

INDIGENOUS YOUTH ENGAGEMENT IN CANADA'S HEALTH CARE

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ABSTRACT

In this article, we discuss findings from a study on indigenous youth's perspectives on and engagement in health care. We carried out an Internet environmental scan, focus groups, and key informant interviews with urban indigenous youth leaders and front-line indigenous practitioners. We found that youth and practitioners regard the formal health care system as ineffective and disrespectful of youth and culture. Indigenous youth espouse a broader approach to health that considers the linkages between culture, identity, and health. Youth are engaged in a variety of health-related activities, from engagement in design of health services and programs to youth empowerment initiatives. The results highlight the value and implications of affirming indigenous youth's role as determiners of their own health.

Keywords: Aboriginal people, North America; adolescents/youth; culture/cultural competence; determinants of health; social participation

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Statistics indicate that the health care system is failing indigenous² youth in Canada. Whether it is the suicide rates which stand at 5–11 times greater than the national average, or the high rates of drug and alcohol abuse, there is a huge discrepancy between the health status of indigenous and nonindigenous youth (United Nations Children's Fund Canada, 2009). A legacy of discrimination and an illness-oriented, reductionist medical model have crippled indigenous communities (Macdonald et al., 2010; Standing Senate Committee on Human Rights, 2007). Changing the grim statistical portrait requires a shift in the conceptualization and delivery of health care. According to the international discourse on social determinants of health, a more holistic approach to health is required, in which context and the empowerment of marginalized communities matters (World Health Organization, 2007).

This article focuses on indigenous youth's conceptions, voice, and efforts around health care. With half of the indigenous population in Canada below the age of 25, there is an urgent need to understand and support the perspectives of the younger generation.³ Although the value of youth engagement is supported by evidence and recognized within the law, little is known about how youth contribute (or should). We often hear about youth who have dropped out of school and turned to substance abuse, gangs, or other illicit activities, but rarely about those who are participating in their communities to make a better life for themselves and for others (Williams and Mumtaz, 2007).

We undertook an Internet environmental scan of health-related initiatives in which youth have a voice or are participating, followed by focus groups and interviews with indigenous youth leaders and youth-service practitioners. This methodology and the findings are part of a discussion on the significance of engaging indigenous youth in health, human rights discourse, and historical developments for indigenous peoples in Canada.

ENGAGEMENT IN HEALTH: VALUE AND IMPLICATIONS

Among the numerous reasons to engage youth is the UN Convention on the Rights of the Child (CRC). Although technically the CRC applies only

2. We use "Aboriginal" peoples, a term widely recognized in Canada to refer to registered and nonregistered First Nations, Inuit, and Métis peoples.

3. Between 1996 and 2006, the Aboriginal population grew by 45%, compared with 8% for the non-Aboriginal population. Half of the Aboriginal population was under the age of 25. In contrast, about one-third of the non-Aboriginal population was under the age of 25 (Statistics Canada, 2006).

to persons up to the age of 18, given the broadening definition of youth today, it is increasingly informing approaches to work with older persons as well.⁴ Pertinent to the current study is Article 12 of the CRC which states that a child has a "right to express his or her own views freely in all matters that affect the child," Article 24 on "the right of the child to enjoyment of the highest attainable standard of health," and Article 30 which states that a child of indigenous origin has the right to "enjoy his or her own culture." As the most ratified human rights document in the world, the CRC is also a living document that continues to be expanded. The General Comments on Indigenous Children's Rights, for instance, includes a provision which states that "health services should to the extent possible be community based and planned and administered in cooperation with the peoples concerned" (Committee on the Rights of the Child, 2009, para. 51).

Alongside international legislation committed to the promotion of indigenous children's participation, evidence of the multiple health benefits of youth engagement for individuals and communities is growing (Blanchet-Cohen, 2009; Pancer et al., 2002). Engaged youth are less likely to be involved in risky behaviours; they have higher self-esteem and greater commitment to friends, family, and community (Suleiman et al., 2006). Of significance here is the fact that engagement provides for programming and services that are more culturally appropriate (Cook, 2008). Engagement acknowledges people's expertise on their own lived realities, and allows them to take part in and influence processes, decisions, and activities that will affect their health and that of the community in which they live. This perspective frames our study.

The connection made in the literature on youth engagement between health and empowerment is congruent with indigenous people's repeated call for self-determination to address the substandard health conditions of indigenous peoples (Carson et al., 2007). Chandler and Lalonde's (1998) landmark study demonstrated that communities' health was a function of their degree of autonomy; they found that those with more self-government had a lower rate of suicide. This view is also consistent with the discourse on social determinants of health promoted by the World Health Organization (WHO) which recognizes empowerment as central to operationalizing the right to health (Commission on the Social Determinants of Health, 2008; Li et al., 2009). Indeed, for indigenous peoples the recent emphasis on social

4. The United Nations, for instance, defines youth as those between 15–24 years of age, while the Government of Canada extends youth to the age of 29.

determinants of health has been an opportunity to reaffirm the role of self and group identity, the importance of culture and of self-determination (National Collaborating Centre for Aboriginal Health, 2009; Nettleton et al., 2007). As conceived herein, health encompasses physical, social, emotional, and spiritual well-being (United Nations Children's Fund Canada, 2009; WHO, 2007). This view, espoused by indigenous peoples and the WHO, is at odds with the illness-oriented Western medical model that dominates public health care systems worldwide, including the training of health care professionals (Barone, 2010). In these discussions and shifts, what is the perspective of indigenous youth?

The question deserves attention given that across Canada steps are being taken to devolve health-related decision-making powers to communities. In British Columbia, for instance, with the signing of the Tripartite First Nations Health Plan, First Nations are entitled to participate in the governance, management, and delivery of First Nations health services (Health Canada, 2007). The positive role of youth is largely absent from health agendas. Indigenous children and young people are, however, asking to be considered for the strengths and connections they offer and not, as is often currently practised, as a source of a problem that demands to be fixed (Standing Senate Committee on Human Rights, 2007). A section in the *Royal Commission on Aboriginal Peoples* (1996, p. 45) illustrates this perspective: "healthy Aboriginal youth are ready to face the challenges that confront their communities ... [they] are demanding that their voices be heard." Following the Commission, a *National Aboriginal Youth Strategy* was drafted with provincial premiers and national Aboriginal leaders who identified individual and community empowerment as a key principle and the goal of working together for Aboriginal youth "to enjoy a healthy lifestyle," but the strategy has remained inoperative (Working Group on the National Aboriginal Strategy, 1999). At an indigenous social determinants of health conference (National Collaborating Centre for Aboriginal Health, 2009), indigenous youth implored adult participants to teach and include them, saying, "youth feel weak; position us to learn to become strong," and another one: "we want to learn from you, so please extend your hand to us so we hold it." Meaningful youth engagement requires the support of adults (Cook, 2008; Zeldin et al., 2008). Our interest in this article is also in hearing from indigenous adults who work with indigenous youth.

Research indicates that youth engagement requires innovation, challenges of normal practice and power structures possibly meeting resistance

from adults and institutions (Zeldin et al., 2008). Traditionally, indigenous children and youth participated in community activities by observing and taking part in the affairs of the family and community (Blanchet-Cohen and Fernandez, 2003). Each stage of growing was associated with distinct roles and responsibilities that provided children and young people with a sense of belonging to their community. Colonization and modernity have displaced indigenous children and youth, and some have lost their role and place in society. Achieving indigenous youth's participation requires renewal and transformation. In Venezuela, for instance, adaptation to the modern reality has resulted in children expressing themselves through new media, and reconsidering cultural practices not in line with the spirit of the CRC (Blanchet-Cohen and Fernandez, 2003). Research on indigenous youth's political participation shows that, though indigenous youth may not be participating in conventional electoral processes, they are engaged in unconventional and indirect ways, seeking space for their voices, opinions and experiences to be heard (Alfred et al., 2007).

In understanding indigenous youth's perspectives on the current health care system (which encompasses formal services and informal responses) and their involvement in health care, we can learn about how youth navigate their historical and cultural reality; and also how to better support them (Zeldin et al., 2008). As pointed out by Woodgate and Leach (2010) little research has been carried out on youths' perspectives on health. Their study with Canadian youth, aged 12–19, from diverse backgrounds suggests that lifestyle factors dominate youth talk, the social determinants of health being of less concern. To address the lack of information about indigenous youths' desires and participation in the health care system, our study focused on three interconnected research questions: What are indigenous youths' perspectives on current health care services? How are indigenous youth involved (or not) in health? What are indigenous and practitioners' views on better meeting the health needs of indigenous youth?

METHODS

This research was commissioned by the National Collaborating Centre for Aboriginal Health (NCCAH) located at the University of Northern British Columbia (UNBC), whose mandate is to support a renewed public health system in Canada that is inclusive and respectful of First Nations, Inuit, and Métis peoples. Identifying the need to better understand and disseminate indigenous youth's involvement in health care, the Centre contracted an

indigenous youth activist and an applied researcher over a one-year period, who conducted the research along with a permanent researcher from the Centre.

ENVIRONMENTAL SCAN

Our study initially involved an environmental scan of health-related initiatives by indigenous youth activists. This consisted of unpublished organizational, program, and service information available on the Internet, also sometimes referred to as the “grey literature.” Given that most health promotion intervention programs report on top-down planning intervention programs and few peer-reviewed publications report on youth’s perspectives, the scan was an important source of information (Williams and Mumtaz, 2007). A search on the Internet was challenging, however, given the lack of common terminology in the area of indigenous youth health and the absence of a comprehensive database on the topic. For instance, when trying to locate information that pertains to Aboriginal youth as a whole, one had to research separately per Aboriginal group: First Nations, Métis, Inuit. The term “health” also needed to be broken down into specific health issues (i.e. suicide, diabetes, mental health). Forty-five search terms were used to capture the scope of data available on the subject, including different combinations of key concepts of the study such as “Aboriginal youth health,” “international indigenous youth,” or “Aboriginal youth engagement,” as well as terms addressing specific issue areas such as “Aboriginal youth and suicide,” “Aboriginal youth and HIV/AIDS,” and “Aboriginal youth and diabetes.” With an exclusive focus on Canadian material and on program/activities/events that involved youth in health, we tracked a total of 182 visited sites. In reviewing the material, we focused on identifying the different ways of involvement. A list of media of involvement was generated and programs/activities/events classified accordingly.

STUDY PARTICIPANTS

To supplement and validate findings from the environment scan, we chose to do focus groups and key informant interviews with indigenous youth and front-line indigenous practitioners. Focus groups were selected as a method to generate conversation and interactions between youth leaders and experienced practitioners to enrich findings from the environmental scan and identify both problematic issues and best practices in a short period of time (Morgan and Bottorff, 2010). The one-on-one key informant interviews provided more in-depth information from individuals on ques-

tions related to the study. Interview and focus group protocols were drafted and approved by the UNBC Research Ethics Board. Given ethical guidelines that require parental consent for research participants below the age of 19, we limited our study to youth above the age of 19.

The study targeted youth leaders (between 19–29 years of age) known for their involvement in health-related initiatives, and indigenous front-line practitioners recognized for their experience in working with indigenous youth around health (formal or informal). Focus groups were hosted by community organizations working with indigenous youth in two different cities and provinces. Invitations to participate were made by email by the hosting organizations and us, since we had existing relationships and networks with the community. Potential participants were sent an information sheet summarizing the study, confidentiality guidelines, research participation risks/benefits, consent to participate form, and contact information. The overwhelming positive response to the invitation (2 in one city and 3 in the other had a scheduling conflict), shows the benefit of community involvement in recruitment (Daley et al., 2010). Among the twenty participants (7 in one city and 13 in the other), two-thirds were youth leaders and one-third practitioners with over twenty years experience, of which 5 worked in the formal health care system and 3 in Aboriginal social service organizations. Reflecting the urban reality of indigenous migration, the participants all came from different indigenous nations. The size and diversity of the focus groups provided for rich two-hour interactions. Each session was taped and transcribed.

FOCUS GROUPS AND INTERVIEWS

The design of the focus groups emerged from both our prior experience in facilitating interactive sessions and two exploratory round-table discussions held with indigenous youth leaders in the context of a youth forum in which NCCAH was involved. In the focus groups, indigenous youth and practitioners interacted around the question of how and where indigenous youth were participating in health, and what would support further engagement. We began by handing out index cards to each participant to list health programs/initiatives in which they considered youth to be engaged. The responses were then regrouped collectively under headings (i.e., research and advocacy, youth-led organizations, peer-to-peer, issue specific), and compared to the list generated in the environmental scan. Following the discussion, changes were made to the initial list and descriptions, in-

cluding rewording and regrouping. This interactive process served to verify and enrich findings from the environmental scan. Afterwards, a facilitated discussion took place around how indigenous youth want to participate in the public health care system, including suggestions for initiatives or changes that could be built upon in the future.

Interviews consisted of 10 open-ended questions aimed at exploring participant's experiences and perspectives of health. The questions included: Can you give examples of where indigenous young people are involved in the health system in your community? Why do you think they have been successful (or not)? Can you identify challenges to having indigenous youth meaningfully participate? What do you mean? What are the characteristics of participation for indigenous youth? What is the role of culture in indigenous young people's health? A total of 14 (8 with practitioners and 6 with youth leaders) approximately one-hour interviews were conducted in-person either at the interviewee's place of work or at the community organizations where the focus group was held. While seven of the interviewees had previously participated in the focus group, the rest were unfamiliar with the specifics of the study prior to the interview.

DATA ANALYSIS

Our data analysis began with the environmental scan in classifying the programs identified in the web search according to engagement media used to involve youth. On an ongoing basis, we worked at refining our categories, regrouping them when possible. The list of media was then presented to the focus group participants for verification and enhancement. To provide for content validity, all transcripts of the focus groups and interviews were colour-coded separately for themes by each one of us, and we met several times to discuss the meaning of the data and themes. Given the diversity in our own background and life experience, we often had lively discussions.

The make-up of our team was significant to our research, particularly having an indigenous youth activist along with two researchers, one indigenous and one not. As an active indigenous youth, I was able to draw on my personal experiences and views during the data gathering, I was able to access connections as well as information, and during the focus groups and interviews, I made participants comfortable, feeding their eagerness to share ideas. As identified in studies on action research, the blurring of lines between researchers and the researched can be critical to involving more marginalized voices, in this case indigenous youth (Kemmis and McTaggart,

2000). However, being the youth researcher meant that I felt a sense of responsibility to facilitate and deliver our inquiry powerfully and effectively which was more pronounced than for my co-authors who were more removed from the research content given their age and background. Similar to Daley et al.'s (2010) observations for community-based research, as a moderator in focus groups I found it challenging at times to distance myself from contributing to the discussions because I shared with my peers similar hopes and aspirations in terms of striving to affect tangible positive change in the lives of our peers and our communities.

FINDINGS

The first set of themes that emerged from our data suggests that many indigenous youth feel the current health care system is ineffective and disrespectful of youth and culture. These themes set the context for the second section on the place and nature of culture in providing for health. In the third section, we present the creativity and diversity of indigenous youth's involvement in health-related initiatives (see Table 1). The interviews and focus groups informed all three sections, the environmental scan mainly the last one.

Table 1. Summary of Findings

<i>Themes</i>	<i>Sub-themes</i>
1. Indigenous youth feel the current health care system is ineffective and disrespectful of youth and culture	Indigenous youth experienced a differential treatment by health professionals. Inadequate integration of culture.
2. Place and nature of culture in providing for health is critical	Lack of belonging, and cultural discomfort to be central causes of substandard health of their people as well as ongoing systemic challenges. Youth/adults call for a continuity with the past, recognition of multidimensional nature of health and connections between each.
3. Creativity and diversity of indigenous youth's involvement in health related initiatives	Indigenous youth are tackling the myriad of health issues that confront them and are eager to be part of shift in health. A primary concern of indigenous youth was to be involved in the design and delivery of health programs and services Indigenous youth strengthening their ability to make and impact decisions through formal and informal medium

PERSPECTIVES ON HEALTH CARE

Youth feel disrespected

In general, we heard that indigenous youth found the formal health care system to be unwelcoming. Health professionals were often inconsiderate, and dealt with them as clients to be “worked on” instead of people with whom one could relate. In one of the focus groups, for instance, youth role-played a real life experience: a nurse doing an examination in a health clinic without ever directly looking at her young patient. The scene served as a springboard for youth to discuss how frequently nurses and doctors ignored them; rarely were they directly asked questions, even less often were they listened to.

Indigenous youth experienced differential treatment by health professionals. One young person recalled breaking her wrist and the nurse incessantly asking her if she remembered what she was doing the night before, having made the assumption that her patient had been drinking. The participant said the nurse’s false presumption “enraged” her and that the situation was a good example of “why Aboriginal youth are not getting involved because we get labeled.” Besides individual experiences of racism, youth spoke about suffering from systemic inequities. Resulting from a legacy of historical discriminatory practices, for instance, indigenous youth were subject to a health system fraught with jurisdictional wrangling and a lack of consistent health services when moving on and off reserve, where different health policies apply. One young person expressed how she felt, “I get so frustrated with the health system, we get tossed around.” Most had stories about not receiving services because they were transient, an important issue considering the rapid migration rates of indigenous individuals to urban centres.

Inadequate integration of culture

Indigenous youth and practitioners critiqued current integration of culture into the formal health care system. These efforts have often resulted in applying pan-indigenous models disregarding the diversity of indigenous cultures. Indigenous youth from Nunavut, for instance, were particularly critical of models from the south being applied to them; use of the medicine wheel, for instance, is viewed as inconsiderate and disrespectful. Several practitioners commented on the misallocation of health funds, including to generic health awareness campaigns devoid of input from targeted populations.

Youth emphasized the value of “homegrown” initiatives and community-based programming. One youth explained how community ownership in-

creased effectiveness: "Community-driven approaches are also more respectful of cultural differences. I am Ojibway — what may work for me, may not for another." Youth likewise emphasized the role of participation in meeting the diverse cultural needs of indigenous youth. An indigenous youth participant identified the need to make sure children received information that was both correct and appropriate to "who they are." She described an experience where this was not the case: "they were giving a dream catcher — something from Walmart about what people think Indian is." Limiting the transfer of culturally appropriate teaching and materials is the lack of health professionals who have experience or training suitable for cross-cultural settings. As explained one indigenous health practitioner, the current approach to health is inadequate:

All they [i.e., patients] are given in hospital are pills, [but] deep inside is the root of their problem, [and] no one attends to their underlying problems.... They need to have a lot of traditional counseling ... being one person, sometimes I do not have enough time to work with them.

While having the experience and ability to address the issue, she was unable to attend to the need on her own. As commented a youth: "rather than seeing their gift as a spiritual gift those youth are born with — they are given pills." Participants sense not only the clash between the pathological medical approach to health care, but its inability to address the scope and magnitude of the health issues that they experience.

PLACE AND NATURE OF CULTURE IN HEALTH

Another theme of the study related to the place and nature of culture in health. Focus groups and interviews indicated that participants considered the lack of belonging and cultural discomfort to be central causes of the substandard health conditions of their people, as well as ongoing systemic challenges. Culture provided balance and healthy relationships. In the words of one youth, "Culture teaches me ways to stay connected to family and the Creator and [be] true to myself. Sometimes culture is the best way I can relieve stress." In the words of another: "if you don't know who you are, you are not rooted." A practitioner explained that culture functions as "a prevention tool for healing because that way you feel really connected.... Culture is that safe place ... it is really cool to know where you come from."

Many youth commented on the confusion that modernity has brought to their place and role in society. Traditionally, the transition from childhood to adulthood was clearly marked by rites of passage such as igloo-

building for Inuit men and hunting for Nisga'a men. Responsibility levels were dependent on an individual's level of maturity. One participant explained how in "Indian culture, as long as [they] are responsible they can take the [traditional] medicine. They can come to ceremonies all night if they are strong enough and able to partake in the ceremonies." The broadening definition of "youth," now from 13–29, has in many ways been unhelpful. For a 22-year-old focus group participant living in an urban setting, the fuzziness was a sign of disrespect:

[They] say you are a youth. No, I am accomplished. I want to be respected and categorized as an adult.... What is being touched on is part of the frustration. There are 15 ways of defining youth; it's like you can't make up your mind.... [The] only place I feel it is consistent is in my community. I can see where I fit.

For another youth, it was the constant compartmentalization that has crippled the health care system. She stated:

We need to be able to actualize our holistic vision of health. We can't separate everything into individual boxes. Structure does not work for us, our communities are not based on hierarchy — where everyone should be is where their skills are; in the household there are roles for men, women, and youth in decision-making. Young people need to have a voice.

Youth and adults called for continuity with the past, particularly recognition of the multidimensional nature of health that valued the physical, emotional, spiritual, and mental aspects of health and the interconnections between each. Strengthening identity, however, is not simple since over half of the indigenous population lives in urban areas and many youth are disconnected from their traditions, and in some cases, their own cultures. A practitioner working in Vancouver for over 30 years described the situation as follows:

culturally there is a vacuum for our children ... we used to] teach through our talking, discussions, songs and dances ... some of the stories are very significant in teaching about how to behave ... [and] what they are supposed to be doing.

A legacy of residential school and discriminatory practices have left extensive wounds that are being passed from generation to generation. As a result, indigenous youth often have fractured encounters with their cultural traditions. One practitioner explained:

[It's] seen time and time again. [In] tribal journeys they learn spiritual/protocol, [then] come home and dad's sniffing. We get them in a cultural way — but [they] go back home and dad is drinking. He was pumped about rediscovering his culture, and the poor guy was deflated in a second.

A history of injustice has resulted for some in fractured families and a lack of parenting skills; addressing the systemic causes was considered key to addressing the health issues of children and youth.

In response, youth who are disconnected from their home cultures and territories were borrowing from other indigenous cultures, though it may go against traditional protocol. One practitioner advised that this may be necessary and beneficial:

Urban Aboriginal youth are adopting different parts of their spiritual being from others, not their own. There are some commonalities, so it is OK. Lots will go to sweats, circles, smudges, use sweet grass: people feel it is good.

Many youth centres and indigenous health centres in urban areas bring in Elders, offering indigenous ceremonies open to all. For instance, the Anishnawbe-Mushkiki Aboriginal Community Health Centre in Thunder Bay and the Wabano Centre for Aboriginal Health in Ottawa offer health clinic services as well as traditional programs, including drum teaching, talking circles, and craft workshops.⁵ Similar to the past, youth are participating alongside other community members, especially Elders, who facilitate the transmission of teachings, which helps to recreate a sense of belonging and community.

In the context of continuity with the past, youth voices are also bringing shifts in the culture. Symbolic of youth wanting to be recognized for their contributions is when the youth asked to officially offer a CD-compilation of hip-hop songs to their Elders after Elders shared traditional songs at an event. For those who have closer links to their own traditions, the changing of culture and the promotion of pan-indigenous approaches is feared as contributing to the loss of traditional indigenous ways of being and knowing. Below, we take a closer look at the ways youth are responding and creating to improve their health.

DIVERSE AND CREATIVE RESPONSES TO HEALTH

Throughout the study, we found indigenous youth tackling the myriad of health issues that confront them, such as suicide, diabetes, smoking, substance abuse, and HIV/AIDS. There was an eagerness among indigenous youth to be part of a shift; driven by a motivation that for many is deeply personal: "I am sick of seeing my friends dying of addictions, I am actually going to do something — create stories, dances to prevent this and

5. For more information see <http://www.wabano.com/programs.html> and <http://www.anishnawbe-mushkiki.org/>

intervene. It is frustration that motivates me to create unity, hey let's work together." Alongside the grim statistical portrait, youth bring hope: "in a way, the young people have lost the direction for yesterday, but not for tomorrow." Little however is known about the health-related activities underway. As captured by one youth: "There is a lack of showcasing of what is totally working. Youth are creating too, they are capable."

In the environmental scan, the following list of media of involvement were identified, including: youth governance, youth led organizations, civic and political engagement, youth-child designed literacy tools, virtual technologies/media, sports and recreation, education, Aboriginal youth health specific strategies, public awareness campaigns, peer-to-peer programs, participatory action research, culture camps, Elder-youth mentorship, tribal journeys/canoe journeys/art cultural participation. This list was reviewed, complemented, and edited in the focus groups. An interesting finding was that participants felt it inappropriate to prioritize the media according to how much they contributed to health, seeing that all had a role to play. The focus groups also found that many initiatives were not reported on the Internet because they were short-lived, or there was a lack of resources for documentation, much less monitoring or evaluation. One focus group participant commented on her index card: "although [the initiative was] not up and running, [it] was an excellent model of Aboriginal youth engagement, totally youth-driven."

Following an analysis of all the data, we regrouped the media into two broad categories: youth who were engaged in creating youth and culturally friendly design and delivery of health care services, and more broadly in youth empowerment, organizing to strengthen their identity and increase their influence. The fact that indigenous youth considered these activities to be connected to health suggests a holistic approach to health, and how young people consider identity and involvement in decision-making as integral to meeting their health needs.

Design and delivery

A primary concern of indigenous youth was to be involved in the design and delivery of health programs and services. This meant recognizing indigenous youth's expertise, and involving them in planning and implementing their health care. As stated a youth, this was critical for its effectiveness:

First, the mistake many make is not making youth their own experts.... [It's] way more effective if youth are at the table ... ask youth what area they want to learn about? Young girls may not be ready to learn about sexually transmitted

diseases. First sit down and involve them in design.... When youth have ownership, [they] become accountable to the program.

The need to consider involving youth as partners was a perspective also echoed by practitioners. In the words of one:

Children need to be heard. It is not about doing the research; they have to be at the table to decide what their health needs are and how they are going to be met. I feel I need to champion that. Without that there will be no self-determination for children.

And there are cases where this is beginning to happen. In the Nenan Dane_Zaa Deh Zona Child & Family Services organization, located in north-eastern BC, communities used a circle of rights community empowerment process to involve youth. Through this process young people participated in the identification, design, development, and implementation of initiatives and services to better meet their specific needs (Cummings and Currie, 2009).

In making the shift, youth talked specifically about the value of child and youth friendly communication media, and peer-to-peer programs. According to participants, without a youth specific communication strategy, outreach had been problematic. As one focus group member commented: "[It's] really hard to get youth by just a poster ... when it looks really bureaucratic, and they have already participated in tons of things that have not seen follow through." Another participant observed that, "Youth do not just come; if we announce a session on teen pregnancy or sexually transmitted diseases we need to engage them differently." In other words, it takes more than putting the information out there; youth need to see the reason and relevance of their attendance. Also, they need to be recognized and rewarded for their participation through creative incentives. Being the target of much information and programming, youth have become skeptical of all programming devoid of indigenous input.

Youth considered their input to be critical to creating media that is both appropriate and enticing. One participant explained that:

Being creative and innovative is number one with youth. You need to go and talk to the youth directly, and those who gave input need to be part of the implementation." To talk about healthy living, indigenous artists have created comic books with indigenous-looking characters, humour, and other culturally relevant points. These books were one example of a strategy that engaged youth in a meaningful way; indigenous youth related to

the characters and messages being presented and had a voice in the design. Also popular amongst Aboriginal youth was the use of hip hop or break-dance as forms of expression. In fact, one practitioner stated: "Today I feel that hip hop is the only way they are giving their message." In the words and lyrics of these different communication strategies were embedded important health messages speaking to everyday experiences, expressing what they faced, where they were coming from, where they were at, and where they would like to go. Indigenous youth also talked about the effectiveness of using skits or theatre for youth to safely explore some health issues in ways where youth "will pretend, they will feel safer and be more available to learn." Youth involvement is needed to identify media that reach youth.

Another approach promoted by youth is the peer-to-peer approach, whereby youth learn from each other instead of a professional, generally older person. Peers can relate to other youth more easily. Because of a similarity in age, there is a commonality in lived experience. Amongst peers, young people felt more comfortable sharing their personal issues. Peers know how to communicate information in a way that is heard. The number of resources being developed to support peer-to-peer programming in Canada by indigenous youth was notable in the environmental scan. Amongst the many programs identified, based on the peer-to-peer model, is the Making Aboriginal Kids Walk Away (MAKWA) peer leaders in Thunder Bay which promotes tobacco awareness. In this program, young people teach peers about the traditional use of tobacco and its role as a sacred medicine (i.e., alongside sage, cedar). The peer-to-peer approach is also used to promote awareness in other issues, such as AIDS (Young Eagle's Challenge), sexual exploitation (PEERS), violence (see *NWAC Violence Prevention Toolkit*) and diabetes. Youth identify the value of being involved in all stages of the programming cycle. One youth reported positively on her experience in doing so: "I feel that contributing my perspective along all the stages is key; it feels empowering to know that we can make a difference, to see that there are tangible products."

Recognizing youth's voice is, however, not easy when neither practitioners nor youth have experience working this way. Indigenous practitioners reflected on them not being used to considering the youth's perspective. One commented on learning the hard way about the failure of one of his intervention plans because he had not listened to the young person: "I had a plan and I did not hear hers." In the end, instead of helping her, she ran away, placing her in a worse position than before the intervention. To

meaningfully integrate youth in the different stages of program development, implementation, and evaluation, practitioners must learn new ways of interacting with youth, valuing youth input as a critical expertise for bettering health programs and services.

Youth empowerment

The other way that indigenous youth are involved is in strengthening their ability to make and affect decisions. This is happening formally around “organizing” and informally in events and gathering to share and exchange. We considered all these activities had to do with the theme of youth empowerment. Below, we present indigenous youths’ perspectives and the type of activity being undertaken.

The more informal ways youth are strengthening their feelings of belonging and building their identity are through gatherings where youth come together and share stories and experiences, positive and difficult. One participant commented:

They [funders] want numbers but it is not about numbers, it is about smiling children ... we have had youth exchanges, youth from one community sharing with others what is working; this gives youth a bigger voice.

In other words, the impact of a gathering cannot be quantified; it is the less tangible elements that significantly affect youth’s well-being. Indigenous youth requested that attention be paid to these elements, reflecting their view that mental and physical health were interconnected: “when mentally unwell, one cannot move forward in a good way.” Or, as one youth stated, “When we have our identity, when we have our spirit, we can do anything.” Youth support activities where they can “experience what it is to be healthy.”

Cultural camps were another activity singled out by youth to connect youth with the land, their Elders, and community. Rediscovery programs, for instance, recreated the experience of an extended family in the bush, similar to traditional summertime activities of gathering, hunting, and fishing (Henley, 1996; Lertzman, 2002). In the camps, youth connected with themselves and their culture. In the words of a participant:

I always knew that I had Native blood, but I didn’t really know what it meant to be Native until I came to Rediscovery ... I felt connected in that space, with Nature, with myself.

A former participant (at age 15) who is now staff at one of the camps, considered a critical aspect of the camps to be in the building of relation-

ships, a foundational component of health: “as far as health, they need to feel trust.” Trust brings confidence in who they are, in the grounding with the land and other people, in becoming an actor for their own health care and that of their community.

Besides a range of informal ways of empowering youth, indigenous youth are establishing mechanisms and structures to increase their ability to influence areas that affect their lives, including health care. As one youth participant stated: “Youth need to be involved as decision-makers. Everyone talks about the grass-roots, lots of token positions, but we need to be meaningfully involved.” A prime example of a youth-led organization is the Knowledgeable Aboriginal Youth Association (KAYA) in Vancouver which has a mandate to advocate for Aboriginal youth voice, representation, and participation in decision-making. KAYA is part of a new generation of youth-driven organizations that are captivating attention worldwide (Blanchet-Cohen, 2009). A practitioner commented: “Youth drove that. [They have] amazing power once you give tools to them.” Of significance, KAYA has been successful in strengthening youth identity as well as relations with community stakeholders, such as the police force, with which they successfully created a structure for youth and police to work together.

In addition to youth-led organizations, youth are advocating for access to formal decision-making, with youth councils or youth participating on boards. Accordingly, most national Aboriginal organizations and, increasingly, local communities have youth councils. The Nisga’a Lisims Government, for instance, established youth councils in each of their four villages, as well as youth councils for Nisga’a youth who reside in Prince Rupert, Terrace, and Vancouver. In certain Inuit communities, such as Pangnirtung, youth councils include Elders given an affinity between the two generations. Councils play an important role in “grooming” the next generation of leaders, but also, more immediately, bringing attention to youth issues. Amongst the range of youth council activities, health issues rank high on youths’ priorities. For example, the National Inuit Youth Council leads a project on suicide prevention called *Inuusiqatsiarniq*, which emphasizes celebrating life in a positive way. Youth councils often actively seek budget and space for recreational activities, considered key to supporting youth well-being in communities where boredom, inactivity, and systemic issues are key reasons youth get into trouble.

Accordingly, youth in governance are considered a benefit for communities more broadly. A participant explained: “While these initiatives are aimed

at youth, they are also [good] for the community because they give unity." Many youth think that their communities should see resources spent on youth as an investment, not an expense, and that youth should be involved in all community issues, not just those which are youth-specific. Youth considered that they were able to transcend beyond the political divisions that curtail leaders. A participant explained the potential of youth as follows:

The youth agenda has fallen at the bottom of the list. Our leaders are, ironically, fighting against each other. We youth work together.... We need to control the agenda, to set the pace, to learn how to work together.

Youth empowerment and requests for partnering with adults have not always been received openly. Indigenous youth felt their voice was often devalued. For example, a youth council member commented: "The youth component is rarely on the agenda. How often do you get to be the last on the agenda?" In recognition of this reality, a practitioner reflected:

We shut down as leaders ourselves ... [though] when kids are yelling and screaming they are telling us something.... We don't give [them] the opportunity to fight and give back. We are not good at that. We don't hear the anger.

To pave a brighter future, figuring out how to support indigenous youth in initiatives and ensuring that they have voice and ownership is critical. Otherwise, the failures of interventions will continue to accumulate and indigenous youth health will continue to suffer.

DISCUSSION

With regards to the first research question on youth's perspectives on the current health care, this study shows that indigenous youth and service-providers have experienced and reflected on the current flaws within the health care realm in ways that are congruent with the grim portrait drawn by studies on indigenous peoples in general. Similarly, the formal health care system is considered to contribute to the substandard health portrait of indigenous youth, given its limited understanding of health, and ignorance of traditional indigenous knowledge and culture (Barone, 2010; Tate and Meeuwesen, 2000). Lack of interaction between young patients and medical professionals prevails across the entire system, but indigenous youth feel particularly distrusted and discriminated against. When compounded, these racial micro-aggressions have significant impact on how indigenous youth see themselves (Carson et al., 2007).

Perhaps the greatest contribution of the study relates to the second research question on how indigenous youth are involved (or not) in health

care. Although critical of the formal health care system, we found indigenous youth are taking action in diverse and creative ways. The focus is on design and delivery of health programs and services, such as promoting child-youth friendly communication media that are culturally appropriate and relevant. Youth are also involved in empowerment activities through formally organizing themselves or informally sharing and exchanging to support a feeling of belonging and connectedness. Significantly, indigenous youth consider each type of activity has a role to play in creating a supportive context for the well-being of indigenous youth and their community.

In being responsive and creative, youth are promoting approaches adapted to their lived realities and driven by youth needs and perspectives that challenge normal practice and structures, an aspect of youth engagement that, while reported in the literature, rarely relates to indigenous youth (Blanchet-Cohen and Salazar, 2010; Zeldin et al., 2008). According to the literature review, a commitment to youths' perspectives and views appears to be increasing on indigenous people's agendas, and this study suggests that indigenous youth can forge uniquely innovative and appropriate partnerships and solutions. Our finding contrasts with Woodgate and Leach's (2010) study with ethnically diverse urban Canadian youth (ages 12–19) which shows that youth talk is mostly limited to health as it relates to lifestyle factors. Further research with indigenous youth who are not leaders is needed to determine whether our findings are unique to leaders or apply to indigenous youth in general.

A central finding from the stories shared and comments related to the third research question on views on the future is the value youth and practitioners place on culture in realizing optimal health and well-being. While many youth may be unaware of the legislations that support indigenous youth engagement, including the UN Convention on the Rights of the Child, we found that youth are breathing life into the right to participate (Article 12) and to culture (Article 30). Youth consider culture is foundational to this well-being, fostering and nurturing identity, and enhancing opportunities to connect with their community, Elders, and land. Yet youth recognize that meaningful engagement is not simply about returning to the past, but rather building on the past to accommodate to their changed and contemporary realities. Culture is not static, but ever-changing (Rogoff, 2003).

In general, supporting youths' meaningful engagement in health services calls for an urgent need for developing the capacity of adults, whether front-line service practitioners, community leaders, or health professionals,

to work with youth. This study points to the importance of cross-cultural training for medical doctors and nurses and more health professionals of Aboriginal ancestry (Hunter et al., 2004). Youth engagement needs to become a natural way of working, not viewed as a program, as requested in the ethical guidelines developed and presented by the UN Committee on the Rights of the Child (First Nations Child and Family Caring Society of Canada, 2006). To inform the training of service professionals in ways that reflect youth's perspectives, subsequent research is warranted. More broadly, the study reaffirms that indigenous youths' and practitioners' broad understanding of health is similar to indigenous people's general call for self-determination and empowerment, also recognized in the social determinant discourse as critical to bringing long-lasting changes in health (WHO, 2007). Thus, providing for indigenous youth health also calls for attention to involvement in sociopolitical structures.

A final reflection raised by the study relates to the make-up of our research team which enhanced our awareness of what it means to work with youth on research. As an indigenous youth activist, this experience reached me on a deeply personal level. I strengthened my understanding of the importance of youth utilizing our collective voices to create action for change, and the challenge of building and sustaining collaboration between youth and adult researchers who come with a different relationship to the data. As researchers, we learn the value of questioning our assumptions, our writing, and its application. Given the complex world of academia and community epistemologies, we must continue to dwell upon questions such as: how do we ensure the safety and wellbeing of youth researchers? How can indigenous youth be involved in all stages of the research process from design, data gathering, analysis to reporting? How can we ensure that research is communicated to a vast and diverse set of audiences including youth? How do we raise awareness that the health and wellbeing of indigenous youth is everyone's responsibility?

CONCLUSION

Findings from this study provide insight into how the health care system needs to more appropriately recognize indigenous youths' contributions, cultural history, and experiences, but also how indigenous youth are taking action in ways that espouse a broad perspective of health. There is an urgent need to understand the range of activities underway, to support youth programs dependent on funding, youth leadership, or support from the com-

munity. Undertaking future health research so that youth are valued and affirmed in their role as determiners of their own health and well-being can help to build on indigenous youths' contributions in shaping the future of indigenous people's health care in Canada. In-depth research led by indigenous youth is key to realizing this future.

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