Report on the
Health Status and Health Needs
of
Aboriginal Children and Youth

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SOUTHERN ALBERTA HEALTH NETWORK

Report on the Health Status and Health Needs of Aboriginal Children and Youth

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Through dialogue, relationships were developed with these partners that will support the ongoing efforts to better understand both the health related strengths and the disparities that are a part of the Aboriginal communities in southern Alberta and how these influence the health of children and youth. The goal is to develop strategies that will build on the strengths and positively impact the disparities in meaningful ways across southern Alberta.

A particular thank you is extended to the Elders Advisory Group whose voices and experience provided both historical and contemporary insight for this project.

Table of Contents

Executive Summary

In August 2003, the Calgary Health Region Aboriginal Health Program (AHP) and the Southern Alberta Child & Youth Health Network (SACYHN) identified an opportunity to work together to develop strategies that could provide direction to address the health status of Aboriginal children and youth across southern Alberta.

A Project Team, an Elders Advisory Group and a Project Steering Committee were established to complete an Aboriginal child and youth health community consultation process. The goal of this process was to understand the complexities of the issues affecting the health of Aboriginal children and youth and to identify short and long term recommendations and actions.

In conjunction with the community consultation process, a literature review was completed to provide a broad overview of the health of Aboriginal children and youth in Canada and specifically southern Alberta.

Results

Aboriginal youth, parents and agencies were consulted regarding the definition of health, components of health, major health concerns, barriers to health, and ways to improve health for Aboriginal children and youth. Their responses reflected both personal and professional experiences and together these painted a comprehensive picture of the critical factors affecting the health of Aboriginal children and youth health in southern Alberta. The literature review and focus group comments also support the concept that there is hope for improving the health of Aboriginal children and youth across southern Alberta, particularly if effort is made to incorporate both traditional Aboriginal and western perspectives in service delivery approaches. In addition, the Elders Advisory Group reinforced the importance of looking not only at concerns or issues but also at current strengths and opportunities.

Recommendations

The recommendations are based on the themes that emerged from the focus groups and these themes are supported by the literature review. The recommendations fall into the following categories: basic necessities of life, comprehensive and coordinated health services delivery, education for children, youth and families, community control and empowerment and public policy.

A number of the recommendations identified are outside of the scope of SACYHN or AHP and/or they have been made in previous reports on Aboriginal health. However, these recommendations are included as they give voice to the perceptions of the focus group participants and because they continue to be important factors for consideration in addressing the health needs of Aboriginal children and youth.

Since the beginning of this project, many changes and activities have already occurred that positively influence the relationships between the Aboriginal communities and health regions of southern Alberta in our collective effort to influence provision of care for Aboriginal children and youth. These activities are reported and are reflective of current work that may respond to some of the recommendations at least in the short term.

Next Steps

For those involved, participation in this project has facilitated increased knowledge of the health status and health needs of Aboriginal children and youth in southern Alberta. It has also strengthened the ties with Aboriginal communities, including service providers and Elders. It is critical to keep in mind the strengths of Aboriginal families and communities as we work collectively to improve health outcomes for Aboriginal children and youth.

This report will be used as the basis for further discussion and planning with Aboriginal communities in southern Alberta regarding the health needs of Aboriginal children and youth.

Introduction

The Calgary Health Region **Aboriginal Health Program** (AHP) recognizes the unique status of Aboriginal peoples as founding or first peoples. It is committed to the development and implementation of a dedicated regional program that maximizes the health and wellness capacity of Aboriginal people who access services offered by the Calgary Health Region. The goals of the AHP are to:

- enhance the capacity of the individual, family and community to promote health, to prevent illness and injury, and to maximize wellness;
- build partnerships that enhance the community's capacity to address the full range of health determinants and that maximize the efficient and effective sharing of resources;
- improve access to and appropriate utilization of coordinated, comprehensive and holistic traditional and mainstream health and health related services;
- promote Aboriginal leadership, management and participation in all aspects of the AHP;
- maintain and enhance spirit, tradition and culture in all aspects of the Program;
- model excellence in program surveillance, planning, governance, service delivery, and evaluation;
- ensure accountable, effective and sustainable services.

The AHP acts as a vehicle to create or enhance linkages with First Nations and Métis community health service providers within the Calgary Health Region boundaries.

The **Southern Alberta Child & Youth Health Network** (SACYHN or *Network*) is a dynamic and voluntary collaboration among individuals and organizations concerned with the health and well being of children, youth and families. The *Network* was formed in September 2001, and includes parents, child-serving ministries, provincial agencies, regional authorities, First Nations, universities, and non-profit agencies. It provides a forum for planning and setting priorities, and looks at ways to improve health and related

services for children and youth throughout southern Alberta. The geographic area covered by SACYHN includes health regions 1 through 4 in which Treaty 7 First Nation communities are located. The role of SACYHN is to:

- promote high quality, accessible connected programs, services and information resources;
- support the full continuum of care from promotion through specialized treatment for all children and youth from birth through transition to adulthood;
- connect parents, families, and youth across health regions;
- promote families as equal partners in the individual provision of care and in broader service planning;
- build parent, community and professional capacity to address child and youth health concerns;
- support the use of technology and innovative ways of delivering services to improve access and continuity of care.

The AHP and SACYHN identified an opportunity to work together to develop strategies that could provide direction to address the health status of Aboriginal children and youth. Together they developed a community consultation process with Aboriginal youth, parents, and agencies serving Aboriginal children and youth both on and off-reserve in southern Alberta. This project provided the AHP and SACYHN an opportunity to establish new partnerships and strengthen existing ties between the Aboriginal community and child and youth health service providers throughout southern Alberta. The anticipated long-term result will be the development of strategies to improve the overall health of Aboriginal children and youth.

Background

Aboriginal people make up a significant percentage of the Canadian population as nearly one million Canadians self identify as Aboriginal (Statistics Canada, 2001). In southern Alberta, approximately 17,300 Aboriginal children and youth under the age of 15 reside in either one of the five First Nations of Treaty 7 or in urban communities (Statistics Canada, 2001).

The five First Nations communities located within the health regions of southern Alberta includes:

- Kainai Nation within Chinook Health Region
- Piikani Nation within Chinook Health Region
- Siksika Nation within Calgary Health Region
- Stoney Nation within Calgary Health Region
- Tsuu T'ina Nation within Calgary Health Region

Scope of Project

A Project Team comprised of staff of the *Network* and the AHP was established in August 2003. A Project Steering Committee and an Elders Advisory Group were subsequently established in September 2003 to develop and guide the project. An Aboriginal Project Coordinator was contracted to complete a community consultation process and a Project Consultant was contracted to undertake a literature review and assist with the preparation of the final report.

Identified objectives of the project included:

- creating a strategic consultation process
- conducting a series of regional and community consultations to explore the health status of Aboriginal children and youth
- identifying external and internal barriers and issues that affect the health of Aboriginal children and youth
- identifying concrete strategies to address health disparities of Aboriginal children and youth

In addition to the establishment of the groups and staffing mentioned above, the steps involved in the project included:

- completing a community consultation process the goal of which was to understand the complexities affecting the health of Aboriginal children and youth

- completing a literature review which examined current issues in health status and health disparities of Aboriginal children and youth in southern Alberta
- preparation of a draft report
- holding a community validation meeting to review findings
- publication and distribution of a final report
- based on the results of the report, planning health related services and programs that attend to the specific strengths and needs of Aboriginal children and youth throughout southern Alberta.

Literature Review Executive Summary

Introduction

The review synthesizes current literature on the health of Aboriginal children and youth in Canada with a focus on the southern Alberta area. It was commissioned by the Southern Alberta Child & Youth Health Network (SACYHN) and the Calgary Health Region Aboriginal Health Program (AHP). This review is based on literature that has been gathered by members of SACYHN and AHP, an examination of reliable and relevant Internet websites, and electronic databases. This literature review generally uses the term Aboriginal to refer inclusively to First Nations, Métis and Inuit people, but includes references to specific groups such as First Nations people as found in the literature. The full literature review is available for downloading under *publications* on the SACYHN website at www.sacyhn.ca.

Setting the Stage

To place the literature on the current health status of Aboriginal children and youth within context, the underlying worldview on health, historical factors, jurisdictional barriers to health, and limitations to available data were considered. The Aboriginal perspective on health is more holistic than the Eurocentric view of health, and therefore, physical, emotional, mental and spiritual components of health are important to consider.

The effects of European colonialism on these four areas are still being felt today by individuals, families, communities, bands and Nations. Current government policies and practices such as jurisdictional boundaries between federal, provincial and local governments continue to impede Aboriginal people from reaching their full health potential. Another barrier to Aboriginal health is the lack of consistent, comparable, comprehensive data on Aboriginal peoples and research on best and promising health services for Aboriginal children and youth.

Health Status of Aboriginal Children and Youth

- Infant mortality in general, and Sudden Infant Death Syndrome (SIDS) in particular, are greater problems for the Aboriginal population than the general population.
- Aboriginal infants living on-reserve appear to be at the least risk for low birth weight followed by non-Aboriginal infants, with Aboriginal infants in non-reserve areas being at the greatest risk.
- Aboriginal infants are at a greater risk for high birth weight than their non-Aboriginal peers.
- Aboriginal infants are less likely to be breast-fed than their non-Aboriginal peers, but when they are, it is for a longer period of time.
- Aboriginal people appear to be at a greater risk for infections, and these infections may be more severe than in their non-Aboriginal peers.
- Aboriginal children are more likely to be admitted to hospital in the first year of life for respiratory infections, diarrhea, and gastroenteritis.
- Significant percentages of Aboriginal children and youth in southern Alberta are reported as having long-term health conditions.
- The prevalence of type 2 diabetes mellitus or non-insulin dependent diabetes mellitus (NIDDM) is two to six times greater in the Aboriginal population than in the general population and there is a trend towards more youth exhibiting early onset of the disease.

- Obesity, which can be related to the development of NIDDM, is found in 6% of Aboriginal boys and 5% of Aboriginal girls in Canada. Other significant health problems for Aboriginal children and youth in Canada and southern Alberta include: ear problems, allergies, asthma, bronchitis, and to a lesser degree heart conditions and kidney problems.
- Aboriginal children and youth in Canada have a much higher rate of injury and death than the general population.
- Initial data suggests that Aboriginal children and youth do experience some mental health concerns, and are more likely to visit a doctor for mental health concerns than their non-Aboriginal peers.
- Suicide is a significant problem for Aboriginal youth with a suicide rate that is five to six times greater than their non-Aboriginal peers.
- There is substantial concern about substance abuse amongst Aboriginal youth, but other than tobacco, there is little empirical evidence indicating that substance use is greater amongst Aboriginal youth than their non-Aboriginal peers. Similarly, although there is great concern about Fetal Alcohol Spectrum Disorder (FASD) within Aboriginal communities, to date there are no valid comparisons of prevalence rates of FASD for Aboriginal and non-Aboriginal communities.

Contributing Factors to the Health of Aboriginal Children and Youth

There is abundant literature to support that social and economic status, housing, education, racism, culture and community control/self determination significantly affect the health status of Aboriginal people. Aboriginal people are more likely to live in poverty and be unemployed than the average Canadian. A significant proportion of Aboriginal people live in homes that fall below Canadian Housing and Mortgage Corporations standards for adequacy, suitability and affordability and many live in homes that are overcrowded. Rates for high school graduation and attendance at post-secondary schools for Aboriginal people are well below the national average.

There are approximately 93,000 former residential school students alive today and residential schools have left a legacy where traditional means of educating and parenting

have been lost. There is continuing evidence of racism and institutional discrimination against Aboriginal peoples. More positively, culture can affect emotional and spiritual health and a large percentage of Aboriginal youth and their parents who participated in the First Nations and Inuit Regional Health Survey (FNIRHS) indicated that they thought that returning to traditional ways was a good way to promote community wellness. On a similar note there is a positive association between self-determination and health that has been shown in regard to Aboriginal communities and lower suicide rates and reduced physical and sexual abuse.

Promising Strategies

There are promising trends in government policy and the development of promising programs to address the health needs of Aboriginal children and youth. Gathering Strength: Canada's Aboriginal Action Plan has been released to address the 440 recommendations of the 1996 Royal Commission of Aboriginal Peoples (RCAP) and shows potential for creating positive change. At the local level there appears to be a trend towards shifting authority from government to First Nations and to a lesser extent the Métis. There are many promising programs currently being offered to address the health needs of Aboriginal children and youth. Programs and activities offered by the Southern Alberta Child & Youth Health Network and the Calgary Health Region are highlighted in Appendices A and B of the full literature review which is available on the SACYHN website, www.sacyhn.ca, under *publications*.

Recommendations from the Literature

Recommendations from the literature fall into the following themes:

- Comprehensive and coordinated health service delivery
- Education for Aboriginal children and youth
- Understanding of Aboriginal culture and worldview
- Community control and empowerment
- Injury and illness prevention
- Address barriers
- Suicide prevention

Areas for Further Study

Areas for further study include:

- Gathering information on birth weight and patterns of growth for Aboriginal people so that standards more relevant for Aboriginal people can be developed.
- Examining the pattern of obesity and how it relates to the development of NIDDM so that appropriate prevention measures can be developed.
- Further examination of the factors associated with the occurrence of injuries amongst Aboriginal children to identify risk factors and develop prevention strategies.

Summary

This literature review is a broad overview of the health of Aboriginal children and youth in Canada and specifically southern Alberta. Contextual information was provided, current health status information was reviewed, and factors contributing to health status were discussed. Promising strategies, recommendations from the literature and areas for further study were identified. The complete literature review is available under *publications* on the SACYHN website, www.sacyhn.ca.

Methodology

To complete the work required to identify the health issues affecting Aboriginal children and youth in southern Alberta, a Project Team, an Elders Advisory Group, a Project Steering Committee, and a Project Coordinator worked together to establish and undertake a community consultation process. The goal of the consultation process was to understand the complexities of the issues affecting the health of Aboriginal children and youth, and to set the stage for development of a strategic plan with short and long term recommendations and actions.

The selection of the Elders for the Elders Advisory Group was conducted by the AHP. Elders were identified and invited to participate through networking with the Aboriginal community. Each Elder was offered tobacco or extended a formal invitation by letter depending upon the protocol appropriate for the individual. The role of the Elders Advisory Group was to:

- provide advice and guidance to the Steering Committee,
- provide guidance and advice about traditional processes,
- facilitate the introduction of the Project Coordinator and the focus group process in their communities.

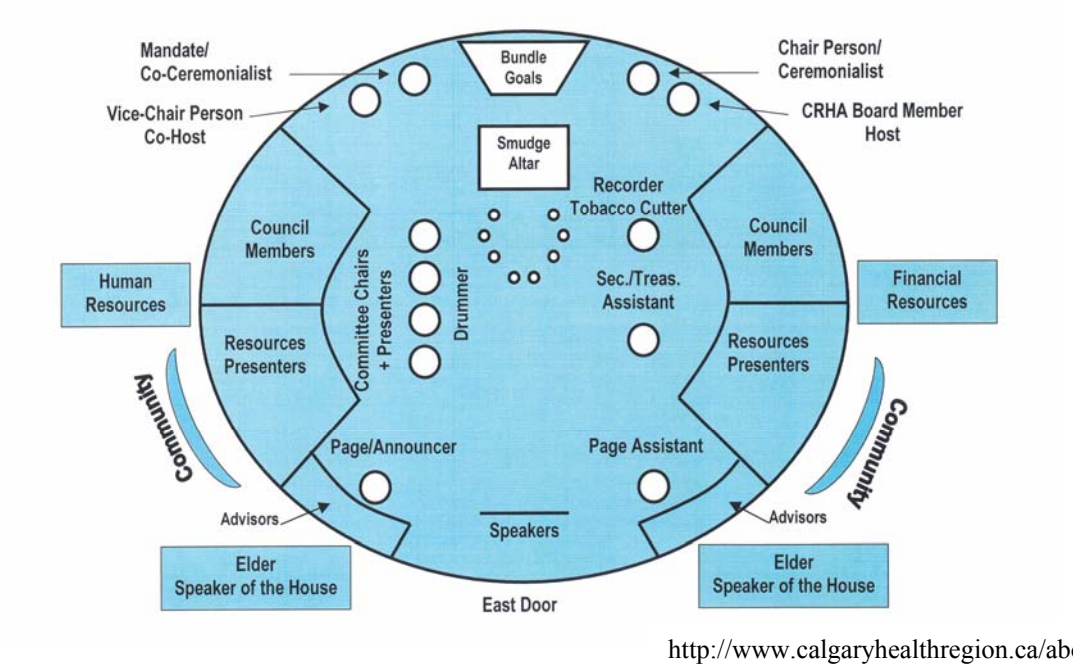
A Project Steering Committee was established to direct the work of the Project Coordinator in a regional and community consultation process. Key individuals who were representative of those who influence the health programming for Aboriginal child and youth health throughout southern Alberta were invited to participate on this cross sector Steering Committee through a formal invitation.

The Project Coordinator was responsible for conducting and documenting all focus group activities, documenting all Elders Advisory Group and Project Steering Committee meetings, conducting thematic analysis of meeting discussions where appropriate, recording and disseminating meeting minutes, providing written reports of interviews and other relevant information, and providing a description of the community consultation process.

The purpose of the consultation process was to elicit information from stakeholders that would help to identify key health issues and strategies required to address the health disparities of Aboriginal children and youth in southern Alberta. This process included focus groups with Aboriginal children and youth, parents and agencies in both urban and rural settings. The use of traditional processes based on the Circle of Life was determined to be important to the success of the process. Traditional methods and

techniques included prayers by Elders, offering of tobacco, observation and use of proper protocol and language and talking circles.

The structure used for the focus groupswas based on the Blackfoot Circle Structure process depicted below. "The Blackfoot Circle Structure model gives all participants non-exclusive access to a process and ensures that they all contribute to the same goal". (Crowshoe & Manneschmidt 2002 p. 37-38)



http://www.calgaryhealthregion.ca/aboriginal/Circle.htm

This model was adapted somewhat with the host/hostesses role assumed by individuals representing the AHP, SACYHN, or the Chinook Health Region. The Project Coordinator facilitated the process, the supporters were the focus group participants, the advisory role was filled by the Elder, and the tobacco cutter was the recording secretary. Discussions usually occurred in a circle manner from left to right, the Elder faced east where possible. Honorarium, food, and tobacco were offered to the Elders.

Before the first focus group was held, an initial meeting was held with the Elders Advisory Group to discuss this method as a way to proceed. Subsequent focus groups began with a smudge and prayer by an Elder.

For the consultation process, the Steering Committee, with support from the Elders Advisory Group, developed five key questions that were used for each of the focus groups. These questions were:

1. What does it mean to be healthy?
2. What are the essential components of health?
3. What are the major health concerns of our children and youth?
4. What are the barriers that get in the way of good health?
5. What can be done to improve child and youth health?

The Project Team attempted to structure the focus groups in such a way that there would be a sample of Aboriginal youth, parents, and child serving agencies from the urban setting as well as from the First Nation communities. The consultations occurred between November 2003 and February 2004. During the consultation process, a total of 9 focus groups were held and approximately 75 individuals participated in the process. The following table describes those who participated:

Category	*Description*	*Number of focus groups*	*Total number of participants*	*Number of returned questionnaires*	*Location*
Agencies	Calgary Agencies & Acute Care	3	18	3	Calgary
	Lethbridge Agencies	1	8	1	Lethbridge
	On-Reserve Directors	1	3	4	Calgary
Parents	Piikani	1	7		Brocket
	T'suu Tina		2		Tsuu T'ina
	Calgary	1	8		Calgary
Youth	Kainai	1	6		Standoff
	Calgary	1	20		Calgary

Limitations

A comprehensive group of Aboriginal (First Nations and Métis) community service providers were invited to participate through personal contact, by letter, telephone, or fax; however, the response to participate was low. Some of the feedback received regarding the low response rate was related to:

- the timing of the focus groups coincided with other activities
- concerns about raising expectations with no concrete results
- current political climate
- need to obtain prior formal approval or support by the Band Council
- lack of personal connection with key contacts or decision makers in the First Nation communities
- some communities preferred to conduct business in their own language

While focus group participants were given an opportunity to validate the data collected, no responses were received. Observation of the circle structure process indicated that this process proved to be confusing and not well understood by some.

Results

As mentioned in the Methods section of this report, several focus groups were held to gather information from Aboriginal people living in urban and rural areas regarding their definition of health, the components of health, what they perceived to be the major health concerns for Aboriginal children and youth and what they thought could be done to improve their health. Several different sectors were consulted including: children and youth, parents, and agencies providing health services to Aboriginal people in urban and rural areas. The following is a summary of the overall themes that were expressed by each sector. Detailed information derived from focus groups is presented in Appendix A.

Summary

Youth, parents and agencies were consulted regarding the definition of health, components of health, major health concerns, barriers to health, and ways to improve health for Aboriginal children and youth. Their responses reflected their experiences and by combining their responses we are able to paint a comprehensive picture of health issues in the Aboriginal community in southern Alberta. Because of the nature of the consultation process, focus group participants spent a major proportion of their time discussing what "required fixing" as opposed to "what is working well". However, both the literature review as well as some of the focus group comments support the concept that there is hope for improving the health of Aboriginal children and youth across southern Alberta. In addition, the Elders Advisory Group reinforced the importance of looking not only at concerns or issues but also at current strengths and opportunities.

Question 1

What does it mean to be healthy?

To Aboriginal people, health is defined holistically and includes all four components of the Circle of Life or Medicine Wheel: physical, mental, spiritual and emotional. Health involves balancing the four aspects within the individual, the family and the community. In order to be healthy, one first requires the basic needs for food, sleep, exercise, good hygiene, clothing and housing. Striving to raise healthy children requires healthy families and communities that can support these children and provide them with role models, guidance and love. The focus group participants indicated that their definition of health included a positive self-concept, a perception of one's self as healthy and a degree of control over one's own health.

Question 2

What are the essential components of health?

There are many interrelated components of health and it is important that Aboriginal and western perspectives on health and methods work in partnership to provide culturally

appropriate health services to communities. The underlying determinants of health such as income and social status, social support networks, education and literacy, employment/working conditions, social environments, physical environments, personal health coping skills, healthy child development, health services and culture were identified by the children, youth, parents and agencies who participated in the focus groups.

They also identified specific components of these broader determinants of health that have great resonance with them. Having basic needs met such as adequate nutrition, sleep, clothing, exercise good hygiene and housing are essential. Avoiding high-risk behaviours such as alcohol and drug use, unsafe sex and lifestyle choices such as eating junk food and playing video games were noted. Everyone needs to have a healthy family with good role models, boundaries, expectations and love. Parents and children identified that they would welcome the opportunity to increase awareness and access to education and prevention services in order to enhance their health and the health of their families. Children and youth would benefit from additional opportunity to be educated about their culture and being given opportunities to participate in cultural activities. It would also be beneficial to have social supports available in the community to support individuals and families in being healthy. Communities need to be healthy and safe and convey an attitude of hope for the future. Individuals thrive when they feel that they have some control over their own health and are consulted in the development and delivery of health services. People need access to health services to maintain health. In the focus groups, access included services that are culturally appropriate, delivered in their own community or with transportation available, affordable, and delivered in a flexible and creative manner. Finally, special populations such as children with special needs and children either in or coming out of care need to have their unique needs addressed.

Question 3

What are the major health concerns of our children and youth?

When asked to identify the major health concerns for children and youth each sector provided information on specific health issues as well as contributing factors. The

specific health concerns identified include: obesity, diabetes, asthma, respiratory problems, cancer, high blood pressure, acne, disease, HIV/AIDS, Fetal Alcohol Spectrum Disorder (FASD), attention deficit disorder, allergies, lactose intolerance, Down Syndrome, sexually transmitted diseases (STD), heart disease, brain injury, strokes, lupus, throat infections, whooping cough, learning difficulties, depression and other mental health concerns, physical disabilities, substance abuse, second hand smoke, and birth defects. Some of the factors that respondents felt directly contributed to these health concerns were the determinants of health, poor prenatal and perinatal care and a lack of immunization.

Besides specific health concerns there were also broader concerns regarding the health of Aboriginal children and youth. Having basic needs such as food, clothing, sleep, and housing insufficiently met were described as major health concerns. This can be complicated by lifestyle issues such as: lack of exercise, poor hygiene, unsafe sex and substance abuse. Coping issues such as conflict, poor anger management, and neglect were also seen as health concerns. Other concerns identified included a lack of an effective support system in their families and/or communities to help children enhance their health and deal with physical, mental, spiritual and emotional difficulties. In the health services domain concerns were expressed regarding a lack of culturally appropriate services and financial, policy and political barriers to accessing health services. Finally a major concern was that children and youth lack a strong and positive sense of self, cultural identity and ability to enhance their own health.

Question 4

What are the barriers that get in the way of good health?

The barriers to good health identified by children, youth, parents and agencies are wide-ranging and consistent with the major health concerns previously identified. A fundamental barrier to good health identified was a lack of the basic necessities of life including adequate food, sleep, exercise, clothing and healthy living conditions and environment. Lifestyle issues such as substance abuse, unhealthy eating habits, sedentary habits, and unsafe sex were also identified as barriers to good health. For children and

youth a significant barrier that was recognized was a lack of a strong and healthy family and social support networks. A lack of education regarding health issues and health enhancing behaviours were identified as a barrier at the individual, family and community level. Mental health and emotional problems and poor coping skills were also put forward as significant challenges to achieving good health.

The individuals involved in the focus groups also recognized that Aboriginal children and youth face an additional significant challenge in coping with racism, negative stereotyping and oppression, which can impact their self-esteem as well as their ability to access health services. It was stated that relationships between Aboriginal people and health service providers can be difficult and that all involved need to work to establish relationships and cultural understanding. In addition, service provision that does not consider the unique needs of Aboriginal communities, individuals and their culture was viewed as a barrier.

Community issues were identified as potentially significant barriers if communities have unhealthy behaviours as the norm, an attitude of hopelessness and apathy, and are unsafe. Finally policy and political issues were seen as a barrier as they limit who can access health services and where they can access them. The perception of individuals and agencies is that jurisdictional issues between the federal and provincial governments and individual First Nations complicate health care delivery. Participants identified that there have been increases in health care costs at the same time programs such as Assured Income for the Severely Handicapped (AISH) and Non Insured Health Benefits (NIHB) have been implementing cutbacks. As a result not all Aboriginal people have equal access to health services and their way of accessing funds for health services seems confusing.

Question 5

What can be done to improve child and youth health?

Along with identifying health issues for children and youth the focus group participants were eager to propose solutions for these concerns. As a starting point they emphasized

the need to provide for basic needs such as food, water, shelter, recreation and hygiene, and to address the underlying determinants of health. They identified the need to avoid unhealthy lifestyle choices and high-risk behaviours. They emphasized the need to improve family relationships and the health and functioning of the family as a whole. The need for strong social support networks in the community made up of community members, health professionals and other caring adults was identified. The need for awareness and education on health related issues and coping strategies was also noted. The need to access a continuum of holistic health services that combines Aboriginal and western approaches to health was emphasized. These services need to be offered in a culturally appropriate way by health providers who are culturally aware, and in a way supported by Aboriginal communities. Participants believe that health care delivery should include Aboriginal people in key roles as health service providers, decision makers and as consumers who are consulted in the development and delivery of services. The focus group participants stressed the importance of policy and political issues that are perceived as barriers (jurisdictional issues, financial barriers) to accessing health services being addressed through initiatives such as partnerships between provincial and federal governments and linking intervention and treatment with community First Nations' governance models.

Recommendations

A number of the recommendations identified are outside of the scope of the Southern Alberta Child & Youth Health Network and the Calgary Health Region's Aboriginal Health Program and/or they have been made in previous reports on Aboriginal health. However, these recommendations are included as they give voice to the perceptions of the focus group participants and because they continue to be important factors for consideration in addressing the health needs of Aboriginal children and youth.

Recommendations

The following recommendations are based on the themes that emerged from the focus groups and these themes are also supported through the literature review. The recommendations fall into the following categories:

- basic necessities of life
- comprehensive and coordinated health services delivery
- education for children, youth and families
- understanding of Aboriginal culture and world view
- community control and empowerment
- social support systems and public policy changes

Basic necessities of life

Every child and youth has a right to the basic necessities of life including adequate food, shelter, clothing, and exercise. All of the recommendations will impact these necessities but some recommendations specifically aimed at addressing these issues are:

- Ensure that every family has and adequate and nutritious diet. This may include ensuring that families have adequate financial resources and providing families with education and support regarding nutrition and meal planning.

- Ensure that every family has adequate shelter. This may include reviewing the current housing situation on-reserve and if necessary petitioning the federal government for improvements to housing through Aboriginal governance structures. It may also include: ensuring that families off-reserve have access to financial resources for securing adequate housing, requiring more regular visits from health services providers to ensure that children are living in adequate and healthy living situations, and providing training and support for parents on keeping a healthy home where needed.

- All children should have access to adequate clothing. Ensure that every family has access to financial resources for proper clothing for the southern Alberta seasons.

- All children should have access to recreational activities. Access entails that the recreational activities be affordable and that children are provided the necessary supports to participate.

Comprehensive and coordinated health service delivery

- A holistic continuum of services from prevention through treatment should be developed that recognizes the four parts of the Circle of Life/Medicine Wheel concept: physical, mental, spiritual and emotional.

- The services provided within the system should contain both Aboriginal and western components and clients should have choice over which services they access.

- The services should be planned and delivered by health professionals and decision makers who are aware of the unique needs of the Aboriginal communities and individuals they serve and are respectful of their culture. This may include Aboriginal professionals and paraprofessionals and non-Aboriginals who are trained in cultural awareness and experienced in working with the Aboriginal population.

- There should be communication, coordination and collaboration among the different agencies that provide health services for Aboriginal children and youth both in both the rural and urban setting.

Education for Aboriginal children, youth and parents

- Education should be provided on health issues, health promoting behaviors, managing health concerns and coping strategies.

- Education should continue to be provided on suicide prevention. Continuing programs on how to support children after a community loss to suicide is required.

- Parents should continue to be offered training on parenting skills and communication skills.

- Aboriginal children and youth should have the opportunity to be educated regarding Aboriginal culture, language and traditions. Elders play a key role in educating Aboriginal children and youth and helping them find their identity.

Understanding of Aboriginal culture and worldview

- Health services should be holistic and respectful of Aboriginal culture.

- Non-Aboriginal health service providers should be knowledgeable regarding the Aboriginal worldview.

- Time and effort is required to be invested with Elders to develop culturally appropriate and respectful ways to work with and provide services to Aboriginal people.

Community control and empowerment

- Aboriginal communities must continue to be consulted and involved in the development and delivery of health services.

- Health care service delivery should be inherently tied to First Nations governance.

- Individuals need the freedom of choice to access the health services they feel will be the most beneficial.

Social support systems and public policy

- It is important to recognize that children are interdependent with their families and communities; therefore, their health needs cannot be addressed in isolation.

- Families need support to function as healthy units with parents who are good role models, practice healthy behaviours, and properly love and care for their children. This support may include parenting skills training, counselling and employment and education opportunities.

- Communities need support to function as healthy units including: programs to address community violence (gangs and domestic violence), unsafe environments (pollution, improper lighting, unsafe traffic etc.) and initiatives to promote hope and a future focus.

- Consider the combined effects of cutbacks to current and available programs on the health of Aboriginal children and youth.

- Work with Health Canada's First Nations Inuit Health Branch in Alberta to simplify and clarify for Aboriginal people what is currently covered under the health benefits plan, how to access coverage and who is eligible.

- Work to address disparities between First Nations people with treaty status living on-reserve and those living off-reserve; and recognize the health issues of non-status Indians and Métis people.

- Consider the intergenerational impacts of issues such as residential school experiences when developing strategies for enhancing the health of Aboriginal children and youth.

Current Activities

Since the beginning of this project, many changes and activities have already occurred that positively influence the relationships between the Aboriginal communities and health regions of southern Alberta in our collective effort to influence provision of care for Aboriginal children and youth. The following description of some AHP and SACYHN initiatives follows the categories used in the recommendation section, with the exception of the category on basic necessities, and is reflective of current work that may respond to some of the recommendations at least in the short-term.

Comprehensive and coordinated health service delivery

- Through funding provided by Health Canada's First Nations and Inuit Health Branch in Alberta, a short term SACYHN project is nearing completion with Kainai and Piikani Nations related to the use of telehealth as a way of providing services closer to home. This project will be completed early in 2005. The knowledge acquired will hopefully support future use of telehealth as a means of providing a portion of care for Aboriginal children and youth living on-reserve.

- A community paediatrician has been providing valued outreach service at the Stoney Health Centre for a number of years. Recently, at the request of the Stoney Nation and utilizing the Outreach Services Framework developed by SACYHN, two additional formal Outreach Service Agreements have been established to provide cardiology and FAS services to children and youth at the Stoney Health Centre.

  As Treaty 7 First Nations identify additional needs for child and youth related health services, SACYHN is able to facilitate discussions regarding meeting the identified need through outreach, including telehealth.

- SACYHN has also begun to negotiate Outreach Service Agreements between service providers from the urban Calgary Health Region (primarily paediatricians) and other child-serving organizations[1] within civic boundaries. Partners in these agreements provide care for Aboriginal children and youth. The results of these Agreements will help to inform how new and creative services could be developed or evolved to attend to the needs of urban Aboriginal families and children.

- The Calgary Health Region is engaged in a community partnership to improve immunization rates among Aboriginal children living in the Calgary area. An Aboriginal community health nurse coordinates this project in conjunction with the public health clinic at the East Health Centre and with the Aboriginal Resource Centre.

- The Calgary Health Region is involved in planning efforts to establish a primary care clinic to serve Aboriginal peoples at Sheldon Chumier Centre, the site of the Colonel Belcher Hospital on 12th Avenue.

- Through Alberta Health and Wellness, SACYHN received funding from Health Canada's Primary Care Capacity Building Fund to improve the ability of primary care providers to identify and address children's mental health issues (Healthy Minds/Healthy Children) and maternal risk factors (Healthy Infants).
    - The **Healthy Infants Initiative** is a collaborative endeavour involving the Alberta Medical Association, the four southern Alberta health regions and Treaty 7 to develop and pilot a standardized maternal health screening tool to identify maternal risk factors. Two Treaty 7 communities (Piikani and Kainai) have formed working groups to address the issues raised by the tool and to help modify the tool to address Aboriginal women's health needs. The modified tool will be piloted in several Treaty 7 communities

[1] Ex. Calgary and Area Child and Family Service, CUPS One World Child Development Centre

by primary care providers to determine its usefulness in identifying and addressing maternal risk factors.

- The **Healthy Minds/Healthy Children** project is designed to seek ways of improving community capacity and coordination of mental health care provided to children and youth. As with Healthy Infants, this project also invites Treaty 7 First Nation participation and is inclusive of both rural and urban populations. At present, Piikani and Stoney (Bearspaw Band at Eden Valley) Nations are participating in this initiative. The project supports primary health care providers in their assessment, treatment and management of children and youth with mental health issues. Activities include limited direct clinical consultation to primary health care providers, supported access to specialized and tertiary care programs, and support to develop and maintain linkages to other programs and services working with youth and families. This support is provided face to face or through the use of telehealth technology.

  In Fall 2004, Healthy Minds/Healthy Children submitted a proposal to Alberta Health and Wellness to develop an interregional assessment and consultation mental health service utilizing telehealth technology that will allow local care providers to access an interdisciplinary team. This team will provide coordination and consultative support to improve the assessment and management of mental health problems without requiring the child, youth and service provider to leave their local community. If successful, it is anticipated that Aboriginal families will be key stakeholders and beneficiaries of this new service.

  The project is also developing resource materials and education opportunities on children's mental health that will be made widely available for primary care providers in southern Alberta.

Education for Aboriginal children, youth and parents

- At Alberta Children's Hospital and within the context of SACYHN, the Family & Community Resource Centre (FCRC) has been developed as a vehicle to provide universal access to comprehensive and reliable child health information and education for families, service providers and community members across southern Alberta. Access is created through the following initiatives:

    - **Information Prescriptions** are a comprehensive reference list on specific child health topics that have been developed and endorsed by clinical experts practising within the child health topic area. Information prescriptions have been developed to date on paediatric depression, diabetes, and autism and asperger's syndrome. Future topics will include childhood obesity, asthma and positive parenting resources. The information prescriptions direct families and service providers to locations as close to home as possible in terms of accessing the resources. The reference lists also identify resource material in a variety of formats (e.g. books, brochures, videos, and websites) which creates greater accessibility by accommodating the wide range of learning styles and abilities of families across southern Alberta.

    - **Reference Librarian** services are also available through the FCRC which allows opportunity for personalized support to obtain needed health resource information. This service helps families and community providers find credible health related information so families can make informed decisions and advocate regarding their child's care. Linked to the reference librarian service is access to medication information provided through a partnership with paediatric pharmacists within Alberta Children's Hospital.

    - **Child Health Community Education** will be provided through the FCRC in response to information and education requests received from families

and community care providers across southern Alberta. A community health calendar of educational offerings is being developed and tested. This calendar will advertise educational sessions on child health related topics and coordinate their reach through telehealth links across southern Alberta.

- The Aboriginal Best Beginnings resource was developed specifically for Aboriginal women of childbearing age, their partners and extended family. Health information contained in this resource is congruent with health issues faced by the Aboriginal communities and is provided in a culturally relevant manner. The development of the Aboriginal Best Beginnings Book was a partnership with several Calgary Health Region programs, Health Canada, Aboriginal health professionals, community organizations and Aboriginal women of childbearing age.

Understanding of Aboriginal culture and world view

- An Aboriginal Cultural Education Coordinator position has been developed within the AHP in the Calgary Health Region. This position is to develop and coordinate a comprehensive education strategy aimed at:
    - increasing staff knowledge and sensitivity in relation to health care for Aboriginal clients
    - increasing Aboriginal client and community knowledge of and familiarity with programs and services within Calgary Health Region.

- Connected to the Aboriginal Health Program's services, the Alberta Children's Hospital has an Aboriginal Liaison position. This position provides instrumental support to Aboriginal clients and families while in hospital or when seen as outpatients, and as they transition back to home communities. The Aboriginal Liaison plays a key role in assisting in the coordination of discharge follow up with rural First Nations communities. Key responsibilities are to provide general support, access to Elders as requested by families, resource information and

referral, and education to team members to promote cultural sensitivity. Other acute care facilities that serve primarily adults also have similar positions.

- In a partnership led by Dr. Barry Trute (Professor of Family Centred Care at the University of Calgary) the Alberta Children's Hospital and SACYHN submitted a proposal in December 2004 to Health Canada for interdisciplinary family-centred care education focussed on child health. The proposal includes graduate level university credit courses, continuing education, a train-the-trainer component, a plan for development of web-based training, and development of parent mentors, all focussed on family-centred care and available throughout southern Alberta. Through SACYHN, Treaty 7 Tribal Council was involved in supporting the proposal and resources have been built in to support each region's participation, including that of Treaty 7 First Nations. It is expected that this project, if funded, will afford an opportunity to explore the specific needs of Aboriginal families within the context of family-centred care.

Community control and empowerment

- Both SACYHN and AHP recognize the importance of responding to the needs as expressed by Aboriginal communities, of taking an inclusive approach, and of being respectful of governance issues. All SACYHN initiatives are open to Treaty 7 and urban Aboriginal involvement.
    - Currently Treaty 7 First Nations are represented on the SACYHN Steering Committee (the direction setting/governance group for SACYHN) through the Treaty 7 Tribal Council. Efforts are underway to invite Aboriginal parent representation to the Steering Committee as well.

    - The *Network* has a keen interest in promoting the voice of young people in policy and planning. To this end a SACYHN Child and Youth Advisory Council was formed in September 2003. Though Aboriginal youth have been invited to participate since the inception of the Council, special

efforts are currently underway to recruit and support the participation of Aboriginal youth from southern Alberta.

- The Circle of Friends Community Developmental Social Marketing Campaign is a partnership project of the Calgary Fetal Alcohol Network (CFAN), Aboriginal community organizations and the Calgary Health Region rural partners, funded by Action for Health. The purpose of the social marketing campaign, which began in January 2004, is to educate 16 – 24 year old youth about the association between alcohol in pregnancy and FASD and how this awareness coupled with their positive influence can prevent FASD and low birth weight. The campaign was designed to equip this population with the knowledge and skills to intervene when their pregnant peers drink alcohol.

  The initial target population included urban, rural and Aboriginal communities. Through community development strategies, the youth took leadership in the design, launch and implementation of the social marketing campaign. The combination of community development or community-based activities with social marketing has proven to be powerful for this initiative

- The AHP of the Calgary Health Region has worked hard to involve Aboriginal communities, both urban and rural, in its ongoing development and planning. The Calgary Health Region has also established an Aboriginal Health Council that advises the Board on issues of concern to Aboriginal people.

Social support systems and public policy

- Treaty 7 Tribal Council, SACYHN, and the AHP collaboratively developed a Treaty 7 Liaison Coordinator position. Funded through the Aboriginal Health Strategies Branch of Alberta Health and Wellness, this role commenced in November 2004 and is designed to provide liaison functions among the Calgary Health Region, SACYHN and Treaty 7 at the planning, development, policy and administrative level to:

- strengthen and facilitate linkages and coordination between the Calgary Health Region and the surrounding First Nations communities within Treaty 7, and

- support the participation of Treaty 7 in the *Network*. Treaty 7 engagement and participation in SACYHN is viewed as critical in addressing the health and well being of Aboriginal children and youth in southern Alberta.

Summary and Next Steps

For those involved, participation in this project has facilitated increased knowledge of the health status and health needs of Aboriginal children and youth in southern Alberta. It has strengthened the ties with Aboriginal communities, including service providers and Elders. It has also reinforced the fundamental importance of approaching Aboriginal child health from a broad, holistic perspective that demonstrates understanding of the relationship among physical, mental, spiritual and emotional needs.

Adequately addressing the health needs of Aboriginal children and youth remains a challenge. In particular, the ongoing difficulty of meeting the basic needs of children and families is of great concern and beyond the scope of any one sector or initiative. The frequency of comments related to basic needs in the focus groups far outstripped any other and addressing these concerns is critical to the health of Aboriginal children and youth in the long term.

Parents, youth and agencies who participated in the focus groups all identified the connectivity between healthy children, healthy families, and healthy communities. As well, respondents highlighted the need to develop innovative approaches to child and youth health incorporating both western and traditional Aboriginal perspectives.

Though significant work is already underway in particular child health areas or with particular communities, collaborative and sustained effort is required to support Aboriginal communities in addressing some of the broader, systemic issues affecting the health of their children and youth. While continuing with specific, targeted child health initiatives, the Southern Alberta Child & Youth Health Network and the Aboriginal Health Program of the Calgary Health Region provide two structures that may be able to contribute to that sustained effort.

The content of this report will continue to be referenced in planning activities for both SACYHN and AHP. The report will also be distributed and used as a basis for discussion, priority setting, and planning with Aboriginal communities in southern Alberta.

Finally, the wisdom of the Elders Advisory Group is not to be taken lightly: It is critical to keep in mind the strengths of Aboriginal families and communities and the good things that are already happening as we work collectively to improve health outcomes for Aboriginal children and youth.

Appendix A: Detailed Focus Group Responses

Question 1

What does it mean to be healthy?

Child and Youth Response

In defining health, the children and youth who participated in the focus groups stressed the importance of meeting basic needs, having a social support network, having spirituality and avoiding alcohol and drug use.

Specific responses recorded:

- Meeting basic needs: having a nutritious diet, exercising regularly and having good hygiene.
- Social support: feeling cared for and valued, having a positive sense of self and being involved in the community.
- Spirituality: practicing Aboriginal spirituality, attending church and meditation.
- Avoiding alcohol and drug use.

Parental Response

Parents who participated in the focus groups defined health more broadly and the themes that emerged from the focus groups were: holistic health, meeting basic needs, access to health services, mental health, social support and culture and spirituality.

Specific responses recorded:

- Holistic health: balance of all four aspects from the Medicine Wheel: physical, mental, spiritual and emotional.
- Meeting basic needs: the absence of illness, good hygiene, nutritious diet, regular exercise, adequate sleep, avoidance of alcohol and other drugs and the avoidance of prenatal exposure to alcohol and other drugs.
- Access to health services: a continuum of health services including preventative, monitoring and therapeutic services, vaccinations and proper use of medications.

- Mental health: good mental health and a positive self-concept.
- Social support: community support and belonging to a loving, nurturing and physically affectionate family.
- Culture and spirituality: learning about your own culture, language, and participating in traditional ceremonies and prayer.

Agency Response

The agency representatives who participated in the focus groups defined health even more broadly. The themes that emerged from the focus groups were: holistic health, meeting basic needs, culture and spirituality, social support, healthy families, a personal perception of health, and control over one's health.

Specific responses recorded:

- Holistic health: the four aspects of the Medicine Wheel: physical, mental, spiritual and emotional must be balanced and balance across individual, family and community levels.
- Basic needs are met: absence of disease, prenatal health, adequate nutrition, exercise, housing, a healthy environment, having an income above the poverty line and access to education.
- Culture and spirituality: following one's own customs, beliefs and prayer.
- Social support: connections and contributions to the community.
- Healthy families: children and youth need homes that are supportive and safe and that demonstrate good coping strategies.
- Self concept: a perception of health.
- Control over health: awareness of health issues, choices regarding health services and the ability to overcome disadvantages to achieve a level of health equal to others.

Questionnaire Response

Parents and agency representatives who responded to the question on the definition of health by questionnaire responded similarly to their counterparts in the focus group. The

themes that emerged were: holistic health, meeting basic needs, access to health services and perceived health.

Specific responses recorded:

- Holistic health: the need for balance between the physical, mental, spiritual and emotional aspects.
- Meeting basic needs: absence of disease, nutritious diet, regular exercise, adequate housing and good hygiene.
- Access to health services: a continuum of health services is needed to attain and to maintain health.
- Self-concept: perception of health and feeling physically and mentally fit enough to enjoy life.

Question 2

What are the essential components of health?

Child and Youth Response

The themes that developed from the responses of children and youth were: having a safe and secure, loving home, meeting basic needs, having access to health services (both Aboriginal and western), social support, education, avoiding risky behaviours, being accepted for who you are, and having safe schools and communities.

Specific responses recorded:

- Having a good home: no violence, no drugs, good security and fire alarms and family problems are addressed.
- Meeting basic needs: a nutritious diet, good personal hygiene, participating in recreation opportunities, appropriate clothing, adequate housing, healthy environment and having adequate financial resources.
- Access to health services: proper care when you are ill, western and traditional Aboriginal medicine and healing practices, vaccinations, transportation

- Avoiding risky behaviours: substance abuse.
- Access to health services: proper care when you are ill, western and traditional Aboriginal medicine and healing practices, vaccinations, and transportation for medical services.
- Social support: mentoring, police officers.
- Accepted for who you are: no prejudice, being understood by others, freedom to be yourself.
- Healthy school environments: no bullying, no drugs, no bias, no dress code and better security.
- Safe communities: block parents, police, street and pedestrian lights and safer roads.

Parental Response

The themes that evolved from the focus group with parents were: healthy family and home environment, meeting basic needs, health education, community support for families and having access to a continuum of holistic health services.

Specific responses recorded:

- Healthy family and home environment: role modeling of healthy behaviours, good communication, clear expectations and boundaries, shared responsibilities, opportunities for independence and a clean home.
- Meeting basic needs: healthy environment, nutritious diet, participation in recreational opportunities, adequate and safe housing.
- Health education for youth that includes: how the body works, nutrition, exercise, avoidance of risky behaviours, HIV/AIDS, suicide prevention.
- Health education for parents that includes: how the body works, parenting skills and suicide prevention and what to do after an incident in the community.
- Community and agencies support the family unit.
- Access to a continuum of health services: access to holistic health services, services available on the reserve, immunization, medications and vitamins to promote health.

Agency Response

The agency representatives who participated in the focus groups identified a variety of components of health ranging from the basic health needs to the need for political change. The themes that evolved were: meeting basic needs, family relationships, the determinants of health, access to a continuum of health services, culture, the need to combine Aboriginal and western health philosophies and services, awareness and prevention, attitude, safe communities, unique needs of special populations, culture, program issues and the need to address political and policy issues.

Specific responses recorded:

- Meeting basic needs: adequate housing, nutritious diet, clothing, and recreation opportunities.
- Good family relationships.
- The determinants of health need to be examined specifically in regards to Aboriginal people.
- Access to a continuum of health services: health care services from prevention through treatment, transportation, creative and flexible provision of health care services, mental health issues need to be identified and addressed early, and the need to measure perceived versus actual access to services.
- Culture: Aboriginal traditions, values, culture and language need to be taught to children and youth. Elders have a key role to play in supporting the identity of Aboriginal children and youth.
- Aboriginal healing and western health care working together: a need to move from the medical model to a more holistic model taking the best from both worlds. Requires a true partnership with traditional healing, culturally appropriate services delivered in culturally appropriate setting, Medicine Wheel and traditional values need to be incorporated into health services, and Aboriginal traditions and Elders need to be honoured when approaching communities with health services or programs. Also, there is a need for Aboriginal professionals and paraprofessionals providing health services.

- Awareness and prevention: education on health related issues, awareness and prevention efforts regarding FASD and teach children and youth about health issues in school.
- Attitude: hope for the future, positive community attitudes and behaviours.
- Safe communities: violence must be de-normalized, comprehensive support for families experiencing domestic abuse.
- Healthy families: with good parenting and support for families transitioning from rural to urban communities (housing, employment skills etc.).
- Special populations: need to assess gaps in services for special needs children and provide support for children returning from care and their families.
- Consultation: youth, family members and other community members need to be consulted regarding health needs and health services.
- Program issues: programs should be universal to avoid stigmatization; programs should be effective and continuous and use innovative ways to reach children and youth (traditional and western). There needs to be a community-gathering place where services are provided (one stop shopping). Language barriers need to be addressed and families may need support working their way through the system and filling out forms (writing skills).
- Politics and Policies: policy issues that contribute to mental health problems, poverty and domestic violence must be addressed. Aboriginal leaders and Elders need to be involved in creating positive change. Need to address the issue that children in the city have less access to support and funding for medication. There needs to be funding to fill the healthcare gap and more clarity with NIHB (what's covered, and how to access).

<u>Questionnaire Response</u>

Parents and agency representatives identified similar themes for components of health as their counterparts who attended focus groups including: meeting basic needs, healthy families, cultural issues, special population needs, positive self concept and connection to community, education on health issues, consulting the community on their needs and programming issues.

Specific responses recorded:

- Meeting basic needs: nutritional diet, access to affordable recreational and social programs, adequate financial support and a healthy environment.
- Healthy families: parental involvement, children need to feel loved and needed by their family and a stable and clean home.
- Culture: children and youth need to know their history, culture and language.
- Special populations: resources for special needs children.
- Positive self-concept and connection to community.
- Education on healthy lifestyles.
- Consultation: community forums to get input on health needs and services.
- Programs: effective and ongoing programming and stronger relationships between Aboriginal people and health care providers.

Question 3

What are the major health concerns of our children and youth?

Child and Youth Response

In responding to questions regarding the major health concerns the children and youth involved in the focus groups predominantly focused on specific health concerns, although they also mentioned meeting basic needs, coping issues and community issues as additional areas of concern.

Specific responses recorded:

- Specific health concerns: overweight, diabetes, asthma, cancer, high blood pressure, acne, disease, HIV/AIDS, FASD, attention deficit disorder, allergies, lactose intolerance, down syndrome, STDs, heart disease, brain injury, strokes, depression and other mental health concerns, physical disabilities, substance abuse, second hand smoke, and birth defects.
- Basic needs unmet: inadequate nutrition, insufficient exercise, poor oral health care, need to visit health care professionals more regularly and poor hygiene.

- Coping issues: conflict, anger management.
- Community issues: dangers in the community (i.e. needles on the street).

Parental Response

In the parent focus groups the themes that emerged were: specific health issues, basic needs unmet, relationships and coping mechanisms, denial, high risk behaviours, health services problems and community influences.

Specific responses recorded:

- Specific health issues: asthma, diabetes, respiratory problems from second hand smoke, prenatal and perinatal care, substance abuse, obesity, suicide, lupus, lack of immunization leading to problems such as whooping cough, FASD, emotional and mental health problems, HIV/AIDS, STDs, throat infections and learning difficulties.
- Basic needs unmet: inadequate nutrition, unhealthy environment and inadequate housing.
- Relationships and coping mechanisms: growing anger among young people and neglect.
- High-risk behaviours: unhealthy sexual behaviour and substance abuse.
- Health services problems: improper diagnosis.
- Community influences: negative media influences, peer pressure and denial of problems.

Agency Response

The agency representatives who participated in the focus groups looked at the major health concerns for children and youth from a broad perspective and the themes that emerged from their discussions included: specific health issues, basic needs unmet, determinants of health, different understandings of health care from the Aboriginal perspectives on health and western perspectives, lifestyle issues, parenting concerns, education, self responsibility, culture, relationships and social systems, access, program issues, community issues, intergenerational issues and policy and political concerns.

Specific responses recorded:

- Specific health issues: FASD, mental health and the stigma associated with mental health issues, diabetes, TB, asthma, respiratory disorders, obesity, and suicide.
- Basic needs unmet: inadequate nutrition, exercise and housing, hygiene, unclean living environment and children improperly clothed for the weather.
- Determinants of health need to be addressed.
- Poor prenatal, infant and child development and health care awareness and practice.
- Different understanding of health care: the Aboriginal perspective on health is more holistic, there may differences between individual and community perspectives on health and Aboriginal and non-Aboriginal agencies have different concerns.
- Lifestyle: risky sexual behaviours, substance abuse, video games which contribute to inactivity and social isolation, youth gambling and a lack of health enhancing behaviours.
- Parenting: poor parenting skills, family conflict, lack of parental guidance, parents need help in communicating with their children and helping them to feel loved and valued.
- Education: lack of understanding and knowledge of healthy behaviours.
- Self-responsibility: youth need to be empowered to take responsibility for themselves and understand how to balance the components of health.
- Culture: children and youth have a lack of cultural identity, need to reclaim traditions and pride and need to practice rites of passage.
- Social systems: inadequate support for children who witness violence.
- Access to health services: there needs to be a continuum of health services from prevention through treatment, transportation, childcare for other siblings when a parent must seek medical attention for a child.
- Program issues: need greater collaboration and cooperation amongst service providing agencies, lack of relationship between health care service providers and Aboriginal communities and there is a lack of cultural awareness by professionals.

- Community concerns: lack of hope, negative peer pressure and stress, denial of the issues and violence are the norms.
- Intergenerational issues: children and youth need to respect Elders and understand what they have experienced in their lifetimes.
- Policy and political issues: insufficient health care costs are covered, jurisdictional issues and a lack of oral health care coverage.

Questionnaire Response

The parents and agency representatives who completed questionnaires identified the following themes in their discussions: basic needs unmet, specific health concerns, parenting issues, high risk behaviours, self concept, education, community concerns and special populations.

Specific responses recorded:

- Basic needs unmet: lack of sleep, inadequate nutrition (especially for infants and toddlers), poverty and inadequate housing.
- Specific health concerns: diabetes, FASD, recurrent ear infections, second hand smoke, respiratory infections, youth pregnancy, poor oral health care and suicide.
- Parenting issues: not enough emphasis on verbal interaction and play with younger children.
- High-risk behaviours: substance abuse and unprotected sex.
- Poor self-esteem.
- Low levels of education.
- Community concerns: street gangs and domestic violence.
- Special populations: lack of support and services for people with developmental delays.

Question 4

What are the barriers that get in the way of good health?

Child and Youth Response

The children and youth who participated in the focus groups provided their thoughts on the barriers to good health and these fell into the following themes: basic needs unmet, lack of social support, lack of education, lack of control over personal health, financial constraints, racism, emotional and mental health problems and poor self-concept.

Specific responses recorded:

- Basic needs unmet: lack of food and inadequate housing.
- Lack of social support: people not caring, not being with adults, lack of support, lack of role models and mentors and no one to talk with.
- Lifestyle: smoking, drinking and drug use, unhealthy eating habits, violence, and sedentary activities like video games.
- Lack of education: lack of knowledge of health issues.
- Lack of control over personal health: lack of freedom of choice and opportunities to enhance health.
- Financial constraints: insufficient financial resources and tax.
- Racism.
- Emotional and psychological difficulties: mental health problems and stress.
- Poor self-concept.

Parental Response

The parents who participated in the focus groups identified the following barriers to health: basic needs unmet, lifestyle, ineffective coping strategies, education, relationship between parents and health educators, family problems, negative media influences, racism, social support, policy and program issues.

Specific responses recorded:

- Basic needs unmet: inadequate nutrition, unhealthy living conditions and unhealthy environment.
- Lifestyle: lack of exercise and substance abuse.
- Ineffective coping: poor coping strategies, eating disorders and suicide.
- Education: lack of knowledge about health promoting behaviours (prenatal and perinatal). Health education needs to occur earlier for children and be culturally appropriate. Education topics include: sex education by health professionals, hygiene education and parenting skills. Use a train the trainer approach in teaching parents and grandparents about health care issues so they can share their knowledge with the children and hold seminars and conferences on health information.
- Relationship between parents and health service providers: need more open communication between parents and health educators.
- Family problems: neglect and lack of parenting skills.
- Negative media influences.
- Racism and negative stereotyping.
- Social support: need more role modelling, having people talk about their experiences one-on-one or in groups.
- Policy and program issues: financial barriers and problems with NIHB, counselling that is inconsistent and when issues arise they need to be dealt with right away rather than just talking about them.

Agency Response

The agency representatives who participated in the focus groups indicated that to identify the barriers to health it would be helpful complete a comprehensive needs assessment with the Aboriginal community. They were able to identify some specific barriers based on their experiences and the experiences of the agencies that they represent. The themes that emerged were: basic needs unmet, poor self-concept, racism, family problems, social support, lack of awareness and education, community concerns, cultural issues, historical

issues, access to health services, program issues, policy and political issues, and inadequate finances.

Specific responses recorded:

- Basic needs unmet: poverty interferes with the ability to meet basic needs, there is a lack of recreational facilities and youth who are on the streets regularly do not have the basics.
- Poor self-concept: poor self-esteem and identity confusion.
- Racism: prejudice and oppression.
- Family problems: poor parenting skills and unhealthy family lifestyles (partially due to residential schools), lack of parental and extended family member involvement, grandparents dying earlier and a lack of guidance, teaching values and support.
- Social support: lack of support for those wanting to change to a healthier lifestyle, more opportunities for role models, mentorship and exposure to the work world.
- Lack of awareness and education on health related issues: need to provide parenting skills training and support and education for parents on how to manage specific health concerns with their child (e.g. diabetes).
- Community concerns: safety concerns, lack of awareness of mental health concerns and services, apathy and lack of hope, lack of community health, perceived threat from authority figures and denial of problems.
- Cultural issues: children and youth have a lack of cultural awareness, loss of language and they do not participate in cultural activities.
- Historical issues: everyone needs to learn about the effects of residential schools on families (help children understand their parents and grandparents).
- Access to health services: after-hours health care is needed, there is a lack of follow through and transition planning from health services and transportation for medical care.
- Program issues: poor communication between hospitals and on-reserve agencies, misunderstandings between on-reserve and off-reserve systems, lack of follow through, agencies and organizations must be accountable for their actions in their

professional and personal lives, health care providers lack understanding on how to provide culturally competent care, the system is not youth friendly.

- Policy and political issues: differences in health services available for First Nations on the reserve and Aboriginals living off-reserve, jurisdictional issues, and political issues within reserves (no jobs because you are not connected to the right people).
- Insufficient finances: increased health care costs and cut backs through AISH and NIHB.

Questionnaire Response

Similar themes emerged from the questionnaires completed by parents and service providers including: basic needs unmet, parenting concerns, education, racism and disparities, social supports, insufficient finances and cultural differences.

Specific responses recorded:

- Basic needs unmet: homelessness and poverty.
- Parenting concerns: teen pregnancy and a lack of parenting skills.
- Social support: lack of encouragement and guidance.
- Education: parents and children need education on health issues and how to enhance health.
- Insufficient finances.
- Racism and disparities: stigmatization and unequal access to services.
- Cultural differences: lack of culturally aware service providers and cultural understanding.
- Program issues: services on the reserves should be provided on a contracted basis by local paediatrician to address fee for service issues and flexibility of scheduling.

Question 5

What can be done to improve child and youth health?

Child and Youth Response

Children and youth who participated in the focus groups remained consistent in answering this question. Their answers followed the themes of: meeting basic needs, avoiding high risk behaviours, access to health services, family relationships, social support and coping strategies. In addition, they recognized that better employment and education were key determinants of health.

Specific responses recorded:

- Meeting basic needs: clean water, proper food available consistent with Canada Food Guide, provide health and recreational programs, better housing, provide washers and dryers and better clothing.
- Avoid high-risk behaviours: don't abuse alcohol and other drugs.
- Access to health services: regularly seeing health professionals.
- Improve family relationships and parents setting good examples.
- Social support: having people you trust available to talk and access to telephone help lines and respecting each other.
- Coping strategies: practice stress reduction activities.
- Determinants of health: better employment and education.

Parental Response

The parents who participated in focus groups had many suggestions on how to improve the health of children and youth. The themes that emerged were: meeting basic needs, access to health services, education and awareness, social support, programs, policy and political issues, address financial barriers to health and develop relationships between health care providers and Aboriginal communities.

Specific responses recorded:

- Meeting basic needs: help decrease the cost of healthy behaviours such as buying healthy food and provide affordable recreational opportunities.
- Access to health services: provide a continuum of health services, increased opportunities for parents to bring their child to the doctor, doctors and pharmacists on the reserve, provide transportation for medical care, provide health promotion services to families, have mental health and education counsellors work with youth and have health nurses doing more home visits to assess home environments.
- Education and awareness: parental education on how to care for your child physically and spiritually. Awareness building and education for everyone on health issues including FASD. Promoting that you should be contributing to your own health on a regular basis.
- Social support: positive role modelling for children and youth.
- Programs: decrease territorial issues between programs and provide day program for children and youth.
- Policy and political issues: work through problems with NIHB.
- Address financial barriers to health care.
- Establish relationships between Aboriginal communities and health care providers.

<u>Agency Response</u>

In addressing ways to improve the health of children and youth agency representatives focused primarily on agency issues and larger policy and political issues. The themes that emerged were: agency relations, health service providers cultural awareness, Aboriginal health care providers, determinants of health, access to health services, consultation and planning, program issues, policy and political issues, stigmatization, social support, culture, and education.

Specific responses recorded:

- Agency relations: agencies need to improve communication and work more collaboratively, liaising between programs on and off reserve agencies, using a team concept and an integrated service delivery model, discharge planning when someone leaves the hospital with communication between the hospital and on-reserve agencies and have shared training opportunities for agencies on and off reserve.
- Health service providers' cultural awareness: educate the medical community and decision makers about the needs of the Aboriginal community and raising awareness related to cultural sensitivity, invest in developing a protocol for working with Aboriginal communities that is respectful of their culture (working with Elders, getting permission etc.).
- Aboriginal health care providers: hire and retain more Aboriginal health care providers and Aboriginal family workers, more Aboriginal people in management and decision making roles and value life experience along with education for Aboriginal people.
- Determinants of health: address the underlying issues of poor health (poverty, racism, historical issues).
- Access to health services: develop specialized programs such as an Aboriginal children's clinic, provide health services where Aboriginal people are (reserves or where they currently access services), improve resources for young mothers off-reserve, use telehealth, have health providers do more home visits to educate about health issues, do comprehensive health assessments for children and youth, provide flexible scheduling for health services, provide transportation to medical services.
- Consultation and planning: continue to consult with Aboriginal communities regarding health issues and health services, identify and examine barriers for accessing health services, develop strategies that specifically target Aboriginal health concerns and use a population health approach, do a needs assessment for special needs children and youth and develop an inventory of available services.

- Program issues: need to focus on the whole child not just the child and provide opportunities for Aboriginal people to help themselves.
- Policy and political issues: develop joint provincial and federal partnerships to alleviate jurisdictional issues, link intervention and treatment with community in First Nations governance model and address funding issues and reduce inconsistencies.
- Stigmatization: stop making Aboriginal children the examples of FASD, as it is present in all communities.
- Social support: more role modelling and mentorship.
- Culture: help Aboriginal children to identify with their spirituality, language and culture.
- Education: infant care for new mothers on breastfeeding, diaper cleaning etc.

Questionnaire Response

Parents and agency representatives who completed questionnaires identified the following themes for improving the health of Aboriginal children and youth: education, consultation with the community, access to health services, social support and agency relations.

Specific responses recorded:

- Education: prevention messages should be taught in the schools, parenting programs, expose children and youth to traditional teachings.
- Consultation: continue to consult the community regarding their needs and health services.
- Access to health services: provide additional support for postnatal care until children are twelve years of age, implement social development programs and provide health services on reserves and/or where Aboriginal people are already going for services.
- Social support: provide ongoing support to children and youth.
- Agency relations: improve communication between on and off reserve agencies.

Appendix B: Terms Reference Project Steering Committee

Purpose

Complementing the project's traditional processes and under the guidance and advice of the Elder's Advisory Group, the Project Steering Committee will develop and implement a coordinated regional and community consultation process to identify key health issues and strategies required to address the health disparities of Aboriginal children and youth in southern Alberta.

Responsibilities

This Steering Committee will:

- provide the Elders Advisory Group with expert child health related information as required;
- support and promote the complementary relationship between Aboriginal traditional holistic approaches and the mainstream health care system regarding children and youth;
- provide direction to the work of the Project Coordinator, including the development of a project work plan and timelines;
- ensure the establishment of appropriate consultation processes;
- define the reporting structure and processes for the Project Coordinator;
- identify key stakeholders and facilitate access wherever possible;
- provide input into initial process and final report from the Project Coordinator;
- recommend the approval of the consultation process and the final report complementing the blessing from the Elders Advisory Group;
- facilitate communication about the project and disseminate project findings.

Structure

The Committee may consist of representation from the following:

- Kainai Nation, Health
- Piikani Nation, Health
- Siksika Nation, Health
- Stoney First Nation, Health
    - Nakota, Bearspaw, and Eden Valley
- Tsuu T'ina Nation, Health
- Department of Indian and Northern Affairs
- First Nations and Inuit Health Branch
- Métis Nation of Alberta Zone 3

- Calgary and Area Child and Family Services
- Calgary Health Region, Rural Representative
- Chinook Health Region
- City of Calgary Aboriginal Services representative
- Department of Paediatrics, Alberta Children's Hospital
- Southern Alberta Child & Youth Health Network (SACYHN)
- Project Coordinator

The two co–chairs will be the Outreach Services Manager of SACYHN and the Program Coordinator of the Calgary Health Region Aboriginal Health Program. The Project Coordinator will provide the support for this group of experts. The Manager for the Calgary Health Region Aboriginal Health Program and Director for SACYHN will provide consultation and guidance as required.

Terms of office

This Steering Committee is expected to function for the duration of the project, October 2003 through March 31, 2004.

All committee members are encouraged to abide by the seven sacred teachings, which guide the Aboriginal Community Health Council and the Calgary Health Region Aboriginal Health Program.

Authority

The work and recommendations of the Project Steering Committee shall be communicated to the Elders Advisory Group through the co-chairs. Progress and results shall be communicated to both the Aboriginal Community Health Council and to the Calgary Health Region Senior Management through the Manager, Regional Aboriginal Health Program; to the Southern Alberta Child & Youth Health Network Steering Committee through the Director of SACYHN; and through the natural laws of the Creator.

The Project Steering Committee shall act in an expert advisory capacity to the project.

Meetings

The Committee shall meet a minimum of four times or more frequently at the discretion of the co-chair(s) with adequate notice of the time, date and location.

Observers and invited guests are expected to consider traditional protocol and to respect the range of Aboriginal traditions, values, customs, beliefs and values. Discussion may be engaged through a talking circle format, conducted by a proper facilitator who may be the co-chair.

Roberts Rules of Order may apply; an agenda will be presented for review by the members. Duly convened meetings shall be recorded and meeting minutes disseminated

All meetings shall be open to the public and the Aboriginal population is encouraged to attend.

Decision making

Shall be through consensus

Approved: November 17/03

Appendix C: Terms Reference Elders Advisory Group

Purpose

To provide advice, guidance and direction in a culturally sensitive manner for the development of a coordinated regional and community consultation plan and to promote and enhance use of traditional processes.

Functions

- to provide clear and concise advice, direction, and guidance to the Project Coordinator in relation to the accomplishment of the project goals and objectives;
- to support Aboriginal traditional holistic approaches to health and the mainstream health care system;
- to work collaboratively with the Project Steering Committee, and the Project Coordinator;
- to ensure the establishment of proper consultation and project consultant reporting structure; and
- to recommend the approval of the consultation process, the final report by blessing the whole project at its conclusion of this phase.

Advisory Group composition

The Advisory Group may consist of representation from the following:

- Métis Elders from the community and may include the rural areas
- Inuit Elders from the community
- First Nations Elders from the community and may include the rural areas

The Chairperson will be an Elder chosen by the Elders Advisory Group by consensus and the two co–chairs will be Outreach Services Manager of the Southern Alberta Child & Youth Health Network and the Aboriginal Health Program Coordinator.

Terms of office

September 2003 to March 31, 2004 or until project completion.

All Elders Advisory Group members are encouraged to abide by the seven sacred teachings which guide the Aboriginal Health Council and the Aboriginal Health Program.

Authority

The work and recommendations of the Elders Advisory Group shall be communicated through the co-chairs. Progress and results shall be communicated through the Calgary Health Region Senior Management to the Aboriginal Community Health Council, to the Southern Alberta Child & Youth Health Network Steering Committee through the Director of SACYHN, and through the natural laws of the Creator. The Elders Advisory group shall act in an expert advisory capacity to the project.

Meetings

The Elders Advisory Group shall meet a minimum of four times annually or more frequently at the discretion of the co–chair(s) with adequate notice of the time, date and location.

Observers and invited guests may voice their opinion when the floor is open or at the discretion of the co-chair(s) but may not participate in the decision making. Their opinion may be taken into consideration, which will be at the discretion of the Elders Advisory Group.

Observers and invited guests are expected to consider traditional protocol and to respect the range of Aboriginal traditions, values, customs, beliefs and values. In the light of advancing traditional processes all participants, observers and invited guests are encouraged to show respect, humility and kindness towards the Elders Advisory Group while in session.

All meetings shall be open to the public and the Aboriginal population is encouraged to attend.

Decision making

Shall be through consensus and Roberts Rules of Order do not apply.

Appendix D: Project Participants

Project Team

Ms. Janice Popp, Director, SACYHN

Ms. Donna Lentjes, Former Manager, AHP

Mr. Brett Hodson, Interim Manager, AHP

Ms. Sybil Young, Outreach Services Manager, SACYHN

Ms. Linda Okanee, AHP Coordinator

Ms. Heather Crowshoe-Hirsch, Project Coordinator

Ms. Ronda Trumper, Project Consultant

Ms. Deanne Piche, Student

Elders Advisory Group

Mr. Ed Borchert, Métis Nation of Alberta Region III

Ms. Pat Breaker, Siksika Nation

Ms. Cassie Lefthand, Stoney Nation, Eden Valley

Ms. Olive Manitopyes, Calgary

Mr. Martin Eagle Child, Kainai Nation

Ms. Margaret Hindman, Kainai Nation

Ms. Christine Littlechief, Siksika Nation

Ms. Yvonne Meunier, Calgary

Ms. Grace Daniels, Stoney Nation, Morley

Ms. Corrine Eagletail Frazier, Tsuu T'ina Nation

Project Steering Committee

Ms. Susan Bare Shin Bone, Executive Director Kainaiwa Child & Family Services Corporation

Ms. Elizabeth Bell, Aboriginal community member

Robert Campbell, Director Population Health, Chinook Health Region

Ms. Bev Fournier, Executive Manager, Calgary & Area Child & Family Services

Dr. Joyce Harder, Department of Paediatrics

Ms. Marlene Lanz, Vice President Calgary Metis Nation, Region 3

Mr. Harold Lipton, Project Manager, Healthy Minds/Healthy Children, SACYHN

Ms. Tina Nash, Aboriginal Mental Health Coordinator

Dr. Debra Pace, Siksika Health Representative

Ms. Bev Renaud, City of Calgary, Aboriginal Services

Ms. Esther Rogers, Director of Health Bearspaw Stoney Nation

Dr. Heidi Schroter, Community Paediatrician

Ms. Kari Simonson, Manager Continuing Care, Canmore General Hospital

Ms. Gloria Skinner, Manager, Native Services Unit, Calgary and Area Child & Family Services

Mr. Barry Tymchuk, Zone Director, First Nations and Inuit Health Branch

Ms. Audrey Weasel Traveller, Education Officer, INAC