

# HIGH IMPACT PRACTICES

Evidence-informed practices in home and community care that result in better care, better outcomes and better value.

## Integrated Approach to Services for Families with Children with Complex Needs

Niniijaanis Nide Program: My Child, My Heart 

This High Impact Practice describes a community-based, coordinated and integrated program for children with complex care needs and their families, living on-reserve in Manitoba's Interlake Region. It profiles the collaboration between the Pinaymootang First Nation and First Nations and Inuit Health Branch to facilitate access to comprehensive services that support the health and well-being of children and their families.

### BACKGROUND

Health and social supports for indigenous children with complex care needs, especially those living on-reserve, are provided through a broad range of health care professionals and government departments. Gaps in service eligibility, funding and availability between federal, provincial and local entities often result in unmet needs for indigenous children. According to the Assembly of First Nations, First Nations people receive two-and-a-half times fewer services than other Canadians in like circumstances.<sup>i</sup> On many reserves, access to health care is limited due to socioeconomic status, geography, lack of infrastructure, inadequate human resources, language and cultural barriers.<sup>ii</sup> Indigenous children are forced to leave behind their communities, families and support networks to access the appropriate medical supports and services.<sup>iii</sup> Family members who are vital to the care of children with complex needs are often unable to physically, mentally and emotionally cope with the care needs of their child and have no support services to alleviate these challenges.

The Pinaymootang First Nations people believe it is their moral and legal obligation to care for their children which they see as “a gift from the Creator.” Their population is 2,812 with 43% living on-reserve. Approximately 50% of the on-reserve population is under 20 years of age. Located within the Manitoba Interlake Region, the nearest hospital facility to their community is approximately 30 minutes away in Ashern, and it is three hours to the Health Science Centre-Children's Hospital in Winnipeg. Integrated and innovative programs, such as “My Child, My Heart,” ensure equitable access to services for Pinaymootang children with complex care needs. The program supports children with congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system that create functional limitations.

### MY CHILD, MY HEART

In December 2015, in collaboration with the First Nations and Inuit Health Branch, the Pinaymootang First Nation Health Centre developed a pilot project entitled “Integrated Approach to Services for Families with Children with Complex Needs.” The project was funded through Health Canada's Health Service Integration Fund. Known as the “Niniijaanis Nide Program” (My Child, My Heart), this initiative encompasses advocacy and intervention elements to support families of children with complex care needs between the ages of 10 months and 18 years, living on-reserve. Children and their families enter the program through self-referral or referrals made by Pinaymootang

First Nation's health programming and community networks. The program staff include a case manager (Licensed Practical Nurse) and three child development workers (Certified Health Care Aide) who work collaboratively to ensure the well-being of clients. Part of the accredited health facility services, the program adheres to quality standards and practices outlined by Accreditation Canada. Identified through the Pinaymootang First Nation's traditional belief of "love, respect and courage," the program is grounded in six key core values:

1. Children are best cared for at home and within families.
2. Special needs of children and families have to be met, as well as their basic needs.
3. Parents know their child better than anyone else and must be treated respectfully.
4. Professional supports must be coordinated and responsive to the needs of individual children and families.
5. Identified risks must be managed in ways that provide safety and good quality of life to the child and family.
6. Partnership working across disciplines and agencies is essential.

Building on these values, the goal of the My Child, My Heart program is to ensure that children with complex care needs and their families can access services without denial, delay or disruptions.

## PROGRAM DEVELOPMENT & IMPLEMENTATION

The My Child, My Heart program was created through extensive conversations with families, input from health care providers and broad consultations with community support providers. The objective of the consultations was to gain a deep understanding of the needs of children and families, as well as the spectrum of values and challenges experienced in the community. The results of the multi-stakeholders consultations informed the development of five unique phases of "My Child, My Heart" that each child and family experience.

### Phase 1. Establishing a Relationship

Establishing a culturally safe space for the children and families from the moment they enter the program is an essential component in improving care compliance and patients' outcomes in First Nation communities. Cultural safety is experienced by patients when health care providers communicate and act in respectful, inclusive ways. It is necessary to establish a culturally safe relationship to counterbalance underlying issues caused by the intergenerational effect of colonialism, residential schools and inadequate social services and safe health care on reserves—all of which have led many Aboriginal people to not trust, nor feel comfortable in, the health care system.

Ensuring a culturally sensitive and safe program requires multiple actions. The first is recruiting and training local people who understand the community culture and embrace

the Pinaymootang First Nation's six key core values of protecting children. Second, the program includes designated actions to listen to and understand the child's and family's needs and stories. Upon referral to the program, a child development worker begins a relationship with the child by spending time and getting to know each other. The program case manager meets with the child and parent(s) to begin the assessment process that encourages a sharing of information on the child's strengths and unique challenges, likes, dislikes and life goals. In building rapport and trust in this important relationship phase, the child and family can feel more at ease and empowered while receiving care.

**"The parenting group was transformative; it completely changed my approach to my kids and in my work and in life."**

*—Parent, My Child, My Heart Program*

### Phase 2. Identification of Needs and Objectives

The goal of this phase is to identify the unique needs of the child and family, and develop objectives for the two core components of the program:

1. Basic care and support—services that address the ongoing health and social needs of the child
2. Goal-oriented work—specific, time-limited activities build to achieve the specific child-oriented goals and family-oriented goals (e.g., stress and coping mechanisms)

The case manager conducts a holistic assessment of the child through multiple developmental domains: physical, gross/fine motor, emotional, self-help skills, social, cognitive and speech/language. The goal of the comprehensive assessment is to protect the child's right to develop his or her full cognitive, emotional, social and physical potential. In collaboration with the family, a detailed description of the child's needs is developed and used to create a care plan, including therapeutic objectives and goals.

The following assessments are used to identify the family's needs and develop capacity-building strategies for the family:

- Parent Stress Index:<sup>iv</sup> This 36-item tool measures parental distress, parent/child interactions and child characteristics that promote parental stress. Higher scores reflect higher level of distress.
- Social Support Index:<sup>v</sup> This tool measures 17 characteristics of parents' experiences with their support networks both within and outside the family. A higher score reflects a higher sense of support.
- Family Quality of Life Evaluation:<sup>vi</sup> This 25-item questionnaire measures five family domains: family interaction, parenting, emotional well-being, physical/mental well-being and disability-related supports.

### Phase 3. Program Implementation (For Unique Child and Family Needs)

**Basic Care and Support:** The program provides advocacy, help with system navigation and connection to community resources. Based on the assessment, a referral is made to services within community. This includes child and family support, education, social assistance, and health and home care programs available through the Pinaymootang Health Centre and Anishinaabe Child and Family Services. The child development worker monitors the children and families throughout their care so there is continuity within the program and to ensure needs and services are being delivered.

**Goal-Oriented Work:** Under the direction of the case manager, the child development worker helps plan, develop and implement recreational, social and educational activities for children and their families. The activities offered by the program rely on the interest, creativity and sense of pride that derive from the knowledge of First Nations traditions and culture. Educational workshops are created to help children and their families acquire a positive self-image of themselves, as well as help increase their independence to allow them to function appropriately in the community. Programs or workshops provided on a one-to-one basis or in a group environment include respite care, crisis intervention, guided language development, family support meetings, behaviour management and life skills training. Specific parenting resources (e.g., Growing Great Kids and Small Steps, Power to the Parent, Big Futures and No Body's Perfect) are integrated into the curriculum for individual families.

### Phase 4. Generalization of Goals (Optimizing Provider Capacity)

In rural and remote communities, health care professionals are often required to access their full scope of practice to compensate for limited access to specialists. To build capacity and maximize existing health human resources, program staff are enrolled in mandatory training to equip them with the basic knowledge relating to child development. This ensures the child and family receive support until they can access services from respective health care specialists. For example, staff are trained in speech and language-building strategies (to supplement the services provided by a speech-language pathologist), physical exercises relating to mobility issues (to support physiotherapy services), and basic learning such as holding pencils, cutting exercises, writing, and reading (to reinforce occupational therapist services). In recognizing parents as essential in their child's care, the child development worker transfers knowledge to the families as well so these strategies can happen on an ongoing basis in the child's comfortable surroundings and be extended into every part of the child's day.

### Phase 5. Evaluation and Continuing Basic Care and Support Needs

Service and outcome evaluations are completed using telephone and in-person home visits by the case manager at regular intervals—3, 6 and 12 months into the program. To ensure basic care and support needs of the child are met, the case manager evaluates the length of time needed to meet the anticipated goals in the plan along the child's seven domain functions. Families are re-evaluated on the same initial assessments tools—Parent Stress Index, Social Support Index and Family Quality of Life Evaluation.<sup>vii</sup> In addition, Measure of Process of Care is conducted to learn parents' perception of and satisfaction with the services provided for their child on five dimensions:

1. Enabling and partnership
2. Providing general information
3. Providing specific information about the child
4. Coordinated/comprehensive care for the child and family
5. Respectful and supportive care

Child-oriented goals and family-oriented goals are evaluated using a Goal Attainment Scaling (GAS). GAS is a method of measuring individual progress toward goals that are identified during the initial assessment. Using a five-point scale, the child/family are measured to determine whether they achieved less, as expected or more than was expected.

During the 12-month assessment, the case manager reviews the past three assessments with the family, obtains qualitative input through family discussion and identifies progress changes.





# OUTCOMES

Since the program inception, 25 children with complex care needs and 16 families have been enrolled over an 11 month period. The ages of the children range from 22 months to 14 years. Children have a diverse range of diagnoses, including Sturge-Weber syndrome, Ritscher-Schinzel syndrome, chromosome p12 deletion, epilepsy, hydrocephalus, microcephaly, autism, ADHD, dextrocardia, speech delayed, hearing impairment, anxiety disorder and global developmental delays. Initial program evaluations show the program has brought many positive aspects to the lives of children, families and the Pinaymootang community as a whole. Below is a summary of the early benefits of the program:

CHILDREN WITH COMPLEX CARE NEEDS	PARENTS/CAREGIVERS	COMMUNITY
<ul style="list-style-type: none"><li>• Increase independence</li><li>• Increase socialization</li><li>• Increase enjoyment</li><li>• Increase sense of accomplishment from achieving goals/seeing progress</li><li>• Decrease problematic behaviours</li><li>• Receive individualized, specialized support</li><li>• Receive stimulation</li><li>• Increase independent sleep</li></ul>	<ul style="list-style-type: none"><li>• Increase trust in the system – families are starting to seek support within their home environments</li><li>• Increase competency</li><li>• Increase connection with child</li><li>• Increase sense of support</li><li>• Increase sense of value from being active participants</li><li>• Increase coping skills with behaviours of their children</li><li>• Decrease stress</li><li>• Change parenting behaviour</li><li>• Receive funding</li><li>• Receive respite</li><li>• Participate in parent program</li><li>• Connect with other parents</li></ul>	<ul style="list-style-type: none"><li>• Increase partnership connection (St. Amant Centre, Rehabilitation Centre for Children, Dreams Take Flight, Community Networks)</li><li>• Increase integration of existing initiatives</li><li>• Increase local capacity</li><li>• Increase access to care in a timely and efficient manner</li><li>• Decrease children falling through the gaps through early identification</li><li>• Facilitate opportunities targeted to special needs families</li></ul>

# FUTURE OPPORTUNITIES

Pinaymootang First Nation Health Centre will continue evolve the My Child, My Heart program so that children can live their lives to the fullest at home and in their home community. As access to specialized care still remains a challenge for many children, plans are underway to bolster generalist training and specialties that are under-supplied by bringing more training and care to the community. Pinaymootang First Nation Health Centre has been selected to lead the development of Practice Standards and Program Guidelines that will be shared with every First Nation in Manitoba.

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For more information, contact [gwen@pfnhealth.com](mailto:gwen@pfnhealth.com) or [april@pfnhealth.com](mailto:april@pfnhealth.com)

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