goals:

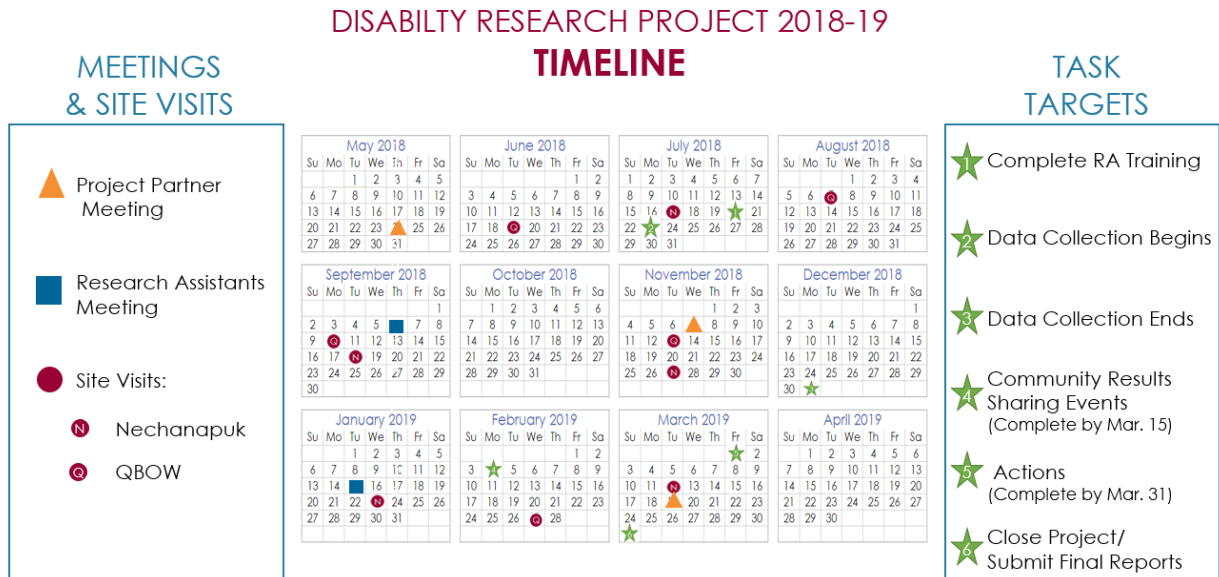
- Engage First Nations Child and Family Services in the research project
- Utilize culturally relevant practices and resources to engage stakeholders
- Learn more about the ways in which disability is defined and conceptualized in distinct communities
- Better understand service availability, gaps, and needs
- Explore means of integrating or adapting the developed tool with FNCFS agency data information systems and practices
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Objectives:

- Create and document a list of current services and resources for children and youth (including those nearing the point of aging out of care) with disabilities being served
- Work towards the creation of standardized methods and practice to better document the details of children and youth with disabilities
- Conduct one-on-one interviews with stakeholders (agency staff, service providers, caregivers/foster parents, etc.) to better understand community-specific perspectives, experiences, and needs
- Use the Disability Information Tool developed in the project to:
 - Document if disability is the reason for the referral/ investigation or requirement of service
 - Document the nature and incidence of disabilities
 - Document gaps in services for children and youth with disabilities
 - Document the number of children waiting for diagnoses or assessment and/or treatment/services
 - Document the services accessed by children and youth in care on reserve with disabilities
 - Identify trends in disability rates
 - Document Impacts of services/lack of services
 - Document how treatment/services contribute to the quality of life of children, youth and families
 - Document the factors supporting and challenging the improvement of the services/programs for child/youth

Timeline

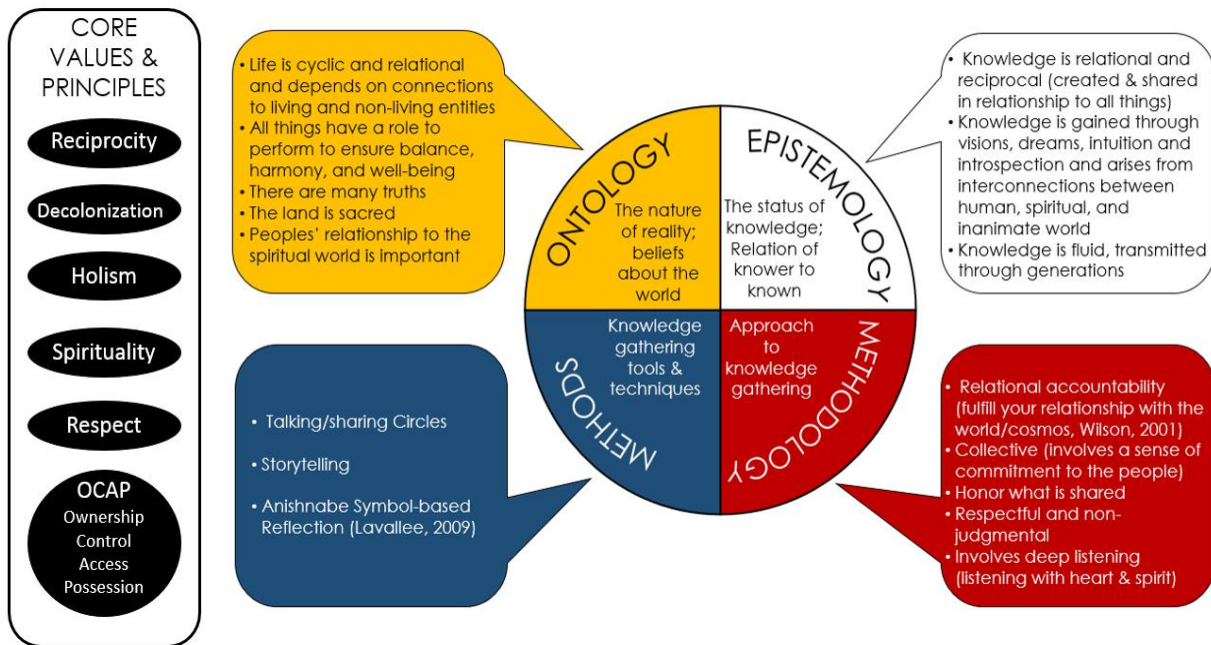
The 2018-19 Disability Research project ran from April 2018 to March 2019. The diagram below outlines the key tasks and target dates:



Methods

All research projects and research-related activities conducted by SFNFCI are guided by the Institute's Indigenous Research Paradigm. This paradigm is rooted in an Indigenous worldview that emphasizes relationships as well as social and political efforts towards decolonization (Kuokkanen, 2000). It reflects a holistic view emphasizing interconnectedness and is grounded in reciprocity, respect and the desire to create and maintain balance and harmony (Battiste & Youngblood, 2000). SFNFCI's Indigenous Research Paradigm supports community-based research practices that are culturally relevant and benefit the community (Kovach, 2009). The diagram below summarizes the values, beliefs, and assumptions represented in SFNFCI's Indigenous Research Paradigm:

SFNFCI INDIGENOUS RESEARCH PARADIGM



In addition to being guided by the paradigm, SFNFCI is committed to transparency and ethical practice. As such, we follow the OCAP principles (First Nations Information Governance Centre, 2014; Schnarch, 2004) which ensure that the participants and their communities OWN their information, CONTROL what information is shared and how it is used, have easy ACCESS to their information, and actually POSSESS that information (a copy of the Consent Form used in this project is included as Appendix1).

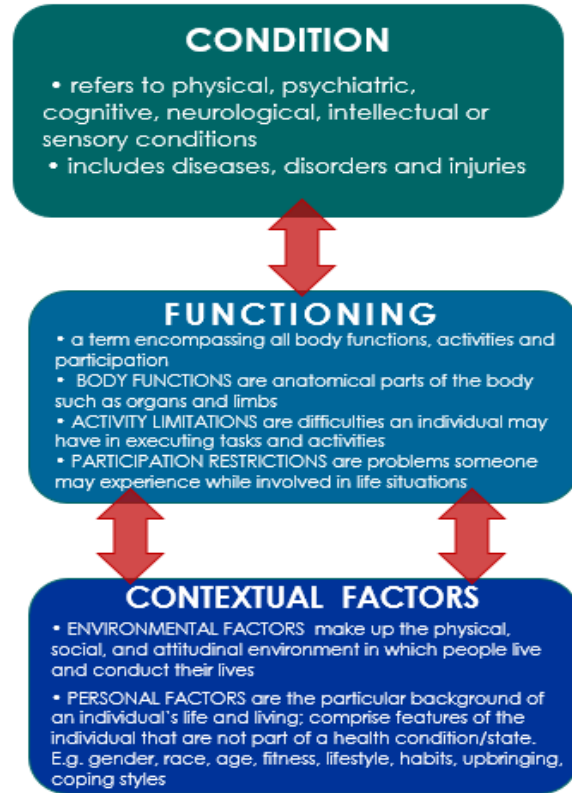
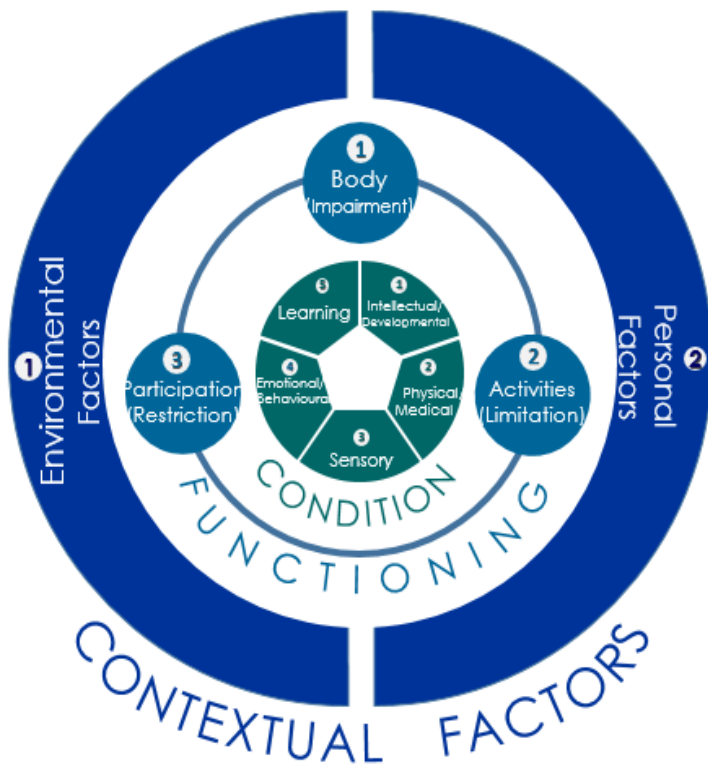
The methods used in this project are informed by a conceptual model of disability created for this research work. Our model is built upon two main sources – the World Health Organization (2007) and the Saskatchewan Disability Strategy (2015).

In 2015, the government of Saskatchewan launched an official Disability Strategy, “in an effort to develop a standard way to describe and understand

disability that can be used across Saskatchewan programs” (Saskatchewan Disability Strategy, 2015, p.49). The Strategy defines disability as “a limitation in functioning that is the result of a dynamic interaction between an individual’s health condition(s) and personal and environmental factors” (p.49). This approach recognizes disability as a common, universal human experience, but shifts the focus from causes to impacts, concentrating on the interaction between personal and environmental factors. This approach assumes that disability can be a transitory condition because “people can move into and out of a state of disability depending upon their personal situation” (p.50). Overall, this approach considers the whole person and contributes to an “understanding of the many ways people experience disability, the impacts on daily living and the capacity for participation and inclusion” (p. 50).

The World Health Organization has done a lot of research, instrument development, and advocacy around disabilities. In their *International Classification of Functioning, Disability, and Health* (2007), disability is defined as any impairment, activity limitation or participation restriction which limits functioning within the context (personal and environmental) of a person’s life. The WHO approach provides a “multi-perspective approach to the classification of functioning and disability as an interactive and evolutionary process” (2007, p. 17).

Inspired by these two approaches, this project considers three main areas: condition, functioning, and contextual factors. Condition, the actual disorder or disability, may be at the center, but is not the main focus. Instead, there is an emphasis on functioning – how the person’s physical functioning, activities, and social participation are impacted. Finally, significant focus is also placed on the broader context – both personal and environmental factors. It is assumed that there is a constant, fluid interaction between the particular condition and the world in which the person lives.



This model of disability was used to develop the Disability Information Tool (DIT)—one of the main methods of data collection used in this project (included as Appendix 2). This tool was developed, initially, in the Disability Project 2017-18 and is used to systematically collect standardized information in the three main areas outlined in the Disability Model: condition, functioning, and context. This tool is a 4-page document with multiple-choice fields as well as many narrative fields that allow researchers to enter further details and descriptions. In addition to being a hard-copy, printable document, the tool also exists in a digital format on the platform Survey Monkey. Data can either be entered directly into the digital version, or inputted manually after being collected in the printed version.

The DIT collects information in six distinct sections:

- 1 • Demographics
- 2 • Child Welfare Information
- 3 • Health Condition
- 4 • Assessment, Diagnoses, & Services
- 5 • Functioning
- 6 • Contextual Factors

There have been multiple updates and adjustments made to the tool (a running list of changes is documented and included as Appendix 3). The tool is used by project researchers and research assistants as a means of collecting information from agency case files (child files and in some cases parent files). This year both agencies elected to have ALL of their open/active protection files reviewed through this process. Each agency generated a list of open/active files as of May 31, 2018 and using that list, researchers systematically went through each file, completing as much of the tool questions as the information in the file would allow. On average, this process took approximately one hour per file, and in many cases, the researcher would consult with current or past case workers to obtain additional information or to fill in gaps in documentation.

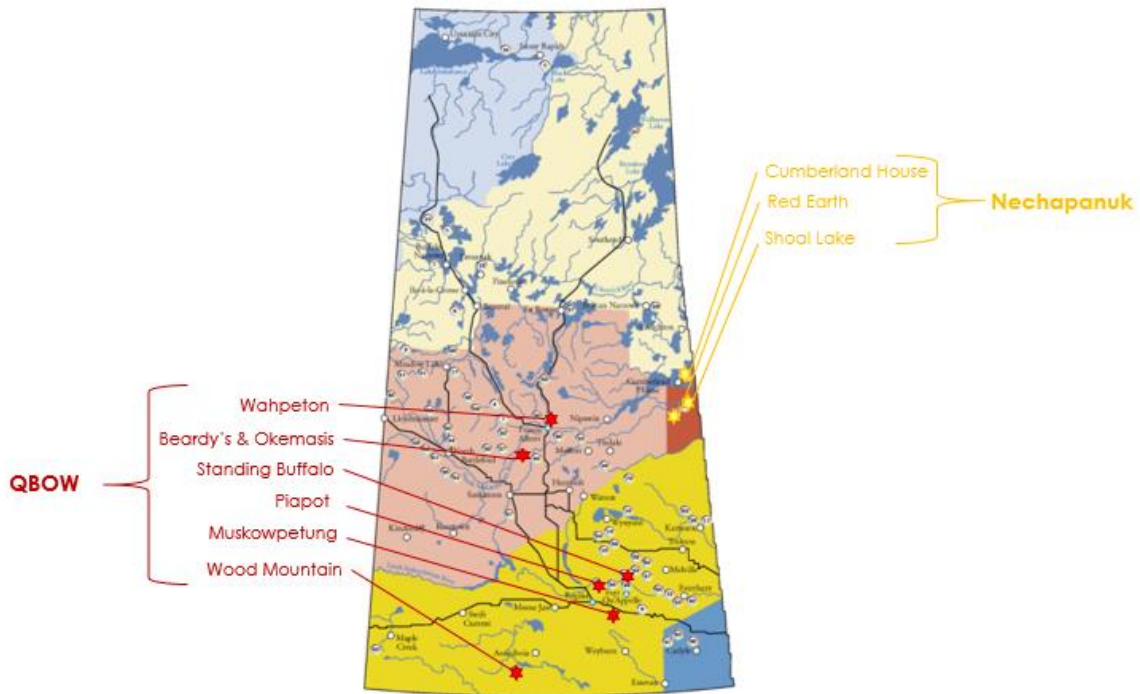
A “DIT Guide” was created and shared with research staff to provide additional information and definitions in order to standardize the data collection process and ensure that there was consistency across different researchers/DIT collectors.

In total, 131 DITs were completed, 71 from QBOW and 60 from Nechapanuk. Further details and results from the DIT are included in future sections of the report.

PARTNERS

Agencies & Communities

This year's project involved two FNCFS agencies – QBOW (with its main office in Fort Qu'Appelle) and Nechapanuk (main office in Red Earth).



QBOW Child & Family Services Inc. is a child welfare agency providing services to six distinct communities:

- Beady's & Okemasis Cree Nation
- Muscowpetung Salteaux Nation
- Piapot First Nation
- Standing Buffalo Dakota Nation
- Wahpeton Dakota Nation
- Wood Mountain Lakota Nation



QBOW Protection Staff
DLSA Training
December 15, 2018

The agency is “dedicated to protecting all children in the communities we serve through an approach combining the mutual benefit of culture, tradition, and informed social programs.” One of the priorities of QBOW CFS is to “preserve healthy families by using the positive intents of culture and traditions as the base for development in each respective community.” As such, they offer both protection and prevention services. Prevention is a significant focus of the agency which uses a ‘First Nations Prevention Services Model’, to focus on systematic issues effecting the diverse communities and individuals it serves.

Nechapanuk Centre CFS serves three communities in the eastern part of the province: Red Earth Cree Nation, Shoal Lake Cree Nation, and Cumberland House Cree Nation. They offer full protection and prevention services to each of their three communities. Their main office is on Red Earth and they also have a sub-office and Family Centre in Cumberland House.



*Nechapanuk Research Team
L-R Former Executive Director. Rhea Crane, SFNFCI Researcher Raissa Graumans,
Research Assistant/Data Base Manager Rona McKay
August 17, 2018*

The chart below summarizes the main responsibilities of the Institute and the project partners.

PARTNER ROLES & RESPONSIBILITIES

Partner Agencies	SFNFCI
FINANCES	
<ul style="list-style-type: none"> • Initially pay for local project staff and expenses, and submit an invoice to SFNFCI for reimbursement. These may include: <ul style="list-style-type: none"> • Research Assistant Wages • Elder fees • Facility Rental Costs • Catering Costs • Travel Expenses 	<ul style="list-style-type: none"> • Hold & Manage Budget project funds from ISC. This includes: <ul style="list-style-type: none"> • Maintaining accurate financial records • Paying researcher wage • Reimbursing agencies for project-related expenses
RESEARCH ASSISTANTS	
<ul style="list-style-type: none"> • EDs will recommend/assign 1 or 2 RAs (current agency employees) • Provide RA(s) access to confidential files/documents • Allow RA(s) to speak with workers in confidence about files, if needed 	<ul style="list-style-type: none"> • Reimburse the agency for up to 150 hours of RA work at \$20/hour, depending on level or participation • Provide training and support to RAs
ACTIONS	
<ul style="list-style-type: none"> • EDs will ensure that staff will be available to help organize/facilitate the actions that come out of the research (e.g. training events, workshops, etc). • This work may include: <ul style="list-style-type: none"> • putting up posters, sharing info and sending out invitations • recruiting participants • making phone calls, sending emails 	<ul style="list-style-type: none"> • Use research findings and partner input suggestions to plan and organize 'Actions' • contact and manage the contracts for facilitators/trainers • Manage Actions-related budget
DATA & REPORTING	
<ul style="list-style-type: none"> • Provide suggestions and feedback on all documents and report drafts 	<ul style="list-style-type: none"> • Manage the collection, organizing, and analyzing of all data • Save and protect all Consent Forms and any other sensitive data/documents • Draft a final project report and other documents to share findings/results

RESULTS

Disability Information Tool (DIT)

The Disability Information Tool was introduced in the Methods section above, so the pages to follow will focus on results, highlighting some of the main findings and relevant statistics derived from use of the DIT. In most cases, for the purpose of this combined report, data for all 131 cases/DITs is combined rather

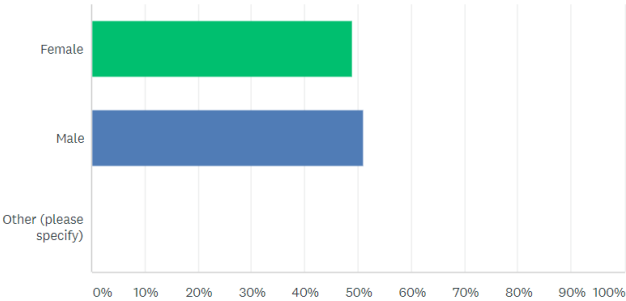
than presented as a comparison between the two partner agencies. In addition to this final report, each agency also received an agency-specific report that provided more in depth information for their files and presented data according to the communities served. In these agency-specific reports data was presented mostly in terms of community, allowing the agencies greater insight into the status and needs of the individual communities they serve.

DISABILITY RESEARCH PROJECT 2018-19									
AGENCY	MONTH						AGENCY TOTALS	PROJECT TOTAL	
	JULY	AUGUST	SEPTEMBER	OCTOBER	NOVEMBER	DECEMBER			
Nechapanuk	0	9	6	13	16	0	16	60	131
QBOW	5	22	24	4	7	9	COMPLETE	71	

The sections to follow will provide some demographic information on the 131 cases captured through the DIT. Select results will be presented from each of the six main sections of the tool.

1 • Demographics

In terms of gender, there was a fairly even split between males and females:



ANSWER CHOICES	RESPONSES
Female	48.85% 64
Male	51.15% 67
Other (please specify)	Responses 0.00% 0
TOTAL	131

ABORIGINAL STATUS

Over 96% of the children and youth currently in care of QBOW and Nechapanuk are Status/Treaty.

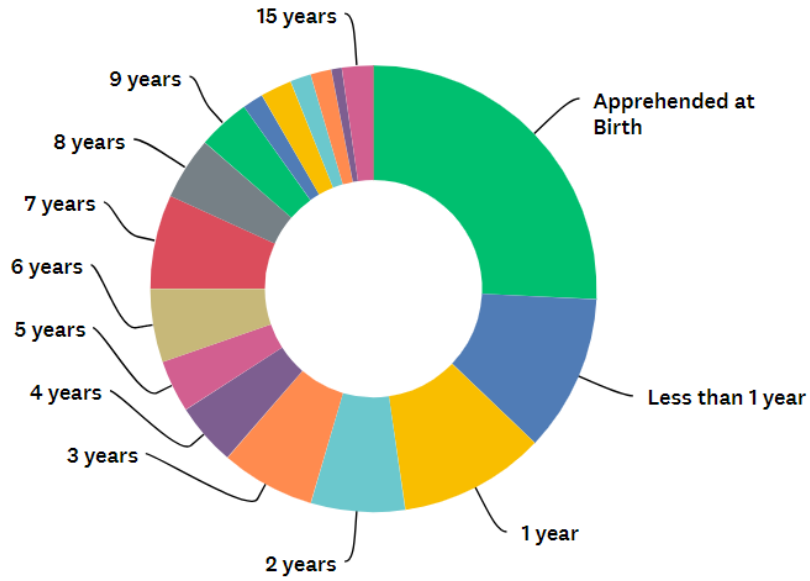
ANSWER CHOICES	RESPONSES
Not known	0.76% 1
Status/Treaty	96.21% 127
Metis	0.76% 1
Non-Aboriginal	0.00% 0
Non-Status	2.27% 3
Inuit	0.00% 0
TOTAL	132

2 • Child Welfare Information

The DIT collects information on a number of aspects of child welfare. Select results will be shared relating to apprehension, time in care, placements, and legal status.

AGE WHEN FIRST CASE WAS OPENED

When the statistics regarding the age at which children have come into the care of the agency, the largest category are those apprehended at birth. In this case that means that 26% or 34 children (of the 131) are being apprehended right at birth. The second and third largest categories are less than one year, which represented 15 of 131 or 11% of open files, and one year which was 14 of 131 cases (also 11%). That means that nearly half of all the children and youth currently in the care of QBOW and Nechapanuk were apprehended by the age of one.



ANSWER CHOICES	RESPONSES	
Apprehended at Birth	25.76%	34
Less than 1 year	11.36%	15
1 year	10.61%	14
2 years	6.82%	9
3 years	6.82%	9
4 years	4.55%	6
5 years	3.79%	5
6 years	5.30%	7
7 years	6.82%	9
8 years	4.55%	6
9 years	3.79%	5
10 years	1.52%	2
11 years	2.27%	3
12 years	1.52%	2
13 years	1.52%	2
14 years	0.76%	1
15 years	2.27%	3
16 years	0.00%	0
17 years	0.00%	0
18 years	0.00%	0
TOTAL		132

AVERAGE TIME SPENT IN CARE

TIME IN CARE	QBOW	N'CHK
0-3 months	12	0
4-6 months	6	1
7-12 months	6	16
1-3 years	12	11
4-6 years	5	14
7-10 years	10	15
10+ years	14	3
Average time in care	52 mnths (4.37 years)	49 mnths (4.08 years)

When we look at how long children are spending in care, the largest group for QBOW was those who had been in care for ten or more years, while for Nechapanuk it was those who had been with the agency for between 7 to 12 months (at the time of data collection). On average children and youth with both agencies have been in care for between 4 and 4 and a half years.

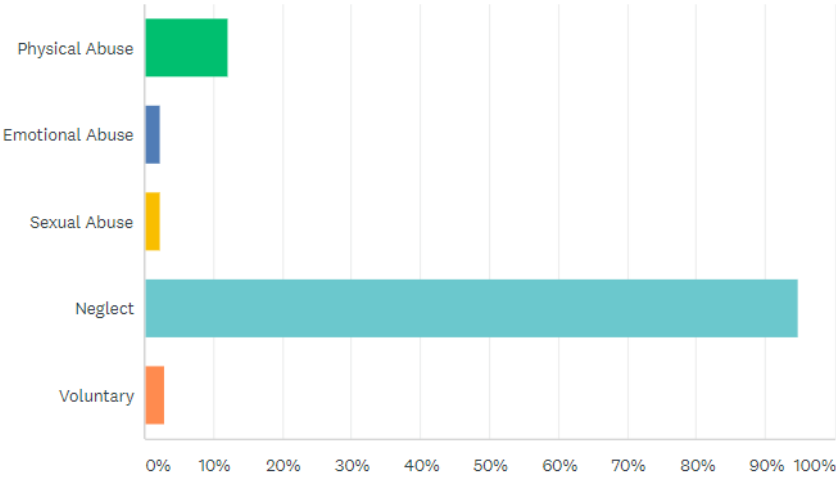
NUMBER OF APPREHENSIONS

Statistics on the number of apprehensions tracks the number of times a child/youth has been in and out of the system. For both agencies the majority of children had one single apprehension. The maximum number of apprehensions experienced by a single child was 5 for QBOW and 8 for Nechapanuk.

#	N'K	QBOW
1	35	43
2	12	16
3	6	4
4	3	1
5	1	1
6	0	0
7	2	0
8	1	0

REASONS FOR COMING INTO CARE

Following provincial legislation, there are five main categories that the agencies use to explain why a child comes into care: physical abuse, emotional abuse, sexual abuse, neglect. For both agencies, neglect was far and away the most common reason cited.



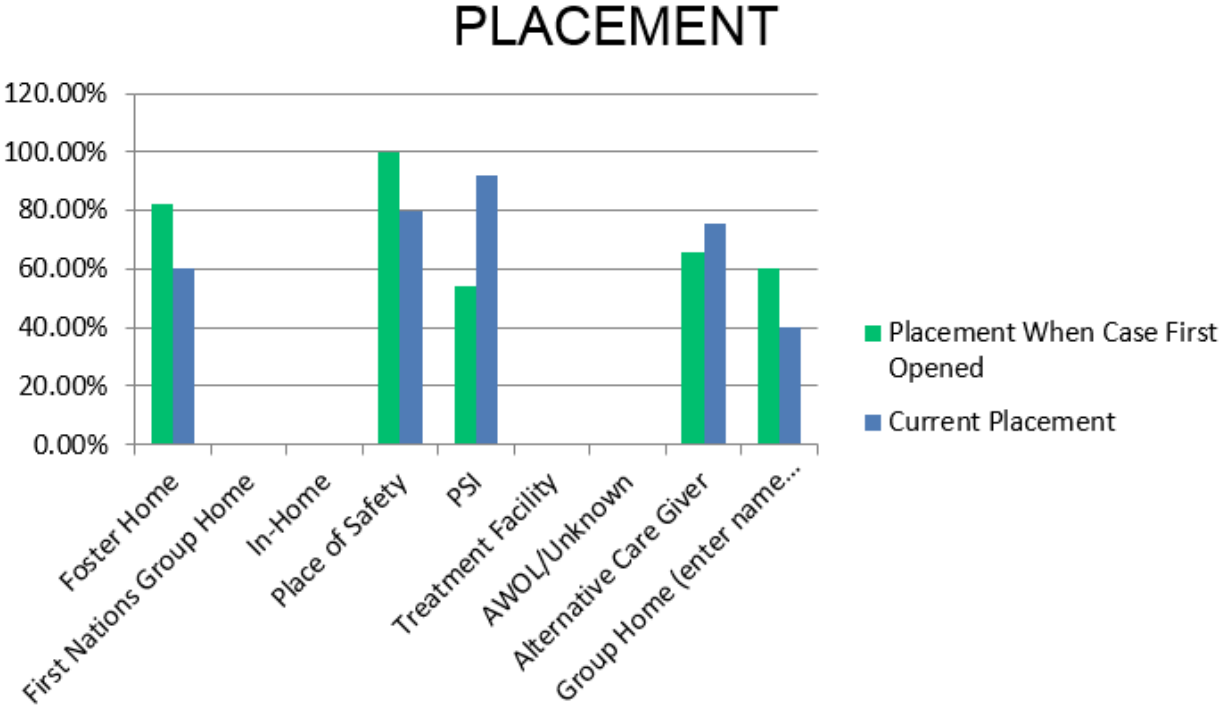
ANSWER CHOICES	RESPONSES
Physical Abuse	12.12% 16
Emotional Abuse	2.27% 3
Sexual Abuse	2.27% 3
Neglect	94.70% 125
Voluntary	3.03% 4
Total Respondents: 132	

In addition to collecting quantitative data related to apprehension, the DIT also allows for narrative answers to be entered into a text field. A word cloud, which visually represents the words used in a given body of text, indicating frequency by the size of the representation, was created from these narratives.

This graph demonstrates that while apprehension orders, section 9's and parental service agreement are most common when children first come into care, there is a definite shift to longer-term statuses, including Section 56 status which extend support until the age of 21, and long-term or permanent wards.

PLACEMENTS

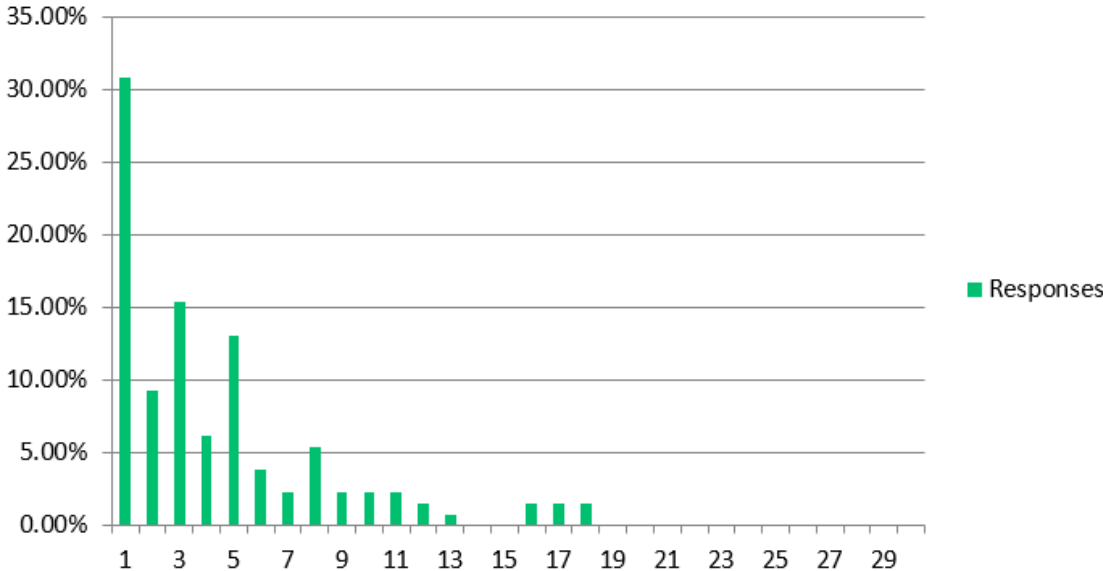
Placements refer, literally, to the place where a child or youth in care lives and include a variety of options, reflected in the chart below.



As with legal status, placement types are noted initially- when the child/youth first comes into care, and currently- where they child/youth lives now. The graph seems to indicate a general shift from temporary placements, such as Place of Safety or Foster home, to more permanent placements such as Person of Sufficient Interest (PSI) or Alternative Caregiver Placements (which, it should be noted, are often extended family members).

Another statistic to consider in regards to placement is the number or frequency of placements – these statistics answer questions such as how many different placements has a child/youth been in? What types of placements has a child/youth been in? How often is a child/youth moving? The chart below summarizes the combined number of placements data for both agencies.

Total Number of Placements/Moves



# OF PLACEMENTS		
1 MOVE	40	31%
2-5 MOVES	57	44%
6-10 MOVES	21	16%
11-15 MOVES	6	5%
16 + MOVES	6	5%

Overall, most children, across both agencies, are only experiencing a single placement. This indicates strong stability, particularly when the average time in care (around 4.5 years) for the agencies is considered. With that being said, close to half (44%) of the children and youth in the care of QBOW and Nechapanuk have moved between two and five times. There were also 6 children/youth who had moved 16 or more times since coming into care.

This is significant information for the agencies to consider given that research shows that “Children with cognitive, emotional/ behavioral, and physical disabilities were over four times more likely to be permanently living in non-kin foster care than to be reunified” (Romney, et al., 2006, p. 965). In fact, children and youth with disabilities remain longer in child welfare (Slayter & Springer, 2011) and are also at higher risk of being placed in out-of-home care or non-kin care (compare to children/youth with no disabilities/health conditions) (Dion et al., 2018; Lightfoot, Hill & Laliberte, 2011; Romney et al., 2006; Slayter, 2016). Further to this, once they enter the system children and youth with disabilities are more likely to experience placement instability or breakdown and to live in a non-kinship foster family setting, a pre-adoptive foster home, in an institution, or to experience long-term foster care (Dion et al., 2018, p. 177, Slayter & Springer, 2011; Slayter, 2016).

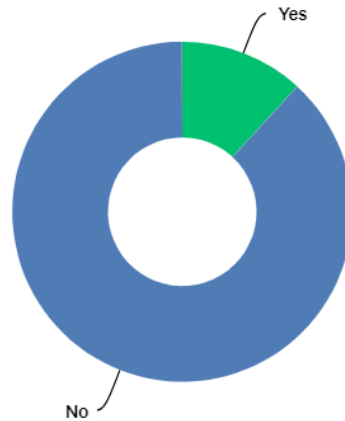
DAILY LIVINGS SUPPORT ASSESSMENT

The Daily Livings Support Assessment (DLSA) is an annual questionnaire conducted with caregivers/foster parents of children with higher than average caretaking needs. Results from the questionnaire are scored and may result in additional monthly financial support.

Across both agencies 12% of those files from which this information was collected (93 files) indicated that the caregiver was receiving DLSA support.

Does this child/caregiver receive Daily Living Support Assessment (DLSA) funding?

Answered: 93 Skipped: 40



ANSWER CHOICES	RESPONSES
Yes	11.83% 11
No	88.17% 82
TOTAL	93

3 & 4 • Condition and Assessment, Diagnoses, & Services

These two sections of the DIT have been combined here since much of the information is related.

CONDITION

The DIT collected data on conditions in five categories: (1) intellectual/developmental; (2) physical/medical; (3) emotional/behavioural; (4) learning; (5) sensory. For each condition, researcher were asked to note if the child/youth was:

1. formerly diagnosed
2. awaiting assessment/ diagnosis

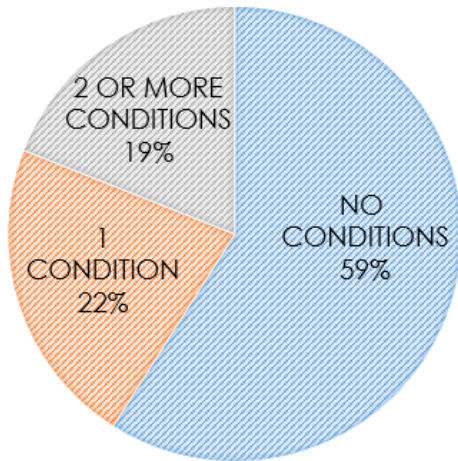
3. if the file indicated that the child was suspected of having the condition, but the child had neither been diagnosed nor referred for assessment/diagnosis

There were 23 separate conditions noted in the files (of both agencies combined), with the majority (40%) being in the category of Intellectual/Developmental. The most common condition across agencies was FASD which affects 25 of the total 131 children/youth (19%). The second most common condition was ADHD (14 of 131 children/youth (11%).

EMOTIONAL/ BEHAVIOURAL			INTELLECTUAL/ DEVELOPMENTAL			PHYSICAL/ MEDICAL			LEARNING			SENSORY		
	Neach'k	QBOW		Neach'k	QBOW		Neach'k	QBOW		Neach'k	QBOW		Neach'k	QBOW
ADHD	4	10	FASD	11	14	Asthma/ Respiratory Illness	3	7	Gen. Lang'e Delay	2	2	Deafness		2
Anxiety	1	4	Dev' mental Delay	7	6	Skin/Excema		2	Laguage Processing		2			
Depression		2	Autism		3	Cerberal Palsy	1	1						
PTSD		1				Aquired Brain Injury		1						
Schizo-phrenia		1				Epilepsy	1	1						
Psychosis		1				Heart	1	1						
Mood Disorder		1				Seizure Disorder	1							
Paranoia	1													
Eating Disorder	1													
ODD	7	1												
35 of 106		33%	43 of 106		40%	20 of 106		19%	6 of 106		6%	2 of 106		2%

Overall, more than half of the children and youth whose files were reviewed had no indication of any condition (59%, 72 children/youth). That leaves 52 children and youth who between them have 106 documented conditions. This indicates that on average most children/youth have more than one concurrent condition. The diagrams below visually depicts the statistics on conditions:

■ NO CONDITION ■ 1 CONDITION ■ MULTIPLE CONDITIONS



**52 CHILDREN/YOUTH
106 CONDITIONS**

72 CHILDREN = NO CONDITIONS
 28 CHILDREN = 1 CONDITION
 11 CHILDREN = 2 CONDITIONS
 7 CHILDREN = 3 CONDITIONS
 3 CHILDREN = 4 CONDITIONS
 3 CHILDREN = 5 CONDITIONS

ADDICTIONS, SUICIDE & SELF HARM

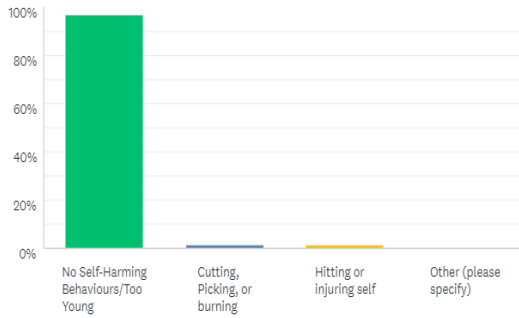
While not part of the first version of the DIT, sections on addictions, suicide, and self-harm were added last year to capture data on such experiences since they are a major concern to many FNCFS agencies.

Results from this year's project show that alcohol and drug use/abuse, suicide, and self-harm are not affecting significant portions of QBOW or Nechapanuk's children and youth in care. Over 90% of the cases reviewed showed no history in the categories of addictions, self-harm, and suicide for the children and youth in care with the agencies.

Addictions		
Answer Choices	Responses	
No Addictions Issues/Too young	95.28%	121
Alcohol	2.36%	3
Drugs	1.57%	2
Solvents	2.36%	3
Other (please specify)	0.00%	0
	Answered	127

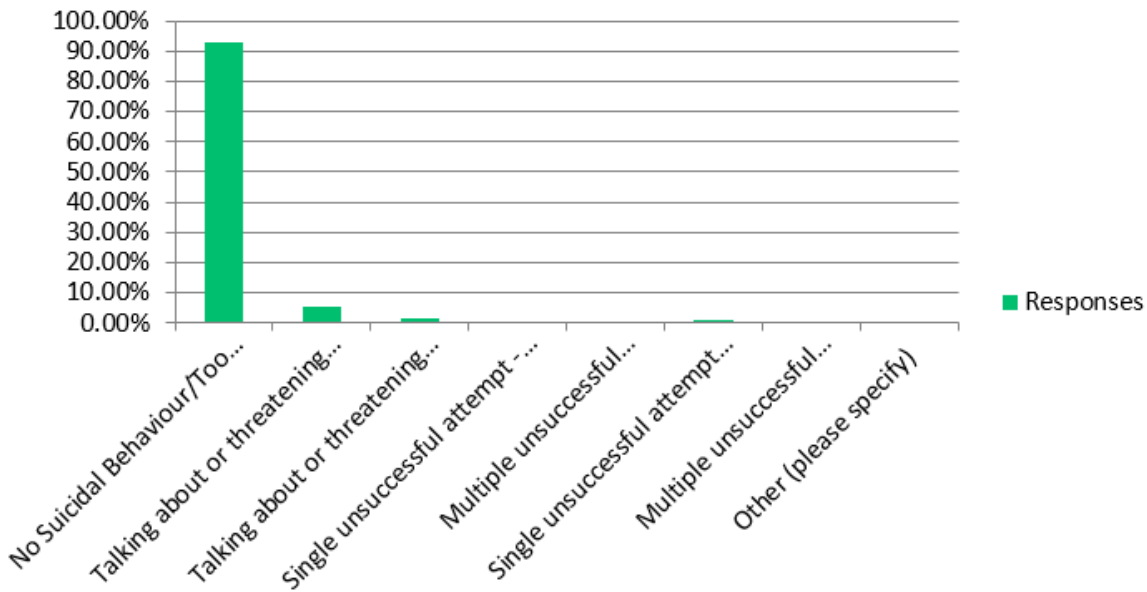
Indicate type(s) of self-harm used by child/youth

Answered: 128 Skipped: 5



Indicate type(s) of self-harm used by child/youth		
Answer Choices	Responses	
No Self-Harming Behaviours/Too Young	96.88%	124
Cutting, Picking, or burning	1.56%	2
Hitting or injuring self	1.56%	2
Other (please specify)	0.00%	0
	Answered	128

Indicate type(s) of suicidal behavior:



ANSWER CHOICES	RESPONSES
▼ No Suicidal Behaviour/Too Young	92.97% 119
▼ Talking about or threatening to kill or hurt themselves	5.47% 7
▼ Talking about or threatening to kill or hurt themselves resulting in professional treatment/intervention	1.56% 2
▼ Single unsuccessful attempt - no hospitalization	0.00% 0
▼ Multiple unsuccessful attempts - no hospitalization	0.00% 0
▼ Single unsuccessful attempt resulting in hospitalization and/or medical/psychiatric treatment	0.78% 1
▼ Multiple unsuccessful attempts resulting in hospitalization and/or medical/psychiatric treatment	0.00% 0
▼ Other (please specify)	Responses 0.00% 0
Total Respondents: 128	

SERVICES

This section of the DIT collects information on the services and supports accessed by children/youth – both current/ongoing and past/discontinued.

The information collected in Services documents the type of service, the provider, whether the service is accessed on or off reserve, and the frequency with which the service is accessed (weekly, monthly, quarterly, randomly/as needed). For discontinued services – those which the child/youth once accessed but no longer does, the reason(s) for discontinuation are also noted (if the information is available in the file).

The chart below provides an overview of the current services accessed by children and youth across both agencies. The information combines data from QBOW (45 cases, 114 services) and Nechapanuk (12 cases, 25 services).

Service	Number
Dentist/Orthodontist	35
Physician/Pediatrician	34
Optometrist	31
Speech & Language Therapy	11
Counseling/ Mental Health Therapy	10
Specialist (neurologist, ear/nose/throat, dermatologist, etc)	5
Occupational/ Physical Therapy	5
Multiple Services Through Alvin Buckwold and/or Ranch Ehrlo	4
ECIP (Early Childhood Intervention Program)	2
Psychiatrist	2

This year, an additional field was added to the service section of the DIT to allow researchers to indicate incompleteness, or a lack of service information in the files. Of the total 131 files, 92 across both agencies combined, were deemed incomplete in regards to the service information documented:

If information on services is missing or lacking from the file, check one of the boxes:

Answer Choices	Responses	
No Service Information in file	54.35%	50
Incomplete Service Information in file	45.65%	42
	Answered	92

These results indicate that 70% of all files (across both agencies) are missing valuable information relating to services. Service related information is not always documented systematically in files and third party reports, assessment results and other medical and service information is often missing from case files. This information may be used by the agencies to better understand the completeness of files and to identify specific areas in need of further development or support.

5 • FUNCTIONING

The DIT collects information on Functioning in terms of the level of limitation or restriction that the child/youth experiences in physical or bodily functions as well as various social functions. Various areas of functioning are accessed in two broad categories: 1. *BODY IMPAIRMENTS* – a. Mental, b. Sensory, c. Cardiovascular/Digestive; 2. *ACTIVITY & PARTICIPATION LIMITATIONS*- a. Learning and Communication, b. Mobility, c. Self Care, d. Relationships, and e. Social Participation). The scale used in the DIT to assess functioning is a four point scale:

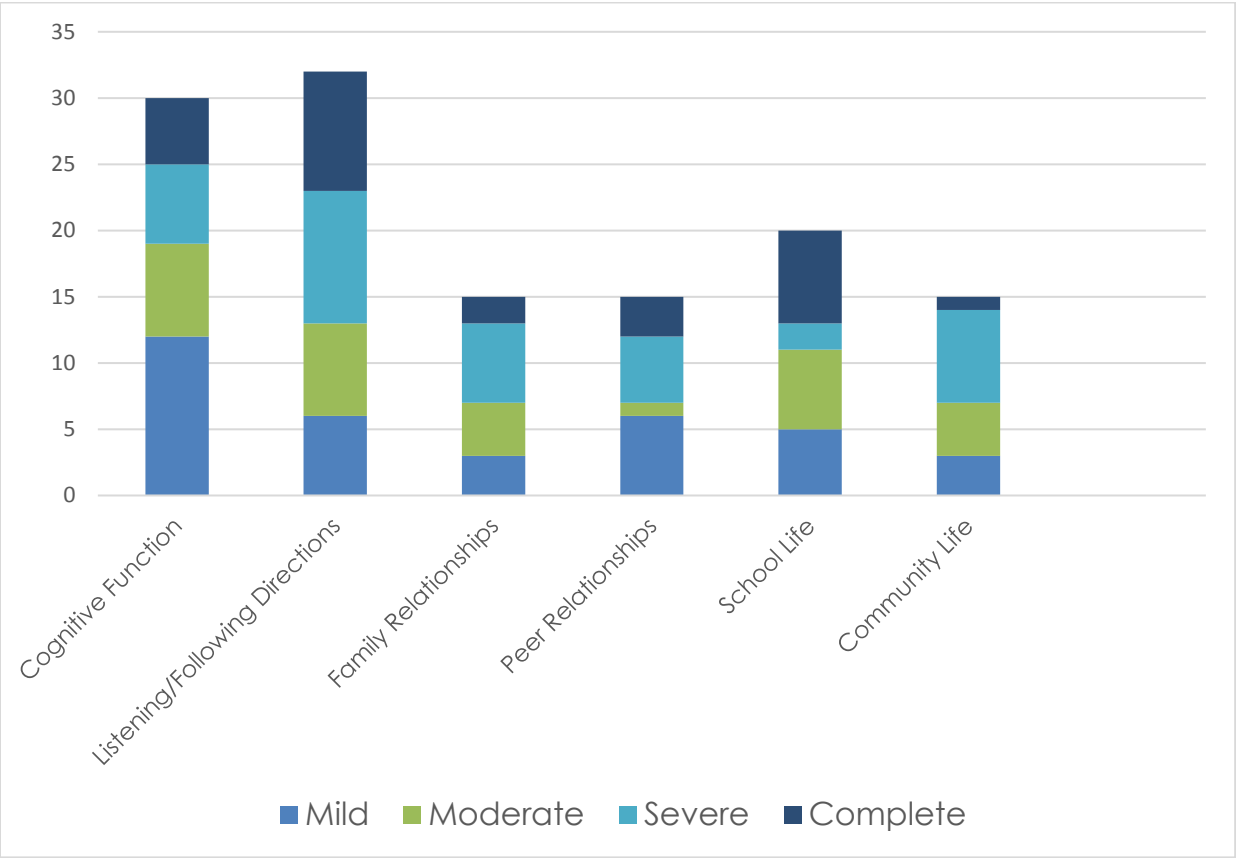
“MILD” = a problem that is present less than 25% of the time with an intensity the child/youth can tolerate and which happened rarely over the last 30 days

“MODERATE” = a problem that is present less than 50% of the time, with an intensity which is interfering in the child/youth’s day to day life and which happened occasionally over the last 30 days

“SEVERE” = a problem that is present more than 50% of the time, with an intensity which is partially disrupting the child/youth’s day to day life and which happened frequently over the last 30 days

“COMPLETE” = a problem present more than 95% of the time, with an intensity which is totally disrupting the child/youth’s day to day life and which happened every day over the last 30 days.

While information was collected on a broad range of functioning impacts, the chart below highlights results for key mental, learning, relationships, and social functions.



Generally speaking, questions on functioning were completed in the DIT if there was clear and direct information in the file to allow the degree of functional impairment to be rated or assessed. Additionally, there was not an option, within the tool, to indicate no functional impairment. Thus, it should be kept in mind that functioning for all children was not necessarily assessed or noted, and that the absence of an answer does not necessarily equate to an absence of functional impairment.

Cognitive Function					
	MILD	MODERATE	SEVERE	COMPLETE	TOTAL
MENTAL	40.00% 12	23.33% 7	20.00% 6	16.67% 5	30
Listening/Following Directions					
	MILD	MODERATE	SEVERE	COMPLETE	TOTAL
LEARNING & COMMUNICATION	18.75% 6	21.88% 7	31.25% 10	28.13% 9	32
Family Relationships					
	MILD	MODERATE	SEVERE	COMPLETE	TOTAL
RELATIONSHIPS	20.00% 3	26.67% 4	40.00% 6	13.33% 2	15
Peer Relationships					
	MILD	MODERATE	SEVERE	COMPLETE	TOTAL
RELATIONSHIPS	40.00% 6	6.67% 1	33.33% 5	20.00% 3	15
School Life					
	MILD	MODERATE	SEVERE	COMPLETE	TOTAL
SOCIAL PARTICIPATION	25.00% 5	30.00% 6	10.00% 2	35.00% 7	20
Community Life					
	MILD	MODERATE	SEVERE	COMPLETE	TOTAL
SOCIAL PARTICIPATION	20.00% 3	26.67% 4	46.67% 7	6.67% 1	15

7• Contextual Factors

Contextual Factors capture some of the larger life events or circumstances that shape the lives of the children and youth whose file is being reviewed. In previous years this section of the tool included an open text box where details, narrative accounts, and notes could be captured. Analysis revealed that many of the major events and experiences were common, or shared across children, so this year the tool was adapted to have a check box list of the most common major events/experiences. An open text box was also available for additional details and narrative explanations or the descriptions of events and experiences not included in the check list.

The chart below summarizes the list of factors and responses per agency.

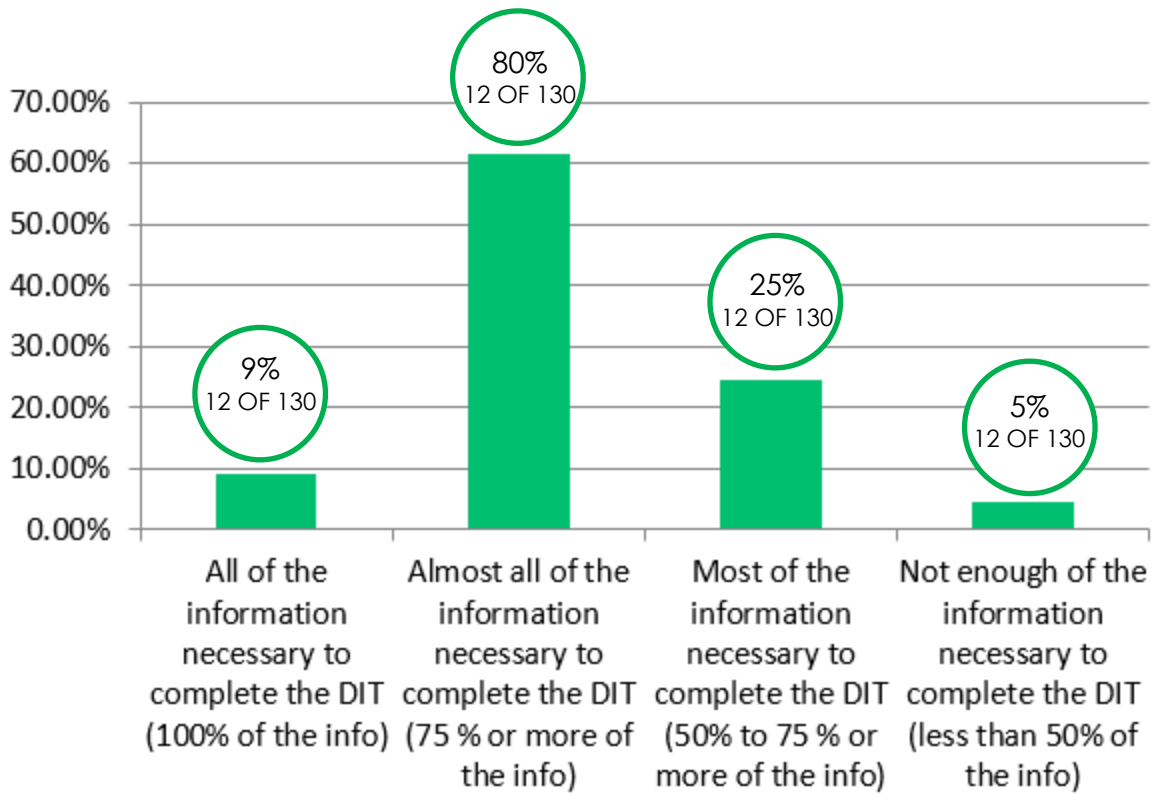
Indicate which (if any) trauma(s) or life event(s) the child has experienced:						
Answer Choices	NECHAPANUK 40 Responses		QBOW 47 Responses		COMBINED RESULTS	
Death of 1 or both parents	13%	5	11%	5	12%	10
Death of close family member(s)/friends	3%	1	15%	7	9%	8
Witnessed violence	30%	12	21%	10	25%	22
Witnessed excessive drug/alcohol use	20%	8	36%	17	29%	25
Experienced sexual abuse	8%	3	9%	4	8%	7
Mother admits to or is suspected of using drugs or alcohol while pregnant	18%	7	28%	13	23%	20
Separated from other siblings in care	75%	30	36%	17	54%	47
Experienced Excessive Moves	15%	6	2%	1	8%	7
Prolonged hospitalization (2+ weeks on 1 occasion)	5%	2	13%	6	9%	8
Involvement with the Justice System	3%	1	6%	3	5%	4
One or both biological parents is/was incarcerated	8%	3	32%	15	21%	18
One or both biological parents were in care as a child/youth	5%	2	11%	5	8%	7
	Answered 40		Answered 47		Answered 87	

For both agencies, the most frequent experience was being separated from other siblings in care (75% of 40 responses for Nechapanuk; 36% of 47 responses for QBOW). High on the list of other common and/or shared experiences were witnessing violence (30% of 40 responses for Nechapanuk; 21% of 47 responses for QBOW) and witnessing excessive drug/alcohol use (20% of 40 responses for Nechapanuk; 36% of 47 responses for QBOW). A significant number of children/youth from both agencies also have a mother who has admitted or is suspected of consuming drugs and/or alcohol while pregnant (18% of 40 responses for Nechapanuk; 28% of 47 responses for QBOW). For children in the care of QBOW, a significant number of their biological parents are or were incarcerated.

Overall, these contextual factors serve to document the complex and many times difficult events that children in care experience. Moreover, such data also indicates that most children are dealing with multiple traumatic experiences. This information may be used by the agency to better understand the types of traumas impacting the children in their care and may also be used to inform the development and prioritization of Prevention programming.

FILE INFORMATION

Another addition to this years DIT was a multiple choice question at the end that allowed researchers to indicate the level or amount of information available in the case file. There were four options, added to ensure that blank or skipped questions were not interpreted as non-experiences or false negatives. Additionally this question can be used by agency directors and supervisors to gain insight into the completeness, as well as the level and quality of documentation, in files.



This child/youth's file contained:

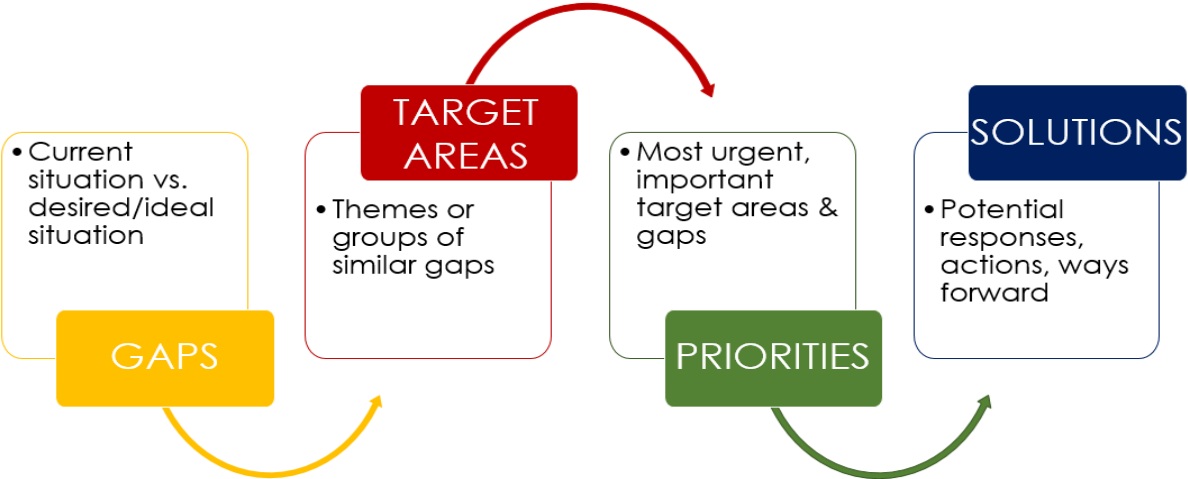
Answer Choices	Responses	
All of the information necessary to complete the DIT (100% of the info)	9%	12
Almost all of the information necessary to complete the DIT (75% or more of the info)	61%	80
Most of the information necessary to complete the DIT (50% to 75% or more of the info)	25%	32
Not enough of the information necessary to complete the DIT (less than 50% of the info)	5%	6
	Answered	130

Focus Groups

In addition to the quantitative DIT tool, focus groups and one-on-one interviews were conducted to generate additional qualitative information. The focus groups in this instance were held with 2 separate groups of caregivers working with QBOW. These groups brought together caregivers who were currently receiving DLSA (Daily Living Support Assessment) funding and caring for children with noted high or special needs. One group was held for QBOW DLSA caregivers from its southern communities (Wood Mountain, Standing Buffalo, Piapot, Muscowpetung- held in Standing Buffalo on November 7, 2019) and a second group for northern communities – Wahpeton and Beardy's Okemasis was held in Prince Albert on December 19, 2018. In all, seven DLSA caregivers and six staff participated. These focus group sessions engaged caregivers in a manner not frequently done by the agencies in the past and allowed them to reflect on their experiences and voice their needs and priorities.

A simple needs assessment model was used to guide and frame discussions:

QBOW DLSA CAREGIVERS: A NEEDS ASSESSMENT



Participating caregivers were extremely engaged, sharing personal stories of success and struggle and being very open about how it has been working with agency staff. The focus was on priorities for change and solutions generated by the caregivers themselves. The chart below summarizes the key themes that came out of the focus groups and the priorities for actions identified by participants:



The caregivers who participated were very grateful for an opportunity to meet with other caregivers, to share stories and ideas, and to have some direct say in how they would like things to be. The top priority for action was to have more regular meetings. The caregivers were very interested in ensuring that there would be follow up and further action taken. They felt that establishing a

Caregiver Support Group or Network was an excellent idea that could benefit both them as a group and the agency as a whole. Notes from the meetings were shared back with participants and agency staff have committed to more direct and regular engagement of caregivers.

The second main priority identified by caregivers was Training. They were unanimous in their desire for more information and support around disabilities and special needs. They want to see more regular workshops on disabilities and trauma and more specific, hands-on training in how to manage challenging behaviour. Additionally, they were keen to learn more about Jordan's Principle and access support in filling out applications, being a part of larger group applications, and being able to access additional support for the children and youth in their care.

Interviews

The second qualitative method used in this year's project was one-on-one interviews. This year, only one of the agencies requested that interviews be conducted with their caregivers. To achieve this, the executive director invited the lead researcher to attend the week long cultural camp they hold for caregivers each year. The researcher traveled out to the camp near Shoal Lake from August 13-17, 2018. Over the course of her time at camp, the lead researcher was able to complete 15 interviews with caregivers (either as individuals or couples).



*Nechapanuk Caregiver Camp
August 17, 2018*

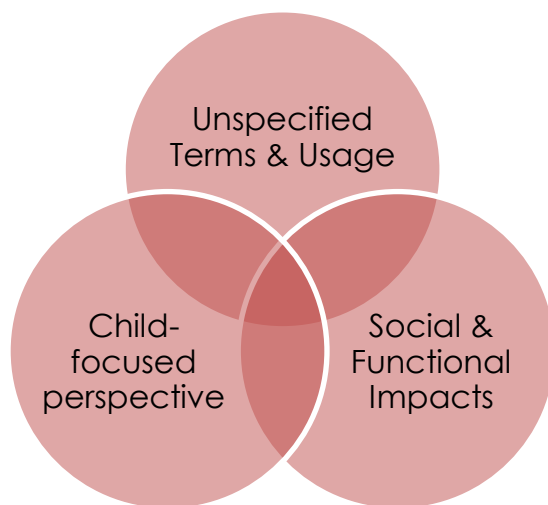
The chart below provides a snapshot of interviewees:

INTERVIEW PARTICIPANTS: NECHAPANUK CAREGIVERS			
	Community	Years as a Caregiver	Current Number of Children in Home
1	Red Earth	5 years	4 children
2	Red Earth	12 years	4 children
3	Red Earth	12 years	4 children
4	Red Earth	13 years	children
5	Shoal Lake	13 years	1 child
6	Shoal Lake	13 years	1 child
7	Red Earth	2 years	1 child
8	Red Earth	2 years	1 child
9	Red Earth	17 years	3 children
10	Red Earth	17 years	3 children
11	Red Earth	30+ years	1 child
12	Red Earth	7 years	2 children
13	Red Earth	1 year	1 child
14	Cumberland House	2 years	1 child
15	Cumberland House	3.5 years	3 children

The interviews were open-ended and informal. They involved three basic questions:

1. Tell me a little bit about yourself and the child/children in your care
2. What types of services/supports do you currently access for your child/children?
3. What types of serves/supports/other do you need to make things easier and/or better care for your child/children?

In addition to exploring service related experiences, one of the other intentions of one-on-one interviews was to explore the ways that individuals and communities conceptualize disability. It's widely acknowledged that knowledge of "the ways that 'disability' is defined, conceptualized, and enacted in Indigenous communities is limited" (Sabatello & Schultz (Eds.), 2014). Moreover, Indigenous ways of understanding disability often differ from mainstream or governmental approaches (Gething, 1994). In the context of this project, when understandings of the concept 'disability' are considered, there are three main findings: the term 'disability' is not often used; an individualized, child-specific view is typically employed; and rather than a focus on a given condition or disability, there is a focus on social and functional impacts.



UNSPECIFIED TERMS & USAGE

Overall, it appears that in the communities represented in this project, "disabilities" as an English language term and concept is not consistently used. Rather, in conversations there is a more fluid and nonspecific use of general terms like 'delay', or 'having challenges' in certain areas, etc. One caregiver acknowledged that "We never use the term 'disabilities', we do say 'special

needs'. We have never heard the word 'exceptionalities'." Project participants rarely used formal diagnostic terms – autism, ADHD, etc. in regards to a specific child, but rather focused on particular behaviours or ways of being.

SOCIAL AND FUNCTIONAL IMPACTS

Project participants clearly recognize certain conditions, including both physical and mental/emotional states, as disabling when they interfere with an individual's ability to function and participate in typical social contexts – community and cultural activities, family life, school, etc. Participants tend to value inclusion and feel that it is important for children and youth with special needs to be able to meaningfully participate in all aspects of community life. With that being said, there was also substantial discussion related to shame and fear. Many talked about how a lack of understanding or familiarity with disability often leads to avoidance and isolation within the community.

One project participant acknowledged that "for me, my past experience is that I tend to avoid people or kids with disabilities because I don't know what to do or say." These are views and actions few personally admitted to, however, several participants did talk about stigma and the way others treat those with special needs. In one instance, a caregiver spoke from personal experience, explaining that a close relative had a child with Downs Syndrome and speech delay. She explained that they moved off of the reserve into the city "because there is no ambulance here and not many services. It was hard for them, people didn't treat her very well. People and kids even, have attitudes that made her not want to move back to the community."

PERSON/CHILD FOCUSED PERSPECTIVE

Participants often displayed a person- or child-focused perspective that emphasized the unique qualities, characteristics, and needs of each particular

child/youth. They also tended to focus on how disability impacted the lives of the child and their family, and typically framed these impacts in positive and inclusive terms:

“It is our culture to look at kids with special needs as who they are, not as different.”

“Every kid is a gift from god. When they are born with a disability it is not a punishment – it is a chance to love them, like all kids. It gives a chance to learn deeper love.”

In contrast to some of the perspectives and stories shared around stigma and labeling, several participants spoke to the openness of communities – welcoming people as they are rather than distinguishing them because of differences: “Kids with disabilities, there's no separation, they are not treated differently. Kids respect each other and there's no labelling, no difference.”

Evidently, the manner in which disability is conceptualized and the actions and attitudes of communities are not simple, uniform, or fixed. Much more work is needed to fully grasp the ways in which distinct communities understand and use (or don't use) the term.

Beyond the concept of disabilities, a thematic analysis of the interview data allowed for the identification of three main aspects of disability-related services and supports:

1. WHAT'S WORKING

Caregiver comments and words classified in this theme were those that identified positive aspects of their experiences- things that supported and aided them in caring for one or more children with special needs.

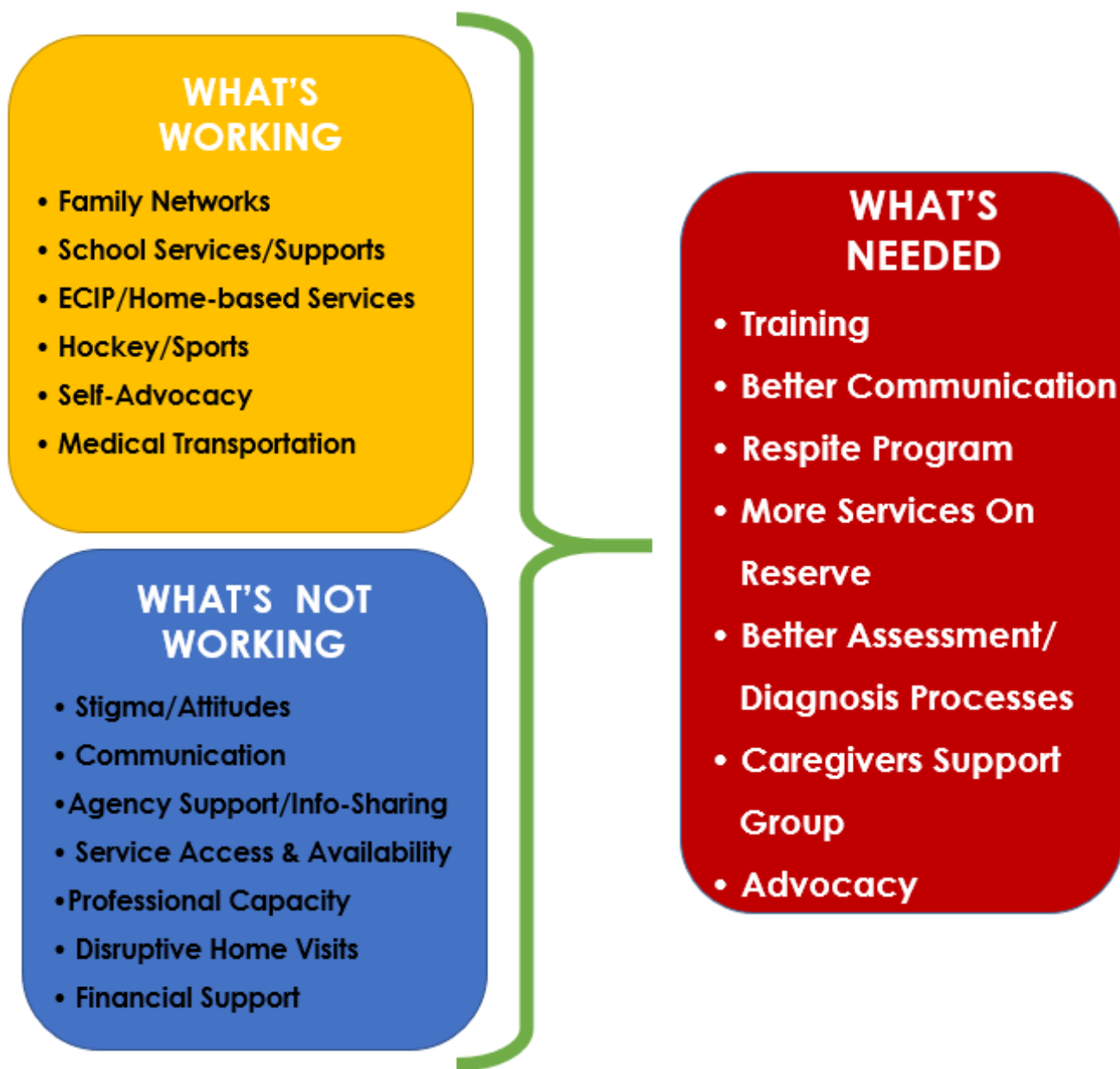
2. WHAT'S NOT WORKING

Ideas and opinions in this thematic category capture the barriers or impediments faced by caregivers. The things they identified here are the

problematic or challenging aspects of their experience, and the areas where they feel the most improvement and/or change is required.

3. WHAT'S NEEDED

This third thematic category brings together all of the suggestions, recommendations, and requests made by caregivers in regards to what they need to effectively care for the special needs children placed with them.



WHAT'S WORKING

One of the strongest supports available to caregivers of children and youth with special needs are the family and friends who aid with day to day tasks, provide respite, and offer emotional support. These support networks were mentioned by several caregivers as crucial to their ability to adequately care for the children placed with them:

“Like us, a lot of grandparents are taking care of their grandkids. It can be a challenge to raise grandchildren or other foster kids, but it's part of our culture, it's what we do, how we live and care for each other.”

“There are many grandparents, even quite old people who are willing to take in kids or their kids' kids because they want to keep families together, but it can be hard. It's good for them too, though – it keeps them young! Haha.”

“My other daughter helps out a lot and we live together so we can work together to care for the children. I have other children who live just next door, so we help each other.”

“Older biological children are also foster parents, so there is a lot of support and they are always helping each other.”

Some of the things that caregivers identify as a positive in their lives as caregivers were the services offered through the schools. One said directly- “The school programs are good.” Others compared school-based supports to those available through the agency, stating “At school we get more support than through the agency.” Overall, it appears that for many caregivers on reserve, the services and supports offered through the schools are some of the only ones they access: “We get help for them at the school, but don't get any other services outside of the school.”

Another helpful service identified by caregivers was the medical transportation available in their communities: “The medical taxi is good – through FNIHB. They

help you to book rooms and organize everything, so that is good and helpful when we have to travel out. “

Self-advocacy has been included in the ‘What’s Working’ list because it is one of the primary ways that caregivers identify and access services. One caregiver, for example, explained: “With my kids I’ve had to take it upon myself to get second opinions and to really make sure they were getting the care they need and deserve.” While there are positive outcomes associated to self-advocacy, it’s not all positive, for many wish that they had less of that responsibility placed on them and that, instead, there were other supports available to them in this area.

WHAT’S NOT WORKING

The most prevalent answers, ideas, and opinions classified in this theme relate to communication and information sharing. Here, some of the confusion expressed by caregivers speaks to the impacts and results of poor information sharing: *“I think FSIN or PAGC works with the school to see kids with behavior problems. PAGC comes every year, or a couple times a year to do assessments and referrals. I think she had an assessment before.”* Many of the concerns of care givers in this theme were also connected directly to the agency, in this case, Nechapanuk, were many expressed frustration with the lack of information sharing:

“Some of the problems are with communication. The different agencies communicate directly with the kids’ mother, but then they don’t tell me anything. She also doesn’t tell me anything, so then I don’t know what is going on...”

“The agency just dropped her off. They didn’t give us any information – no health card, no information, no report card or school information, no medical information, nothing about her family or where she came from. Nothing, nothing. We had to do everything by ourselves.”

“In terms of the agency (Nechapanuk) the main issue is that no information is given when you get a child. They are just dropped off, with no clothes, we don't know their birthdays or if they have any allergies of something like that.”

Evidently, caregivers feel that their jobs in caring for children would be made much better if there was a more consistent flow of information from the agency, particularly at that crucial time when a child is initially placed in their home.

Disruptive home visits were another issue raised by several caregivers. 4 of the 16 caregivers interviewed mentioned the need or desire to discontinue home visits because they were so disruptive and having detrimental effects on the children:

“After home visits he goes backwards. He's different when he comes home. He gets very quiet and doesn't want to do anything.”

“We cut home visits off because she had to be in the hospital after going on a visit – they don't know how to take care of her properly. The agency is trying to arrange another one, so we'll see. It is terrible because when she gets back she is always sick and it's me that has to make sure she gets better and get her to catch back up to where and how she was before the visit.”

“The father of the foster kids neglect them and he's an alcoholic. On visits they have to come back early and they don't even want to see their dad and those visits are disruptive and hard for the family.”

Finances are often included as a barrier or problematic area in child welfare. On this topic one caregiver said: “Many times, with many of the kids we have to pay from our own money. It's okay, but it would better if things were organized better.” Generally speaking, caregivers would like to see an increase in rates in order that the true expenses and cost of living on reserve are taken into account. They would also like to see more streamlined and simplified financial processes that are less bureaucratic and take less time and effort on their part.

WHAT'S NEEDED

The ideas and opinions in regards to what is needed have been grouped into three broad themes for discussion purposes: A. Training & Capacity Building; B. Services & Supports; C. Partnerships & Advocacy.

WHAT'S NEEDED: #1 TRAINING & CAPACITY BUILDING

"We are interested in getting more training in ways to learn about behavior; make positive changes. We are grateful and very interested in disabilities and in getting more skills in how to deal with difficult behavior."

"I would definitely like to learn more about disability kids – keeping them full-time."

"I would be very interested in training – especially disability training, because I would like to learn more to help take care of the kids."

"I would really like to attend a disability training, or any training really. I could use some help in how to get the kids to listen."

"I would definitely like disability training. I think that would be really useful."

"She has an EA at school, but a lot of the EAs have no training and some of them do nothing at all. Now she is reading and she is a great artist, but it is hard. She could be doing so much better and make better progress if she actually had people working with her that know things and have training and education about how to help kids like her."

In the area of training and capacity building, there needs to be more opportunities for caregivers, staff, and children and youth in the system to further their knowledge and experience with concepts, techniques, interventions, and knowledge that are relevant to their lives. In terms of capacity, caregivers feel that agencies, organizations, and departments that provide services (including CFS agencies and schools) need to invest in their

staff and ensure that their workers have the training and support required to do a good job and truly provide a quality service.

WHAT'S NEEDED: #2 SERVICES & SUPPORTS

"She gets nothing – no help, no services. In the community there is nothing.

ASSESSMENT & DIAGNOSIS

"She needs an assessment, but we haven't figured out how to go about that. It is important and we need to know how to fill out forms and claim disability and all of that."

"Getting an assessment or diagnosis is very important for her to get support and to improve. That is why we are here – to help her improve and move forward, to get better."

"It is important to get a diagnosis or a label so we can know what's going on and how to deal with her and the best ways to help her."

RESPIRE

"Quality of care is a major concern because in smaller or rural clinics sometimes you don't get the same quality of care as you get in bigger centers or cities...there isn't really follow up."

"Respite is an important thing that is not really available to families. People have no special training, so it would be good to develop that so that people who need help or a break can get it and know that their kids are safe and well taken care of."

AGENCY

"We've had her for 3 months now and there has not been a single home visit. I think the agency needs to do more home visits and be more involved with the families."

From caregivers, there is a consistent demand for more services across all areas of physical and mental health. Many lamented the lack of quality services and supports available on reserve and two of the most important areas, from caregiver perspectives, are Assessment/Diagnosis and Respite. Caregivers are very much interested in having an actual respite program established where they would have safe options that they would not have to set up themselves. The assessment and diagnostic process can be extremely complicated and involved referrals that may take upwards of two years to result in any actual service or appointment. Caregivers require greater assistance and support in navigating the health system and would like to see more timely and simple to access assessment services available.

WHAT'S NEEDED:
#3 PARTNERSHIPS & ADVOCACY

INFORMATION SHARING

"The agency just dropped her off. They didn't give us any information – no health card, no report card or school information, no medical information, nothing about her family or where she came from. Nothing, nothing. We had to do everything by our selves."

"He was also referred to a counsellor – but I thought that is all she, the psychologist, did was medicate and increase his dose, so I thought that we don't need to go there."

"I think FSIN or PAGC works with the school to see kids with behavior problems. PAGC comes every year, or a couple times a year to do assessments and referrals. I think she had an assessment before."

"The only service, I guess you could say, that she gets is the youth program through the agency. They pick her up, but there is no information sharing, so we never really know what they are doing or when. A monthly calendar or something like that would be really good to have."

CAREGIVER SUPPORT NETWORK

"It would be good to have a foster parents group – to help each other, to get a louder voice to change some things and to support one another."

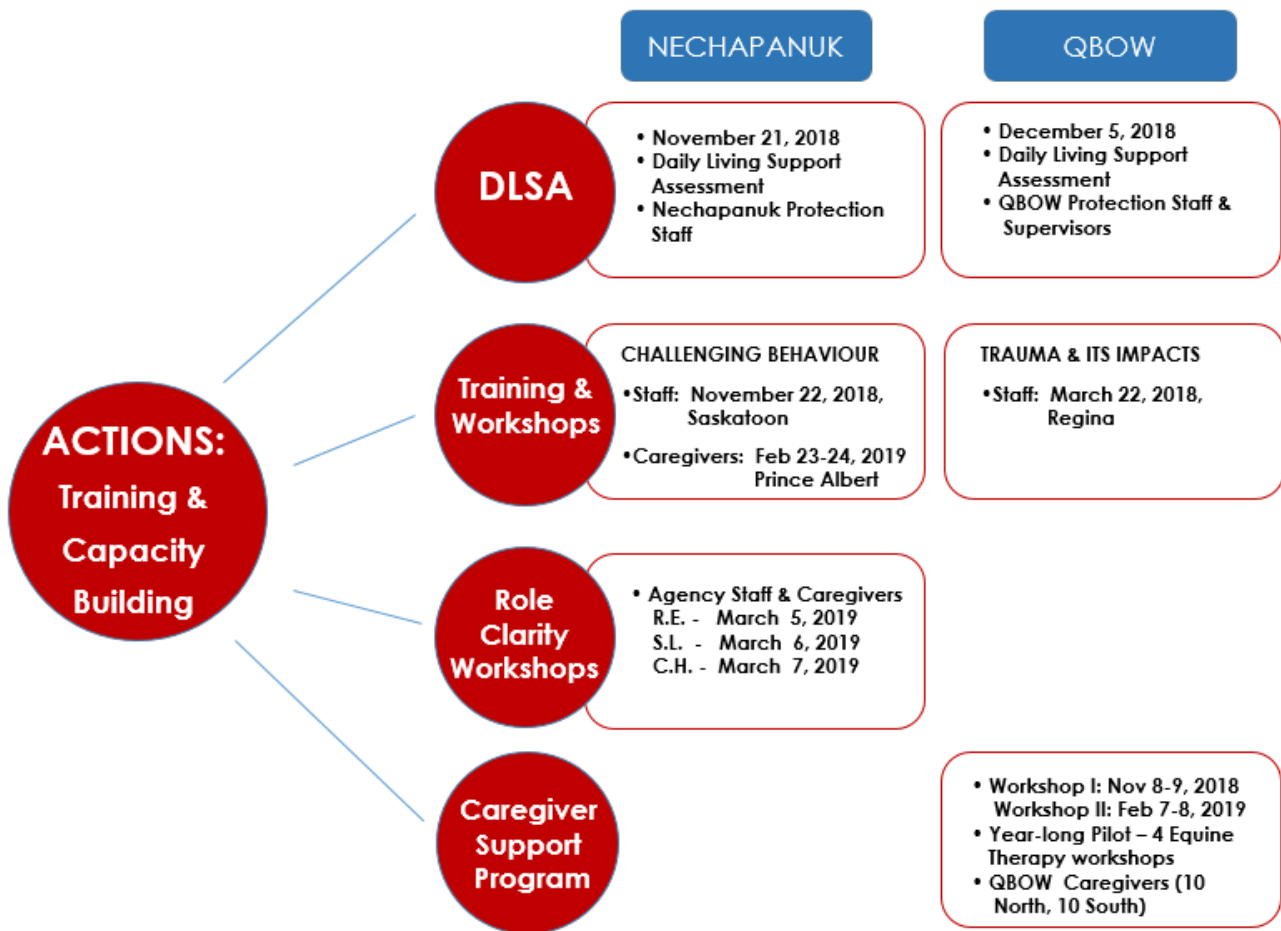
The final area of need identified by caregivers was Partnerships and Advocacy. Here, a focus of the recommendations and requests of participants was related to information sharing – both at an inter-agency level and a personal level. Caregivers are eager to see an improvement in the flow of information and in the frequency and consistency with which that information is shared. Secondly, caregivers are also keen to establish, or have the agency facilitate, a caregiver support group, or network. They feel it is important and extremely valuable to meet with other who share many of the experiences, successes, and frustrations that they do. They also see such a group or network as an opportunity for advocacy and more effectively voicing concerns or recommendations.

All in all, the caregivers who participated in this project are a passionate, dedicated group, very much invested in providing the best possible care to the children placed in their homes. They are motivated and engaged and

interested in learning more and furthering relevant skill sets. In the case of both agencies it appears that there is not enough engagement of caregivers, as a group. Caregivers welcome visits from agency staff and are desperate for more information on the children placed with them. When combined with the results from the DLSA Caregiver focus groups, there are many clear priorities that should be considered by agency staffs and boards. The role of caregivers in the child welfare system is so vitally important, that agencies would do well to consider additional means of ensuring the voices of their caregivers are heard and that they are meaningfully engaged – through trainings, events, and possibly, regular group meetings.

ACTIONS

A main component of the Disability Research Partnership Project is Actions – the various trainings or events that are organized in response to the needs, priorities, and wishes of project partners and participants. In this year's project, four main actions were organized, some for both agency and some specific to each. The diagram below provides a summary of the project actions which are described in further detail below:



Daily Living Support Assessment (DLSA)

The Daily Living Support Assessment (DLSA) is a functional assessment used to determine the impact of disability on daily living:

- It should be completed for each child in out of home care with developmental delay and/or physical disabilities and/or high needs
- MSS (Ministry of Social Services) provides the training, which is required in order to do a DLSA with an agency caregiver
- The results of the DLSA determine how much additional funding the caregiver is eligible for

Through the project we were able to connect with the provincial trainers in the Ministry of Social Services and host trainings for the protection staff of both

QBOW and Nechapanuk. These training sessions enable all those who complete the training to conduct the DLSA annual interviews with clients and support qualifying caregivers with additional funding and supports.

TRAINING & WORKSHOPS

Based on the priorities and preferences of each agency partner, separate workshops were organized.

Nechapanuk was most interested in learning more about Challenging Behaviour and providing training opportunities for both staff and caregivers to help develop knowledge and practical skills in dealing with such behaviours. On November 22, 2018 Nechapanuk staff participated in a one-day workshop by behavioural specialist Dr. Cassandra Philips. An expanded version of the workshop was then offered, over two full days, to 50 Nechapanuk caregivers in February. The topics and skill development areas covered included:

- The Functions of Behaviour
- Addressing Tantrums and Defiance
- Measuring Intervention Impact
- Consistency and Response
- Caregiver Styles
- Addressing Grief
- ADHD, Dyslexia, FASD, Autism
- When to intervene



*Challenging Behaviour
Training-Staff
November 22, 2018*



*Challenging Behaviour
Training-Caregivers
February 23, 2019*

Both staff and caregivers found the workshop extremely beneficial. Below are highlights from the caregiver feedback after attending the two-day training:

	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
I learned a lot of new information about disabilities and special needs	0	0	10 of 44 (23%)	34 of 44 (77%)
I learned new useful skills and techniques for dealing with challenging behavior	0	0	7 of 44 (16%)	36 of 44 (84%)
I will use the knowledge and skills that I learned	0	0	8 of 44 (18%)	36 of 44 (82%)

98% (39 of 40 who answered the question) recommend this training.

Participant Feedback Quotes:

"Very good workshop- learned about lots of info! We need these workshops back home."

"Everything was very important and I would use these tools at home."

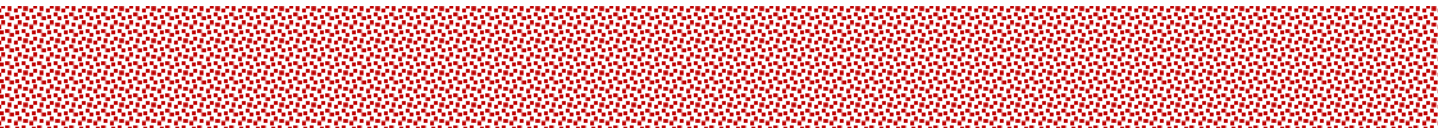
"There should be more workshops like this for First Nations communities."

"Very good info given and understandable. I'm glad I came to this workshop!"

Role Clarity Workshops

The Role Clarity Workshops were a 2-3 hour workshop facilitated by the SFNFCI SDM Consultant and Ministry of Social Services First Nations and Metis Consultant who work with Nechapanuk. These workshops

- Outlined child welfare policies and procedures related to Nechapanuk (including contact standards, legal status, guardianship, etc.)
- Addressed importance of communication and working together



- Gave Caregivers an opportunity to ask questions, voice concerns, and share ideas and experiences

QBOW Caregiver Support Program

The Caregiver Support Program was designed in partnership with QBOW and is based around equine therapy. The agency had already established a working relationship with a local equine therapist, so this program was a formalized pilot that built on this relationship to provide training and support to 20 agency caregivers. The purpose, goals, and objectives of this program are:

Purpose:

The purpose of the Caregiver Support Pilot Program is to develop and evaluate a program that will provide training, therapeutic support, and practical skills to QBOW caregivers in an effort to establish a long-term and culturally relevant support program for agency caregivers. An overview of the program along with goals, objectives, and feedback are provided below.

Goals:

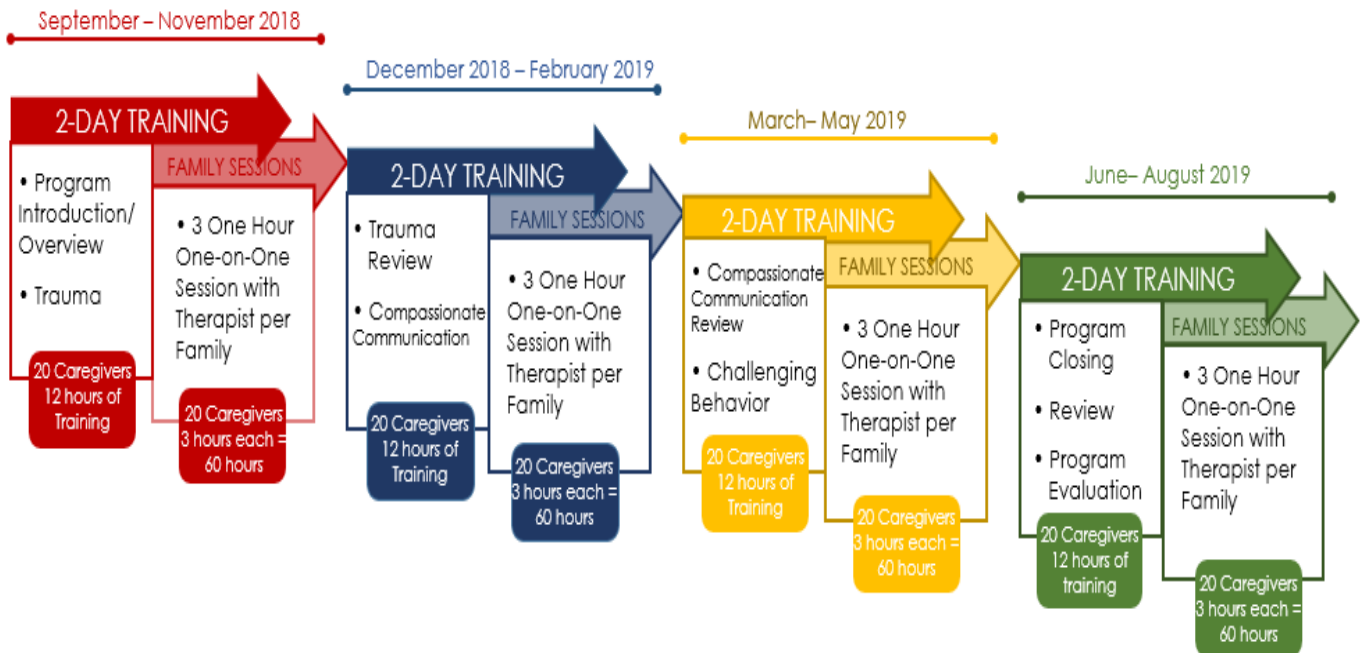
- Develop and evaluate a pilot program to support QBOW caregivers
- Increase the knowledge, skill, and experience of caregivers in three core areas:
 1. Trauma;
 2. Communication; and
 3. Managing challenging behaviours
- Provide a safe and supportive environment for learning, sharing, and connecting with other caregivers
- Offer caregivers and the children/youth in their care an opportunity to experience Equine Therapy and its potential benefits (emotional and psychological healing, compassionate interaction, self awareness, etc.)

Objectives:

- Utilize culturally relevant practices and resources to support caregivers
- Bring a diverse group of QBOW caregivers together for a series of hands-on training workshops (48 hours of training through four 2-day workshops)

- Facilitate connection and relationship building between caregivers
- Contract local therapist, Beatle Soop (Elkdog Equine-Assisted Counseling) to develop and deliver training and therapy sessions tailored to the particular needs of QBOW Caregivers
- Provide monthly one-hour sessions of one-on-one equine therapy for each family in order to reinforce and further develop the skills and knowledge taught in the workshops
- Conduct a pre- and post- evaluation with all participating caregivers in order to evaluate the success of the program

This pilot program is one full year- beginning in the fall of 2018. The program includes both group workshops and individual therapy sessions. The chart below summarizes the program and the key activities, described in further detail after.



Key Activities

- Workshops

- Four two-day workshops are the core of the Caregiver Support Program. In these workshops, therapist Beatle Soop will deliver curriculum and facilitate activities that promote greater awareness, deeper understanding and also fundamental skills that will support participants in their caretaking of children and youth.

- Each 2-day workshop will include 12 hours of training on a specific topic. The topics to be covered throughout the Program are:

1. Trauma

- What is trauma? How does trauma impact the body and brain? How can trauma be treated and healed?

2. Communication

- What is compassionate communication? How can conflicts be transformed into moments of learning and connecting to what is most important to us and others?

3. Managing challenging behaviours

-How do you identify the functions and roots of behavior? What are some strategies and skills for responding to difficult behavior?

- One-on-one Equine Therapy Sessions

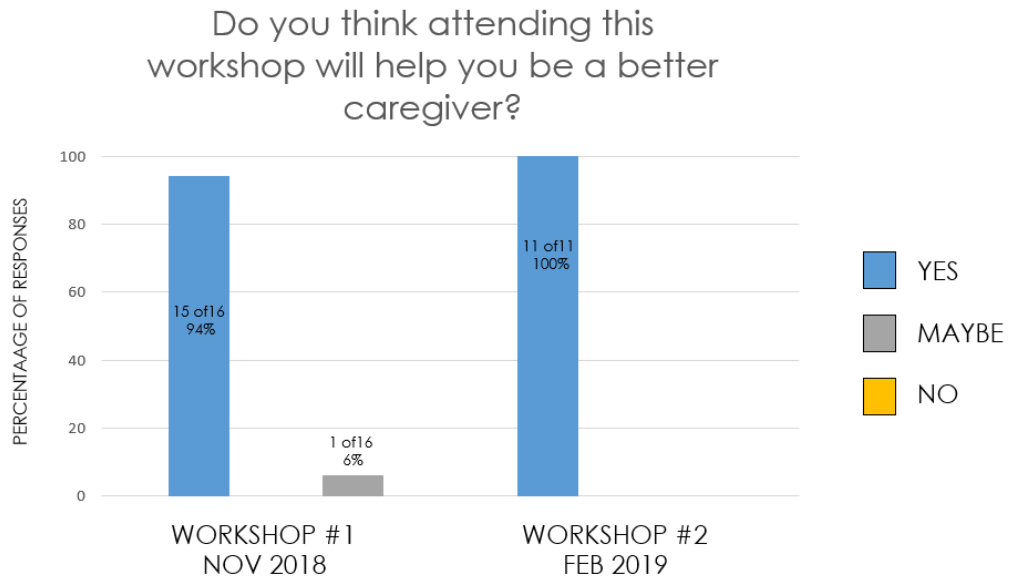
- Each family will receive three one-hour therapy sessions following each workshop. This works about to approximately one session per family per month. While the workshops are geared towards adult caregivers, these sessions are meant for the whole family and will include the youth/children in care.

-These monthly sessions will build on the information and skills covered in the workshops and provide an opportunity for the therapist to work directly with the family on specific needs or challenges that are particular to them.

- Evaluation

-Because this is the first time QBOW is offering structured programming or training to Caregivers, this pilot project will include evaluations and feedback processes that will identify: strengths and weaknesses of the program/format; beneficial outcomes; financial feasibility; feedback from both caregivers and the children/youth in their care; input from program therapist.

Feedback results from the 2 workshops offered through the Disability Project



Participant Quotes

"I have children in my care that suffer from trauma from youth and I learnt a lot why they are the way they are."

"Learning more and more as we go!"

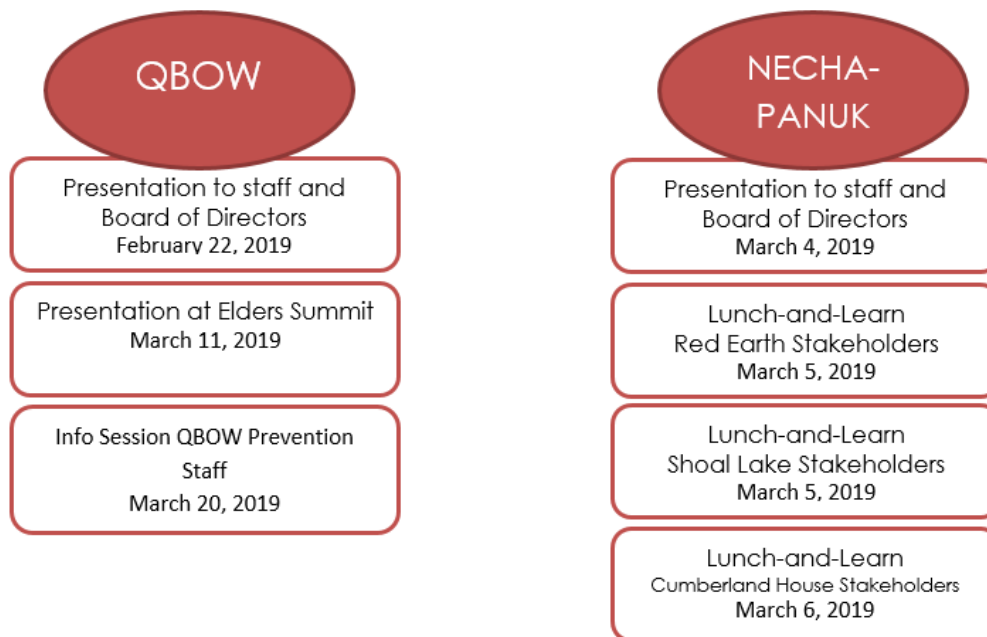
"The training opened my eyes to see a different perspective."

"Thanks for the opportunity to improve our fostering. Excellent workshop. Hope to see more!"



RESULTS SHARING

Near the close of the project, results were shared with agencies and stakeholders through a series of presentations and events. These presentations and discussions allowed project participants to vet their contributions along with the interpretations and results from the project overall. Feedback from the sessions, for both agencies, were taken into account and incorporated into this final report.



*Shoal Lake Lunch and Learn
March 6, 2019*



RECOMMENDATIONS

Overall, the results of this project point to a need for **more information** and **more support**. These needs apply equally to agency staff, caregivers, and children/youth in the system. The words of one caregiver are a poignant reminder of what is at stake as we consider the results and recommendation from this project:

“There are really so many things that need to change, and the sad thing is, it’s the kids and the kids that can’t speak up for themselves especially, that suffer the most because of it.”

One way of ensuring that the suffering of children is minimized is to establish a **stronger continuum of care** for families in the communities served by QBOW and Nechapanuk. This means programs, services, and supports that begin before a family becomes involved with the agency and continue after a youth ages out of care.



The core recommendation, then, is that agencies focus on programming, partnerships, and capacity building before, during, and after a child comes into care.

BEFORE CARE

PROGRAMS

FNCFS agencies are continually strengthening their Prevention programming, and this project attests to the importance of this work and the need to support families before they reach a point where their children must be removed. One of the top recommendations of this report is to develop meaningful, community-based and culturally-relevant programming that addresses many of the complex factors that contribute to children coming into care:

- Poverty
- Housing
- Trauma
- Addictions
- Violence

It has been noted that

Economically distressed areas experience higher rates of child maltreatment reports that often correlate with inadequate housing and single-parenthood. Community poverty has also been linked to health disparities and language development in children. Naturally, this implies that interventions at the level of the community are critical for children's development, especially in disadvantaged circumstances. (Institute of Fiscal Studies and Democracy, 2018, p. 56)

In the context of the communities served by the two partner agencies in this project, such issues as housing and poverty are definite factors impacting the health and safety of families. Additionally, UNICEF's *Child Protection Strategy* states that

Responsive child protection systems should build on the strengths of issue-specific programming by ensuring that specific forms of vulnerability are addressed, including those related to gender, disability, HIV, and indigenous populations, and be able to measure outcomes for different groups. (UNICEF, 2008, p. 8)

It is crucial then, that agencies develop programming that confronts various social determinants of health and wellbeing.

In the area of programing it is also recommended that a priority be to support cultural identity and community connection. Resilience involves “processes that draw from multiple sources of strength and resources to allow people to face, live with, manage and overcome challenges” (Kirmayer et al., 2009, p. 63). Agency Prevention programming should have as a primary aim increasing the resiliency of its community members – an aim which can be successfully achieved by concentrating on culture and cultural practices. Kirmayer (2009) states that

Resilience theories emphasize the importance of family, community and culture in countering the stresses that families encounter. Culture and community can provide a sense of mastery, self-esteem and ethnic identity. Resilience in this context involves holistic, complex and interacting relationships that balance the whole person from a mind, body, spirit and social-environmental perspective. (p. 66)

Many others have similarly emphasized the positive and protective effects of a strong cultural identity- “Culture and ethnic identity can exert positive influences on family resilience. Culture helps families to make sense of change and is a source of stability and support and a way of dealing with the problems of daily life” (McCubbin & McCubbin, 2005, P. 32). Both agencies should focus efforts on responsive, relevant programs that are grounded in local culture – using local languages, practices, ceremonies, and beliefs to support the health and strengthening of families.

Partnerships

Before families become involved with the child welfare system, agencies should work to develop strategic partnerships (within and beyond the community) that support interagency collaboration and create a more holistic and complete support system for local families. CFS agencies cannot be solely responsible for the health and support of communities, however they can, through strong

partnerships, help to close gaps and create a more easy to navigate system of services and supports that address the complex needs of families. Shannon & Tappan (2011) suggest that "Viewing CPS as a catalyst for services rather than the sole service provider can change negative perceptions that families have of CPS. CPS systems can focus on bringing community partners together to support the needs of children with developmental disabilities and their families." (p. 304). It will be important then not only to develop, but also to share information about the agency and its programs and services – to raise awareness as to what is offered through the agency, but also to counteract the sometimes negative or fearful views that community members may hold towards the agency. Another recommendation in this area is to create a Resource Book with service provider information (e.g. ECIP, FASD Network, etc.). This could be a great resource for agency staff, allowing them to provide up to date information directly to clients.

Capacity

When it comes to increasing capacity, the primary recommendation is to train all staff in DLSA, disabilities, and trauma. Research shows that many child protection workers admit that they lack knowledge on how to screen for maltreatment among children with a disability (Orellove, Hollahan, & Myles, 2000) and what the best or most appropriate intervention may be (Sobsey, 1994). This is true of the workers at QBOW and Nechapanuk as well, with many expressing a desire for more specific knowledge on disabilities and special needs. Researchers have also outlined why it is important for child welfare professionals to be able to identify children with disabilities and special needs:

First, children with developmental disabilities are more likely to be maltreated than are children who do not have developmental disabilities.... Second, Child Protection Services (CPS) systems already

serve significant numbers of children with developmental disabilities ... Third, developmental services are critical for children who enter CPS systems because they often have unmet developmental needs ... Finally, the CPS screening and investigation process offers an opportunity to identify disabilities and refer for services and community supports regardless of maltreatment substantiation. (Shannon & Tappan, 2011, p. 297)

Following this logic, it makes sense for FNCFS agencies in the province to increase their knowledge and familiarity not only with the characteristics of certain conditions but also the services and supports that exist. Similarly, the knowledge and skills of caregivers should also be a priority since they are the ones responsible for the daily lives and wellbeing of children and youth in care.

In terms of agency- specific capacity, the value of consistent documentation and data collection should inform more diligent practices and inspire ways of collecting information that makes sense within the context of that specific agency. These methods and means of data collection should not be an added burden for case workers, but be integrated into existing practice and requirements as much as possible. Along similar lines, caseloads should be kept to a minimum to enable adequate time for workers to effectively document their work and to support stronger relationship development between workers and clients.

In Care

Programs

Building on the recommendations for programming 'Before Care', the agency should develop innovative, culture-based programming that responds to the needs and priorities of the children and families coming into care. Once a child comes into care and the agency begins working with the family, there should be services and supports that respond directly to their needs – perhaps

in the area of trauma, adjustment, grief and loss, etc. When the agency develops and offers relevant programming, it should be widely advertised in order that clients and community members may take advantage and participate. Programs should also be delivered consistently, with weekly and/or monthly schedules being shared. As one caregiver shared- "They [the agency prevention staff] pick her up, but there is no information sharing, so we never really know what they are doing or when. A monthly calendar or something like that would be really good to have."

Partnerships

As with the previous programming category, the recommendations in the area of partnership for the in-care phase also suggest strengthening relationships with partners through regular interagency meetings/events and inclusive case planning. It is also recommended that opportunities for cost and resource sharing, particularly for larger programs/events, be sought out since these too can contribute to increasing knowledge and capacity within communities.

Strategic partnerships are particularly recommended in relation to assessment and diagnosis processes. From not knowing who to call or where to start, to excessive waitlists and the logistics of traveling out of the community for appointments, accessing assessment and diagnostic services can be extremely challenging. It is recommended therefore that the agency establish partnerships with relevant agencies and departments to explore new and innovative ways to create a streamlined process and easier access to assessment/diagnostic services. As the Jordan's Principle Working Group noted in their 2015 report, "inequitable access to programs and services actually drives up the number of First Nations children in foster and other out-of-home care" (p.8).

Capacity

The capacity building recommendations for this phase relate, again, to the need for ongoing support for workers in relation to documentation and data collection. It is also essential that early and strong case planning happen with families in ways which empower, engage, and motivate families.

Additionally, one recommendation that would contribute to an agency's capacity is the adequate training and support of staff. Particularly in the area of prevention, those staff who are tasked with developing and running programs should be specifically trained, certified, and supported in those particular program areas in order that they have the knowledge, skills, and confidence to effectively run programs and support community participants.

Agency capacity may also be increased by adding additional positions that

- contribute to the overall health and happiness of staff
 - for example adding a Mental Health therapist and/or Elder to the staff to work specifically with agency workers and clients
- address specific needs or areas of specialization, for example:
 - Birth Family Support Worker (who concentrates on working with the parents/families who have had their children removed)
 - Transition Worker (who concentrates on the youth aging out)
 - Service Coordinator (who could develop a specialized knowledge of services (medical, mental health, recreation, etc.) and the related processes of application, referral, access, transportation, etc. This person could help families and caregivers navigate those service systems)
 - Culture Worker (who would specialize in cultural programming, including offering/coordinating ceremonies, culture camps, storytelling sessions, language classes, etc.)

After Care

Programs

When focusing on youth nearing the point where they will transition out of care, it is important to offer programming and services geared specifically to this group, focusing on relevant topics such as cultural identity, self-esteem, life skills, financial literacy, etc. As indicated in programming recommendations above, the focus should be on instilling a strong sense of First Nations identity in the youth. It is a well established fact that connecting youth with their culture and ensuring that they know who they are and where they come from serve as protective factors. Other aspects of First Nations culture, for example, “valuing children as gifts from the Creator or close relationships with extended family members, also serve as protector factors. Further, manifestations of one's culture through ceremonies and language are important sources of pride and self-esteem” (Dion Stout & Kipling, 2003; First Nations Information Governance Centre, 2014) (see Appendix 4 for a list of Cultural Activities Known to Contribute to Resilience).

One valuable programming recommendation could be to create a Kids in Care Network with specific roles for youth who have aged out. Such a network could celebrate successes and cultural identity, identifying key factors in successful transition and providing opportunities for youth who have been through the system to have a voice and to give back and guide younger children/youth who are still living in care.

Many project participants voiced concern over the fact that when youth with special needs or complex medical needs age out of care, there is nowhere for them to go. It is recommended therefore, that supportive living or Adult homes be created on reserve to provide a safe place for adults to live semi-independently within the community.

Partnerships

Here, strategic partners would be those, on and off reserve, who serve young adults and adults. These may include Community Living Services Division (CLSD) or other organizations targeting employment, training, etc. It is also recommended that agencies partner with their Bands to establish long term infrastructure (housing, services, employment, etc.) for older youth and adults with special needs.

Capacity

Building on the recommendations set forth in the previous two phases, capacity building in relation to 'after care' could involve the addition of a dedicated position focused on youth aging out and post-care transitions. The priority areas for growth and development in this phase should be identified, at least in part, through community engagement where current and past youth in care, caregivers, and other service providers who serve this population could meaningfully contribute their ideas, concerns, and suggestions. It is also recommended that the agencies develop ways to keep in contact and collect information and longitudinal statistics on youth who age out.



*Cumberland House Final
Results Lunch and Learn*

March 7, 2019

Recommendations Summary

	PROGRAMS	PARTNERSHIPS	CAPACITY
BEFORE CARE	<ul style="list-style-type: none"> -Develop culturally-based prevention programs that address: <ul style="list-style-type: none"> • Poverty • Housing • Trauma • Addictions • Violence - Offer programs that develop and support cultural identity & community connection -Regularly evaluate and update programming 	<ul style="list-style-type: none"> -Develop strategic partnerships (with Health, Education, Social Dev'tment) that support interagency collaboration - Create a Resource Book with service provider info (e.g. ECIP, FASD Network, etc.) - Share info about the agency and its programs and services 	<ul style="list-style-type: none"> - Train all staff in DLSA, disabilities, and trauma - Offer regular training and workshops for Caregivers - Complete community Needs Assessments - Keep case loads low - Consistent documentation and data collection
IN CARE	<ul style="list-style-type: none"> - Develop innovative, culture-based programming that responds to the needs and priorities of your communities - Advertise program information and monthly schedules - Ensure that program staff are adequately trained, certified, & supported 	<ul style="list-style-type: none"> - Support relationships with partners through regular interagency meetings/events and inclusive case planning - Cost and resource share for larger programs/events -Establish partnerships to create a streamlined process for assessment/diagnosis 	<ul style="list-style-type: none"> -On going support for workers re: documentation and data -Early & strong case planning with families - Create additional positions: <ul style="list-style-type: none"> • Mental Health therapist/Elder • Birth Family Support Worker • Transition Worker • Service Coordinator • Culture Worker
AFTER CARE	<ul style="list-style-type: none"> - Develop programming for youth 16 + (cultural identity, self esteem, life skills, financial literacy, etc.) - Create supportive living/ Adult homes on reserve - Create a Kids in Care Network with specific roles for youth who have aged out 	<ul style="list-style-type: none"> - Strengthen working relationships with CLSD, and other organizations on and off reserve that serve adults - Partner with Band to establish long term infrastructure (housing, services, employment, etc.) for youth with special needs 	<ul style="list-style-type: none"> - Develop ways to keep in contact and collect info and longitudinal stats on youth who age out - Create a position dedicated to youth aging out/transitions

The results and recommendations of this project emphasize the importance of building and supporting cultural identity through relevant and responsive programming. In order to successfully achieve this, there needs to be substantial and consistent investment in the capacity of agency staff, caregivers, and communities overall. These investments may take the form of

training, more open and reliable information sharing, and opportunities for stakeholders to become meaningfully involved in community activities and strategic planning.

“Indigenous children living with disabilities and their families, no matter where they live, deserve no less than the coordinated and collective efforts of many advocates, activists, educators, researchers, policymakers, and funders to help transform jurisdictional and funding challenges into a helpful path forward.” (Johnson, 2015, p. 10). This project, and the foundation of knowledge it establishes and the recommendations it offers, represent meaningful and actionable means of clearing this ‘path forward.’ The type of partnerships that are the foundation of this project demonstrate the value of collaborative work for improving outcomes for the participating agencies and vulnerable members of their communities.

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APPENDIXES

Appendix 1 Consent Form



DISABILITY RESEARCH PARTNERSHIP 2018-19

Consent Form

PROJECT Disability Research Partnership 2018-19

The main goal of this project is to better understand the needs of children and youth in care with disabilities to better serve them.

- This project began in May, 2018 and ends in March, 2019
- The goals of this project are to:
 - Establish a culturally-relevant definition of disability
 - Document:
 - the nature and incidence of disabilities among children/youth in care within the participating communities
 - the impacts of disability
 - service gaps and needs
 - Use a data collection instrument to gather relevant information from participating Child & Family Services (CFS) agency case files
 - Organize actions (trainings, resources, etc) to further support the agencies in their work with children and youth with disabilities

FUNDER: Indigenous Services Canada (ISC)

RESEARCHERS: The lead researcher in this project is Raissa Graumann who works as a research for Saskatchewan First Nations Family and Community Institute (SFNFCI). She will work in partnership with the executive directors from each participating agency and the research assistants appointed to the project.

COLLECTING INFORMATION: The Researchers will be collecting information from current agency child protection files with the 'Disability Information Tool.' They will also do interviews with families and service providers within the communities served by the agencies. All project work will be done in a good and respectful way.

BENEFITS & RISKS: There are no expected risks of participating in this project, however, some of the questions may be personal or sensitive and could cause emotional discomfort or distress. We do not intend to cause any harm and will support you as best we can. Our agency partners are trained social workers and we can connect you with local elders or additional resources if you need help or support.



DISABILITY RESEARCH PARTNERSHIP 2018-19

The benefits of participating may include:

- increasing how much people know and understand about disability experiences in remote, First Nations communities
- helping to voice the community's thoughts and ideas related to disabilities

PARTICIPATION: If you want to participate in this project it is completely up to you. You can quit the project at any time and for any reason. If you do not want us to use your interview, you can just let us know and we will destroy all digital and print copies. If you decide to participate you will talk to the researchers for about one hour – it might be shorter or longer, but you can stop whenever you want.

GIFTING FOR PARTICIPATION: Reciprocity and gifting are First Nations traditions and one of SFNCCI's core values is respect. So, each participant will receive a gift for sharing their knowledge, stories, and time.

PRIVACY: Many steps will be taken to keep your information confidential and to protect your identity:

- All consent forms will be kept in a locked cabinet that only the lead researcher and her direct supervisor can access
- All of the digital files related to this project will be stored on a password protected computer
- Every participant will be given a pseudonym (fake name) or be called by a descriptor (for example a teacher, a parent, a worker, etc.) in all reports and written documents in the project
- The researchers have all signed Oaths of Confidentiality where they promise to protect your information
- No personal information will be released to anyone else for any reason

Nothing you say in these interviews will affect any of the services you receive from the CFS agency you work with or any other agency involved in the project.

DATA STORAGE: We will make a recording of our conversation. This recording will be saved on the Researcher's computer, which is protected by a password. If you want a digital or print copy of your interview, please ask the Researchers.

SHARING THE RESULTS: Presentations, reports, and articles will be created from the interviews and information gathered in this project. Your name will not be used. These will be shared with participants, organizations, and the general public. You can get a copy of the final report from ADCFS or SFNCCI.



DISABILITY RESEARCH PARTNERSHIP 2018-19

AGREEING TO PARTICIPATE (PARTICIPANT COPY):

I, _____ (print your name), understand all of this information about the Disability Research Project. I agree to participate in this project as it is described above.

I have signed two copies of this form. I will keep one copy for myself and give the other copy to the Researchers.

Name of Participant

Community

Signature of Participant

Date

Name of Researcher

Signature of Researcher

Date

If you have any questions or concerns, please contact us:

Raissa Graumans

Researcher- SFNFCI
306-373-2874 ext. 223
raissa@sfnfci.ca

Shelley Thomas Prokop

Director of Programs- SFNFCI
306-373-2874 ext. 227
shelley@sfnfci.ca

AGREEING TO PARTICIPATE (PROJECT COPY):

I, _____ (print your name), understand all of this information about the Disability Research Project.

I agree to participate in this project as it is described above.

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Appendix 2 Disability Information Tool

Disability Information Tool: Disabilities and Functioning of Children in Care Disability Research Partnership 2018-19

1. Agency:		2. Date Completed: ____/____/____ Day Month Year			
SECTION A: DEMOGRAPHICS					
3. GENDER		<input type="checkbox"/> 1-Female		<input type="checkbox"/> 2-Male	
		<input type="checkbox"/> 3-Other: _____			
4. AGE	Date of Birth			8. SCHOOL LEVEL	
	Day	Month	Year		
5. Age when Case Opened		6. Current Age		[] 2-Home-schooled	
				[] 3- Post-Secondary	
7. TOTAL TIME IN CARE				[] 4- Special Program in School	
				[] 5- Does not attend school	
9. ABORIGINAL STATUS	<input type="checkbox"/> 1-Not Known		<input type="checkbox"/> 2-Status (Treaty)		<input type="checkbox"/> 3-Metis
	<input type="checkbox"/> 4-Non-Aboriginal		<input type="checkbox"/> 5-Non-Status		<input type="checkbox"/> 6-Inuit
			10. LANGUAGE SPOKEN		[] 1-Cree
					[] 2-Dene
					[] 3-Nakota/Dakota/Lakota
					[] 4-Saulteaux
					[] 5-English
					[] 6-French
					[] 7-Other: _____
SECTION B: CHILD WELFARE INFORMATION					
Make 2 entries below. Use "F" for legal status when CASE FIRST OPENED and "C" for CURRENT legal status					
11. LEGAL STATUS		<input type="checkbox"/> 1-Apprehension		<input type="checkbox"/> 2- Sect. 9	
		<input type="checkbox"/> 3- Temp Ward (3/6 mnths)		<input type="checkbox"/> 4- PSI-Definite/Indefinite	
		<input type="checkbox"/> 5- Sect. 56-Ext. of S'pprt		<input type="checkbox"/> 6- Sect. 10: 16/17 Pgrm	
		<input type="checkbox"/> 7- Supervision Order		<input type="checkbox"/> 8- Long-term Ward	
		<input type="checkbox"/> 9- Permanent Ward		<input type="checkbox"/> 10- PSA	
Make 2 entries below. Use "F" for placement when CASE FIRST OPENED and "C" for CURRENT placement					
12. PLACEMENT		<input type="checkbox"/> 1-Foster Home		<input type="checkbox"/> 2-First Nations Group Home	
		<input type="checkbox"/> 3- In Home		<input type="checkbox"/> 4- P.S.I.	
		<input type="checkbox"/> 5- Group Home Name: _____		<input type="checkbox"/> 6- Treatment Facility	
				<input type="checkbox"/> 7- AWOL/Unknown	
				<input type="checkbox"/> 8-Alt Care Giver	
13. Total Number of Placements: (number of times moved)			14. Total Number of Apprehensions:		
15. Does this child/caregiver of child receive Daily Living Support Assessment (DLSA) funding? <input type="checkbox"/> Yes <input type="checkbox"/> No					
16. Reason(s) for Coming Into Care		<input type="checkbox"/> 1- Physical Abuse		<input type="checkbox"/> 2- Emotional Abuse	
		<input type="checkbox"/> 3- Sexual Abuse		<input type="checkbox"/> 4- Neglect	
		<input type="checkbox"/> 5- Voluntary			
17. Provide brief summary of reasons for coming into care/apprehension context:					
SECTION C: HEALTH CONDITION					
Addictions, Self Harm, & Suicide					
18. Type of Addiction/Substance Abuse:			19. Types of Self Harm:		
<input type="checkbox"/> i. No addiction issues/too young			<input type="checkbox"/> i. No self-harm behavior/too young		
<input type="checkbox"/> ii. Alcohol			<input type="checkbox"/> ii. Cutting/Picking/Burning		
<input type="checkbox"/> iii. Drugs			<input type="checkbox"/> iii. Hitting or Injuring Self		
<input type="checkbox"/> iv. Solvents			<input type="checkbox"/> iv. Other: _____		
<input type="checkbox"/> v. Other: _____					
20. Types of Suicidal behavior:					
<input type="checkbox"/> i. No suicidal behavior/too young					
<input type="checkbox"/> ii. Talking about or threatening to kill or hurt themselves					
<input type="checkbox"/> iii. Talking about or threatening to kill or hurt themselves resulting in professional treatment					
<input type="checkbox"/> iv. Single unsuccessful attempt - no hospitalization					
<input type="checkbox"/> v. Multiple unsuccessful attempts - no hospitalization					
<input type="checkbox"/> vi. Single unsuccessful attempt resulting in hospitalization and/or medical/psychiatric treatment					
<input type="checkbox"/> vii. Multiple unsuccessful attempts resulting in hospitalization and/or medical/psychiatric treatment					
<input type="checkbox"/> viii. Other: _____					

21. Condition				2. PHYSICAL / MEDICAL			
1. INTELLECTUAL/DEVELOPMENTAL				2. PHYSICAL / MEDICAL			
	Diagnosed	Awaiting Assessment	Suspected		Diagnosed	Awaiting Assessment	Suspected
1.a. Down's Syndrome	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.	2.a. Cerebral Palsy	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.
1.b. FASD	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.	2.b. Acqrd Brain Injury	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.
1.c. Autism Spectrum	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.	2.c. SpinaBifida	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.
1.d. Dev'mental Delay	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.	2.d. Epilepsy	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.
1.e. Other:	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.	2.e. Other:	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.
3. EMOTIONAL/ BEHAVIORAL				4. LEARNING			
	Diagnosed	Awaiting Assessment	Suspected		Diagnosed	Awaiting Assessment	Suspected
3.a. ADHD/ADD	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.	4.a. Learning Delay	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.
3.b. OCD	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.	4.b. Dyslexia	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.
3.c. ODD	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.	4.c. Language Processing Disorder	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.
3.d. Anxiety Disorder	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.	4.d. Other:	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.
3.e. Eating Disorder	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.	22. Condition Section Notes:			
3.f. Schizophrenia	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.				
3.g. Other:	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.				
5. SENSORY							
	Diagnosed	Awaiting Assessment	Suspected				
5.a. Blindness	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.				
5.b. Deafness	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.				
5.c. Sensory Processing Disdr	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.				
5.d. Other:	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	<input type="checkbox"/> iii.				
SECTION D: ASSESSMENT, DIAGNOSIS, AND SERVICES							
If child has a formal DIAGNOSIS, fill in A & B							
23. Date of Diagnosis:	<input type="checkbox"/> i. At Birth			24. Who made the Diagnosis?	<input type="checkbox"/> i. Medical Doctor		
	<input type="checkbox"/> ii. ____ / ____ / ____ Day Month Year				<input type="checkbox"/> ii. Psychologist		
	<input type="checkbox"/> iii. Diagnosis Date Unknown				<input type="checkbox"/> iii. Other: _____		
					<input type="checkbox"/> iv. Unknown		
If the child is AWAITING ASSESSMENT, fill in A & B							
25. Who requested the assessment/made the referral?	<input type="checkbox"/> i. Parent/Caregiver			26. When was the referral/request for Assessment made?	____ / ____ / ____ Day Month Year		
	<input type="checkbox"/> ii. Social Worker				<input type="checkbox"/> i. Less than 6 months ago		
	<input type="checkbox"/> iii. Medical Doctor				<input type="checkbox"/> ii. 6months – 1 year ago		
	<input type="checkbox"/> iv. School				<input type="checkbox"/> iii. 1-3 years ago		
	<input type="checkbox"/> v. Other: _____				<input type="checkbox"/> iv. More than 3 years ago		
In each category mark the supports that the child needs and indicate if they are consistently available or not:							
27. MEDICAL SUPPORTS	Needed & Available	Needed but Not Available	28. TECHNICAL SUPPORTS	Needed & Available	Needed but Not Available		
a. Medication	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	a. Hearing Aid	<input type="checkbox"/> i.	<input type="checkbox"/> ii.		
b. Special Foods	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	b. Pacemaker	<input type="checkbox"/> i.	<input type="checkbox"/> ii.		
c. Oxygen	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	c. Computer/lpad	<input type="checkbox"/> i.	<input type="checkbox"/> ii.		
d. Other:	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	d. Other:	<input type="checkbox"/> i.	<input type="checkbox"/> ii.		
29. MECHANICAL SUPPORTS	Needed & Available	Needed but Not Available	30. PERSONAL SUPPORTS	Needed & Available	Needed but Not Available		
a. Wheelchair	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	a. School Support (EA, special ed, etc.)	<input type="checkbox"/> i.	<input type="checkbox"/> ii.		
b. Accessible bus/car	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	b. 24 Hour Supervision	<input type="checkbox"/> i.	<input type="checkbox"/> ii.		
c. Lift	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	c. Respite	<input type="checkbox"/> i.	<input type="checkbox"/> ii.		
d. Other:	<input type="checkbox"/> i.	<input type="checkbox"/> ii.	d. Other:	<input type="checkbox"/> i.	<input type="checkbox"/> ii.		

Fill in information on the Programs, Services, and Therapies that the child does ('current') or has ('past') accessed:

31. CURRENT SERVICES				
SERVICE/PROGRAM	PROVIDER	FUNDER	LOCATION	FREQUENCY
a.				
b.				
c.				
d.				

32. PAST (DISCONTINUED) SERVICES				
SERVICE/PROGRAM	PROVIDER	FUNDER	LOCATION	REASON FOR DISCONTINUATION
a.				
b.				
c.				
d.				

33. NEEDED BUT NOT AVAILABLE SERVICES				
a.				
b.				
c.				

34. CHECK THE BOX IF NO SERVICE INFORMATION IS INCLUDED IN THE FILE:
 NO service information in file

SECTION E: FUNCTIONING

Indicate the level of IMPAIRMENT for the BODILY SYSTEMS/FUNCTIONS that apply:

BODY IMPAIRMENTS		a. MILD	b. MODERATE	c. SEVERE	d. COMPLETE
34. MENTAL	a. Attention	[]	[]	[]	[]
	b. Memory	[]	[]	[]	[]
	c. Emotional Function	[]	[]	[]	[]
	d. Cognitive Function	[]	[]	[]	[]
	e. Language	[]	[]	[]	[]
	f. Other:	[]	[]	[]	[]
35. SENSORY	a. Seeing	[]	[]	[]	[]
	b. Hearing	[]	[]	[]	[]
	c. Pain	[]	[]	[]	[]
	d. Other:	[]	[]	[]	[]
36. CARDIOVASCULAR, DIGESTIVE, ETC.	a. Heart/Blood Pressure	[]	[]	[]	[]
	b. Immune System (allergies, etc.)	[]	[]	[]	[]
	c. Lungs/Breathing	[]	[]	[]	[]
	d. Digestion	[]	[]	[]	[]
	e. Urination/Defecation	[]	[]	[]	[]
	f. Joints/Bones	[]	[]	[]	[]
	g. Muscle tone/power/movement	[]	[]	[]	[]
	h. Reproductive System	[]	[]	[]	[]
	i. Other:	[]	[]	[]	[]

Indicate the level of LIMITATION/RESTRICTION for the ACTIVITIES that apply:

ACTIVITY & PARTICIPATION LIMITATIONS		a. MILD	b. MODERATE	c. SEVERE	d. COMPLETE
37. LEARNING & COMMUNICATION	a. Listening/Following Directions	[]	[]	[]	[]
	b. Reading	[]	[]	[]	[]
	c. Writing	[]	[]	[]	[]
	d. Speaking	[]	[]	[]	[]
	e. Conversation	[]	[]	[]	[]
	f. Other:	[]	[]	[]	[]

38. MOBILITY	a. Lifting & Carrying Objects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	b. Fine hand use (pointing, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	c. Walking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	d. Moving with Equipment (wheelchair, walker, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	e. Using Transportation (car, bus, ski-do, plane, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	f. Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. SELF-CARE	a. Washing oneself (bathing, brushing teeth, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	b. Toileting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	c. Eating/Drinking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	d. Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. RELATIONSHIPS	a. Interpersonal Interactions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	b. Relating to Strangers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	c. Family Relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	d. Peer Relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	e. Other				
41. SOCIAL PARTICIPATION	a. School Life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	b. Community Life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	c. Recreation & Leisure Activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	d. Cultural/Religious Activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	e. Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SECTION F: CONTEXTUAL FACTORS					
42. Indicate which (if any) trauma(s) and life event(s) the child has experienced:					
<input type="checkbox"/> i. Death of 1 or both parents	<input type="checkbox"/> vii. Separated from other siblings in care				
<input type="checkbox"/> ii. Death of close family member(s)/friends	<input type="checkbox"/> viii. Prolonged hospitalization (2+ weeks on 1 occasion)				
<input type="checkbox"/> iii. Witnessed violence	<input type="checkbox"/> ix. Involvement with the Justice System				
<input type="checkbox"/> iv. Witnessed excessive drug/alcohol use	<input type="checkbox"/> x. Experienced excessive moves/placements				
<input type="checkbox"/> v. Experienced sexual abuse	<input type="checkbox"/> xi. One or both bio parents are incarcerated				
<input type="checkbox"/> vi. Mother admits to or is suspected of using drugs or alcohol while pregnant	<input type="checkbox"/> xii. One or both bio parents were in care when young				
43. Additional personal/ contextual factors Or Relevant details					
44. This child/youth's file contained:					
<input type="checkbox"/> All of the information necessary to complete the DIT (100% of the info)					
<input type="checkbox"/> Almost all of the information necessary to complete the DIT (75 % or more of the info)					
<input type="checkbox"/> Most of the information necessary to complete the DIT (50% to 75 % or more of the info)					
<input type="checkbox"/> Not enough of the information necessary to complete the DIT (less than 50% of the info)					

Appendix 3 DIT: Chart of Changes

Chart of Changes: DISABILITY INFORMATION TOOL				
DATE	SECTION/QUESTION	ADDED	EDITED	REMOVED
May 23, 2017	First Draft Created	-1 ST VERSION CREATED-		
June 12, 2017	Reasons for Coming into Care- corresponding Section 11 from <i>Child & Family Services Act</i>			X
June 12, 2017	Suicide and Addictions	X		
June 12, 2017	Age When Case Opened	X		
June 23, 2017	Personal Factors (separate sections for social background, life events, habits, and other)			X
June 23, 2017	Needed but not available services	X		
June 23, 2017	Case Previously Opened/ Additional Investigations		X	
June 23, 2017	Placement option 7. Correctional Facility			X
Aug 21, 2018	Total time in Care	X		
Aug 21, 2018	Date of Diagnosis Unknown	X		
Aug 21, 2018	File contained options (all, almost all, most, not enough information)	X		
Aug 21, 2018	Case Previously Opened/ Additional Investigations			X
Sept 13, 2018	Section 46-Voluntary (in Legal Status Section)	X		
Sept 13, 2018	'One or both parents were in care as child/youth' (Contextual Factors section)	X		
Sept 13, 2018	Check box for "No service information included in the file"	X		
Sept 13, 2018	Does child/caregiver qualify for DLSA	X		
Oct 10, 2018	Placement option "Place of Safety"	X		
Nov 15, 2018	Apprehended at Birth option for 'Age when Case Opened'	X		

APPENDIX 4: Cultural Activities Known to Contribute to Resilience:

Source:

National Indian Child Welfare Association (NICWA). (Ensuring the Seventh Generation: A Youth Suicide Prevention toolkit for Tribal Child Welfare Programs. NICWA, Portland. Accessed January 18, 2019: <http://www.icctc.org/August2013/PMM%20Handouts/Youth%20Suicide%20Prevention%20Toolkit.pdf>

Cultural Activities Known to Contribute to Resilience:

Kinship/Family/Gender Roles

- Participating in extended family culture
- Learning about family structure and traditions
- Maintaining strong family ties
- Hearing or telling family stories (knowing their family/cultural history)
- Participating in traditional male and female cultural roles
- Searching for a connection with relatives or Native ancestry

Tribal Arts and Crafts

- Making cradleboards and dream catchers
- Making shawls, sewing quilts, carving
- Weaving baskets, making flints
- Making jewelry, beading, doing quill work

Tribal Clothing

- Making traditional attire/regalia for pow-wows and other ceremonies
- Making ribbon shirts
- Making moccasins, tanning hides, working with animal skins

Subsistence/Food/Medicines

- Gathering, harvesting, planting, growing, preserving, or cooking traditional foods
- Hunting, fishing, exercising treaty rights
- Knowing or participating in hunting/gathering-related ceremony
- Knowing plants, bark, roots, herbs, medicines
- Learning the teaching about plants, animals, foods, and medicines'

Music/Dance/Pow-wows

- Attending a pow-wow, dancing, drumming, singing
- Learning lyrics or specific dances and the history behind songs and dances
- Learning song etiquette: where and when a song can be sung Games/sports

- Playing culture-specific games such as hand/stick games
- Playing indigenous sports such as lacrosse

Ceremony, Rituals, and Protocol

- Participating in rituals, knowing how to act, how to prepare
- Participating in smudging, mediation, sacred dance, fasting, visioning
- Paying attention to dreams
- Participating in a talking circle
- Practicing Native protocol for showing respect and honor
- Developing communication skills with elders
- Practicing spirituality
- Knowing and practicing protocols for handling sacred or traditional items
- Showing respect for beliefs at ceremony
- Seeing traditional healers for help
- Learning rules for who can attend ceremonies
- Knowing passing away (death) ceremonies
- Knowing sacred animals
- Understanding people’s interconnectedness with the natural world

History/Cultural Knowledge/Cultural Skills

- Knowing tribal history, laws, treaty rights, reservations, clans
- Knowing the meaning of sovereignty
- Learning Indian names for places
- Speaking a Native language
- Knowing sacred places—protecting them as cultural monuments
- Learning about traditional living houses/buildings/lodges
- Understanding the impact of colonialism—genocide, blankets to spread diseases
- Understanding the history of activism, importance of protesting
- Understanding sport mascots and their negative impact

Traditional Forms of Living

- Learning to tell tribal stories and legends
- Learning about canoe journey/families
- Learning horsemanship
- Learning about the birds and what they do
- Camping and participating in survival retreats
- Taking care of Mother Earth