Relevance of the Aboriginal Children’s Health and Well-being Measure (ACHWM)

Beyond Wikwemikong

Submission Type: Original Research

Authors:

Nancy L. Young, PhD *
Professor and Research Chair
Laurentian University
935 Ramsey Lake Road
Sudbury, Ontario, Canada
P3E 2C6
(705) 675 1151 ex. 4014
nyoung@laurentian.ca

Mary Jo Wabano, MHK
Health Services Director
Nahndahweh Tchigehegamig Wikwemikong Health Centre
16A Complex Drive
Wikwemikong, Ontario, Canada
POP 2J0
(705) 859 5164
mjwabano@wikyhealth.ca

Shannon Blight, MSW
Director of Nanaandawewenin
Weechi-it-te-win Family Services Inc.
1457 Idylwild Drive
Fort Frances, Ontario, Canada
P9A 3N1
(807) 274 3201
Shannon.blight@weechi.ca

Karen Baker-Anderson
Executive Director
76 Queen Street
Vanier, Ontario, Canada
K1K 1X7
(613) 744 3133
kbaker@ottawainuitchildrens.com

Roger Beaudin
Health Services Department Manager
M’Chigeeng First Nation Health Centre
689A Hwy 551
M’Chigeeng, Ontario, Canada
P0P 1G0
(705) 377 4240
rogerb@mchigeeng.ca

Leslie F. McGregor
Health & Social Services Manager
Whitefish River First Nation
17-A Rainbow Ridge Road
Birch Island, Ontario, Canada
P0P 1A0
(705) 285 4335
lmcgregor@whitefishriver.ca

Lorrilee E McGregor
Whitefish River First Nation Administration Office
17-A Rainbow Ridge Road
Birch Island, Ontario, Canada
P0P 1A0
(705) 285 4335
le_mcgregor@laurentian.ca

Tricia A Burke, BA
Research Coordinator
Laurentian University
935 Ramsey Lake Road
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Keywords:

Surveys and Questionnaires; Indigenous Population; Culture; Interview; Child; Adolescent.

Abstract

Objective

The Aboriginal Children’s Health and Well-being Measure® (ACHWM) was developed to meet the need for a culturally-relevant measure of health and well-being for Aboriginal children (ages 8 to 18 years) in Canada. It was developed with one First Nation Community: the Wikwemikong Unceded Indian Reserve. The intention from inception was to ensure the relevance of the ACHWM to other Aboriginal communities. The purpose of this paper is to describe the relevance of the ACHWM beyond Wikwemikong.
Methods

This paper presents the results of a community-based and collaborative research study that was jointly led by an academic researcher and a First Nations Health leader. The research began with the 58-question version of the ACHWM developed in Wikwemikong. The ACHWM was then submitted to a well-established process of community review in four new communities, in sequence: Weechi-it-te-win Family Services; M’Chigeeng First Nation; Whitefish River First Nation; and the Ottawa Inuit Children’s Centre (OICC). The review process included an initial review by local experts, followed by a detailed review with children and caregivers through a detailed cognitive debriefing process. Each community identified changes necessary to ensure appropriate fit in their community. The results from all communities were then aggregated and analysed to determine the similarities and differences.

Results

This research was conducted in 2014 and 2015 at four sites. Interviews with 23 children and 21 caregivers were completed. Key lessons were learned in all communities that enabled the team to improve the ACHWM in subtle but important ways. A total of 12 questions were revised, and 4 new questions were added during the process. This produced a 62-question version of the ACHWM that was endorsed by all communities.

Conclusions

The ACHWM has been improved through a detailed review process in 4 additional communities and resulted in a stable 62-question version of the survey. This process has demonstrated the relevance of the ACHWM to a variety of Aboriginal communities. This survey provides Aboriginal communities with a culturally appropriate tool to assess and track
their children’s health outcomes, enabling them gather new evidence of child health needs and the effectiveness of programs in the future.
Background

Aboriginal children (First Nations, Inuit and Métis) are the fastest growing segment of the paediatric population in Canada[1, 2]. The Aboriginal population in Canada was estimated at 1.4 million, or 4.3% of the Canadian population, based on the 2011 National Household Survey[2]. This reflects population growth of 20.1% between 2006 and 2011, compared with 5.2% for the non-Aboriginal population[2]. Within this population, 62.5% identified as First Nation, 33.1% as Métis, and 4.4% as Inuit. Approximately 36% are children age 18 or younger[2]. There are unique challenges to the planning and evaluation of services for these children. For example, in Ontario, about half of First Nation children reside on one of 133 First Nation reserves[3], most of which are geographically isolated[4]. In 2009, these communities collectively ranked 68th on the Human Development Index, while Canada ranked 3rd internationally[1].

Aboriginal children experience serious health inequities compared to their mainstream peers[1, 5]. A key example is the high rate of youth suicide, which is typically five to six times the mainstream average[6] and when combined with self-inflicted injury, is the leading cause of death among Aboriginal youth (ages 10-19 years)[7]. Métis and Inuit children also experience significant health inequities[1]. Because many Aboriginal children live in rural and or remote communities, they rely on local health services for support.

While much of Canada now practices health care using evidence-based medicine[8, 9], Aboriginal health centres have not had access to culturally-relevant and contextually-feasible tools to gather local evidence to inform practice in a resource-constrained environment.
The Aboriginal Children’s Health and Well-being Measure (ACHWM), is a child self-report survey that measures health and well-being[10]. It was developed to address the needs of Aboriginal health directors, to gather local data to guide the planning and evaluation of health services. Mainstream measures were not appropriate for use in their communities[10]. Thus, cultural relevance was of critical importance in the development process.

The ACHWM or Aaniish Naa Gegii, as it is known in Ojibway, was developed as part of a collaborative research project co-led by a First Nation health director and an academic researcher from Laurentian University in 2010 and 2011[10] who worked in collaboration with other Aboriginal health leaders and Elders. First Nation children were actively engaged in the process throughout its development and testing. It is culturally-appropriate for First Nations children and has been successfully adapted for independent completion by children (8 to 18 years of age) using Android tablets. This approach to measuring Aboriginal child health is valid[11, 12], reliable[13], and has the support of the Chiefs of Ontario (COO BCR #13/15).

While the development began in one community, the intent was always to ensure its relevance to other Aboriginal communities, including other First Nations, Inuit and Métis children[10]. The purpose of this paper is to document the tailoring of the ACHWM to meet the needs of other Aboriginal communities.

The literature on cross-cultural adaptation of quality of life measures recommends a detailed review of the question content and translation of questions into the new language, followed by an extensive interview process[14-16]. This process is important to ensure that the measure’s interpretation and meaning is congruous across the different cultures. Since the ACHWM is a measure of health and well-being, the guidelines for quality of life measures were considered most appropriate for use in this study. In 2009, a revised set of guidelines were published to
adapt the process for use with rare conditions[17]. This paper follows the guidelines published by Price et al (2009), which have previously been applied by members of this team (NLY and TAB)[18-21].

Methods
During 2013 and 2014 a small research team, led by a First Nation Health Director (MJW) and a University Professor (NLY), engaged four new communities in this collaborative research. The communities who participated in this project were: Weechi-it-te-win Family Services; M’Chigeeng First Nation; Whitefish River First Nation; and the Ottawa Inuit Children’s Centre (OICC). Note that the Wikwemikong Unceded Indian Reserve completed this process as part of the initial development of the ACHWM[10], and the Métis community in Sudbury has also participated in this process[22], however their results are presented in a separate paper. Researchers from Laurentian University and health leaders from Wikwemikong combined to form the ACHWM team on this project.

Communities
The ACHWM originated in Wikwemikong which is an unceded (non-treaty) community of First Nation people located on Manitoulin Island in northeastern Ontario (www.wikwemikong.ca). The people of Wikwemikong have resided on these lands since the 1600’s and come from three tribal nations: Odawa, Pottawatomi and Ojibway. Together they form the Three Fires Confederacy. Their lands are comprised of 42,547 hectares on Manitoulin Island and 13,806 hectares on the mainland. The Wikwemikong band membership is estimated at 7,200 with approximately 45% living on-reserve in one of seven settlements: Kaboni, Buzwah, South Bay, Rabbit Island, Murray Hill, Cape Smith, and Wikwemikongsing. The community has many health-related resources including a health centre, nursing home,
ambulance station and youth centre run by the health department. The community also has three schools, covering kindergarten to grade 12.

Weechi-it-te-win Family Services (WFS) is an Aboriginal child welfare agency supporting 10 remote First Nations from northwestern Ontario (www.weechi.ca). The 10 communities are all independent First Nations within the Treaty #3 (1873) region of Ontario: Big Grassy; Big Island; Couchiching; Lac La Croix; Naicatchewenin; Nigigoonsiminikaaning; Rainy River; Ojibways of Onegaming; Seine River; and Mitaanjigamiing First Nations. WFS was founded with a vision of revitalizing an Anishinabe child care system rooted in the customs, traditions and values of the Anishinabe people. It was granted status as a child welfare agency in 1987. The agency advocates for a system that places emphasis on family preservation, community healing and the revitalizing of traditional laws, structures, and practices in order to restore balance and meaning to the lives of their people. At the time of implementation, WFS was caring for approximately 124 children between the ages of 9 to 19 from the 10 communities.

M’Chigeeng is a First Nation community located on Manitoulin Island, along the shores of the North Channel of Lake Huron, in northeastern Ontario (www.mchigeeng.ca). The M’Chigeeng territory was settled in the mid-19th century and has a registered band membership of 2,543 of which approximately 40% live on-reserve lands of 3,095 hectares. [Bond Head Treaty #45 (1836) and McDougal Treaty #94 (1862)] This community has a health centre and an elementary school serving grades kindergarten to 8 (Lakeview) with older children being required to leave the community for education within the mainstream educational system approximately 15 minutes away. This First Nation is a member of the Anishinabek Nation of the Union of Ontario Indians (UOI) and United Chiefs and Councils of Mnidoo Mnising (UCCM).
Whitefish River is a First Nation community located on the shores of Georgian Bay and the North Channel in northeastern Ontario (www.whitefishriver.ca). It has 1,200 band members and approximately 37% live on the First Nation reserve. Their land base is 5,600 hectares in size [Robinson-Huron Treaty #61, 1850]. This community has an elementary school (Shawanosowe) educating children from Kindergarten to grade 6, with older children being required to leave the community for education within the mainstream educational system 25 minutes away.

The Ottawa Inuit Children’s Centre (OICC) is a not-for profit agency that supports Inuit children living in Ottawa Ontario (www.ottawainuitchildrens.com). This centre provides cultural, educational, recreational and social support services to urban children and families. It is important to note that all communities volunteered to participate in this project. Ethics approval was obtained from the Manitoulin Anishinaabek Research Review Committee (MARRC) and the Laurentian University Research Ethics Board. The research was conducted as a collaboration between the ACHWM development team (Wikwemikong Unceded Indian Reserve and Laurentian University), and each new partner community. Thus, there were four Research Agreements (one for each community) that were each signed by the collaborating teams.

**Cultural Adaptation Process**

The relevance to each of the four new communities was assessed independently, through an iterative process that had three sequential steps. A similar process had previously been used by members of this team (NLY, TB) in other contexts[17, 20, 23]. One important alteration in the process was implemented: there was no requirement to come to consensus; rather each community was permitted to modify the measure to fit the needs of their children. This was
important to reflect the diversity of the sample and respect the autonomy of the sovereign nations. As each community completed the process, the findings were reviewed by the research team, and shared with all other communities. Thus each community started the process with the benefit of being aware of the results from previous communities, and at the end each community had access to lessons learned from preceding communities.

The first step was to determine whether the questions within the ACHWM were considered appropriate from the perspectives of health leaders, mental health workers, and Elders in the new community. If there were key concerns identified, these were addressed and adaptations were made to the ACHWM.

The second step was to determine whether the questions within the ACHWM were interpreted in a consistent and accurate way by children between the ages of 8 and 18 years in that community. This was assessed through detailed cognitive debriefing interviews with children and parents (or primary caregivers) separately. These interviews were conducted by a health worker from the community who had been trained by the ACHWM team. A member of the ACHWM team sat in on all interviews to take notes on the findings. Thus, there were 3 participants in each interview: one child or parent, one community health team member, and one ACHWM team member. Often the child and parent interviews were conducted simultaneously, in separate rooms. All interviews were conducted in a location selected by the local health team.

During the interview, the participant (child or parent) was asked to read questions out loud while the note taker listened for words that were difficult. Participants were probed for examples to support their choice of answers as a way to ensure they understood the concept. The local health team member guided the participant through the survey and facilitated
discussion of any problem areas. When concerns were identified, the participants were asked to suggest solutions (i.e., alternative wording of questions). The ACHWM team member recorded detailed information on the findings in a data base. After each pair of interviews (child and parent) were complete, the whole team discussed the findings briefly. Note that ACHWM process requires a brief meeting with a local health worker immediately after the survey, when necessary to ensure support for the child.

The third step focused on revisions to improve the questions in the context of the new community. After every second or third pair of interviews was completed there was a more extensive discussion, based on the findings, to determine if there were consistent problems with specific questions across multiple respondents that needed to be addressed. When this occurred, the ACHWM was revised based on recommended solutions provided by participants, and the new survey was presented to the next pair of participants to determine if the revision was consistently and accurately understood. This iterative process continued until a stable well-understood version was achieved.

This process was conducted in one community at a time, beginning with Weechi-it-te-win and ending with the OICC. Weechi-it-te-win began with the original 58-question version of the ACHWM[10]. M’Chigeeng began with the original 58-question version showing the changes that were made in Weechi-it-te-win. This process continued, and at the end, the survey with revisions made by all communities were shared with all other communities so that the learning was cumulative.

**Analysis**

The results from the four new communities were aggregated and reviewed by the ACHWM team. The team identified the common findings and adaptations across all communities. The
collective findings were shared with all communities and each was given the opportunity to independently incorporate or disregard the changes that had been identified by others.

Ethics Approval

Approvals were obtained from the Laurentian University Research Ethics Board, the local Board of Directors at Weechi-it-te-win and OICC, and Chief and Council in M’Chigeeng First Nation and Whitefish River First Nation.

Results

Most communities required a minimum of three detailed preparation meetings to conduct this collaborative research. The local community leaders (SB, RB, LM and KBA) played a critical role as champions for the project within their respective communities.

The initial review of the measure by experts in three of the communities did not identify any changes that were essential to implement prior to presenting the survey to children and parents as part of the second stage of the process, with one important exception. The local team at the OICC identified 5 questions that required changes to reflect Inuit culture. An example of a community-specific adaptation was the concept of “mother earth” which is a key component of Anishinabe culture, but is not recognized by the Inuit. However, through discussion with children, parents, and leaders at the OICC it was determined that “the land” is a parallel concept among the Inuit. Changes such as these were unique to each community, but resulted in a survey that was consistently interpreted at the level of the overall concepts addressed.

The cognitive debriefing interviews were completed in June 2014 (Weechi-it-te-win), August 2014 (M’Chigeeng), October 2014 (Whitefish River) and January of 2015 (OICC) involving a total of 23 children, 21 caregivers and numerous local staff. Key lessons were learned in all communities that enabled the team to improve the ACHWM in subtle but important ways.
During the collective process with four new communities a total of 23 questions (37%) underwent minor revisions: 12 questions had important changes across all communities, 9 questions had community-specific adaptations and 4 new questions were added (note that 2 of the new questions underwent both changes for all communities and had a community-specific variation). Examples are provided below. This process resulted in a stable version of the ACHWM that is now relevant across diverse communities. The collective results were shared with participating communities in March of 2015. The results from all four communities are summarized in Table 1 below.

[INSERT TABLE 1 APPROXIMATELY HERE]

**Summary of Changes for Each Community**

At Weechi-it-te win, concerns were identified on 28 questions. Within this group, 8 concerns were related to reading specific words and did not require revisions because the tablet has the ability to read to children. Furthermore, 10 of the concerns were isolated to a few individuals, and were inconsistent, thus revisions were not required. Revisions were made to 9 questions based on participants’ comments. Five of these changes were to remove the possessive pronoun “my” preceding “elders”. Seven questions referred to “family” or “community”. Since many participants identified with one or more family and community, the wording in the WFS version was changed to be inclusive of all families and communities. In addition, one question was adapted for this community and one new question was added based on the results obtained from WFS.

In M’Chigeeng, concerns were identified on 3 questions. Within this group, 1 concern was related to reading specific words and no changes were made because the tablet’s text to speech function can accommodate lower literacy levels. Changes were made to 2 questions to improve
the understanding of those questions, and the new question developed in WFS was confirmed in M’Chigeeng. Thus, a total of 2 changes were made based on the experiences in M’Chigeeng.

In Whitefish River, concerns were identified on 6 questions. Within this group, 2 concerns were related to reading specific words and no changes were required. The remaining concerns were isolated and did not require revisions. Thus, all questions were confirmed based on the experiences in Whitefish River.

At the Ottawa Inuit Children’s Centre, concerns were identified on 6 questions. Within this group, concerns on 2 questions were isolated and did not require changes. Most importantly, the participants identified 3 new questions. For example; the children at the OICC identified the importance of food security and generated a new question “I worry about getting enough to eat”. A total of 11 changes were made based on the results from OICC. The 3 new questions and were subsequently reviewed and accepted by all other communities and have become part of the ACHWM for use in all communities.

It became clear in working with each community that the naming and logo for the survey were important because they influenced the degree to which the children viewed the survey as being relevant to them. The initial name of the survey was the Aboriginal Children’s Health and Well-being Measure (ACHWM), and the project logo incorporates two children and the medicine wheel symbol. The formal name is still used as the primary identity for the measure.

In January of 2014 the survey was given an Ojibway name by the children in Wikwemikong. They call it: Aaniish Naa Gegii meaning “how are you” in Ojibway. The Inuit perceived the medicine wheel component of the logo as a sign that this survey was not culturally-relevant to their community. It was agreed that the survey each community was free to refer to the measure with a name in their native language. Thus, the survey is known as Qanuippit in
Inuktitut at the OICC. Additionally, the OICC have also adopted a modified logo with the permission of the ACHWM developers. The ACHWM continues to be known as the Aaniish Naa Gegii in the Ojibway nations of Wikwemikong, M’Chigeeng and Whitefish River First Nation. It is known as Aaniin Ezhi-Yaayin at WFS, who use a northwestern Ontario dialect of Ojibway. This enhances the relevance of the measure for each community.

**Limitations**

The three First Nation communities included in this collaboration were home to Anishinabek people, and were road accessible communities from across Northern Ontario. Similar findings from the Inuit reported in this paper, as well as findings from interviews with Métis children and caregivers (reported separately) and consultations with health and education providers in many other First Nation communities in more remote areas of northern Ontario suggest that results are robust. However, because of the cultural diversity between Aboriginal communities, it is important to assess the relevance for other communities. This paper presents a well-tested process as a template for assessing local relevance and adapting the survey, if necessary, to meet specific local needs. This is in keeping with the approach of this research program, guided in part by the recommendations from the Many Hands One Dream Summit, to ensure that solutions comes from within each community[24], and foster empowerment[25].

**Conclusions**

The revised version of the ACHWM is the main outcome for this research project, as it incorporates important concepts from four new communities. This was made possible through the active participation of children and caregivers in each community, who carefully considered the wording and meaning of each question, and contributed to a common stable core group of questions.
There were also two salient aspects unique to the collaborative approach of this project that are worthy to note. The first was the Research Agreement, achieved through explicit discussions between the researchers and community collaborators in which all team members shared their goals and their expectations. This process was very valuable in the development of common goals specific to the local context of each participating community and led to Research Agreements that were tailored to address the needs of all partners. Second, was the inclusion of children and parents throughout the study, who were engaged in interviews, designed to fine-tune the survey. Local staff were trained to conduct the interviews, with the support of an ACHWM team member, to improve the comfort level of the children. These interviews provided great value in uniting team members and building collaboration through shared experiences with the local children. Both the Research Agreements and active involvement of children early in the research process are recommended best practices based on this research project, as they ensure that the voices of communities, as well as the words of the children and their caregivers and guardians, are prioritized.

This research project was only possible through collaborations. These collaborations were successful because of the two important processes just described. It is also important to ensure: (a) that there is a local champion (preferably a manager or director) who can navigate the required approvals and support the implementation at a local level; (b) that there are appropriate health resources (e.g., mental health workers) to support implementation; (c) that the team is flexible and able to adapt to the local context; (d) that all are committed to collaboration and capacity building; and (e) that there are several face to face meetings with excellent ongoing communication to achieve success.
Lessons learned through the stories of ancestors are of extraordinary value, but new knowledge co-generated through respectful research partnerships were also important. Through the collective and collaborative processes in the four new communities, the ACHWM has been adapted to produce one version shared by all communities. This novel survey process is community-driven and responds to a call to “stop talking …, listen and hear” the voices of children[26].
References


7. Adelson N. The Embodiment of Inequity: Health Disparities in Aboriginal Canada. 


Table 1: Overview of Results by Community

<table>
<thead>
<tr>
<th></th>
<th>Weechi-it-te-win Family Services</th>
<th>M’Chigeeng First Nation</th>
<th>Whitefish River First Nation</th>
<th>Ottawa Inuit Children’s Centre</th>
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