# **Indigenous Children's Health Report:**

HEALTH ASSESSMENT IN ACTION

#### EDITED BY:

Janet Smylie MD MPH Canada
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### **Executive Summary**

### INTRODUCTION: GLOBAL DISPARITIES IN INDIGENOUS CHILDREN'S HEALTH

This report documents what we know about the health of Indigenous children (from birth to age twelve) and evaluates the quality of Indigenous child health data collection in Canada, Australia, New Zealand, and the United States.

Striking Indigenous/non-Indigenous health disparities were identified in all four countries, including:

- Infant Mortality Rates that are 1.7 to 4 times higher than those of non-Indigenous infants
- higher rates of sudden infant death syndrome
- higher rates of child injury, accidental death, and suicide
- higher rates of ear infections
- a disproportionate burden of respiratory tract illness and mortality
- a disproportionate burden of dental caries
- increased exposure to environmental contaminants, including tobacco smoke

Other common themes identified across the four countries include:

- a need to improve Indigenous child health ethnicity data
- the identification of colonization as a shared and underlying determinant of Indigenous health
- disparate numbers of Indigenous children live below the poverty line and/or in overcrowded accommodation and this directly impacts their health
- differential access to healthcare, economic and social resources for Indigenous children and their families compared to non-Indigenous populations

Given the diverse genetic heritage of these widely dispersed Indigenous groups, we must conclude that

similar exclusionary social policies active in all four countries are at the root of these profound and unjust differences in child health.

## INDIGENOUS CHILDREN'S HEALTH ASSESSMENT IN ACTION

This report was funded by Health Canada. It was conducted by a team of international Indigenous child health researchers, led by Dr. Janet Smylie at the Centre for Research on Inner City Health, St. Michael's Hospital. The report draws upon on a systematic search of public health data, including scholarly articles at the national and provincial/territorial level. The report first addresses First Nations, Inuit, and Métis children's health status and assessment in Canada. In later chapters, Indigenous children's health status and assessment are reported for Australia, New Zealand, and the United States

Sound measurement and reporting of public health data are essential steps for overcoming health disparities but these are obviously only the first steps. Investment in very strong policies and programming are required to ensure that Indigenous children experience the same levels of well-being, prosperity, environmental support, and access to health care as non-Indigenous children. This report documents best practices and describes how health assessment data can be put to action to inform strong policies and programs to improve Indigenous child health.

Our report provides a convincing example of the value that can be added by forming partnerships and working across jurisdictions – locally, regionally, nationally, and internationally. In writing this report, our collective intention has been to equip Indigenous

health stakeholders within and across our nations with rigorous data, and to support them as they work together to redress Indigenous child health disparities. The time to take action is long overdue.

## ABORIGINAL CHILDREN IN CANADA: KEY HEALTH DISPARITIES

First Nations, Inuit and Métis children and their families experience major disparities in the social determinants of health, compared to other Canadians. At the root of these disparities are historic and ongoing impacts of European colonization, which directly and indirectly impact health. Approximately one-third of Aboriginal children live in low-income families and food-security is a serious concern. Substandard housing conditions, including crowding, need for repairs and poor water quality, disproportionately affect Aboriginal peoples.

Given these determinants of health, it is not surprising that First Nations, Inuit, and Métis children experience the following significant health status disparities:

- Infant mortality among First Nations with status is nearly twice the rate in the general Canadian population
- Infant Mortality among Inuit is four times higher than the general Canadian population
- Sudden Infant Death Syndrome rates for First
   Nations with status in British Columbia and Inuit in
   Nunavik are three to twelve times higher than non First Nations and/or non-Inuit rates respectively.
- Higher incidence of high birthweight babies for First Nations and Métis compared to general Canadian rates

- Higher incidence of preterm babies for Inuit in Nunavut compared to the general Canadian population
- Disproportionate burden of respiratory tract infection among First Nations living on-reserve and Inuit children, with no data for First Nations without status, Métis and urban Aboriginal children.
- The obesity rate for First Nations children living on reserve of 36%, compared to 8% for Canadian children overall.
- Activity Limitation (ie. physical activity limited by a health condition) among First Nations, Inuit, and Métis children between the ages of 6 and 14 years is more than double the rate among Canadian children overall.
- Vital registration, health care utilization, and surveillance data are nearly non-existent for First Nations without status, Métis, and urban Aboriginal children.

# ABORIGINAL CHILDREN IN CANADA: DEFICIENCIES IN CURRENT PUBLIC HEALTH ASSESSMENT DATA

In the 2006 Census, almost 1.2 million persons in Canada reported Aboriginal identity. At the national level, Aboriginal people in Canada represented themselves as belonging to one of several major groups: First Nations (Status Indians on-reserve, Status Indians off-reserve, and non-Status Indians), Inuit, and Métis. Aboriginal children age 14 years and younger account for 30% of the total Aboriginal population. Aboriginal children often live in families headed by single parents and are often raised by young mothers. Many also live in large families, including multiple-generation households.



Significant deficiencies in current public health assessment data for Aboriginal children are evident. Foremost is the lack of opportunity for individuals to self-identify as First Nations, Inuit or Métis in most health data systems, including: vital registries, primary care and hospital records, and surveillance systems. Second, we found substandard data collection sources and methods, which result in inaccurate statistics. Finally, there is also a lack of organized linkages of First Nations, Inuit, and Métis health data to First Nations, Inuit, and Métis health policies, programs and services.

## A GLOBAL PERSPECTIVE ON INDIGENOUS CHILDREN'S HEALTH

Each international chapter provides a rich introduction to the history of colonization and its continuing impacts on Indigenous health and wellbeing for diverse Indigenous populations including Māori, American Indian, Alaskan & Hawaiian Natives, Aboriginal Australians and Torres Straits Islander children. These chapters provide a comprehensive explanation of local Indigenous child health disparities across a range of physical and social health indicators including (but by no means limited to) exposure to environmental contaminants, access to health care, accidents/injury rates, infant mortality rates, Sudden Infant Death Syndrome, asthma and respiratory infection rates. Where possible, national level data has been reported to facilitate comparative perspectives on disparities between Indigenous and non-Indigenous children's health status. These national data sets also shed light on Indigenous children's health data collection standards and practices. We discuss current trends, best practices

and critiques of ethnicity-based child health data collection methods.

Throughout the chapters in this report, multiple examples of Indigenous resistance and resilience are also provided, including: the successful transmission of Indigenous languages to children; improvements in Indigenous educational achievement – often despite inadequate education systems; the participation of extended family in parenting; and the participation of Indigenous communities in specific health assessment and response activities when opportunities present.

#### **WORKING TOGETHER FOR POLICY ACTION**

We held a key stakeholders consultation meeting in May 2008, to present our preliminary findings and ask for feedback, comments, and recommendations. This event brought together 21 key Indigenous researchers and policy-makers from Canada, United States, Australia and Aotearoa. This meeting endorsed a cohesive research, practice and policy approach to advance our ability to improve the health and mortality of all Aboriginal children in Canada. Improvements in the availability of comprehensive and accurate child health data will assist greatly in concerted efforts to improve the health of Indigenous children internationally.

Indigenous health stakeholders in our home nations have already researched and articulated clear policy approaches that would address the ongoing disadvantages experienced by our children and their families. In Canada, this includes the recommendations of the Royal Commission of Aboriginal People and the submissions made at the Kelowna Accord discussions.





### **Introduction and Report Overview**

### A Global Perspective on Indigenous Child Health in Canada & Beyond

I am extremely pleased to have been able to participate in the production of "The Health of Indigenous Children: Health Assessment in Action" report. It has been an incredible honor to have been supported in the writing by international Indigenous children's health colleagues Jane Freemantle and Daniel McAullay (AUS), Sue Crengle (NZ) and Maile Taualii (US), as well as postdoctoral fellows Kelly McShane and Gilbert Gallaher and research co-ordinator Paul Adomako. The international contributors have been generous and astute in their sharing of examples of best practices in both the collection and the application of Indigenous child health assessment information.

The focus of the report is First Nations, Inuit, and Métis children's health status and assessment in Canada (from birth to age twelve). There are also chapters on Indigenous children's health status and assessment for Australia, New Zealand, and the United States. Not only does the report include information describing what we know about the health of Indigenous children and how we know this, but it also includes best practices on how health assessment information can be applied to improve the health of Indigenous children. Critical to the resolution of Indigenous child health disparities is both the generation of health information and the application of this information to health policies, programs, and services.

Report objectives include:

- To summarize what we know about the health of Indigenous children living in Canada, Australia, New Zealand, and the United States.
- To contribute to the translation of health information into evidence-based policies, practices, and services for Aboriginal children in Canada by highlighting best practices in the collection and use of health data.
- 3. To identify priority areas for Indigenous children's health indicator development.
- 4. To identify key Indigenous children's health status inequities in the four countries.

Our hope is that this report will be used as a reference and advocacy tool by key Indigenous children's health stakeholders in Canada and abroad. With this in mind, we held a key stakeholders consultation meeting in May 2008, to present our preliminary findings and ask for feedback, comments, and recommendations.

While the focus of the report is First Nations, Inuit, and Métis children's health status and assessment in Canada, the chapters on Indigenous children's health in Australia, New Zealand and the United States not only provide insightful country specific overviews, they also highlight common problems and successful strategies. We identify cross-cutting issues; locate the roots of Indigenous

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<sup>&#</sup>x27;We have used the term Aboriginal to refer collectively to First Nations, Inuit, and Métis populations in Canada and the term Indigenous when we are referring to Indigenous populations internationally. Aboriginal is also used in the Australian chapter to refer to the group of Indigenous Australians also known as Aboriginal.

<sup>1</sup> International Symposium on the Social Determinants of Indigenous Health, Social determinants and Indigenous health: The International experience and its policy implications. In: Report on specially prepared document, presentations and discussion at the International Symposium on the Social Determinants of Indigenous Health. Adelaide, Australia: Available at http://www.who.int/ social determinants/resources/ indigenous health adelaide report\_07.pdf. Accessed June 6, 2008.

child health disparities in colonization; document differential access to healthcare, economic, and social resources; and share successful strategies for change.

There is a need to improve Indigenous child health ethnicity data. Serious deficiencies in the quality and coverage of Indigenous ethnicity data are described in all four country specific chapters. Canada is the only country that does not have systems in place for Indigenous self-identity in the majority of hospital, surveillance, and vital registration (i.e. birth and death registration) systems. This results in the notable absence of disease specific mortality and hospitalization data in the Canadian chapter. All authors were clear that reliable data describing Indigenous child health is necessary to inform policy; contribute to the design and implementation of effective child health programs and services; and to evaluate policies, programs, and services. The best practice examples of Indigenous health measurement in this report are consistently founded on the central involvement of Indigenous people in health data collection, analysis, management, governance, and application.

Indigenous children and their families experience striking health status disparities compared to non-Indigenous populations regardless of nation. Common health status disparities between Indigenous and non-Indigenous children found in all four countries include: infant mortality rates that are 1.7 to 4 times higher than those of non-Indigenous infants; higher rates of sudden infant death syndrome; higher rates of child injury, accidental death, and suicide; higher rates of ear infections; a disproportionate burden of respiratory tract illness and mortality; a disproportionate burden of dental caries; and increased exposure to environmental contaminants, including tobacco smoke.

There is an overwhelming consensus among the authors and stakeholders that the roots of these health status inequities are found in social rather than biologic determinants of health. Colonization has been identified as a shared and underlying determinant of Indigenous health by the contributors to this report as well as participants at the recently held International Symposium on the Social Determinants of Indigenous Health.1 Each country author describes historic and ongoing governmental policies that have contributed to and perpetuate the dislocation of Indigenous people from their homelands; the disenfranchisement of Indigenous peoples from their rights to selfdetermination; the undermining of economic and social development; and the fragmentation of families, communities, and nations. Colonial policies are directly linked to the current day poverty experienced by many Indigenous children globally. The shared health status disparities are not surprising when the disparate

numbers of Indigenous children living below the poverty line and/or in overcrowded accommodation in all four countries are taken into consideration.

The resolution of Indigenous health inequities requires not only an examination of Indigenous health status and determinants but also an examination of the patterns of access to critical societal resources, such as health care among both Indigenous and non-Indigenous populations. This report identifies that differential access to health care services is another cross-cutting factor that appears to be contributing to disparities in health between Indigenous and non-Indigenous children and their families. In Canada, Australia, New Zealand and the United States there were absolute and relative reductions in access to care for Indigenous children. In New Zealand, these inequities in access to primary care have been linked to increased numbers of preventable hospitalizations for Māori and Pacific Islander children compared to non-Indigenous children.

Although mainstream public health measurement systems are under developed in the area of strength-based assessment, and despite the overwhelming burden of Indigenous child health inequities, a distinct theme of resilience and resistance emerges. Throughout the chapters in this report there are examples of: the successful transmission of Indigenous

languages to children; improvements in Indigenous educational achievement – often despite inadequate education systems; the participation of extended family in parenting; and the participation of Indigenous communities in specific health assessment and response activities when opportunities present.

Indigenous health stakeholders in our home nations have already researched and articulated clear policy approaches that would address the ongoing disadvantages experienced by our children and their families. In Canada, this includes the recommendations of the Royal Commission of Aboriginal People<sup>2</sup> and the submissions made at the Kelowna Accord discussions. The collective intention of the authors in the writing of this report is that it be used as a reference and advocacy tool by these same Indigenous health stakeholders as they work together to support comprehensive policy actions that will fundamentally address the pressing issues of Indigenous child health disparities that we have documented within and across our nations.

<sup>2</sup> Royal Commission on Aboriginal Peoples. *Report of the Royal Commission on Aboriginal Peoples*. Ottawa: Indian and Northern Affairs Canada; 1996.



### Health of First Nations, Inuit, and Métis Children in Canada

2.1 Introduction. This chapter describes the health and health outcomes of Aboriginal children living in Canada. It includes an overview of demographics, a discussion of Aboriginal children's health measurement systems, a description of social determinants, a detailing of First Nations, Inuit, and Métis child health status and some examples of best or promising practices. The goal of the chapter is to provide First Nations, Inuit, and Métis child health stakeholders with a comprehensive overview of First Nations, Inuit, and Métis child health in support of their efforts to address ongoing inequities of health determinants and health status, therefore ensuring that all children in Canada enjoy their right to health. The authors recognize that improvements in the assessment of and response to inequities in Aboriginal child health need to be founded on partnerships between First Nations, Inuit, and Métis health stakeholders and health workers with a background in public health assessment.



#### 2.2 DATA SOURCES AND METHODS

This chapter focuses on First Nations, Inuit, and Métis children's health data at the national and provincial/territorial level. Where there are gaps in available national or provincial/territorial data, and/ or the health determinant or indicator was deemed significant, we opted to cite regional or community-specific rates.

Information in this report for First Nations living on-reserve is drawn primarily from the First Nations Regional Longitudinal Health Survey (RHS)<sup>1</sup>, the 2006 Census,<sup>2,3,4</sup> and Indian and Northern Affairs Canada's (INAC) Indian Registry.<sup>5</sup> Information for First Nations living off-reserve, Inuit, and Métis are drawn primarily from the 2006 Census,<sup>2,3,4,6</sup> the 2001,<sup>7,8</sup> and 2006<sup>9</sup> Aboriginal Peoples Survey (APS), and 2006 Aboriginal Children's Survey (ACS).<sup>10</sup>

In order to identify additional sources of data on the health of First Nations, Inuit, and Métis children in Canada, a series of searches were conducted for public health data, scholarly articles, and published reports. Public health data available for First Nations, Inuit, and Métis at populations at the national and provincial/ territorial level had already been systematically reviewed by our group in an earlier study.<sup>11</sup> To supplement the available public health data, we also systematically searched the published literature. In consultation with a medical information specialist, a set of key words for population and subject headings was derived, as well as a list of databases to search. The keywords that were used included the population keywords: Native, Indian, Aboriginal, Inuit, Métis, and First Nations. As well, additional population descriptors were used to focus on children. These words included: infant and child. For subject headings, the following terms were used in combination with the population keywords: health, health status indicators, health status, health status disparities, health surveys,

mental disorders, and suicide. The databases that were searched were MEDLINE; Bibliography of Native North Americans; and Health Sciences: A SAGE Full-Text Collection. From this initial search, a total of 718 articles were identified. This first set of abstracts was screened by a Masters-level Research Assistant (PA) using the following criteria: (1) included a population of children; (2) disease prevalence, incidence presented; and (3) Aboriginal population in Canada. Using these criteria, 123 articles were retained. The abstracts were then independently reviewed by two Aboriginal health researchers (JS and KM) and were retained if they met the following criteria: (1) provided statistics specifically for First Nations, Inuit, or Métis (not 'Aboriginal' broadly defined) and (2) national, provincial, or territorial level statistics. Articles which pertained to important child health issues, not otherwise covered in the literature were retained even when neither criterion was met. The final set of articles reviewed for inclusion in this report comprised 27 articles.

Based on the two methods detailed above, a comprehensive set of statistical sources of First Nations, Inuit, and Métis children's health was identified and is listed in *Table 1* in the *Additional Tables* section.

We have attempted to be as inclusive as possible in providing data for all First Nations, Inuit, and Métis children. At times this has been challenging, as the data sources are not always inclusive and/or consistent in their terminology or indicators. For example, there are data quality issues and associated limitations of First Nations census data. There appears to be a significant undercount of First Nations persons – particularly First Nations persons living on–reserve. According to the 2006 census the total 'Registered Indian' population was 564,870.<sup>2</sup> This is almost 200,000 less than the 763,555 that INAC's Indian Registry shows for 2006.<sup>5</sup> In addition, the 2006 Aboriginal Peoples Survey and 2006 Aboriginal Children's Survey did not include First

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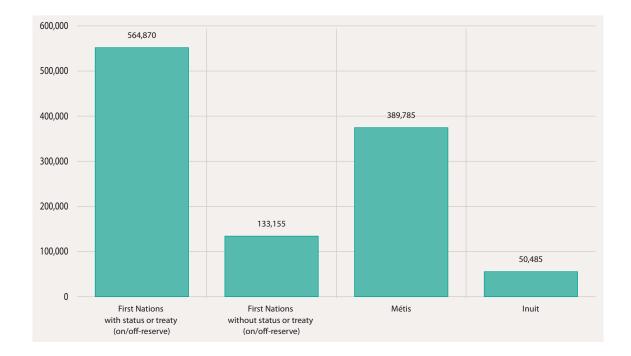


Figure 1
Aboriginal Population
Composition

Source: Census 2006

Currently in
Canada, Aboriginal
people represent
themselves politically
as belonging to one
of several major
groups: First Nations
(Status Indians
on-reserve, Status
Indians off-reserve,
and non-Status
Indians), Inuit,
and Métis.

Nations peoples living on-reserve. Fortunately we are able to draw on the First Nations Regional Longitudinal Health Survey to address this deficiency and ensure that First Nations on-reserve information is included. The existing reports for the 2006 Aboriginal Peoples Survey and the 2006 Aboriginal Children's Survey also uniquely combine those who are 'Status or Registered Indians' living off-reserve with those who are 'Treaty Indians' living off-reserve. For this reason, when we are citing the 2006 Aboriginal Peoples Survey and the 2006 Aboriginal Children's Survey data we use the terms 'First Nations with status or treaty living off-reserve' and 'First Nations without status or treaty living off-reserve'. In all other cases when referring to First Nations data, if the term First Nations is used without qualifiers, it means that the data is inclusive of the total First Nations population (i.e., status and non-status as well as onreserve and off-reserve). Data from the First Nations Regional Longitudinal Health Survey is always for First Nations persons living on-reserve who participated in the survey. In all other cases we clarify the First Nations population being described by identifying if it is 'status' or 'non-status' and/or 'on-reserve' or 'off/reserve'. Further challenges were found with locating information for First Nations persons without status, Métis people, and Aboriginal people living in urban areas. With the exception of the Aboriginal Peoples Survey and the

Aboriginal Children's Survey, health information for these groups is close to non-existent.

## 2.3 DEMOGRAPHICS OF ABORIGINAL CHILDREN IN CANADA

Currently in Canada, Aboriginal people represent themselves politically as belonging to one of several major groups: First Nations (Status Indians on-reserve, Status Indians off-reserve, and non-Status Indians), Inuit, and Métis. These groupings reflect Section 35 of Canada's Constitution Act as well as the federal Indian Act, which defines the term 'Status Indian'. From a cultural perspective, Aboriginal people in Canada comprise over 50 distinct and diverse groups, each with its own distinct language and traditional land base.12 Further, each of these larger groups represents a complex network of communities and kinship systems, often with their own distinct language dialects. ibid According to the 2006 census,<sup>2</sup> just under 1.2 million persons in Canada report Aboriginal identity: approximately 60% identified as 'North American Indian,'a 33% identified as Métis, 4% identified as Inuit, and the remaining 3% identified with more than one Aboriginal group and/or self-reported as 'registered Indians' or members of First Nations bands but didn't identify as Aboriginal.2 (See Figure 1) These numbers underestimate the actual Aboriginal population, as there was significant non-participation in the census

<sup>&</sup>lt;sup>a</sup>This is the census term used to identify persons of First Nations ancestry. It is in quotation marks, because the word Indian is recognized as a misnomer for Aboriginal people of First Nations ancestry.

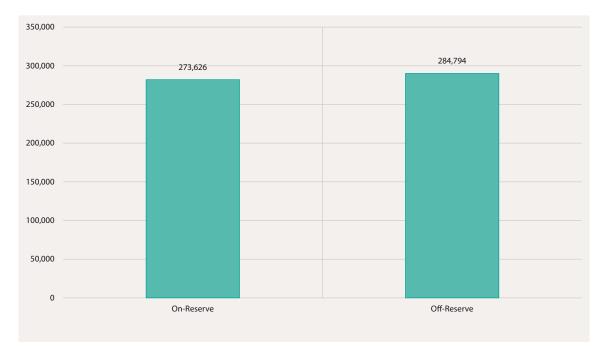




Figure 2
First Nations with Status by
Place of Residence

Source: Census 2006

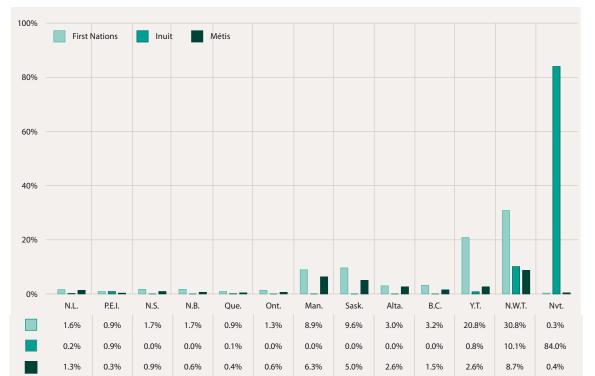


Figure 3
Proportion of Total
Population Identifying
as Aboriginal

Source: Census 2006

by a number of First Nations living on-reserve<sup>b</sup> and possibly other Aboriginal groups. Additionally, it is likely that a significant number of individuals chose not to self-identify as Aboriginal to government workers. Currently, 81% of the First Nations population is considered 'Status Indian'. Approximately half of First Nations (51%) live

off-reserve, with 76% of those living off-reserve living in urban areas.<sup>2</sup> (See *Figure 2*.) The majority of Métis live in urban areas (69%) and a growing number of Inuit (22%) live outside of Inuit Nunaat<sup>c</sup> (See *Figure 3* for the portion of the population by region that identified as First Nations, Inuit, and Métis.)

<sup>&</sup>lt;sup>b</sup> As discussed earlier INAC figures indicate that the census undercount of First Nations persons with status is approximately 200,000 individuals

<sup>&</sup>lt;sup>c</sup> Inuit Nunaat comprises four Inuit regions: Nunatsiavut, Nunavik, Nunavut, and Inuvialuit.

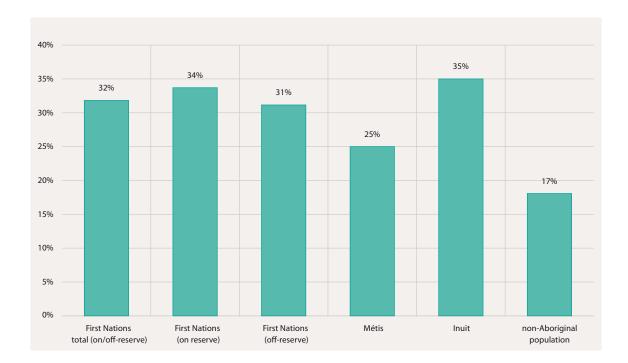
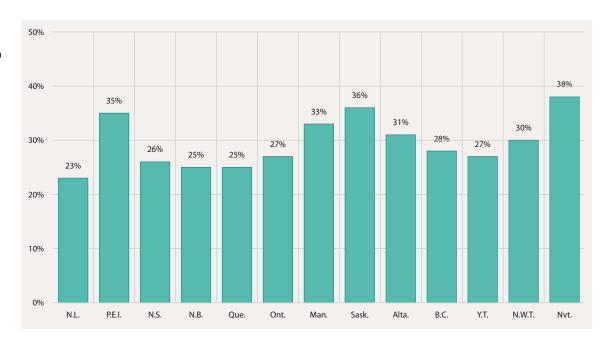


Figure 4
Aboriginal Population
Under 14 Years of Age

Source: Census 2006

Figure 5
Proportion of Aboriginal
Population that are Children
aged 14 & under

Source: Census 2006



The population of Aboriginal children in Canada represents a sizeable portion of the total Aboriginal population (See *Figure 4*). In *Figure 5*, there are some regional differences in the proportion of Aboriginal children (in relation to the total Aboriginal population), with higher proportions observed in Nunavut, Saskatchewan and Prince Edward Island. The large and growing populations of First Nations, Inuit, and Métis infants, children, and youth is linked to a birth rate that is 1.5 times higher than the non-Aboriginal birth rate.<sup>2</sup> Specifically, the fertility rate



between 1996 and 2001 for First Nations women was 2.9 children, 2.2 for Métis women, and 3.4 for Inuit women, compared to a rate of 1.5 among all Canadian women. As evidenced in *Figure 6*, in comparison to the non-Aboriginal population, the First Nations, Inuit, and Métis populations have a larger segment of young adults (15-24 years) and smaller segment of older adults (65 and over). This young and growing population impacts health and education systems, and the future labour market, particularly in provinces and

territories such as Manitoba, Saskatchewan, Alberta, and Nunavut where there are high concentrations of Aboriginal people.

The First Nations, Inuit, and Métis populations are all much younger than the rest of the Canadian population, with a collective median age of 27 years, compared to 40 years in the non-Aboriginal population. Specifically, the median age of the First Nations population was 25 years, 22 years for the Inuit population and 30 years for the Métis population.<sup>2</sup>

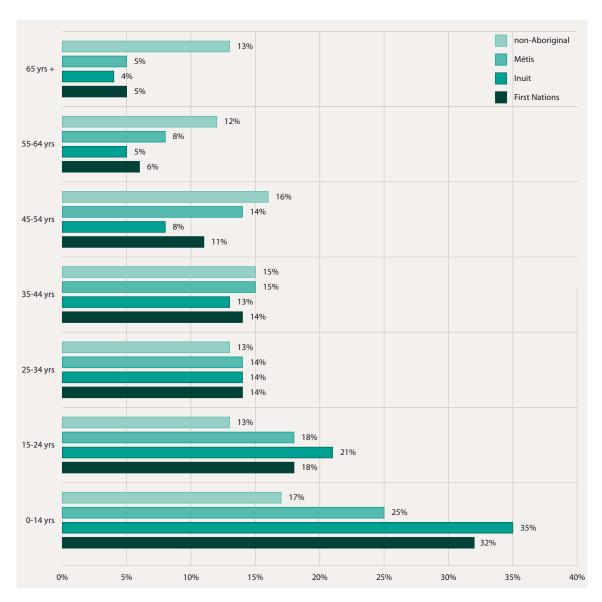


Figure 6
Proportion of Population by
Age Category

Source: Census 2006

Aboriginal children often live in families headed by single parents (See *Figures 7 and 8*). According to the 2006 Aboriginal Children's Survey, 2006 Census, and the First Nations Regional Longitudinal Health Survey, considerably more First Nations, Inuit, and Métis children live in single parent families, as compared to non-Aboriginal Children (See *Figure 7*). <sup>1,2,10</sup> Note that First Nations children living on-reserve were not included in the APS and are therefore not included in the chart for children aged five and under. They are included in *Figure 8* which draws on the 2006 Census,

as well as the First Nations Regional Longitudinal Health Survey for older children. 1,2

The majority of lone-parent families are led by mothers and many of these mothers are younger when compared to non-Aboriginal families. According to the 2006 Aboriginal Children's Survey, 27% of young (aged five and under) First Nations children living off-reserve, 22% of young Métis children, and 26% of young Inuit children, had mothers between the ages of 15 and 24.10 The rate of young mothers between the ages of 15 and 24 for non-Aboriginal families was 8%.

Figure 7
Percentage of Young
Children (aged 5 & under)
Living in Lone
Parent Families

Source: ACS 2006, Census 2006

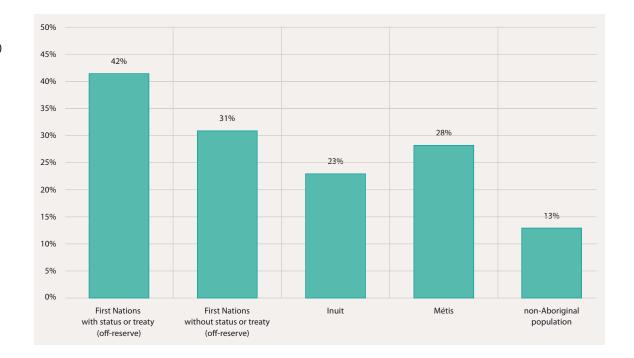
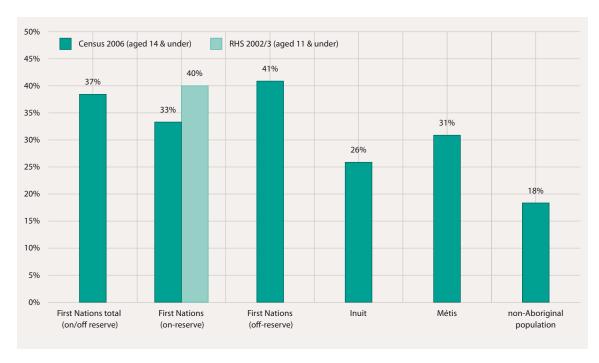


Figure 8
Percentage of Children
Living in Lone
Parent Families

Source: APS 2006, RHS 2002/3, Census 2006



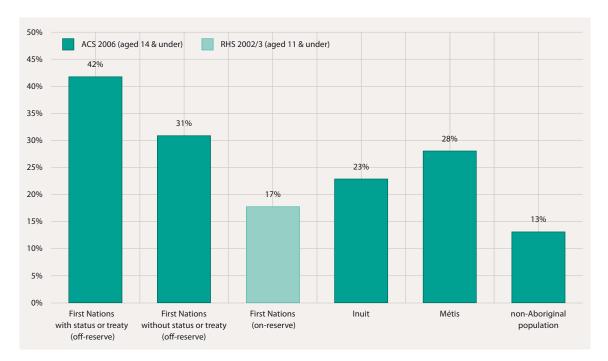




Figure 9
Percentage of Children
Living in Multiple
Generation Households

Source: ACS 2006, Census 2006

Aboriginal families are more likely to be large families. According to the First Nations Regional Longitudinal Health Survey, 63% of First Nations children living on reserve aged 11 and under lived in families with three or more children. According to the 2006 Aboriginal Children's Survey, 17% of young First Nations children living off-reserve and 28% of young Inuit children, lived in families with four or more children, compared to 8% of young non-Aboriginal children. For Métis families, 32% of young Métis children lived in families with three or more children, compared to 25% of non-Aboriginal children. On the survey of th

Results from the Aboriginal Children's Survey 2006 and the First Nations Regional Longitudinal Health Survey (see *Figure 9*) showed that Aboriginal children are also twice as likely as non-Aboriginal children to live in multiple-generation households (children, parents, grandparents). Additionally, a number of children lived with their grandparents: 9% of First Nations children living off-reserve, 8% of Métis, and 16% for Inuit children lived with grandparents (either as part of a multiple generation household or living with grandparents alone). The comparable rate for non-Aboriginal children aged five and under living in the same household with their grandparents is 5%. Note that these ACS results again exclude First Nations families living on-reserve.



# 2.4 ASSESSING AND RESPONDING TO THE HEALTH NEEDS OF ABORIGINAL CHILDREN IN CANADA

Health workers are trained to identify their client's illness and its cause or source. Public health assessment similarly measures health and its determinants among populations. The assessment of Aboriginal children's health challenges public health stakeholders to take into account not only illness, but also wellness, using methods that build on these children's rich and diverse cultural, linguistic and geographic heritage.

Public health assessment data typically relies on five main sources: (1) Census data; (2) Vital registration; (3) Acute and chronic disease surveillance; (4) Primary and tertiary health services utilization records; and (5) Surveys. In Canada, health data exists at the national, provincial/territorial, regional, and community levels. For First Nations, Inuit and Métis peoples, there is limited health assessment data due to problems with data coverage and quality. Smylie and Anderson<sup>14</sup> have detailed the significant issues with each of the five health data sources (see Text Box 1 in Additional Tables Section). Broadly speaking, in the health care and vital statistics system, there are few opportunities for individuals to self-identify themselves or their children as First Nations, Inuit or Métis. When opportunities to self-identify do exist, Métis and First Nations persons without status are almost always excluded. This results

in the lack of accurate and inclusive First Nations, Inuit, and Métis identifiers or flags in vital registration, acute and chronic disease surveillance, and health service utilization data sets. There is an urgent need to remedy this situation and provide more opportunities for First Nations, Inuit, and Métis to self-identify in health information systems. In addition, there are instances of substandard data collection sources and methods, which have resulted in inaccurate statistics. For example, under reporting of First Nations infant mortality has recently been identified at national and provincial levels. 14,15

Also essential to public health data systems is their connection to and integration with health policies, programs, and services. The various sources of health data need to be planned and organized so together they form a comprehensive set of health system performance measures. These performance measures should give an integrated picture of the vitality and wellbeing of Aboriginal children as well as the environments in which they live and grow. Data on its own, without an organized interface to health policies, programs and services, has little meaning or utility. The organized linkage of First Nations, Inuit, and Métis health data to First Nations, Inuit, and Métis health policies, programs and services is another area where there are significant challenges in Canada. This may be related to the use of health survey data to address

gaps in vital registration, acute and chronic disease surveillance and health service utilization data sets. While we were able to locate a significant amount of First Nations, Inuit, and Métis data using the methods described below, it was much more difficult to put these data sets together to provide a comprehensive overview of First Nations, Inuit, and Métis children's health and an assessment of the strengths and limitations of First Nations, Inuit and Métis children's health policies, programs, and services.

An additional challenge facing First Nations, Inuit, and Métis health information stakeholders is the issue of jurisdictional complexity. Multiple jurisdictions can be involved in collecting, analyzing, disseminating and responding to health information, and the levels of interface vary. For example, in one province, First Nations infant mortality rates were being calculated by both the provincial health department as well as the regional office of Health Canada, First Nations and Inuit Health Branch (FNIHB). Two slightly different rates were produced. The regional First Nations governing authority felt that they should share responsibility for the governance of this information, but were not yet actively included in data collection, analysis, or dissemination activities.

At a national level, the need for data that relates to, and can be applied to specific ethnic and geographic contexts is not always understood. For example, the recent Maternal Experiences Survey, which was conducted by Statistics Canada at the request of Canadian Perinatal Surveillance System, Public Health Agency of Canada, was not adequately powered to provide First Nations, Inuit, and Métis specific data. Hence, the experiences of an Inuit women living in Nunavut may be compiled with those of a First Nations women living in downtown Toronto. Such data will be of little use to regional policy makers and service providers anxious for data that would help them improve their local services, which clearly are very different. Ideally, such national level surveys need to be powered to provide data that is specific to First Nations (status and non-status), Inuit and Métis with further ability to stratify for geography (ie. urban/ rural/settlement for Métis; on-reserve/off-reserve for First Nations with status; urban/rural for First Nations without status; and territorial land claim area/urban for Inuit). These are the ethnic and geographic groupings upon which current health services are structured.

# 2.5 COLONIZATION AS AN UNDERLYING DETERMINANT OF INDIGENOUS CHILDREN'S HEALTH

Everyone agrees that there is one critical social determinant of health, the effect of colonization.<sup>116</sup>

The colonization of Indigenous peoples globally has been increasingly recognized as a fundamental underlying determinant of health. Participants at the first International Symposium on the Social Determinants of Indigenous Health documented the links between colonial policies and the following: dislocation from traditional lands, cultural suppression, political marginalization, forced assimilation, and the excess burden of health disparities experienced by Indigenous peoples. <sup>16</sup>

First Nations, Inuit and Métis peoples in Canada continue to endure the effects of European colonization with direct impacts on health. Government policies have supported the disruption of family networks, the forced dislocation of communities from traditional lands, and increased environmental degradation of natural resources due to industrial processes. Historically, First Nations, Inuit, and Métis knowledge regarding infant, child and family health was shared verbally and experientially among family and extended kin. The overt suppression of Aboriginal cultures and languages has caused severe repercussions to the intergenerational transmission of knowledge and traditional teachings.

Colonial processes in Canada varied according to Aboriginal group, time, and geographic location. <sup>12</sup> First Nations, Inuit, and Métis peoples have all experienced dislocation from and appropriation of their traditional territories. <sup>ibid</sup> For example, the Indian Acts imposed a system for the management of First Nations lands which legalized removal of First Nations communities (who had signed treaties) from their homelands to 'reserve lands' controlled by the Government of Canada on behalf of 'Indians' As a result, the livelihoods of these communities were undermined as their local economies were strongly tied to traditional lands.

After Métis homelands were sold by the Hudson Bay Company to the Government of Canada, the Manitoba Act of 1870 reserved 1.4 million acres of Crown land for the unmarried children of Métis.<sup>17</sup> However, incoming settlers showed disregard for Métis land claims and the implementation of the land provisions for the Métis in the Manitoba Act was plagued by

delays, speculation, and theft. Consequently, the majority of land set aside for Métis children in the Manitoba Act ended up being acquired by speculators for only a fraction of its value and in the end Métis occupied less than a quarter of the land. ibid

Between 1936 and 1963, federal relocation policies 'encouraged' Inuit to relocate into permanent villages in areas selected by the government<sup>17</sup> and required children to attend schools in these villages in order to receive family allowance. The hunting conditions of the new sites were suboptimal, leading to food insecurity, unemployment, and housing issues. Furthermore, the move to permanent settlements was accompanied by outbreaks of tuberculosis. By 1964, more than 70% of Keewatin Inuit had been in tuberculosis sanatoria. In some cases, children sent to sanatoria were later adopted by southern families without their parents being informed.<sup>17</sup>

Federal policies also supported the abduction of Aboriginal children to residential schools, where language and culture were actively suppressed and child neglect and abuse were commonplace. Indian Act legislation in 1920 made school attendance compulsory for all First Nations children between the ages of 7 to 15 years. Between 1849 and 1983, approximately 100 residential schools operated in Canada and included First Nations, Métis and Inuit students.<sup>17</sup> According to the Aboriginal Peoples Survey in 20069, 16% of Inuit children aged 6 to 14 years had a parent who attended a residential school and 49% of Inuit children aged 6 to 14 years had parents with at least one relative (mother, grandfather, etc.) or spouse who attended a residential school. According to the RHS 2002-3, 16.5% of First Nations children (aged 11 and under) living onreserves had at least one parent and 58.6% had at least one grandparent who attended residential schools.1

The residential school experience is described in the following excerpt from the 1999 First Nations and Inuit Regional Health Survey Report:

In some areas as many as five separate generations of children were removed from their homes, families, culture, and language...many of the children endured long years of isolation and loneliness...Scores of children died from disease; others were emotionally and spiritually destroyed by the harsh discipline and living conditions.<sup>18</sup>

Inuit children also endured the residential school experience. Mary Carpenter, an Inuk woman summarizes her experience of residential school:

After a lifetime of beating, going hungry, standing in a corridor on one leg, and walking in the snow with no shoes for speaking Inuvialuktun, and having a heavy stinging paste rubbed on my face, which they did to stop us from expressing our Eskimo custom of raising our eyebrows for 'yes' and wrinkling our nose for 'no,' I soon lost the ability to speak my mother tongue. When a language dies, the world it was generated from is broken down too.<sup>19</sup>

Métis children and youth in some parts of the country also attended residential schools, and were commonly excluded and/or barred from attending community schools set up for the children of European colonists.

The impact of residential schools goes far beyond the impact on individual survivors; the trauma is evident across generations of families. Dr. Cornelia Wieman highlights the enduring aftermath of the residential schools, asserting that:

In addition to the damage caused to the individual survivors who endured emotional, physical, and sexual abuse, we must consider the long-term, cumulative intergenerational effects on First Nations Communities... including dislocation from one's community, loss of pride and self-respect, loss of identity, language, spirituality, culture, and ability to parent.<sup>20</sup>

The evidence suggests that health status, health service, and/or economic considerations themselves are not sufficient to describe the excess burden of health disparities experienced by Indigenous children and their families, nor are they adequate to identify appropriate strategies for remediation. Historic and ongoing colonial policies need to be addressed. Key to the reversal of colonization is the restitution of the right of Indigenous peoples to self-determination, including the implementation of the standards in the UN declaration on the Rights of Indigenous Peoples.<sup>21</sup>

# 2.6 ADDITIONAL SOCIAL DETERMINANTS OF FIRST NATIONS, INUIT, AND MÉTIS CHILDREN'S HEALTH

#### **Employment**

Overall, rates of unemployment are higher for Aboriginal peoples compared to non-Aboriginal Canadians. Results from the 2006 Aboriginal Peoples Survey found that unemployment rates<sup>d</sup> for the adult population (15 years and over) were four to five times higher for the Aboriginal population compared to the non-Aboriginal population<sup>7</sup> (See *Figure 10*). Rates for employment<sup>e</sup> were generally comparable across the First Nations, Inuit, Métis, and Non-Aboriginal

<sup>&</sup>lt;sup>d</sup>The unemployment rate particular group (age, sex, marital status, geographic area, etc.) is the number of persons unemployed, expressed as a percentage of the total population in that particular group (adults aged 15 and over).

The employment rate for a particular group (age, sex, marital status, geographic area, etc.) is the number of persons employed in the week (Sunday to Saturday) prior to Census Day (May 16, 2006), expressed as a percentage of the total population in that particular group (adults aged 15 and over).

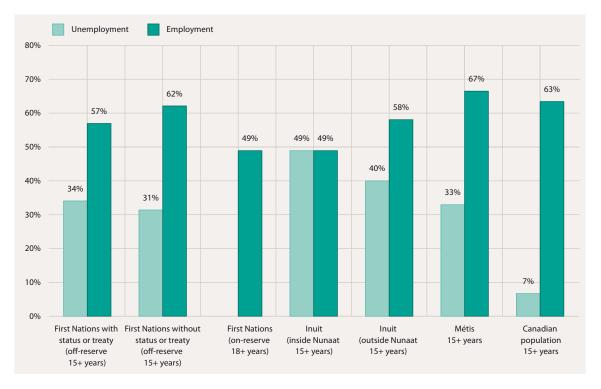


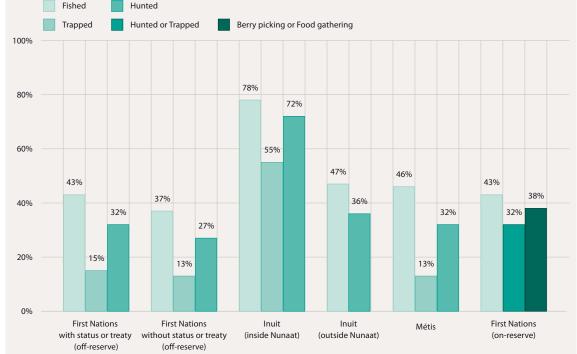


Figure 10 **Rates of Unemployment** & Employment

Source: APS 2006, RHS 2002/3, Census 2006







population. According to the 2006 Census, the rate of employment for the First Nations on-reserve adult population (over 18 years of age) was 49%.3

The harvesting of country food was included as a labor activity on the 2006 Aboriginal Peoples Survey and the 2002/2003 First Nations Regional Longitudinal Health Survey. Gathering or harvesting country food for personal consumption was an important labour activity across all groups. Inuit respondents, living inside Inuit Nunaat, had significantly higher rates of hunting, fishing and trapping, compared to off-reserve First Nations and Métis groups (See Figure 11).<sup>1,9</sup>

**Total** Métis Inuit Non First Nations First Nations **Aboriginal** (on and off (on reserve **Aboriginal** reserve) only) Women 16,079 15,489 13,800 17,002 15,387 21,765 (all age groups) Men 22,386 19,061 13,607 27,881 19,229 33,214 (all age groups) Total (Men and 18,962 17,007 13,705 21,498 17,268 27,097 Women)

Table 2
Median Employment
Income for Aboriginal and
non-Aboriginal Population
in Canada (based on
2005 earnings)

Source: 2006 Census.

#### **Income**

Median income for the Aboriginal and non-Aboriginal population is presented in *Table 2*.<sup>4</sup> Significant disparities exist for First Nations, Inuit, and Métis, in comparison to the non-Aboriginal population. The most marked disparities are for First Nations living on reserve.

Further, according to the Aboriginal Children's Survey 2006, 41% of young First Nations children (aged five and under) living off-reserve and 32% of young Métis children were from low-income families, compared to 18% of non-Aboriginal young children.<sup>10</sup> Differences in frequency of low-income families were also noted between urban and rural residences. For First Nations families living off-reserve with young children (aged five and under), a higher percentage of urban families were in the low-income category as compared to families living in rural areas (54% and 27% respectively). A similar trend was found for Métis; 36% of families with young Métis children in urban areas were in the low-income category, compared to 20% of rural families. Rates for Inuit families with young children (aged five and under) were calculated differently based on geography. For young Inuit children living outside of Inuit Nunaat and living in a Census Metropolitan Area (CMA), 45% were living in low-income families, compared to 21% of young non-Aboriginal children living in CMAs. There were no rates available for First Nations children living on-reserve or for Inuit children living inside Inuit

In the Aboriginal Peoples Survey, 17% of status or treaty First Nations living off-reserve and 11% of non-status or non-treaty First Nations living off-reserve, utilized social assistance or welfare as an income source. For Inuit living within Inuit Nunaat, rates were 24% compared to rates of 13% for Inuit living outside Inuit Nunaat. The rate for Métis respondents was 7%. The APS excluded First Nations living on-reserve.

These income disparities are all the more alarming given the household and demographic characteristics of Aboriginal families. As mentioned previously, many Aboriginal children live in lone parent households. Additionally, children and youth account for just under half of the Aboriginal population. Therefore, the reduced annual incomes of Aboriginal adults described above will often be providing for a larger group of dependents, compared to non-Aboriginal households.

#### **Education**

Only the First Nations Regional Longitudinal Health Survey has data on parental education. According to RHS 2002/3, 54% of mothers and 43% of fathers were high school graduates.<sup>1</sup>

Nunaat.<sup>10</sup> For the total Canadian population, 14.5% of young children under 6 years old and 13% of children aged six to 14 years old lived in a low income family. Overall, this suggests that young Aboriginal children and their families are more often living in poverty, as compared to non-Aboriginal families.

<sup>&</sup>lt;sup>f</sup> A CMA is an urban area with a population of more than 100,000 people

<sup>&</sup>lt;sup>9</sup> The CCHS excludes on-reserve First Nations populations and Inuit populations living in the territories.

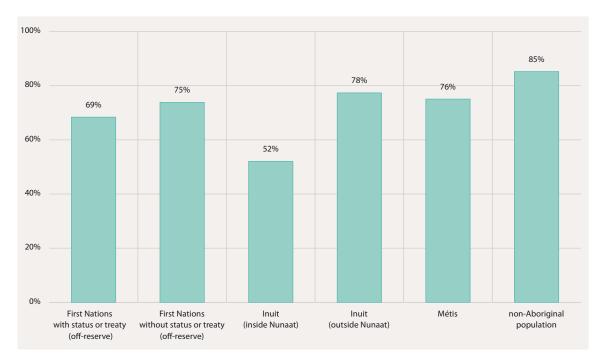




Figure 12 High School Completion

Source: APS 2006, Census 2006

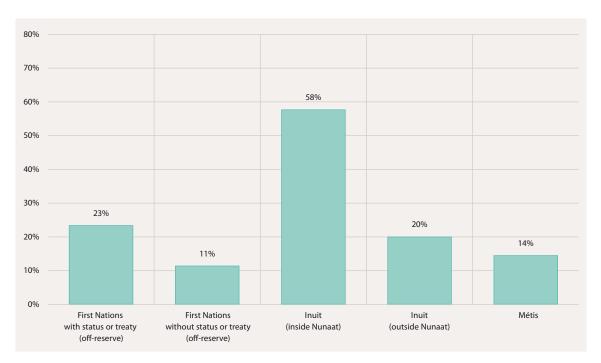


Figure 13
Exposure to Aboriginal
Teachers or Teacher Aides
(elementary or
secondary school)

Source: APS 2006

As there are currently no specific data on parental education for First Nations off-reserve, Inuit, and Metis, we report figures for the general adult population. According to the 2006 Census, rates for high school completion are generally somewhat lower for Aboriginal populations, as compared to the non-Aboriginal population. In particular, Inuit living inside Inuit Nunaat have considerably lower rates of high school completion (See *Figure 12*).6

Other data in the 2006 Census examined student exposure to Aboriginal teachers at the elementary or

high school level. Evidenced from *Figure 13*, there were significant differences in these rates for First Nations, Inuit, and Métis.<sup>6</sup> These trends could suggest that having treaty or status, and living within Inuit Nunaat may provide increased opportunities for exposure to Aboriginal teachers and possibly Aboriginal-based teachings and philosophies.

#### **Food Security**

There is only sparse and inconsistent information regarding the rates of food security and insecurity

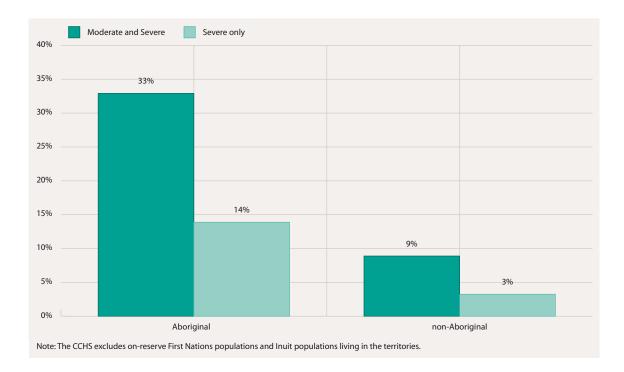


Figure 14
Food Insecurity

Source: CCHS 2004

among First Nations, Inuit, and Métis populations. Data collection and quality is further complicated by the use of different measurement instruments, most of which have not been validated in First Nations, Inuit, and Métis contexts. Given the strong links between food security, income, and employment, <sup>22</sup> the paucity of information regarding food security is particularly concerning. As we know from the income and employment statistics detailed above, some Aboriginal people will be at risk of food insecurity, possibly leading to negative health outcomes.

Results from the 2004 Canadian Community Health Survey (CCHS)<sup>g</sup> indicated disproportionately high rates of food insecurity for the Aboriginal population, when compared to the non-Aboriginal population<sup>22</sup> (See

Figure 14). Rates of food insecurity for First Nations populations living on-reserve vary from 21% to 83%<sup>23</sup> According to the 2006 APS, 30% of Inuit children in Canada had at some point experienced hunger as a result of their family having run out of food or money to buy food. Of those who experienced hunger, 24% experienced it regularly at the end of the month and 21% had experienced it more than once a month.<sup>9</sup> It is also important to recognize that the frequency of food insecurity may in fact be higher than observed as a community organizations may be 'filling the gaps' through community food banks and meal vouchers.

Remote and/or northern Aboriginal communities can face additional food security challenges, as nutritious food can be difficult and costly to find. For

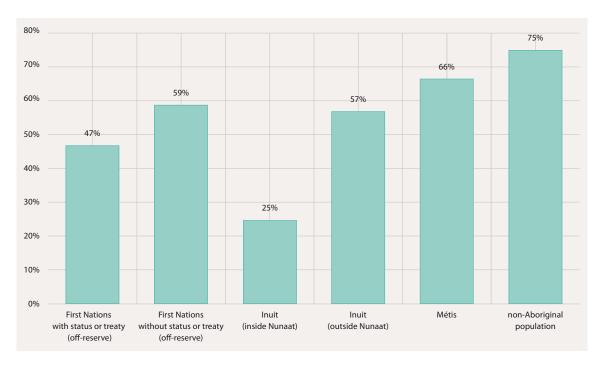


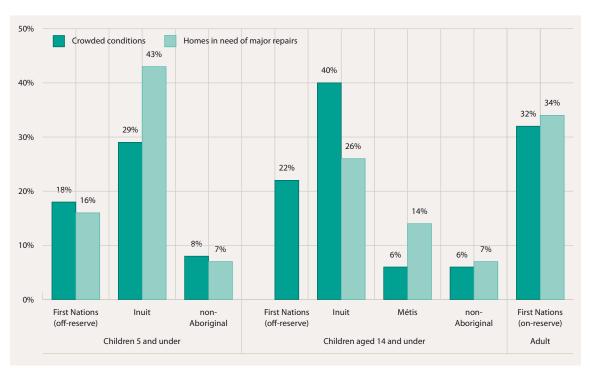


Figure 15
Home Ownership

Source: APS 2006, Census 2006

Figure 16
Housing Conditions

Source: ACS 2006, RHS 2002/3, Census 2006



example, a healthy food basket to feed a family of four for a week costs between \$350-450 in Inuit Nunaat, compared to \$200 in the south.<sup>24</sup>

#### Housing

According to the 2006 APS, rates of home ownership were lower for Aboriginal populations, compared to non-Aboriginal population. Furthermore, there was significant variability among First Nations, Inuit

and Métis populations (See *Figure 15*). Data was not available for First Nations living on-reserve.

Results from the 2006 Census and ACS 2006 show overall higher rates of crowding<sup>h</sup> and homes in need of repairs for families with Aboriginal children, as compared with non-Aboriginal families (See *Figure 16*). <sup>2,6,10</sup> More specifically, Inuit participants reported significantly higher rates of problems with housing, as well as lower rates of home ownership. This

<sup>&</sup>lt;sup>h</sup> Crowded conditions is defined as more than one person per room.

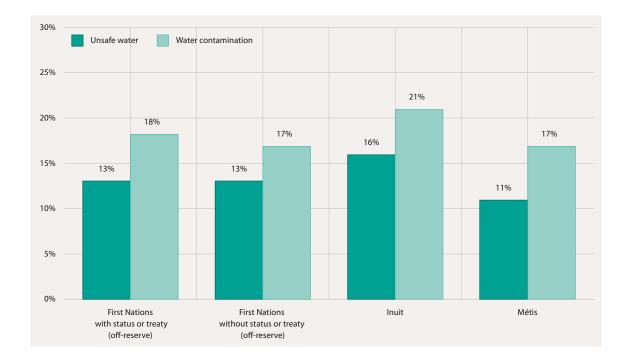
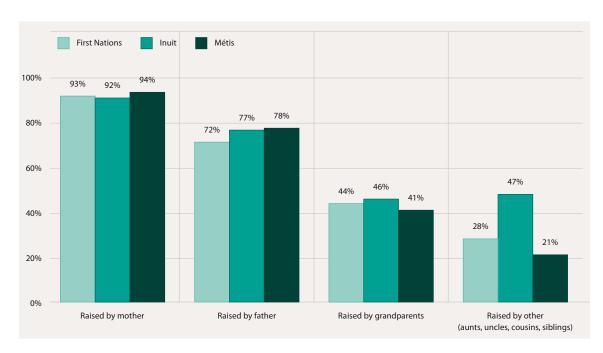


Figure 17
Water Quality Issues

Source: APS 2006

Figure 18
Kinship Networks

Source: ACS 2006



could suggest that landlords are not maintaining an acceptable level of safety in their rental units. Data for First Nations living on-reserve was not included in this 2006 Census/ACS analysis. According to the RHS 2002/3, 32% of adults reported their homes were crowded and 34% reported of adults reported their homes were in need of major repairs. <sup>11</sup>

In addition, between 10% and 20% of Aboriginal people participating in the 2006APS report water quality issues in their homes (See *Figure 17*). The water quality situation is even more alarming for First Nations people living on reserve, with only 68% of

participants in the RHS 2002/3 reporting that water in their home was safe to drink.<sup>1</sup> No comparable statistics from the 2006 census have been released for the general Canadian population.

#### **Kinship and Support Networks**

Many First Nations, Inuit, and Métis parents and extended family are involved in raising young children (under six years old). The majority of Aboriginal children were raised by their mother and father, and approximately half were raised by grandparents. (See *Figure 18*). No statistics from the 2006 census have been released for

Since 99% of the adults participating in the RHS had children living with them, the RHS figures are comparable to the 2006 Census/ACS figures and are included in Figure 16.

the general Canadian population or for the First Nations population living on-reserve. The only comparable statistics for the Canadian population are from the NLSCY 2006/07 for children aged five and under.<sup>25</sup> When asked who the child lived with, 86% of children lived with biological parents, 11% lived with biological mother and did not live with their father, and 0.6% lived with biological father and did not live with biological mother (although this last statistic was flagged to indicate that caution should be used in its interpretation).

#### **Communication Technology**

The 2006 Aboriginal Peoples Survey and Statistics Canada indicated that most Aboriginal adults had used a computer and the internet in the past year (See *Figure 19*).<sup>7,26</sup> Slightly lower rates were found for

Inuit specifically living inside Inuit Nunaat, which might reflect the limited number of internet services providers, the high costs of computer and internet access, or computer illiteracy. According to the RHS 2002/3, 41% of participant First Nations adults living on-reserve reported having a home computer and 29% reported having access to the internet in their home.<sup>1</sup>

#### Language

Results from the 2006 Aboriginal Peoples Survey showed considerable variability in language fluency among First Nations, Inuit, and Métis adults (See *Figure 20*).<sup>7</sup> Rates of Aboriginal language retention among First Nations, Inuit, and Métis children are included in the health status sections below. Rates for



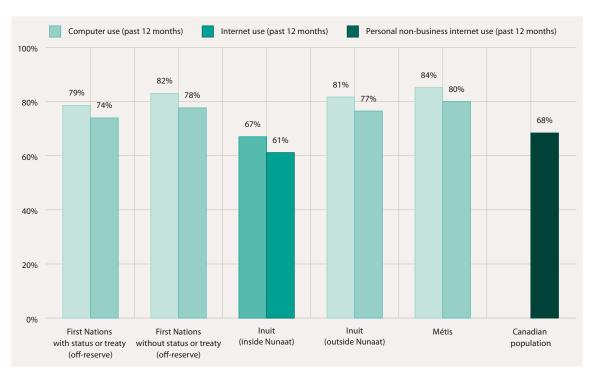


Figure 19 Communication Technology Use

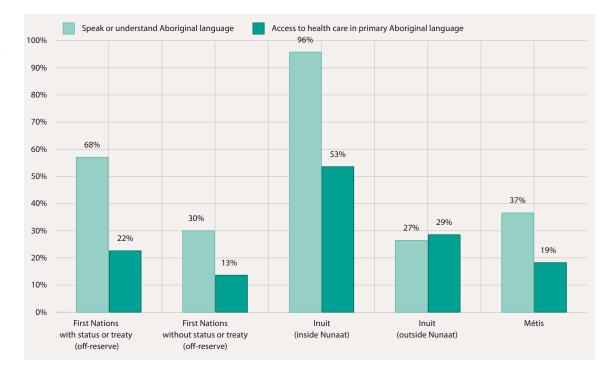
Source: APS 2006, Canadian Internet Use Survey 2005 accessing care in an Aboriginal language were around 20% (See *Figure 20*). It is unclear if these rates include use of an interpreter or simply accessing a health-care provider who speaks an Aboriginal language. First Nations living on-reserve were not included in these analyses. Increasing the amount of health services available in an Aboriginal language could significantly contribute to access and utilization of health services for diverse Aboriginal populations. The discrepancy between the language capacities of those surveyed and available health services in a primary Aboriginal language highlights a critical opportunity for growth and improvement in the delivery of appropriate and inclusive health programs and initiatives.

#### 2.7 CHILDREN'S HEALTH STATUS

Refer to the end of this section (*v. Figures*) for children's health status figures. Comparisons in this section are made to the National Longitudinal Survey of Children and Youth (NLSCY).<sup>25,27</sup> Ideally, we would have presented comparisons to the non Aboriginal participants in the NLSCY however, due to the very small sample size of the Aboriginal participants included in the NLSCY, data for the Aboriginal and non-Aboriginal subsamples has been suppressed to protect confidentiality. Instead, we therefore make comparisons with data from the general Canadian sample, which includes a small proportion of Aboriginal children.

Figure 20
Aboriginal Language Use &
Access to Health Services in
Aboriginal Language

Source: APS 2006



# First Nations Section Highlights

- Infant mortality rates for status First Nations appear to be decreasing but remain approximately twice as high as Canadian infant mortality rates. There are no infant mortality rates for non-status First Nations.
- In 2002/3, rates of high birth weight (>4.0kg) were significantly higher for First Nations children living on reserve (21%) compared to the non-Aboriginal population (13.1%).
- In 2006, rates for breastfeeding initiation, sustained breastfeeding at four months, and sustained breastfeeding at six months for status or treaty First Nations living off-reserve were 69%, 56%, and 48% respectively. In 2002/3 rates for initiation and sustained breastfeeding at six months for First Nations on-reserve were 63% and 43% respectively.
- According to the RHS, 3.6% of First Nations children living on reserve had bronchitis; more than double the rate for the Canadian population (1.4%).
- In 2006, 42% of status or treaty First Nations children aged six to 14 years living off-reserve and 45% of non-status or non-treaty First Nations children aged six to 14 years living off-reserve had one ore more severe chronic health conditions.
- In 2006, 15% of status or treaty First Nations children aged five years or less living off-reserve had asthma or used an inhaler/puffer. In 2002/3 14% of First Nations children aged 11 or younger living on reserve had asthma.
- In 2006, 18% of status or treaty First Nations children aged six to 14 years living off reserve and 22% of non-status or non-treaty First Nations children aged six to 14 living off-reserve suffered from one or more activity limitations; according to the RHS 8.1% of First Nations children(11 and under) living off-reserve suffer from an activity limitation.
- According to the RHS, 55% of First Nations children (aged 11 and under) living on-reserve reported always or almost always eating a nutritious and balanced diet.
- In 2006, 25% of status or treaty First Nations children aged five years or less living off-reserve and 9% of status or treaty First Nations children aged five years or less living off-reserve were able to speak or understand an Aboriginal language. In 2002/3, 25% of First Nations children aged 11 or younger living on reserve were able to speak or understand an Aboriginal language.
- 96% of First Nations children (aged 11 and under) living on-reserve had at least one person helped them understand their culture.
- In 2006, 12% of status or treaty First Nations children aged five years or less living off-reserve and 8% of non-status or non-treaty First Nations children aged five years or living off-reserve were unable to obtain health care or medication when needed in the past 12 months.
- 15.4% of First Nations children (aged 11 and under) living on reserve were reported to have an emotional or behavioural problem.
- 29.5% of First Nations children between 12 and 14 years old living on reserve smoked tobacco in 2002/3.

# I. FIRST NATIONS

#### **Self-rated health**

The measure of 'self-rated' health has yet to be validated in Aboriginal communities, and in general is considered problematic in the field of population health.<sup>28</sup> For example, individuals may rate their health in comparison to others. Thus, their perception of their own health is a relative comparison, and if the absolute level of health of a group is low, the perception will not accurately reflect a true measure of health. Results from the Aboriginal Children's Survey (2006) found that

nearly all children are described in 'good,' 'very good,' or 'excellent' health (See *Figure 21*), which is comparable to the rate for the Canadian population.<sup>10,25,27</sup>

# Infant mortality and perinatal health outcomes

This section covers infant mortality, birth weight, preterm birth, breastfeeding, sudden infant death syndrome (SIDS), and fetal alcohol spectrum disorder (FASD).

# **Infant mortality**

The Joint Working Group of Infant Mortality has identified that high quality infant mortality rates are



The Joint Working Group of Infant Mortality has identified that high quality infant mortality rates are currently only available for regional subgroups of the First Nations and Inuit population in Canada and exclude the Métis population. Moreover, these rates do not exist at a national level.

currently only available for regional subgroups of the First Nations and Inuit population in Canada and exclude the Métis population. Moreover, these rates do not exist at a national level.<sup>29</sup>

The averaged infant mortality rate for First Nations families with status, living both on and off reserve for 1976-1980 was 29 deaths per 1,000 live births.30 This was over two times the infant mortality rate for Canada during the same time period. ibid More recently, First Nations infant mortality rates appear to be decreasing with respect to absolute numbers but remain approximately twice as high as Canadian infant mortality rates (which have also been decreasing). In British Columbia, using vital statistics data from 1981 to 2000, the overall infant death rates were 2.27 times higher for status First Nations compared to non-First Nations living in rural areas, and 2.08 times higher for status First Nations compared to non-First Nations living in urban areas.31 In Manitoba, using vital statistics data from 1991 to 2000, the infant mortality rate for First Nations persons self-identifying on birth and/or infant death registrations as First Nations with status was 10.2 deaths per 1,000 births compared to a non-First Nations rate of 5.4. The rate disparity was most marked for post-neonatal death (death between 29 days to 364 days of age), for which the First Nations rate was more than three times the non-First Nations rate (6.1 per 1,000 compared to 1.7 per 1,000).32

It is important to note that no reliable infant mortality rates exist for First Nations persons living in other parts of the country and for First Nations persons without status. Additional regional rates are produced by First Nations and Inuit Health Branch and/or the provinces for the four Western provinces, however due to variations in the calculation methods, as well as quality, they have not been included.<sup>16</sup>

#### Birth weight

Rates of low birth weight for First Nations living on and off-reserve with status were similar to those of the Canadian population. Rates of low birthweight for First Nations without treaty or status living off-reserve were higher than those of the Canadian population (see *Figure 22a*). Rates for high birth weight (>4.0kg) showed some variation, with higher rates observed for First Nations living on-reserve and First Nations with status or treaty living off-reserve. <sup>1,10,27</sup> (See *Figure 22b*).

In a study examining all births of First Nations infants with status in British Columbia between 1981 and 2000, First Nations infants with status had heavier birth weights, as compared to non-First Nations infants.<sup>31</sup>

The reasons for the elevated proportions of high birth weight First Nations babies are unclear and this issue requires further investigation.

#### **Preterm birth**

There is no consistent provincial or territorial tracking of preterm birth rates among First Nations. A provincial research study of preterm birth among First Nations with status in British Columbia revealed preterm birth rates that were consistently over 40% to 70% higher than those of non-First Nations.<sup>31</sup> In Manitoba, published rates of preterm birth for First Nations with status are only slightly elevated compared to those of non-First Nations,<sup>33,34</sup> with higher rates for First Nations persons living off-reserve compared to on-reserve.

Elevated rates of preterm birth have been linked to increases in multiple births, increased frequency of obstetrical interventions, early complications during pregnancy (e.g., vaginal bleeding, gestational hypertension), inadequate prenatal care and high levels of perceived stress.<sup>34</sup> Accordingly, the high rates of preterm birth may be related to health service delivery and maternal well-being.

#### **Breastfeeding**

Rates of breastfeeding initiation for First Nations were slightly lower than the rate for the Canadian population (in particular for the on-reserve population). <sup>1,27</sup> However, rates of sustained breastfeeding (at six months in particular) were higher than the rate for the Canadian population (See *Figures 23, 24, and 25*). This suggests that mothers who decide to breastfeed are adequately supported to continue breastfeeding, but that fewer

mothers are deciding to breastfeed. This might be related to an increased rate of preterm labour that can interfere with the early interactions and opportunities for breastfeeding. It might also be indicative of the limited success of breastfeeding promotion efforts. Mothers may be receiving ongoing support from within their family (as evidenced by the strong kinship networks), which would explain the higher rates of sustained breastfeeding.

# Sudden infant death syndrome (SIDS)

In a population-based study in the province of British Columbia, which included all First Nations with status births between 1981 and 2000, the incidence of postneonatal SIDS was higher for both rural and urban First Nations with status, as compared to both rural and urban non-First Nations.<sup>31</sup>

In a study of all infants born in Quebec (Nunavik region) from 1985 to 1997, the incidence of SIDS for Indian (North American Native language base) was 2.6 per 1,000, which was higher than among infants of French language background (0.5 per 1,000), English background (0.4 per 1,000), and other language background infants (0.5 per 1,000).<sup>35</sup> Infant's ethnicity was identified using mother's language. SIDS has been linked to certain risk factors including infant sleep position, poverty and environmental smoke exposure.

#### Fetal alcohol spectrum disorder (FASD)

Much controversy surrounds the diagnosis of fetal alcohol spectrum disorder (FASD), particularly for Aboriginal communities. The diagnostic category is relatively new and diagnostic instruments are only now being standardized. For the Aboriginal population, the struggle for accurate diagnosis is greater and complex as access to trained physicians is often limited. Furthermore, the physical diagnostic features of FASD (e.g., typical facial features, height, head size) were established for Caucasian children and their use in Aboriginal settings can lead to misdiagnosis or over-diagnosis of FASD. The Additionally, standardized testing instruments for cognitive and behavioural features of FASD have yet to be validated with Aboriginal populations.

Presently, no population-based estimates for FASD exist for First Nations, Inuit or Métis children in Canada. Furthermore, most studies that are conducted at a provincial or territorial level are criticized for a failure to use blind examiners for maternal alcohol use. 38 According to parental self-report in the RHS 2002/3, 1.8% of participant First Nations children (aged 11 and under) suffer from Fetal Alcohol Effects (considered a broader diagnostic category) 1.

One comprehensive community level study has been conducted to determine prevalence rates of FASD; between January 1998 and June 1999, the prevalence of FASD was 193 per 1,000 (or 19.25%) for children in grades one to eight in one Atlantic First Nations community.<sup>39</sup>

According to Health Canada, among the general Canadian population the incidence of FASD is 1 out of every 500 to 3,000 live births per year, and the incidence of FAE is five to 10 times the incidence of FASD.<sup>38</sup>

#### **Nutrition**

There is relatively little data regarding the nutrition of First Nations children, despite the evidence indicating high rates of food insecurity discussed earlier. According to the RHS 2002/3, 55% of First Nations children (aged 11 and under) living on-reserve reported always or almost always eating a nutritious and balanced diet. According to the APS 2001, 90% of First Nations children (aged six to 14) living off-reserve and 84% of First Nations children living on selected reserves had breakfast five to seven days a week. In a study conducted with six of nine Cree villages in the James Bay region, between January 1995 and October 1998, 31.9% of infants had anemia. No national, provincial or territorial rates of anemia in First Nations children were identified.

#### Infectious diseases

# Immunization and immunizationpreventable diseases

No national, provincial or territorial rates were identified for immunization against preventable childhood infections (measles, mumps, rubella, haemophilus influenza, diphtheria, polio, tetanus, pertussus, pneumococcus, and varicella zoster).

# Otitis media

Rates for ear infections or problems are presented in *Figure 26*. Rates were comparable for status or treaty First Nations living off-reserve, non-status or non-treaty First Nations living off-reserve, and First Nations children living on-reserve. At present, we do not have a comparison for the Canadian or non-Aboriginal population.

# **Respiratory tract infection**

Respiratory tract infections constitute a major cause of childhood morbidity and mortality. According to the RHS 2002/3, 3.6% of First Nations children living on reserve had bronchitis, which was more than double the rate for the Canadian population (1.4%). It should be noted that the statistic for First Nations children



living on reserve is flagged and must be interpreted with caution due to high sampling variability.

Inadequate housing conditions, including poor ventilation and crowding, directly contribute to the elevated rates of respiratory tract infections.<sup>41</sup>

With the exception of TB (below) national, provincial and territorial hospitalization and mortality rates for childhood respiratory tract infection are noticeably absent.

#### **Tuberculosis (TB)**

According to the RHS 2002/3, 0.5% of First Nations children living on reserve (aged 11 and under) had tuberculosis (although this number should be interpreted with caution because of high sampling variability.<sup>1</sup>

Yip et al. (2007) examined cases of pediatric tuberculosis in the province of Alberta, including a sample of First Nations with status. <sup>42</sup> It should be noted that the Canadian 'other' category included: non-Status First Nations, Métis, Inuit, and Canadian-born non-Aboriginal children of foreign-born or Canadian-born parents. Thus, this statistic on tuberculosis is not representative of the entire population of First Nations children in Alberta. The overall rate of pediatric tuberculosis in Alberta between 1990 and 2004 was 1.1 per 100,000 person-years. The rate for First Nations with status was higher in comparison to the Canadian-born 'other' (First Nations with status rate ratio of 29.69) after controlling for gender.

Tuberculosis has been linked to health determinants including crowded housing<sup>43</sup> and living in remote areas where access to medical professionals is more difficult.<sup>44</sup>

## **Hepatitis**

Jin and Martin (2003) counted all viral hepatitis A cases (children and adults) on First Nations reserves in British Columbia that were reported to the First Nations and Inuit Health Branch between January 1991 and September 1996.<sup>45</sup> The incidence rate was 31 per 100,000 persons per year, which was double the rate for the general population of British Columbia (15.1 per 100,000).

Viral hepatitis has been linked to housing conditions and other determinants of health; higher incidence rates were associated with crowded housing and water quality problems.<sup>45</sup>

#### HIV

No national, provincial or territorial rates identified.

#### **Chronic disease**

Rates of chronic disease for First Nations children are between 28% and 45% (See *Figures 27 and 28*). <sup>10</sup> Such elevated rates suggest that efforts in preventive treatment are falling short. As well, it indicates that frequent medical care and access to specialists is required. Unfortunately, there is very limited data on such health care access

#### Obesity

Childhood obesity has been recognized by policymakers as a significant problem facing Canadian children. Data regarding obesity prevalence rates are limited for First Nations children. The only available data is for First Nations children living on-reserve. In comparison to the Canadian population, rates of obesity are over four times higher (See *Figure 29*).

Obesity has been linked to a number of determinants of health. In particular, obesity in First Nations children has been linked to family income, parental education, and physical activity. For First Nations children, the significant disparities in obesity rates are clear evidence of the impact of determinants of health. This disparity suggests that prevention measures are ineffective. For example, access to preventative healthcare would be able to identify nutritional issues before a weight problem is pronounced.

#### **Diabetes**

The epidemic of diabetes among First Nations adults continues to grow.<sup>46</sup> Elevated rates of diabetes<sup>47,48,49</sup> have also been reported among subpopulations of First Nations youth, although nothing has been

<sup>1</sup>The RHS used the internationally accepted definition for childhood obesity, which is based on calculation of the child's body mass index and the internationally accepted cut-off points to define obesity for that child's particular age group.<sup>1</sup>

reported for children under the age of 12. However, the presence of childhood obesity may be a precursor to diabetes later in life. There is at least one report of a First Nations youth in Manitoba who died from diabetes. Efforts to combat obesity, increase physical activity, and improve access to medical care are key to preventing diabetes.

#### **Physical activity**

According to the Aboriginal Children's Survey 2006, 63% of status or treaty First Nations children (aged six to 14 years) living off-reserve and 69% of non-status or non-treaty First Nations children (aged six to 14 years) living off-reserve played sports one or more times a week. 10 The RHS 2002/3, asked 20 questions about various types of physical activity, including multiple sports; thus, an appropriate comparison was not possible. 1 No comparable rate was identified for the Canadian or non-Aboriginal population.

#### **Asthma**

Rates of asthma for First Nations children were between 12% and 16% (See *Figure 30*), and comparable to the rate for Canadian children. 1,10,27

#### **Allergies**

Rates of allergies were generally similar for First Nations children, as compared to the rate for Canadian children (see *Figure 31*).<sup>1,10,27</sup>

# Cancer

No national, provincial or territorial rates identified.

#### **Heart Condition**

Rates of heart conditions for First Nations children were comparable across First Nations groups (See *Figure 32*).<sup>1,10</sup>

# Child development and disability

# Disabilities

The rate of activity limitations for First Nations children living off-reserve was higher than the rate for Canadian children. The rate for First Nations children living on-reserve was comparable to the rate for Canadian children (See *Figure 33*). <sup>1,10,27</sup>

With respect to specific hearing and visual impairments, rates of hearing impairments were much lower than rates of visual impairments (See *Figures 34a & 34b*). <sup>1,10</sup> It is unclear how many First Nations children have access to proper eye care, which is concerning given the high rates of visual impairments. Furthermore, the impact of visual impairments on children's learning

and development remains unclear. Perhaps this is linked to the higher rates of learning problems.

# Attention deficit hyperactivity disorder (ADHD)

Based on the RHS 2002/3, 2.6% of First Nations children living on reserve had ADHD, which is consistent with the rate for Canadian children. No rates are available for First Nations children living off-reserve.

#### Learning disorders

Based on the RHS 2002/3, 2.9% of First Nations children (aged 11 and under) living on reserve had a learning disorder, which was reportedly consistent with the rate for the Canadian population. According to the APS 2001, it is estimated that 3% of First Nations children living on selected reserves and 9% of First Nations children living off-reserve, suffered from a learning disorder. Note that the statistic for First Nations children on selected reserves is flagged to be interpreted with caution.

# **Language and Cultural Engagement**

Rates of language comprehension and ability to speak an Aboriginal language did show some differences; First Nations children without status or treaty had lower rates when compared to Inuit or Métis children (See *Figure 35*). <sup>10</sup> Language retention is fundamental to identity and results suggest that colonization has had a substantial impact on the transmission of language and culture. Additionally, the relative infrequency of Aboriginal teachers providing instruction suggests that the school system is not an effective environment for fostering language development.

According to the RHS 2002/3, 96% of First Nations children (aged 11 and under) living on-reserve had at least one person helped them understand their culture. A variety of different people helped them; 67% reported help from their parents and 62% reported help from their grandparents.<sup>1</sup>

According to the Aboriginal Children's Survey (2006), 45% of First Nations children (aged five and under) living off-reserve had someone who helped them understand Aboriginal history and culture. Most were helped by their parents (60%) and grandparents (50%). Differences were noted for First Nations children with status (54% had someone who helped them) and First Nations children without status (32% had someone who helped them).<sup>10</sup>

# Injuries

This section deals with injuries, accidents and accidental deaths. It should be noted that some suicides are classified as accidental deaths.





Rates for injuries were higher for First Nations children living on reserve, as compared to rates for the Canadian population (See *Figure 36*). 1,27

Some injuries may have occurred at home and perhaps could be linked to substandard and/or crowded housing. Other injuries may have been the result of a lack of safety equipment (e.g., car seats, helmets), failed prevention efforts, lack of availability of safety equipment and/or financial constraints.

Harrop et al (2007) examined injury mortality rates for First Nations children (aged 19 years and under) in Alberta. Over a 10-year period (1985 to 1994), annual injury mortality rate decreased from 129 per 100,000 to 68 per 100,000, representing a 47% decline. This decline was comparable to the rate decrease for non-First Nations children. However, injury mortality rates were consistently higher for non-First Nations children.

It is unclear how access to quality medical care factors into the increased rates of injury mortality. Remote and isolated areas present challenges for travelling to tertiary care centres.

# Smoking, alcohol, and drug use

There is very little information on alcohol and drug use for children less than 14 years old. According to the RHS 2002/3, the rate for smoking tobacco was 29.5% for First Nations children between 12 and 14 years old living on reserve. The average age of smoking initiation was 12.7 years old and some respondents started as young as four years old. For First Nations children between 12 and 14 years old living on reserve, 22.3% reported having had alcohol in the past 12 months and 14.9% reported having used marijuana in the past 12 months. 1

#### **Mental health**

This section covers socioemotional problems, depression, and suicide. There is no data on access to medical care for mental health concerns specifically, and similarly no data on access to mental health professionals, such as psychiatrists, clinical psychologists, or social workers.

# Socioemotional problems

According to the RHS 2002/3, 15.4% of First Nations children (aged 11 and under) living on reserve were reported to have an emotional or behavioural problem. This rate was considered comparable to the rate for the Canadian population according to the NLSCY, however it should be noted that items from the NLSCY 2000/2001 were worded differently. 27

#### Depression

According to the RHS 2002/3, 28% of First Nations girls aged 11 to 14 years living on reserve, reported feeling sad or depressed. This rate was two-times higher than the rate for First Nations boys aged 11 to 14 years also living on reserve (13.3%).<sup>1</sup>

#### Suicide

Suicide data sets that did not include children under the age of 12 were excluded. According to the RHS 2002/3, among First Nations girls aged 12 to 14 years living on reserve, 6.7% reported suicidal thoughts and 2.6% reported a suicide attempt. In comparison, among First Nations boys aged 12 to 14 years old living on reserve, 1.8% reported suicidal thoughts and none reported a suicide attempt.

In a population based study of First Nations children with status living in Alberta (from 1985-1994), suicide ranked second as the leading cause of injury for children aged 10 to 14 years. The suicide rate for First Nations children was 12.8 per 100,000 per year, considerable higher than the rate for non-Aboriginal children (at 2.4 per 100,000 per year).

Suicide is the result of a variety of pre-existing factors, including hopelessness, depression, and substance misuse. Links have been established between the experience of trauma during residential schooling and mental health, substance abuse problems, and suicide for adult survivors of residential schooling. As well, there is emerging evidence and recognition of the intergenerational effects of residential schooling. It is likely that the effects of residential schooling and subsequent family disruption are evidenced in the mental health of children.

#### **Dental health**

Rates of dental problems varied for First Nations children, with fewer problems noted for non-status or non-treaty children (See *Figure 37*). However, young children without status or treaty also had low rates of accessing dental services, making it possible that dental problems were not diagnosed (See *Figure 38*). Rates of access to dental care were comparable to those of the Canadian population. Rates for access to dental care were lower for older First Nations children living on-reserve, compared to those living off-reserve.

#### **Environmental exposures**

The rate of prenatal environmental tobacco exposure (smoking in the home of a pregnant First Nations mother) reported by participants in the RHS 2002/3, was about one out of every two families living on reserve (48.2%). No national, provincial or territorial rates were identified for environmental exposures such as mold in houses, crowding in homes, and environmental contaminants (e.g., PCBs). Also, recall that the housing condition and water quality of some First Nations children and their families is substandard (see *Additional social determinants* section).

#### Access to health care

Rates for accessing a family doctor, general practitioner or pediatrician were comparable for young First Nations children, although status or treaty First Nations children off-reserve were more likely to have been unable to obtain health care or medication. The reasons for this are unclear. Rates of access to care for the Canadian population were comparable (See *Figure 39*)<sup>10,25</sup> Perceptions of health care facilities were equal for both status or treaty and non-status or non-treaty First Nations children living off-reserve (See *Figure 40*).<sup>10</sup> Rates of access to medical care for older children showed a similar pattern (See *Figure 41*).<sup>10</sup>

The RHS 2002/3 asked different questions regarding access to health care. The focus was on barriers for adults in accessing health services. The following barriers were identified by participants: Doctor or nurse not available (18.5% of adult participants); service not available (14.7% of adult participants); not being able to afford childcare costs (7.1% of adult participants).<sup>1</sup>

Additional data on interactions, proximity to health care facilities, and quality of health care are necessary to understand the health care experience of First Nations children and their families.



# **Inuit Section Highlights**

- Over a three year period from 1999 to 2001, the infant mortality rate for Canada was 4.4 per 1,000 births compared to a rate 13.9 per 1,000 births for Nunavut.
- In Quebec (Nunavik region) from 1985 to 1997, the incidence of SIDS for Inuit was 6.0 per 1,000, which was higher than rates among infants of French language background (0.5/1,000) or Indian (North American Native language base) background (2.6/1,000).
- 33% of Inuit children aged six to 14 years were diagnosed with one or more severe chronic health conditions in 2006
- Between 1998 and 2000 18.2% of births in the Baffin Island region were preterm.
- In 2006, 66% of Inuit women initiated breastfeeding and 54% maintained breastfeeding after six months.
- In 2006, 15% of Inuit children aged six to 14 years old had an ear infection or ear problem.
- According to a 2006 follow up study in Nunavik, 97% of children had one or more episodes of upper respiratory tract infection and 83% had one or more episodes of lower respiratory tract infection before the age of five.
- In 2006, 48% of Inuit children aged five years or less could speak or understand an Aboriginal language compared to 72% of Inuit children aged six to 14 years.
- In 2001, 56% of smokers in Nunavut were children and youth aged 12 to 19 years.
- In 2006, 53% of Inuit children aged five years or less and 35% of Inuit children aged six to 14 years had seen a family doctor, general practitioner or pediatrician in the past 12 months.

#### II. INUIT

Refer to the end of this section (*v. Figures*) for children's health status figures.

#### **Self-rated health**

The measure of 'self-rated' health has yet to be validated in Aboriginal communities, and in general is considered problematic in the field of population health.<sup>28</sup> For example, individuals may rate their health in comparison to others. Thus, their perception of their own health is a relative comparison, and if the absolute level of health of a group is low, the perception will not accurately reflect a true measure of health. Results from the Aboriginal Children's Survey (2006) found that nearly all Inuit children described being in 'good,' 'very good,' or 'excellent' health (See *Figure 21*), which is comparable to the rates for the Canadian population. <sup>10,25,27</sup>

# Infant mortality and perinatal health outcomes

This section covers infant mortality, birth weight, preterm birth, breastfeeding, sudden infant death syndrome (SIDS), and fetal alcohol spectrum disorder (FASD).

# **Infant mortality**

At present, IMR for Inuit are inferred using population based statistics in territories. This is due to the lack of Aboriginal identifiers on death registrations. Authors of a recent study generated abridged life tables using census and vital statistics data for residents of census subdivisions in which 33% or more of the population was Inuit – this included all communities in the four Inuit land claim settlement territories. The infant mortality rate for Inuit inhabited areas decreased from 25.6 deaths per 1,000 births for 1989-1993 to 21.9 deaths per 1,000 births for 1994-1998 to 18.5 deaths per 1,000 live births for 1999-2003. These rates persisted to be four times the general Canadian rate, which also fell during the period of the study.<sup>51</sup>

The rate for infant mortality in 2001 in Nunavut was 15.6 per 1,000 births, which is almost four times greater than the rate for Canada (4.4 per 1,000 births). Over a three year period, from 1999 to 2001, the rate for Canada was 4.4 and the rate for Nunavut was 13.9 per 1,000 births.<sup>52</sup>

#### Birth weight

The rate of low birthweight for Inuit was slightly higher compared to the Canadian population. The rate of high birthweight was slightly lower than that of the Canadian population (see *Figure 22*).<sup>10</sup>

For Nunavut, high birth weight was 8.7% and 9.2% and for Canada it was 5.2% and 5.8%, for males and females, respectively. Over a three year period from 1999 to 2001, the rate for low birth weight was 7.6% for Nunavut and 5.5 for Canada.<sup>52</sup>

#### **Preterm birth**

There is no consistent provincial or territorial tracking of preterm birth rates among Inuit. Muggah et al (2003) collected information on all live births in the Baffin Region between 1998 and 2000.<sup>53</sup> A sample of 835 Inuit births and 45 non-Inuit births was identified. Among Inuit women, 18.2% of births were preterm (before 37 weeks) and 2.4% of births were extremely preterm (before 32 weeks). These rates are much higher than reported rates of preterm births in other regions of Canada for the same time period.<sup>54</sup>

Elevated rates of preterm birth have been linked to increases in multiple births, increased frequency of obstetrical interventions, early complications during pregnancy (e.g., vaginal bleeding, gestational hypertension), inadequate prenatal care and high levels of perceived stress.<sup>33</sup> In a study of risk factors for Inuit preterm birth in Baffin Region,<sup>53</sup> preterm birth was associated with fewer prenatal visits, previous preterm delivery, and previous births.

#### **Breastfeeding**

Rates of breastfeeding initiation for Inuit were lower than the rates for the Canadian population.<sup>1,27</sup> However, rates of sustained breastfeeding (at six months in particular) were higher than the rate for the Canadian population (See Figures 23, 24, and 25). 10,27 Additionally, according to the APS 2001, the average duration for breastfeeding for Inuit children was 15 months.7 The relatively high rates of sustained breastfeeding may reflect a supportive family environment and/or cultural norms. The overall lower rates of breastfeeding initiation for Inuit may be attributable to concern about environmental toxins contained in breastmilk (see discussion in Environmental Exposures). Furthermore, rates of breastfeeding for Inuit might also be lower because adoption is common, which might preclude the possibility of breastfeeding.

# **Sudden Infant Death Syndrome (SIDS)**

In a study of all infants born in Quebec (Nunavik region) from 1985 to 1997, the incidence of SIDS for Inuit was 6.0 per 1,000, which was higher than among infants of French language background (0.5 per 1,000), Indian (North American Native language base; 2.6 per 1,000), English background (0.4 per 1,000), and other language background infants (0.5 per 1,000)<sup>35</sup>. Infants' ethnicity was identified using mother's language. SIDS has been linked to certain risk factors including infant sleep position, poverty and environmental smoke exposure.

#### Fetal alcohol spectrum disorder (FASD)

No national, provincial or territorial rates were identified for Inuit.

# **Nutrition and traditional foods**

According to the APS 2001, 49% of Inuit children (aged six to 14) ate wild meat at least three times a week.<sup>8</sup>

#### Infectious diseases

# Immunization and immunization preventable Illness

No national, provincial or territorial rates were identified for immunization against preventable childhood infections (measles, mumps, rubella, haemophilus influenza, diphtheria, polio, tetanus, pertussus, pneumococcus, and varicella zoster).

According to the Nunavut Comparable Health Indicators Report (2004), there were no reported cases of measles in 2002.<sup>52</sup> There was one new case of invasive meningococcal disease and two cases of invasive Haemophilus influenzae B reported in 2002, which resulted in rates of 7.6 per 100,000 and 57.8 per 100,000 respectively. However, these rates are for the general population, not children specifically.

# Otitis media

Rates for ear infections or problems are elevated for Inuit<sup>10</sup> (See *Figure 26*).

Dallaire et al. (2004) recruited a sample of Inuit infants in Nunavik to participate in a prospective cohort study.<sup>55</sup> All Inuit infants born in Nunavik between November 1995 and March 2001 were eligible to participate. The researchers reported that there were 417 pregnancies in the identified communities during the study period. They reported that 96% of infants had at least one episode of otitis media.

In a follow-up study completed by Dallaire et al. (2006), they reported on the sample group of infants who were now preschoolers. <sup>56</sup> The recruited sample represented 75% of infants born in Nunavik during the study period. Medical charts were reviewed for diagnoses of infection over the first 5 years of the infants' lives. The cumulative incidence, which is the percentage of children with one or more episodes before age five, was 95% for acute otitis media.

Environmental contaminants remain a significant health risk for Inuit living in the north (see below). Researchers have also identified an association between otitis media in infants and exposure to Polychlorinated Biphenyls (PCB). In one study, infants who had experienced one or more acute otitis media infections



had higher prenatal exposures to PCBs (based on cord blood) than healthy infants.<sup>55</sup>

The impact of ear infections on hearing, learning and language ability remains poorly understood among Inuit infants and children.

# Bronchitis and respiratory tract infection

In one study, all Inuit infants born in Nunavik between November 1995 and March 2001 were recruited to participate in a prospective cohort study.<sup>55</sup> The researchers reported that there were 417 pregnancies in the identified communities during the study period. They found that 90% had at least one episode of upper respiratory tract infection and 73.4% had at least one episode of lower respiratory tract infection.

In a follow-up study, they reported on the sample group of infants who were now preschoolers. The recruited sample represented 75% of infants born in Nunavik during the study period. Medical charts were reviewed for diagnoses of infection over the first five years of the infants' lives. The cumulative incidence, which is the percentage of children with one or more episodes before five years of age was 97% for upper respiratory tract infections and 83% for lower respiratory tract infections.

A prospective case study found a hospital admission rate for bronchiolitis of 484 per 1,000 infants of less than six months of age at the Baffin Regional Hospital, which services Iqaluit and ten smaller communities in Nunavut. This is the highest reported rate of hospitalization for respiratory tract infections in the world.<sup>57</sup>

Inadequate housing conditions, including poor ventilation and crowding, directly contribute to the elevated rates of respiratory tract infections.<sup>42</sup>

With the exception of TB (below) national, provincial and territorial hospitalization and mortality rates for childhood respiratory tract infection are noticeably absent.

# **Tuberculosis**

Nguyen et al. (2003) analyzed data on tuberculosis cases in 14 Inuit communities in Nunavik, representing 90% of the total Inuit population in Nunavik. <sup>58</sup> Between 1990 and 2000, the incidence rate decreased to a low of 3.7 per 100,000 in 2000. According to the Public Health Agency of Canada, the rate for 2002 was 93.4 per 100,000 for Nunavut. <sup>59</sup> It should be noted that these rates are not specific for children. The incidence rate for new and relapsed cases in 2000 for the general Canadian population was 5.2 per 100,000. <sup>59</sup>

Tuberculosis has been linked to health determinants including crowded housing and living in remote areas

where access to medical professionals is more difficult, which are significant factors for Inuit.<sup>43</sup>

#### HIV

There are no sources of data for children specifically, and sources for the population in general are not comprehensively reported. For example, statistics reported for Nunavut do not include positive tests for anonymous individuals. According to the Nunavut Comparable Health Indicators Report of 2004, no new cases were reported between 1995 and 2001 and up to five cases were reported in 2002 and 2003 combined.<sup>52</sup> Again, these reports are not specific to Inuit children.

#### **Chronic disease**

Chronic disease affects approximately one in three Inuit children (See *Figures 27 and 28*).<sup>7</sup>

# Obesity

The standard measures used to calculate obesity in Inuit have been called into question. One study found that Inuit have shorter legs, yet relatively higher sitting heights when compared to all other populations. One Thus, their BMI would be disproportionately higher, solely as a result of their shorter legs. Consequently, the incidence of obesity would be overestimated as a result of the invalid BMI measurement. It has been suggested that for Inuit, high BMI may not be indicative of obesity and that calculating BMI using sitting height would provide a more valid estimate of obesity.

At present, national, provincial or territorial rates were not identified for obesity or overweight.

#### Diabetes

No national, provincial or territorial rates identified.

#### **Physical activity**

According to the Aboriginal Children's Survey 2006, 70% of Inuit children (aged six to 14 years) played sports one or more times a week.<sup>10</sup> No comparable rate was identified for the Canadian population.

#### **Asthma**

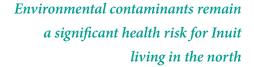
Rates of asthma for Inuit children are lower than the rate for Canadian children (See *Figure 30*). 10,27

#### Allergies

Rates of allergies were slightly lower for Inuit children, as compared to the rate for Canadian children (see *Figure 31*).<sup>10,27</sup>

#### Cancer

No national, provincial or territorial rates identified.



# 3

#### **Heart condition**

The rate of heart conditions for Inuit children was higher than the rates for First Nations and Métis children (See *Figure 32*).<sup>10</sup>

# Child development and disability.

#### Disabilities

Rates for activity limitations for Inuit children were higher than rates for the Canadian population (see *Figure 33*). 10,27

Rates of hearing impairment are higher for Inuit, as compared to other Aboriginal children (See *Figure 34*). <sup>10</sup> As mentioned previously, this might be the consequence of elevated rates of chronic otitis media or ear infections amongst Inuit children. As noted for First Nations children, the impact of visual and hearing impairments on learning for Inuit children remains unclear.

# Attention deficit hyperactivity disorder (ADHD)

No national, provincial or territorial rates identified.

#### Learning disorders

According to the APS 2001, it is estimated that 4% of Inuit children have a learning disability. Note that this statistic is flagged and should be interpreted with caution.<sup>8</sup>

# **Language and Cultural Engagement**

Rates of Aboriginal language comprehension and ability to speak were generally high for Inuit (See *Figure 35*). <sup>10</sup> This is likely linked to high fluency rates among Inuit adults, as well as high rates of student exposure to Aboriginal teachers.

According to the Aboriginal Children's Survey (2006), 65% Inuit children (aged five and under) had someone help them understand Aboriginal culture and history.<sup>10</sup> No rates were reported on who helped them understand.

# **Injuries**

Rates of injury for Inuit were comparable to those of Canadian children (See *Figure 36*).<sup>10</sup>

#### Smoking, alcohol, and drug use

There is very little information on alcohol and drug use for children less than 14 years old. According to the Nunavut Comparable Health Indicators Report (2004), in 2001, 56% of current smokers were children and youth aged 12 to 19 years.<sup>52</sup> This is substantially higher than the rate for the general Canadian population (14.8%).

#### **Mental health**

No national, provincial or territorial rates for socioemotional problems, depression, and suicide were identified for Inuit children. Suicide data sets, that did not include children under the age of 12, were excluded.

#### **Dental health**

Rates of dental problems were elevated for Inuit compared to other Aboriginal children. The rates of dental treatment were somewhat lower (for older Inuit) compared to other Aboriginal children and the Canadian population (See *Figures 37 and 38*). 10,25,27 This suggests deficiencies in the delivery of dental care services.

# **Environmental exposures**

Multiple small studies have been conducted that examine prenatal exposures to environmental contaminants such as lead, environmental contaminants such as organochlorines including DDT, HCB, and PCBs, DDE. These studies have examined cord blood measures among Inuit living in Nunavik and Nunavut. 55,61,62 Elevated levels of mercury were found in the cord blood of infants from Nunavik and Nunavut. Elevated levels of lead were found in Nunavik and Nunavut. Elevated levels of cadmium were found in cord blood in all regions. Infants exposed to the highest levels of PCBs and DDE in Nunavik had the most infections, as compared to infants exposed to the lowest levels of PCBs and DDE. Elevated levels of organochlorines were associated with higher rate of infections during the first six months of infants' lives. Studies in the 1980s and 1990s conducted in villages in northern Quebec found that Inuit



mothers' breast milk had five to six times the amount of PCBs, PCDDs, and PCDFs, when compared to breast milk of mothers living in southern Quebec. <sup>63,64</sup> The authors suggested that the increased levels of PCBs were the result of high consumption of fish and sea mammals among Inuit women.

In a small community-based study in Nunavut, Kovesi et al. (2006) found that exposure to second hand smoke and reduced air exchange, as a result of the small size of the dwellings, were linked to lower respiratory tract infection. <sup>65</sup> They found that 90% of households had smokers present.

Also, recall that housing conditions and water quality for some Inuit children and their families is substandard (see *Additional social determinants* section).

# Access to health care

Rates for accessing a family doctor, general practitioner or pediatrician were considerably lower for Inuit, as compared to other Aboriginal children (See *Figure 39 and 41*). <sup>10</sup> Rates of access to care for the Canadian population were considerably higher. Despite this fact, perceptions of health care facilities among Inuit were consistent with other Aboriginal populations (See *Figure 40*). <sup>10</sup>

The reasons for this are unclear. Additional data on interactions, proximity to health care facilities, and quality of health care are necessary to understand the health care experience of Inuit children and their families.

The discrepancy between access to health care providers and perceptions of health care facilities is interesting. It may be related to the fact that nurses are providing care to Inuit children at local nursing stations, where there are no resident doctors.

# Métis Section Highlights

- Despite accounting for 33% of the Aboriginal population there is currently no information available on infant mortality rates for Métis populations.
- In 2006, rates for breastfeeding initiation and sustained breastfeeding at six months were 74% and 51% respectively for Métis children aged five years or less.
- 42% of Métis children aged six to 14 years had one or more severed chronic health conditions in 2006.
- 28% of Métis children aged five years or less had a long-term health condition diagnosed by a health professional in 2006.
- In 2006, 9% of Métis children aged six to 14 years were diagnosed with an ear infection or ear problem.
- In 2006,13% of Métis children aged five years or less were diagnosed with asthma or used a puffer/inhaler.
- In 2006, 19% of Métis children aged six to 14 years were diagnosed with allergies.
- In 2006, 10% of Métis children aged five years or less could speak or understand an Aboriginal language; the rate was 7% for Métis children aged six to 14 years.
- In 2006, 18% of Métis children aged six to 14 years suffered from one or more activity limitations.
- In 2006, 12% of Métis children aged six to 14 years experienced an injury in the past 12 months.
- 81% of Métis children aged five years or less and 54% of children aged six to 14 years had seen a family doctor, general practitioner or pediatrician in 2006.

#### III. MÉTIS

Refer to the end of this section (*v. Figures*) for children's health status figures.

#### Self-rated health

The measure of 'self-rated' health has yet to be validated in Aboriginal communities, and in general is considered problematic in the field of population health.<sup>28</sup> For example, individuals may rate their health in comparison to others. Thus, their perception of their own health is a relative comparison, and if the absolute level of health of a group is low, the perception will not accurately reflect a true measure of health. Results from the Aboriginal Children's Survey (2006) found that nearly all Métis children are described as having 'good,' 'very good,' or 'excellent' health (See *Figure 21*), which is comparable to the rate for the Canadian population. <sup>10,25,27</sup>

# Infant mortality and perinatal health outcomes

This section covers infant mortality, birth weight, preterm birth, breastfeeding, sudden infant death syndrome (SIDS), and fetal alcohol spectrum disorder (FASD).

# Infant mortality rate

There is currently no information on infant mortality rates for Métis populations in Canada. Métis currently account for 33% of the total Aboriginal population in

Canada and number just under 400,000 persons.<sup>2</sup> The census socio-demographic profile of this population indicates that this is a population that would be at risk for a disproportionate burden of infant mortality and morbidity.<sup>4,6,9</sup>

# Birth weight

The rate of low birth weight was slightly higher for Métis infants compared to the Canadian population, as was the rate of high birthweight (see *Figure 22*).<sup>10,27</sup>

#### **Preterm birth**

No national, provincial or territorial rates identified for Métis.

# Breastfeeding

Rates of breastfeeding initiation for Métis were comparable to the rate for the Canadian population. However, rates of sustained breastfeeding (at six months in particular) were higher than the rate for the Canadian population (See *Figures 23, 24, and 25*). 10,27 As mentioned in both the First Nations and Inuit sections, this suggests that mothers may be receiving ongoing support from within their family which explains higher rates of sustained breastfeeding.

# Sudden infant death syndrome (SIDS)

No national, provincial or territorial rates identified for Métis.



#### Fetal alcohol spectrum disorder (FASD)

No national, provincial or territorial rates identified for Métis.

#### **Nutrition**

According to the APS 2001, 87% of Métis children (aged six to 14) had breakfast five to seven days a week.<sup>7</sup>

#### Infectious diseases

# Immunization and immunization preventable diseases

No national, provincial or territorial rates were identified for immunization against preventable childhood infections (measles, mumps, rubella, haemophilus influenza, diphtheria, polio, tetanus, pertussus, pneumococcus, varicella zoster).

#### Otitis media

Rates for ear infections were comparable to other Aboriginal populations (See *Figure 26*). <sup>10,27</sup> At present, we do not have a comparison for the Canadian or non-Aboriginal population.

# Other infectious diseases

No national, provincial or territorial rates for bronchitis, respiratory tract infection, tuberculosis or HIV were identified for Métis children.

## **Chronic disease**

Rates for chronic disease for Métis children are comparable to those of First Nations and Inuit (See *Figures 27 and 28*).<sup>10</sup>

#### **Physical activity**

According to the Aboriginal Children's Survey 2006, 70% of Métis children (aged six to 14 years) played sports one or more times a week. <sup>10</sup> No comparable rate was identified for the Canadian or non-Aboriginal population.

#### **Asthma**

Rates of asthma for Métis children were comparable to other Aboriginal populations (See *Figure 30*), <sup>10,27</sup> and comparable to the rate for Canadian children.

# Allergies

Rates of allergies were generally comparable for Métis children, as compared to the rate for Canadian children (see *Figure 31*). 10,27

#### **Heart condition**

The rate of heart conditions for Métis children was similar to that of First Nations children and lower than that of Inuit children (See *Figure 32*).<sup>10</sup>

#### Other chronic conditions

No national, provincial or territorial rates were identified for obesity, diabetes, or cancer.

#### Child development and disability

#### Disabilities

Rates of activity limitations for Métis children were higher than the rate for the Canadian children (see *Figure 33*).  $^{10}$ 

Rates for hearing impairments were much lower than rates for visual impairments (See *Figure 32*). As noted in the First Nations section, it is unclear how many Métis children have access to proper eye care, which is concerning given the high rates of visual impairments. Additionally, the impact of visual impairments on children's learning and development remains unclear.

# Attention deficit hyperactivity disorder

No national, provincial or territorial rates identified.

## **Learning disorders**

According to the APS 2001, it is estimated that 8% of Métis children have a learning disability. Note that this statistic is to be interpreted with caution.<sup>7</sup>

# **Language and Cultural Engagement**

Rates of Aboriginal language comprehension and ability to speak were low for Métis children (see *Figure 35*). This may reflect the distinct multilingual (Michif, French, English) language heritage of the Métis.

According to the Aboriginal Children's Survey (2006), 31% of Métis children (aged five and under) had someone who helped them understand Aboriginal culture and history. Most were helped by their parents (56%) and their grandparents (46%).<sup>10</sup>

# **Injuries**

Rates of injuries were similar for Métis as compared to the Canadian population (See *Figure 36*).<sup>10</sup>

# Smoking, alcohol, and drug use

In general, there is very little information on smoking, alcohol, and drug use for children less than 14 years old. No national, provincial or territorial rates were identified.

#### Mental health

No national, provincial or territorial rates of socioemotional problems, depression, and suicide were identified.

#### **Dental health**

Rates of dental problems were lower for young Métis children and comparable for older Métis children, as compared to other Aboriginal populations and the Canadian population (See *Figure 37*). <sup>10</sup> Access to dental care was also comparable to other Aboriginal populations (See *Figure 38*). <sup>10</sup>

# **Environmental exposures**

In a comprehensive review of environmental contaminants, van Oostdam et al. (2005) found that Métis in the north had elevated levels of lead in maternal cord blood.<sup>61</sup>

Also, recall that housing conditions and water quality for some Métis children and their families is substandard (see *Additional social determinants* section).

#### Access to health care

Rates for accessing a family doctor, general practitioner or pediatrician were similar for Métis children, as compared to other Aboriginal children (See *Figures 39 and 41*). Rates of access to care for the Canadian population were comparable. Rates for accessing a traditional Aboriginal healer were low for Métis (See *Figure 41*). Ratings of health care facilities as excellent or very good were comparable to those of other Aboriginal children (See *Figure 40*). As mentioned in the First Nations section, additional data on interactions, proximity to health care facilities, and quality of health care are necessary to understand the heath care experience of Métis children and their famlies.

# IV. INFORMATION GAPS

There are large gaps in the health information available for First Nations, Inuit, and Métis children living in Canada. Most notably, there is very little vital registration (infant mortality and disease specific mortality) and health care utilization data (including hospitalization data) at all levels of aggregation. There is very little data for Métis and non-status First Nations children, as well as Aboriginal children living in urban areas. There is almost no data regarding the prevalence of immunization preventable childhood diseases, immunization rates, obesity, diabetes, cancer, and most mental health indices. Progress continues to be made

in the collection of survey data. For example, the First Nations Regional Longitudinal Health Survey 08–09 is collecting immunization data. However, survey data is a complement to, not a replacement of, vital registration and health care utilization data.

Health care access data is limited to medical and dental health care professionals, little is known about accessing specialists for eye sight and hearing, particularly important given the high rates of vision and hearing impairment. In addition, little information exists on accessing mental health professionals, including clinical psychologists, psychiatrists, and social workers. Furthermore, no information exists on the quality of interactions with health care professionals, and experiences with the healthcare system.

Other challenges include existing data sets that focus on disease and illness outcomes rather than preventative and wellness measures; a paucity of culturally relevant Indigenous specific measures; and the need for validation of many existing measures and scales (such as self-rated health and developmental/psychological indices) in Aboriginal cultural contexts. Again, the First Nations Regional Longitudinal Health Survey is exemplary and unique in it focus on preventative and wellness measure and application of a cultural framework.

Canada's child health measurement gaps are particularly evident when Canada's Aboriginal child health surveillance is compared to the systems in Australia, New Zealand and the United States. All three of these countries have superior systems, particularly with respect to core measures such as mortality and health care utilization. These deficiencies in Canada's Aboriginal child health assessment system represent a missed opportunity to address the health status inequities experienced by Aboriginal children in Canada, compared to the rest of Canadian children. Over the past several years the First Nations Regional Longitudinal Health Survey has been the only comprehensive source of First Nations on-reserve children's health survey data. Recent federal initiatives to improve the availability of Aboriginal children's health information include the initiation of the Aboriginal Children's Survey, which released its first dataset in December 2008.

# **V. FIGURES**

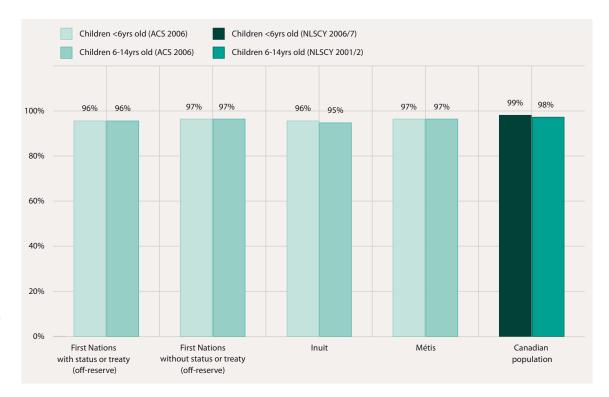
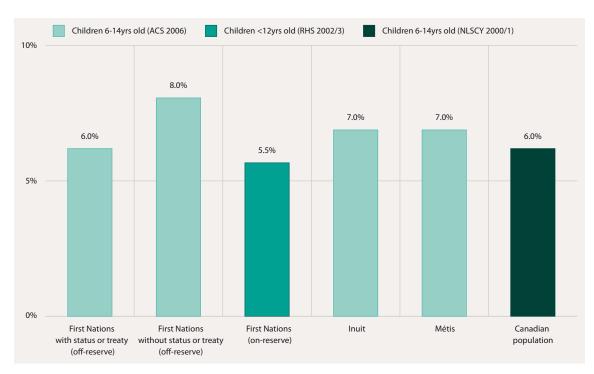


Figure 21 Children's Self-Rated Health (good, very good or excellent)

Source: ACS 2006, NLSCY 2001/2, NLSCY 2006/7

Figure 22a Low Birthweight



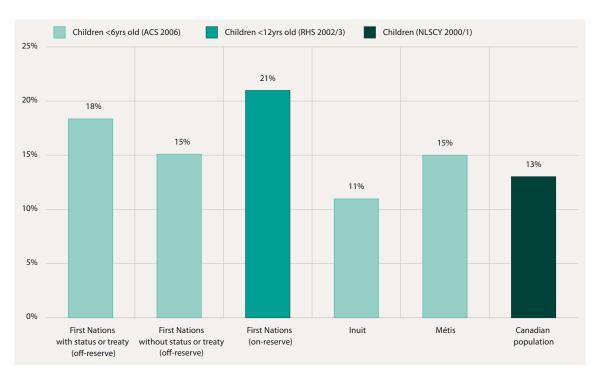


Figure 22b
High Birthweight

Source: ACS 2006, RHS 2002/3, NLSCY 2000/1

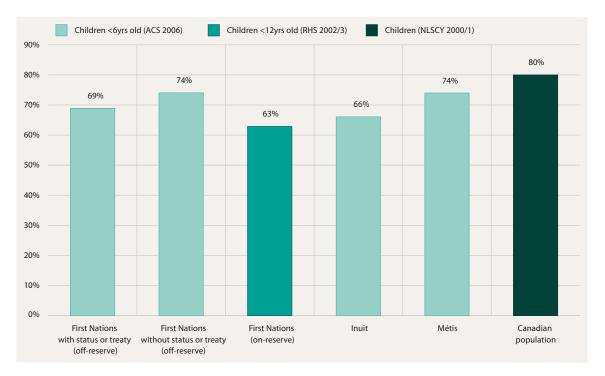


Figure 23
Breastfeeding Initiation

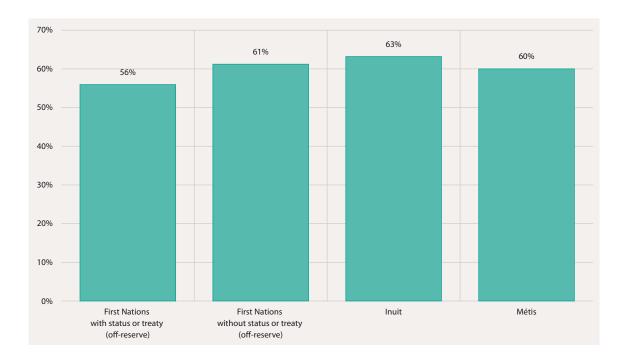
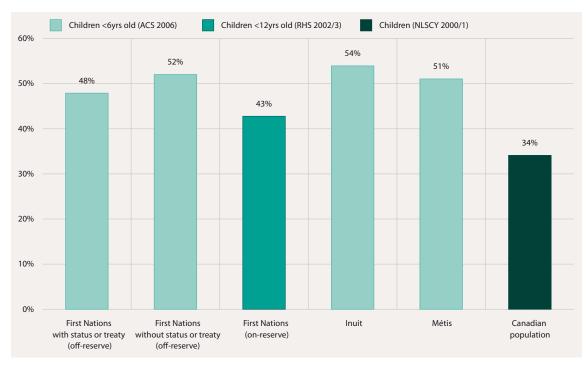


Figure 24
Sustained Breastfeeding (at 4 months)

Source: ACS 2006

Figure 25
Sustained Breastfeeding (at 6 months)





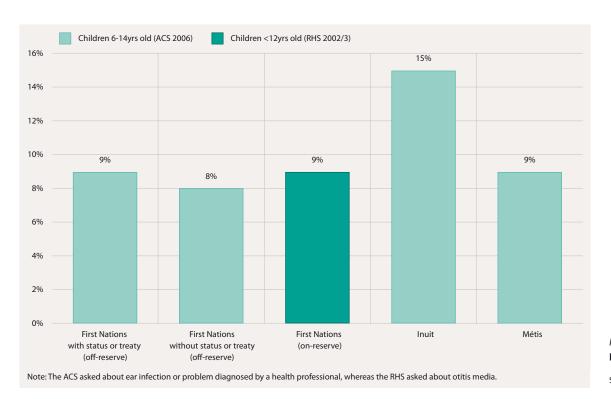


Figure 26
Ear Problems / Infections

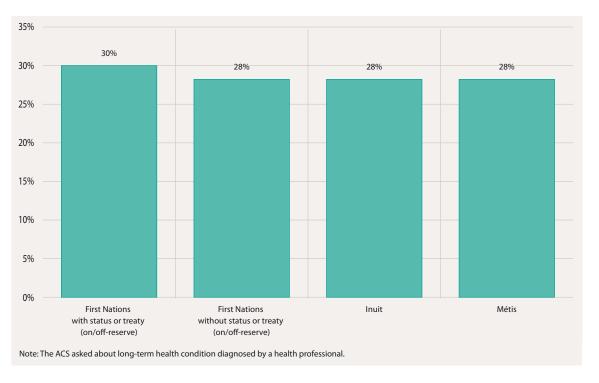


Figure 27 Any Chronic Disease for Young Children (aged 5 & under)

Source: ACS 2006

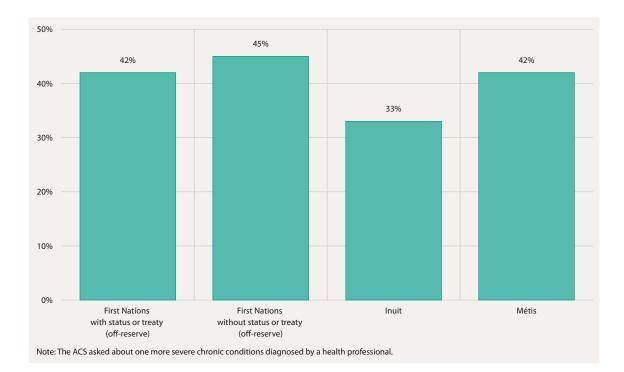


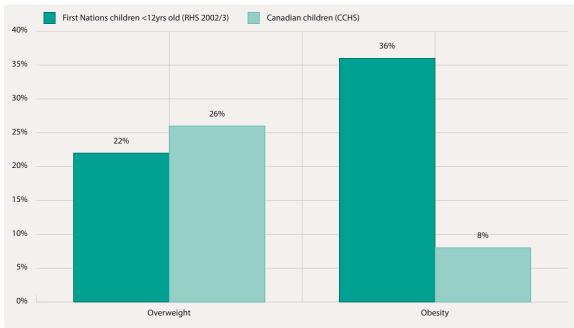
Figure 28

Any Chronic Disease for Children (aged 6 to 14)

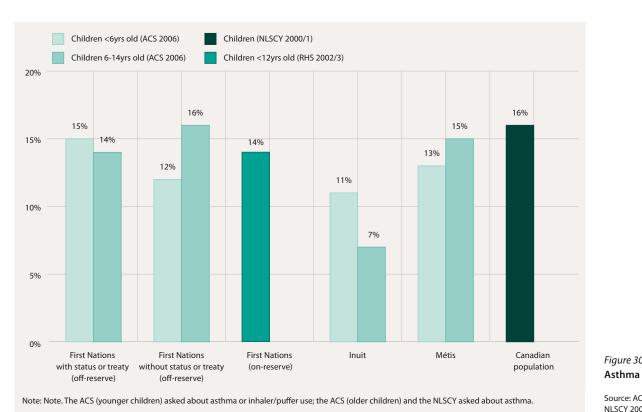
Source: ACS 2006

Figure 29
Overweight & Obesity

Source: RHS 2002/3, CCHS 2004

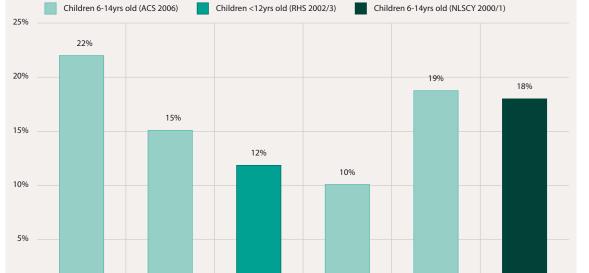


Note: The CCHS excludes on-reserve First Nations populations and Inuit populations living in the territories. The RHS included children aged 11 and under, whereas the CCHS included children age 2 to 17 years.





Source: ACS 2006, RHS 2002/3, NLSCY 2000/1



First Nations

(on-reserve)

Figure 31 Allergies

Source: ACS 2006, RHS 2002/3

with status or treaty

(off-reserve)

First Nations

without status or treaty

(off-reserve)

0%

Canadian

population

Métis

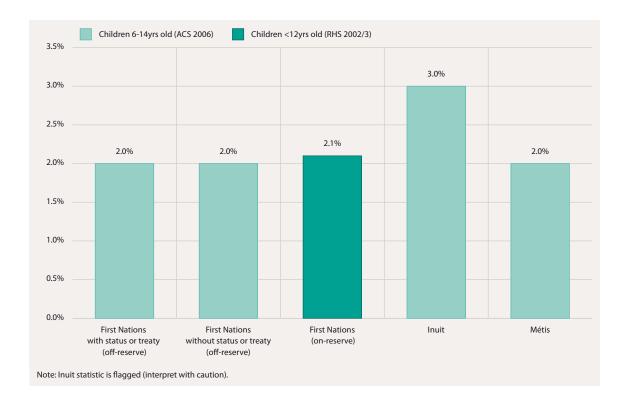
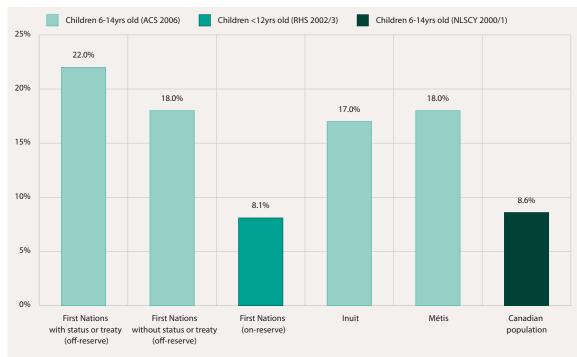


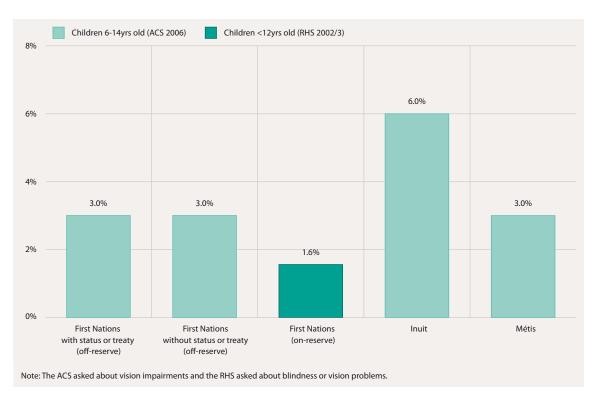
Figure 32 Heart Condition

Figure 33
Activity Limitation

Source: ACS 2006, RHS 2002/3, NLSCY 2000/1



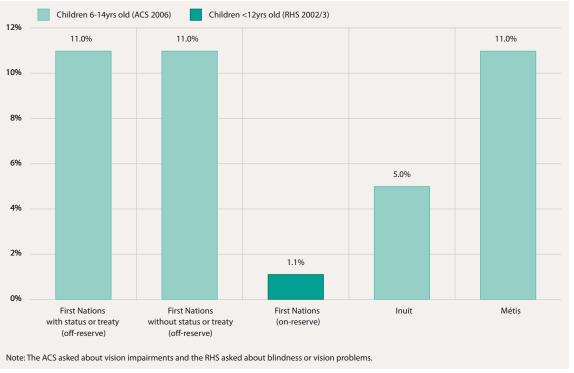
Note: The RHS asked 'presence of a physical, mental condition or health problem which reduces the amount or the kind of activity'. The ACS and the NLSCY asked about in general if physical activity was limited.







Source: ACS 2006, RHS 2002/3



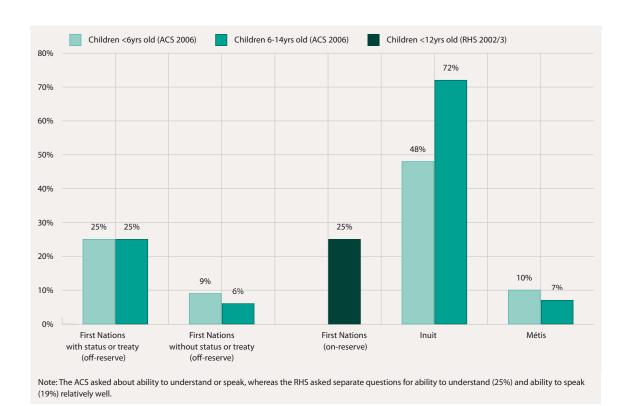
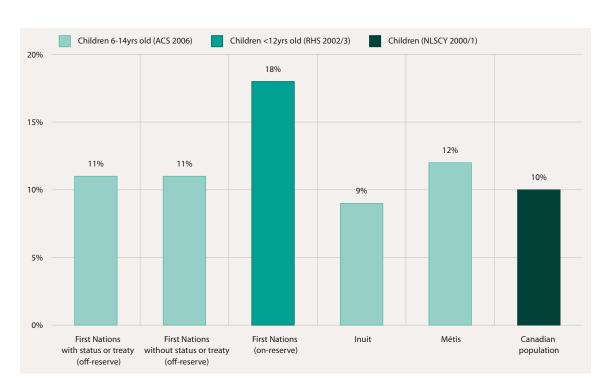


Figure 35
Fluency in
Aboriginal Language

Figure 36 Injuries





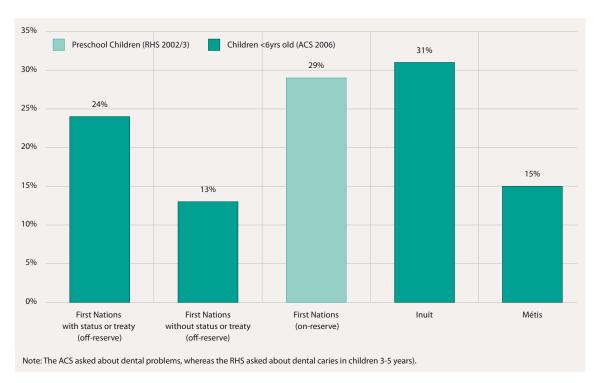


Figure 37

Dental Problems

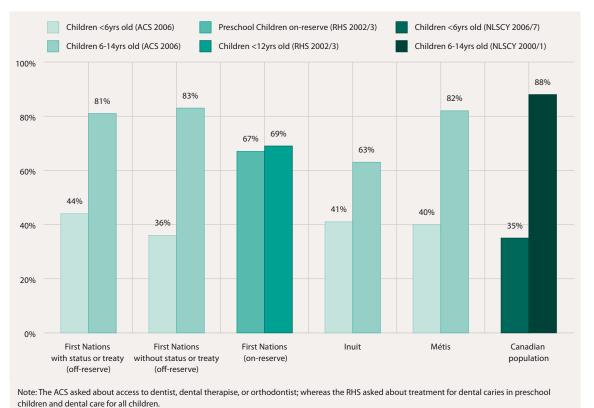


Figure 38
Access to Dental Care

Source: ACS 2006, RHS 2002/3, NLSCY 2000/1, NLSCY 2006/7

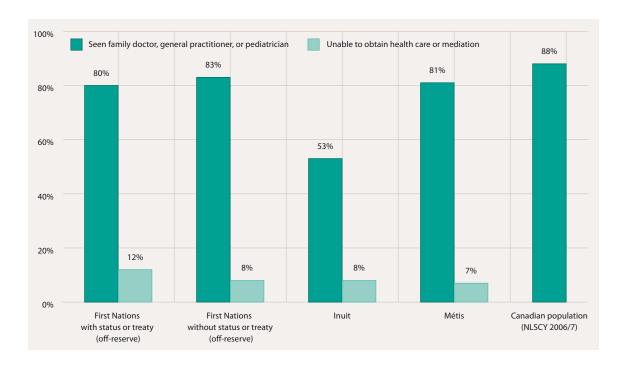
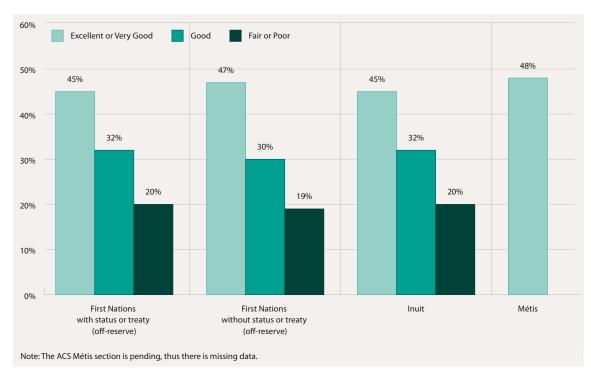


Figure 39 Access to Medical Care for Children Under 6 years old

Source: ACS 2006, NLSCY 2006/7

Figure 40
Perceptions of
Health Care Facilities

Source: ACS 2006





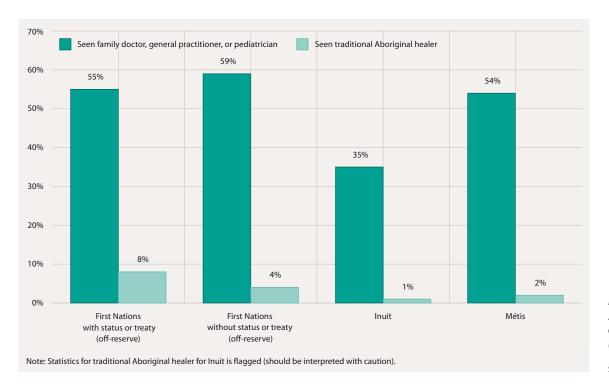


Figure 41
Access to Medical Care for
Children 6 to 14 years old
(ACS 2006)

Source: ACS 2006



# 2.8 BEST PRACTICE AND PROMISING PRACTICE EXAMPLES

# I. The First Nations Regional Longitudinal Health Survey

The First Nations Regional Longitudinal Health Survey is the only First Nations governed national health survey in Canada. <sup>66</sup> It is also the only national survey data for the First Nation on-reserve populations.

The report of the First Nations Regional Longitudinal Health Survey (RHS) 2002/2003 was released in Fall 2005 and contains information from over 30 topic areas, including demographics, language, housing, health status, culture, and community development. It builds on the 1997 First Nations and Inuit Regional Health Survey, which included five Labrador Inuit communities and 181 First Nations communities. The RHS 2002/3 collected 22,602 surveys from 238 First Nations communities across the country. Data collection is currently underway for RHS Phase 2 (2008/2009).

The purpose of the RHS is to obtain longitudinal, comparable data that is centered around First Nations conceptualizations of health, is controlled by First Nations, reflects the priorities of First Nations communities, and respects the principles of OCAP (the

right of Indigenous people to Own, Control, Access and Possess Indigenous health information). The RHS collects information based on both Western and traditional understandings of health and wellbeing. The RHS survey fills a gap left by large national population based surveys which exclude sampling from reserves. Furthermore, in contrast to the RHS, the majority of national population based surveys do not provide respondents an opportunity to self-identify their Aboriginal ethnicity, thereby failing to generate any Indigenous-specific health information.

In addition to its progressive First Nations controlled governance structure, and its broad scope of both Western and traditional health measures, the RHS is an excellent example of health measurement with respect to community engagement and capacity building. See the RHS website for more info: http://www.rhs-ers.ca/english/

# II. Inuit Health Survey

'Qanuippitali?' < How about us? How are we?> represents the first comprehensive examination of the health of Inuit residing in Nunavut, the Inuvialuit settlement region, and Nuntsiavut. This Inuit Health Survey is based on a collaboration of partners from the north and the south, including

academic researchers, communities and health departments. The survey has been developed through a participatory partnership and is co-owned, with the ultimate plan for the survey to be owned in the long-term by Inuit and community representatives. The mission is to improve health care planning, personal health, and community wellness for Inuit. The project is funded by the Government of Canada, Federal Program for International Polar Year, Canadian Institutes of Health Research, Health Canada, Indian and Northern Affairs, the Government of Nunavut and ArcticNet.

The Inuit Health Survey for children ages three to five relies on interviews, questionnaires, and a clinical appointment with health care professionals. Children and their caregivers will be seen in their home communities. The child health survey data collection started in 2007 and concluded in fall 2008 (after 15 months of data collection). Health data will be collected on:

- Nutritional health: levels of vitamin D and iron; exposure to mercury and bacteria (H. pylon which causes iron deficiency); traditional food use and general eating habits (including early infant feeding)
- Healthy growth and bones: heel ultrasound for bone density, height, weight, vitamin and supplements, medication usage
- · Vision testing
- · Medical History

In total, approximately 12% of Inuit from communities in the three regions will be randomly selected to participate. Following data collection, all child participants will receive their personal results in the mail. Communities will receive information on the health of their residents, as well as the areas of focus for health promotion.

# **III. Infant Mortality Working Group**

The Canadian Perinatal Surveillance System, Health Information Analysis Division - First Nations and Inuit Health Branch, Inuit Tapiriit Kanatami, and Métis National Council Joint Working Group on First Nations, Inuit, and Métis Infant Mortality Data (also known as the Joint Working Group on Infant Mortality) was formed in 2005 in response to problems in the accuracy of publically released First Nations infant mortality data, as well as major deficits in the coverage and quality of infant mortality data for Aboriginal populations in Canada. Infant mortality rates are only available for subgroups of the First Nations and Inuit population in Canada. No rates are available for Métis. The infant mortality data that is available is often of substandard quality. For example, problems with the accuracy of several publicly released

infant mortality rates for First Nations populations have been identified by members of our group. These deficits of coverage and quality interfere with the efforts of public health workers to identify and respond to conditions leading to infant death and are unacceptable in a developed country such as Canada. As a working group, the primary goal is to improve the accuracy, reliability, coverage, and appropriateness of First Nations, Inuit, and Métis infant mortality data.

The Joint Working Group approach is premised on the understanding that improvement to First Nations, Inuit, and Métis infant mortality data can only be done through partnerships with First Nations, Inuit and Métis governing and representative organizations. Members include representatives from national Aboriginal governance groups, including the Congress of Aboriginal Peoples, Inuit Tapiriit Kanatami, Métis National Council, and the Native Women's Association of Canada, as well as representatives from the Canadian Perinatal Surveillance System - Public Health Agency of Canada, First Nations and Inuit Health Branch - Health Canada, Statistics Canada, and the Vital Statistics Council of Canada. The Joint Working Group also maintains regular communication with the Assembly of First Nations.

This initiative has a multi-pronged approach to the improvement of First Nations, Inuit, and Métis infant mortality data. This includes: supporting the liaison between provincial and territorial vital registrars and First Nations, Inuit, and Métis stakeholders groups in their region, to develop joint data governance and management agreements, if these do not already exist; support for the First Nations client registry pilots; and discussion of an improved and formulation of a standardized question regarding Aboriginal ethnicity that would accurately identify First Nations, Inuit, and Métis infants and their parents on vital registration forms.

Key achievements to data include: annual presentations to the provincial and territorial vital registrars; a review of First Nations, Inuit, and Métis infant mortality data practices in all provinces and territories; agreement on a draft Aboriginal ethnicity question that could be used by provincial/territorial registrars on the birth registration; funding of two regional pilot projects to support regional planning, consultation, and liaison process and to improve regional First Nations, Inuit and/or Métis infant mortality rates; briefings regarding IMR data to regional and national level First Nations, Inuit, and Métis stakeholders; and the preparation of a national statement on First Nations, Inuit, and Métis Infant Mortality Rates.



# IV. Kahnawake School Diabetes Prevention Project (KSDPP)

Kahnawake is a Mohawk territory near Montreal, Quebec, with a population of 7000. In the 1980s, physicians documented high rates of Type 2 diabetes and the community responded by requesting help to prevent future generations from developing diabetes. The community took action in partnership with academic researchers and developed a prevention program focused on elementary school children, their families, and the community. KSDPP began in 1994 and continues to date. The goal is to decrease the onset of Type 2 diabetes in Kahnawake, through the promotion of health eating, physical activity and a positive attitude.

Most recently, community workers were disheartened to see that obesity rates were elevated in children starting nursery school and kindergarten. Discussions at the Community Advisory Board meetings lead to focus activities geared towards young mothers. This resulted in the refinement of a yearly calendar of eating habits according to the foods on a seasonal level and cooking workshops which focus on young mothers making meals for the family, as well as foods which can be put into a blender to be made into baby food, put in ice cube trays, and frozen for future use. Parents are also provided with information about how the intestines function to break down the foods.

KSDPP has developed a traditional approach to combating diabetes through programs such as 'Healthy Mind in a Healthy Body' workshops which link the relationship between Mind, Body and Spirit and Haudenosaunee Foods Cooking Workshops geared to teach young mothers how to cook economical healthy meals using native cultural and seasonal foods to enhance cultural pride.

#### V. First Nations Health Plan, British Columbia

In 2007, a Tripartite First Nations Health Plan was signed by the First Nations Leadership Council (representing the BC Assembly of First Nations), the First Nations Summit and the Union of BC Indian Chiefs; and the Government of Canada; and the Government of British Columbia. The goals of the First Nations Health Plan is to improve the health and well-being of First Nations in British Columbia, close the gaps in health between First Nations people and other British Columbians, and ensure First Nations are fully involved in decision-making regarding the health of their peoples. In this 10-year trilateral agreement, all three parties have committed to action in four priority areas:

- · Governance, relationships and accountability
- · Health promotion and disease and injury prevention
- · Health services
- Performance tracking

A new First Nations Health Council was established to provide leadership in the implementation of the First Nations Health Plan.

In the area of performance tracking the parties agreed to work together to develop the data and information necessary to improve health services, and to monitor and report on health status and health care information for First Nations in B.C. Specifically, the parties committed to tracking progress for the following indicators: life expectancy at birth; mortality rates (deaths due to all causes); infant mortality rates; diabetes rates; status Indian youth suicide rates; childhood obesity; and practising, certified First Nation health care professionals. A Tripartitie Data Quality and Sharing Agreement between the Government of British Columbia, Health Canada's First Nations and Inuit Health Branch and the First Nations Health Council is being developed and will facilitate data linkages and define how federally and provincially held information on First Nations is to be used and shared. Through this agreement, OCAP principals will govern the collection, analysis and sharing of BC First Nations health information.

#### VI. First Nations EpiCentre of Alberta

The name 'EpiCentre' comes from the Epidemiology Centers established by the US Indian Health Services in 1996. These US Tribal Epicentres are described in the US chapter of this report. The recently established First Nations EpiCentre of Alberta is the first such organization in Canada. The EpiCentre brings together specialists in public health, epidemiology and other disciplines to develop the intelligence needed to improve public health programs for First Nations in Alberta and beyond. The EpiCentre was established in partnership with First Nations communities and federal/provincial governments in Alberta. The mission of the First Nations EpiCentre of Alberta is to improve the quality and use of information required to take action on health, health programs and health determinants while respecting the Treaty rights to health and the cultural diversity of First Nations.

Core business of the EpiCentre includes:

- improving the quality of information available to communities
- developing the capacity of communities to collect, manage, and use health data
- fostering strategic health information partnerships and policies to support public health programs

First Nations, Inuit and Métis children face striking disparities in the social determinants of health, including family income, parental employment, parental education, food security, and housing, compared to non-Aboriginal children.



The EpiCentre has programs in environmental health, diabetes, prescription drugs, community health, planning, and homecare. Staff includes four epidemiologists, a medical geographer, a health economist, a pharmacist, a statistician, and a data analyst. More information can be found on the Epicentre's website: http://www.fnepicentre.org/

#### 2.9 CONCLUSION

The human right to health is internationally recognized. For example, Article 12.1 of the United Nations' International Covenant on Economic, Social and Cultural Rights identifies the 'the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.'67 The next article of the covenant highlights the importance of child and reproductive health, with a provision 'for the reduction of the stillbirth rate and of infant mortality and for the healthy development of the child' (art. 12.2 -a).<sup>67</sup> Despite international agreement that substandard health is unacceptable, First Nations, Inuit, and Métis children in Canada continue to experience inequities in health status and health determinants compared to non-Aboriginal Canadians. The persistence of these inequities and substandard health outcomes is particularly bothersome in Canada, one of the world's richest nations.

First Nations, Inuit and Métis children face striking disparities in the social determinants of health, including family income, parental employment, parental education, food security, and housing, compared to non-Aboriginal children. For example, the Canadian Community Health Survey revealed rates of severe food insecurity that were over five times higher for Aboriginal households compared to non-Aboriginal households and the Aboriginal Peoples Survey 2006

revealed that 30% of Inuit children experience hunger as a result of their family having run out of food or money to buy food. The First Nations Regional Longitudinal Health Survey reveals that only 68% of First Nations participants living on-reserve considered their water safe to drink.

Underlying these classic health determinants is the experience of colonization, which disrupted family networks, dislocated communities from traditional lands, and interfered with the intergenerational transmission of knowledge and culture. Colonial processes continue to have direct and indirect impacts on the health of First Nations, Inuit, and Métis children and their families. The reversal of colonial policies and the restitution of the rights of Indigenous peoples, including the implementation of the standards in the UN declaration on the Rights of Indigenous Peoples, is a necessary prerequisite to fundamental improvements in the health determinants and health status of Aboriginal children.

Despite the knowledge that Aboriginal children in Canada are at risk of adverse health outcomes, given these disparities in social determinants of health, there are large gaps in available health information. When it comes to health surveillance in Canada, many First Nations, Inuit, and Métis children remain invisible or uncounted. For example, currently there is no information regarding the infant mortality of Métis in Canada, despite the fact that Métis account for approximately one third of Canada's Aboriginal population. There is are similar gaps in information for First Nations children without status and Aboriginal children living in urban areas. One of the major health information challenges is the lack of standardized First Nations, Inuit, and Métis identifiers in vital registration, surveillance, and health care utilization databases. Another major challenge is the lack of

The long term goal with respect to
Aboriginal children's health assessment
and health performance measurement
information is clearly better evidence
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integration of First Nations, Inuit, and Métis health information with health care programs and services. In the end, this review was able to identify quite a bit of health determinant and health status data for Aboriginal children living in Canada, however, very little of this data was already linked to the ongoing evaluation the health services and programs that are serving Aboriginal children.

This is not the first time that an Indigenous group has faced a challenge in exercising the 'right to be counted'. It wasn't until 1967 that Aboriginal Australians were recognized as having the right to be counted in the national census and 40% of infants born worldwide still do not have reliable access to birth registration. 68,69 Being recognized in a census and/or through birth registration are essential steps in ensuring that other human rights, including the right to health are achieved. Public health programs designed to safeguard the health of children are founded on health information systems that count or survey health determinants and outcomes drawing on the census, birth and death registrations, health care utilization records, disease reporting, and health surveys. As stated earlier, these shortfalls in Aboriginal child health assessment and health system performance measurement represent a missed opportunity to address the health status inequities experienced by Aboriginal children in Canada, compared to the rest of Canadian children.

The best practice examples at the end of this chapter demonstrate the way forward with respect to the enhancement of Aboriginal children's health information systems in Canada. Notably, all six examples are founded on partnerships between Aboriginal stakeholders and health workers with a background in public health assessment. These models allow for a balance between the desires of First Nations, Inuit, and Métis health stakeholders to play a role in the governance and management of their health information and the pressing need to better health

information to address and prevent unnecessary child illness and death.

At a policy level, the long term goal with respect to Aboriginal children's health assessment and health performance measurement information is clearly better evidence for decision making, resulting in better health outcomes and a reduction in health disparities. The current gaps in health information, while undesirable, do not provide an excuse for inaction. This chapter has clearly detailed pressing inequities in health determinants and health status outcomes for First Nations, Inuit, and Métis children compared to non-Aboriginal children in Canada. These disparities are not new and are not just. Over a decade ago, the Royal Commission on Aboriginal Peoples (RCAP) examined the health of Aboriginal people, including infant, child and maternal health. While some gains were identified, clear disadvantages persisted. In addition, the roots of the disproportionate burden of ill health were linked 'outside the boundaries of ordinary medicine' to 'social, emotional and economic conditions that in turn lead back to the complex, destabilizing and demoralizing legacy of colonialism'. Recommendations of the RCAP were aimed at addressing these underlying causes of health status disparities and included: a significant restructuring of relationships between the federal government and Aboriginal nations; a substantial federal investment in Aboriginal institutions and communities; and a redistribution of lands. Unfortunately, to date very few of these (and other RCAP) recommendations have been implemented. There appears to be an ongoing disconnect between the undeniable evidence regarding the unacceptable disparities in Aboriginal children's health in Canada and the implementation of federal policies that would rectify these disparities. It is our hope that the information in this chapter can be used as an advocacy tool and resource for those working to bridge this disconnect.

#### 2.10 ADDITIONAL TABLES

#### Census data

Data produced when participants identify themselves as First Nations (registered and nonregistered), Métis or Inuit

- Nonparticipation is common
- On many reserves, enumeration is incomplete
- Mobility and overrepresentation of homeless people contributes to undercounting of Aboriginal groups
- The ethnicity question appears on only about 20% of forms
- Aboriginal people may choose not to self-identify to government employees
- Ethnic mobility contributes to inaccuracy of data

# Vital registration data

INAC's Indian Register: First Nations-specific rates generated from cross-linkage of data from four provinces

• Lack of prospectively collected data on ethnicity by voluntary self-identification excludes generation of rates for nonregistered First Nations, Métis and Inuit people

Questions about Aboriginal ethnicity on the registration forms of some provinces and territories

- Privacy concerns about transfer of the INAC registry
- · Lack of standardization of ethnicity questions on forms

# Data from health surveys

National health surveys (none to very limited)

• Most national surveys done by Statistics Canada exclude sampling from reserves, don't ask about Aboriginal ethnicity, or use a sample too small to generate anything other than national pan-Aboriginal data

Aboriginal Peoples Survey: nonregistered First Nations, Métis and Inuit people

- Sampling frames are derived from the census data from self-identified Aboriginal people, so coverage issues are the same as for the census
- Done only every 10 years

First Nations Regional Longitudinal Health Survey: First Nations

people living on-reserve

- · Comprehensive coverage of First Nations reserve communities in most regions of the country
- In some regions not all First Nations reserve communities participate
- Questions reflect health issues and measures that are important to participant First Nations communities
- Content is not entirely comparable to other national surveys

#### Health services utilization data

Compiled by Canadian Institute of Health Information (CIHI)\*

- Compiled by geographic region: no ethnic-specific data
- In some regions where the proportion of Aboriginal people is very high (e.g., Northern Saskatchewan and Nunavut), geography can serve as proxy measure

# Data from surveillance systems

- Registered First Nations people only, by data linkage in National Diabetes Surveillance System and some surveillance systems for notifiable diseases
- · Lack of standardized, inclusive means to permit self identification of Aboriginal ethnicity

Note: INAC = Indian and Northern Affairs Canada.

\*Reports have been published in which provincial health systems linked their databases with the Indian Register or Band Membership lists to generate health-service utilization data specific to Aboriginal people.

Text Box 1
Concern with statistical sources for First Nation, Inuit and Métis health

adapted from Smylie & Anderson, 2006



Source First Nations Longitudinal Regional Health Survey 2002/3 (RHS) Canadian Census 2006	Major Statistical Sources for First Nations, Inuit & Métis Children's Health Source Population  Ins Longitudinal Regional reserve in Canada  Census 2006 Children aged 0 to 14 years  Senting Source Population  Children aged 0 to 14 years  Senting Source Population  Children aged 0 to 14 years  Senting Source Population  Senting Source Population  Only 1 years Population  Senting Source Population  Source Population  Source Population  Senting Source Population  Sourc	Comments  Not all First Nations reserves participated  See Table 3 for concerns
Aboriginal Children's Survey, 2006	Children aged 0 to 14 years Includes Inuit, Métis, and off-reserve First Nations living in urban, rural and northern locations in Canada	Includes only those respondents who completed 2006 census and indicated some form of First Nations, Inuit or Métis identity
Aboriginal Peoples Survey, 2006	Includes Inuit, Métis and off-reserve First Nations living in urban, rural and northern locations in Canada	Includes only those respondents who completed 2006 census and indicated some form of First Nations, Inuit or Métis identity
Maternal Experiences Survey	Census based sampling frame, 6000 + total respondents 411 self-identified First Nations, Inuit, and Métis mothers Reserves excluded	First Canadian survey devoted to pregnancy, labour, birth and postpartum Aboriginal report pending
First Nations Comparable Health Indicators	First Nations with status Some figures are for First Nations on-reserve only	Uses a variety of data sources Technical issues with vital registration rates, as coverage (on/off-reserve) and source of data (death certificate vs. nursing station report) is not consistent across provinces and territories
Inuit Health Survey	Inuit children age 3-5 years living in Nunavut, the Inuvialuit Settlement Region and Nunatsiavut.  Data collection 2007-2008.	No results at time of publication.
Provincial/ territorial ministries of health	Four western provinces produce vital registration and some health care utilization data for First Nations persons with status and/or living on reserve, using birth registration identifier, linkage to INAC registration lists, and/or on-reserve postal codes  Quebec has a 'mother tongue' birth registration identifier  Nunavut vital registration, utilization, and surveillance data includes very small proportion of non-lnuit	Inconsistencies in ethnic identifiers and rate calculation methods result in data of variable quality for western provinces. Métis and Inuit specific rates are not available. Comprehensiveness of data release varies.  Mother tongue identifier in Quebec sensitive and specific for Inuit but much less sensitive for other Aboriginal groups.  Capacity issues in Nunavut prohibit regular and comprehensive health data release.



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## Health of Aboriginal and Torres Strait Islander Children in Australia

"Ampe Akelyernemane Meke Mekarle — Little Children are Sacred — In our Law children are very sacred because they carry the two spring wells of water from our country within them" (traditional Aboriginal law of the Yolngu people of Arnhem Land in the Northern Territory).<sup>1</sup>



'Compared with their non-Aboriginal and Torres Strait Islander Australian counterparts, Aboriginal and Torres Strait Islander children are:

- more likely to be stillborn, to be born pre-term, to have low birth weight, or to die in the first month of life;
- 2 to 3 times more likely to die in the first twelve months of life, and 11 times more likely to die from respiratory causes;
- at a much higher risk of suffering from infectious and parasitic diseases, diseases of the respiratory and circulatory system, hearing loss, rheumatic fever, dental caries, injuries, and clinically significant emotional and behavioural difficulties;
- nearly 30 times more likely to suffer from nutritional anaemia and malnutrition up to 4 years of age;
- cared for by significantly fewer adults, who are also at higher risk of premature death, serious illness, substance abuse, imprisonment, major social and emotional stress, lower household income, lower educational attainment, lower employment, and lower access to appropriate sanitary and household conditions, than other Australian adults.' Australian Medical Association Report Card, 2008

Source: Australian Medical Association<sup>6</sup>

## 3.1 INTRODUCTION

The United Nations International Children's Emergency Fund (UNICEF), better known as the United Nations Children's Fund, suggests that:

the true measure of a nation's standing is how well it attends to its children – their health and safety, their material security, their education and socialization, and their sense of being loved, valued, and included in the families and societies into which they are born. <sup>7</sup>

Indeed, Aboriginal and Torres Strait Islanders view health from a holistic perspective. They believe that:

Aboriginal health is not just the physical wellbeing of an individual but is the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential thereby bringing the total well being of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life. National Aboriginal Health Strategy Working Party<sup>8</sup> available: http://www.health.gov.au/oatsih/pubs/

An analysis of national health information gives a powerful insight into the ongoing legacy of colonization on the Indigenous people of Australia, New Zealand, Canada and the United States of America. While these first-world nations boast first class health systems, the key health indicators clearly show that the traditional custodians of the land do not share equally in the benefits of these systems. There is a pressing social justice issue in the wide disparity in outcomes that results in Indigenous people suffering a far greater health burden than non-Indigenous people. Of great concern is that despite widespread acknowledgment of the gap and actions to address it, progress in its reduction appears to be minimal for many indicators.

Indigenous populations in Australia, New Zealand, Canada and the United States of America share many commonalities of cultures that extend for thousands of years: deeply held spiritual beliefs and practices; prolonged experiences of exploitation, prejudice and discrimination; attempts at forced segregation followed by forced assimilation; large-scale neglect of human rights; inequalities in health status; and an increasing, if at times ignored, effort to achieve international recognition and protection for their peoples and cultures.

It is a human right to be counted in population statistics and Indigenous people should not be invisible in national health statistics. Currently, the measurement of the health of Indigenous people

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Pictured: Hiarnz & Darheio

world-wide is complicated by deficiencies in the data describing Indigenous people. These deficiencies are in part due to inconsistencies in the collection, the sources, completeness, classifications, analysis interpretation and ownership of the data in each jurisdiction. This chapter, while providing an insight into the state of the health of Aboriginal and Torres Strait Islander children, and at times linking their health outcomes to the health outcomes of Indigenous children in other countries, does not attempt to directly compare outcomes between the contributing countries<sup>5</sup>.

# 3.2 THE COLONIZATION OF AUSTRALIAN AND TORRES STRAIT ISLANDER PEOPLE

The colonization of Australia by Great Britain began in 1788 with the arrival of the First Fleet.

The original 'protectorate' system of the 19th and early 20th Century resulted in wide-spread displacement of Aboriginal and Torres Strait Islander people. 'Protectionism' was replaced by a policy of 'assimilation' after a 1937 national conference, at which the assimilation policy was adopted. From this date all States began adopting policies designed to 'assimilate' Indigenous people of mixed descent. Assimilation was 'a highly intensive process necessitating constant surveillance of people's lives'. New legislation was introduced almost everywhere by 1940. The policy of assimilation was replaced by a policy of 'self-determination' in the 1970s.

The 1967 Referendum afforded the Commonwealth Government legislative authority for Aboriginal and Torres Strait Islander people (formally the power rested with the States).5 Prior to the referendum, Aboriginal and Torres Strait Islander Australians were included in Census data under the section 'flora and fauna'. Following the referendum, people were able to self identify as an Aboriginal and or Torres Strait Islander. Since the inclusion of Aboriginal and Torres Strait Islander Australians in the Census, Australia has sought only information about 'general ancestry' as defined by the Census question. The Census definition of an Aboriginal and Torres Strait Islander is "a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives". 15 The 1986 Census did include a question to identify Aboriginal and Torres Strait Islander origin and a question to determine the ancestry or forebears of all people including Indigenous people. However, these questions were cross-edited 9 and thus no distinction can be drawn between the historical ancestry and the current identity of the population. In Australia, since 1981, all Censuses have used the same question to identify Aboriginal and Torres Strait Islander people.9-10

Following the Referendum, the Office of Aboriginal Affairs was set up to establish Aboriginal health units.11 The Aboriginal and Torres Strait Islander Commission was established in 1990 and disbanded in 2005. A number of regional Indigenous Coordination Centres were then convened to advise the Federal Government on funding priorities and process. However, with the change in the Federal Government in 2007, these Centres are being reviewed and the current Aboriginal and Torres Strait Islander Social Justice Commissioner Tom Calma has been appointed to oversee the establishment of a new body that will advise the Federal Government on Indigenous affairs. Historically and currently, there are no Treaties between the Australian Government and the Aboriginal and Torres Strait Islander people.

By the late 1800s there were systematic removal practices being implemented through a range of assimilation and 'protection policies'. A seminal report, the *Bringing Them Home* report, acknowledged that 'Indigenous children had indeed been forcibly separated from their families and communities since the very first days of the European occupation of Australia' by governments and missionaries. These children who were removed came to be known as the Stolen Generations. The public and political debate about the removal of

children was marked by intense political activity from the mid-to-late 1980s. <sup>12</sup> In 1992 Prime Minister Keating acknowledged that 'we took the children from their mothers', at a speech in Redfern. In 1994, legal action was commenced in the Supreme Court of New South Wales by members of the Stolen Generation. <sup>13</sup>

On the 13th of February 2008, more than ten years after the *Bringing Them Home* report was accepted, the Prime Minister, Kevin Rudd, tabled a motion in parliament apologizing to Australia's Indigenous peoples, particularly the Stolen Generations and their families and communities, for laws and policies which had 'inflicted profound grief, suffering and loss on these our fellow Australians'. This motion was passed with acclamation.

The apology included a proposal for a policy commission to be convened and to be responsible for advising the government on how to 'close the gap' between Indigenous and non-Indigenous Australians in 'life expectancy, educational achievement and economic opportunity.'14

## 3.3 DEMOGRAPHICS OF ABORIGINAL AND TORRES STRAIT ISLANDER AUSTRALIANS

Aboriginal and Torres Strait Islander people have a wide range of lifestyles and social, cultural, educational and family backgrounds. What is true of one Indigenous person or group is not necessarily true of another's values and life style. <sup>16</sup> Currently, there are at least 250 documented Aboriginal and Torres Strait Islander language groups.

In June 2006, the estimated Aboriginal and Torres Strait Islander population was 517, 200 or 2.5% of the total Australian population.<sup>17</sup> The Indigenous population is estimated to have increased by 58,700 (13%) between 2001 and 2006. People identifying as Aboriginal made up 90% of the Aboriginal and Torres Strait Islander population, 6% identified as Torres Strait Islander and 4% as Aboriginal and Torres Strait Islanders.<sup>18</sup>

Torres Strait Islanders are the Indigenous people of the Torres Strait Islands, part of the State of Queensland, and are culturally akin to the coastal peoples of Papua New Guinea. They are regarded as being distinct from other Aboriginal peoples in Australia, and are generally referred to separately. The Indigenous people of the Torres Strait have a distinct culture, with slight variants between the different islands. They are a seafaring people and engaged in trade with people of Papua New Guinea. In 2006, there were 6,958 Torres Strait Islander people living in the Torres Strait Indigenous Region (15% of the

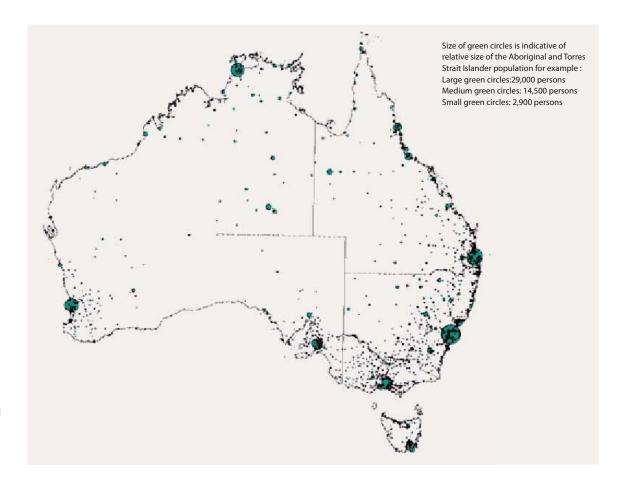


Figure 1
Distribution and relative size of Australian Indigenous population in Indigenous locations, rural towns and urban centres.

Source: Department of the Environment and Heritage<sup>22</sup>

The continuing disparities in health outcomes among Indigenous people in Australia, New Zealand, Canada and the United States of America is in great part the legacy of the colonization of their lands

total count of Torres Strait Islander people), and around 42,000 others living outside this area, mostly in the north of Queensland, particularly in Townsville and Cairns.<sup>20</sup>

### **Geographical distribution**

In 2006, the largest population of Aboriginal and Torres Strait Islander people in Australia lived in major cities (31%). The remaining population was evenly distributed across areas categorised by the Australian Bureau of Statistics as Inner Regional (22%), Outer Regional (23%) and Remote/Very Remote Australia (24%) (See *Figure 1*).

States with relatively high proportions of Aboriginal and Torres Strait Islander people living in major cities included South Australia (48%), Victoria (48%) and New South Wales (42%). In contrast, 81% of the Aboriginal and Torres Strait Islander population in the Northern Territory lived in Remote/Very Remote areas. Similarly, in Western Australia 41% of the Aboriginal and Torres Strait Islander population lived in Remote/Very Remote areas.<sup>23</sup>

## Age structure

The Aboriginal and Torres Strait Islander population at 30 June 2006 had a younger age structure than the

non-Aboriginal and Torres Strait Islander population, with large proportions of young people and small proportions of older people (See *Figure 2*). The median age of the Aboriginal and Torres Strait Islander population at 30 June 2006 was 21.0 years, compared to 37.0 years for the non-Aboriginal and Torres Strait Islander population.

Based on estimates for 2003, there were 179,128 Aboriginal and Torres Strait Islander children living in Australia. All Australian children aged from zero to fourteen years accounted for 20% of the total population. Aboriginal and Torres Strait Islander children aged from zero to fourteen years accounted for 39% of the total Aboriginal and Torres Strait Islander Australian population. Australia is a vast country and the numbers of Aboriginal and Torres Strait Islander children living in the various states and territories of Australia vary significantly. In the Northern Territory, 40% of the child population aged less than fourteen years is Aboriginal and Torres Strait Islander which compares with Victoria, where this percentage is 1%. Further, 30% of Australia's Aboriginal and Torres Strait Islander children aged less than fourteen years live in New South Wales, 28% live in Queensland, 14% in Western Australia, 11% in the Northern Territory, 6% in Victoria and South

Australia, 4% in Tasmania and 0.8% in the Australian Capital Territory.  $^{17}$ 

### **Indigenous families**

The 2006 national Census reported that Aboriginal and Torres Strait Islander families are more likely to be larger, with an average of 3.4 people compared with other Australian households (2.6 people). Aboriginal and Torres Strait Islander families are three times more likely than other single family households to be one-parent families with dependent children or students (30% compared with 10%) but are less likely to be families without dependents. (33% compared with 54%). 17 The characteristics of Aboriginal and Torres Strait Islander families differ from the majority of other Australian families. They tend to be larger, non-nuclear and more fluid in composition. Aboriginal and Torres Strait Islander families have overlapping and extensive kinship, with both adults and children moving between different households.24 These extensive and fluid family structures are more common in remote communities, but are also found in more settled areas of Australia.25

## 3.4 DETERMINANTS OF ABORIGINAL AND TORRES STRAIT ISLANDER CHILD HEALTH

## **Employment**

Being employed leads to improved income for families and communities, which in turn has a positive influence on the health and education of children. It also enhances self-esteem, increases opportunities for self-development, influences interaction at the family and community level, and decreases social alienation. <sup>26</sup> In 2004–2005, after adjusting for the age difference, the unemployment rate for Aboriginal and Torres Strait

Islander people (12.9%) was about three times higher than for non-Aboriginal and Torres Strait Islander people (4.4%) 26. Aboriginal and Torres Strait Islander children were also less likely to have a parent in paid employment and, in 2006, 42% of Aboriginal and Torres Strait Islander children lived in families where there was no parent working, which was three times higher than non-Aboriginal and Torres Strait Islander children.<sup>17</sup>

#### Income

The incomes of Aboriginal and Torres Strait Islander people are generally below those of non-Aboriginal and Torres Strait Islander people, and there tends to be a relatively higher proportion of Aboriginal and Torres Strait Islander people with lower incomes and a lower proportion with higher incomes.<sup>26</sup> People who have lower incomes or are socially disadvantaged in other ways tend to live shorter lives and suffer more illnesses than those who are well off. It is widely acknowledged that health status is affected by the availability of material resources and the income to buy them. Higher incomes can enable the purchase of health-related goods and services, such as better food, housing, recreation and health care, and may provide psychological benefits such as a greater sense of security and control.27

Adverse health outcomes and higher mortality rates are important examples of the effect that low income has on people, and the link between reduced family income and associated poor child health outcomes is compelling. For the period 2002 and 2004–05, after adjusting for inflation, median gross weekly equivilised household income for Aboriginal and Torres Strait Islander people rose by 10% from \$AU 308 to\$AU 340. This compare to \$AU 618 for

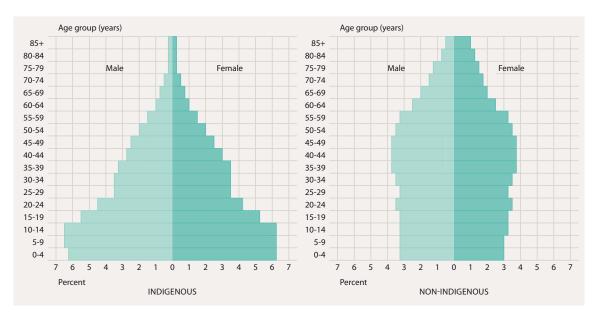


Figure 2
Aboriginal and Torres Strait
Islander and non-Aboriginal
and Torres Strait Islander
population at
30 June 2006

Source: Australian Bureau of Statistics<sup>23</sup>

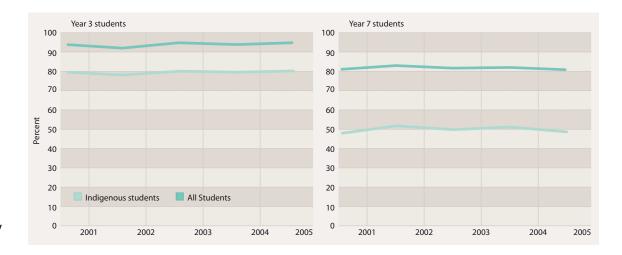


Figure 3
Proportion of students
who achieve the numeracy
benchmark

non-Aboriginal and Torres Strait Islander households in 2004-05.

## Housing

A poor living environment, with for example, low or no access to clean water, functional sewerage systems or appropriate housing conditions, has been associated with tuberculosis, rheumatic heart disease, respiratory diseases, urinary tract diseases, intestinal worms, trachoma and intestinal infections. Many rural and remote Indigenous communities still do not have access to the basic level of environmental health experienced by the rest of the population. Overcrowded housing, in particular, still remains a significant problem. In 2006, an estimated 25% of Aboriginal and Torres Strait Islander people lived in overcrowded accommodation. 17

### **Education**

International research has clearly established that higher levels of educational attainment are associated with improved health outcomes.<sup>29</sup> There is also persistent evidence regarding the importance of completing Year 12 at school.<sup>30</sup> Positive relationships have been observed between levels of educational attainment and positive health outcomes.<sup>31</sup> Young people who do not complete Year 12 are less likely to be fully engaged in study or work compared with those who do complete Year 12, and the fewer years of schooling competed, the less likelihood of engagement in study or work.<sup>32</sup> Aboriginal and Torres Strait Islander children are more likely to have parents who left school early (57% of children in Aboriginal and Torres Strait Islander households are living with parents who had not completed Year 10, compared with 25% of children in other households).

Between 2001 and 2005, 78% of Year 3 Aboriginal and Torres Strait Islander students met the reading benchmark and 80% met the numeracy benchmark.

However, at Year 7 in the same period, 65% of Aboriginal and Torres Strait Islander students met the reading benchmark and 50% met the numeracy benchmark. Between Year 3 in 2001 and Year 7 in 2005, the rate of attainment of the numeracy benchmark almost halved among Aboriginal and Torres Strait Islander students, from 80.2% to 48.8% (See *Figure 3*). Rates of attainment of the reading benchmark dropped from 72% to 65% among these students.<sup>26</sup>

#### **Food security**

The hunter–gatherer lifestyle of Aboriginal and Torres Strait Islander people changed after the arrival of Europeans.<sup>33</sup> Many Aboriginal and Torres Strait Islander people became dependent on Europeans for food, as well as for many other resources. Indigenous population numbers decreased after initial contact with Europeans due to violence, introduced diseases and malnutrition. A rapid change in the diet of many Indigenous people from a fibre-rich, high-protein, low-fat traditional diet to one high in refined carbohydrates and saturated fats increased the risk of diet-related disease. Vulnerability to obesity and non-insulin-dependent diabetes mellitus has been common among other groups that have been subjected to similar rapid lifestyle changes—for example, Pima Indians and Native Americans.<sup>34</sup>

Food security has been largely unreported and could be a major factor contributing to poor childhood growth and nutrition. Good nutrition is necessary for growth and physical and mental health. The effects of diet and nutrition in pregnancy and during a child's early life may have lifelong consequences. Poor fetal growth (or stunting in the first two years of life ) leads to irreversible damage, including shorter adult stature, lower attained schooling and reduced adult income. Healthy nutrition in pregnancy is crucial for the mother, as it influences both her health and that of her baby. Low dietary-energy intake, malnutrition,

Aboriginal and Torres Strait Islander people have a wide range of diverse lifestyles and social, cultural, educational and family backgrounds. What is true of one Indigenous person or group is not necessarily true of another person's values and life style.



inadequate weight gain during pregnancy and low pre-pregnancy weight can lead to intra-uterine growth retardation, which in turn can reduce birth weight. For many Aboriginal and Torres Strait Islander Australians, whether living in urban, rural or remote settings, the availability and cost of healthy nutritious food is a basic public health issue. In 2004–05, among Indigenous children aged twelve to fourteen years in non-remote areas, only 24% met the recommended daily fruit intake of three or more serves, and 59% met the recommended daily vegetable intake of three or more serves. Among teenagers fifteen to seventeen years of age, 20% met the daily fruit consumption guidelines and 61% met the daily vegetable consumption guidelines.<sup>17</sup>

## 3.5 SPECIFIC HEALTH ISSUES AND RISK FACTORS

## **Tobacco smoking**

Smoking during pregnancy is associated with poor perinatal outcomes such as low birth weight, preterm birth and perinatal death. For the period 2001–04, 51% of all Aboriginal and Torres Strait Islander women

reported smoking during pregnancy. Aboriginal and Torres Strait Islander mothers were about three times more likely to smoke in pregnancy compared with non-Aboriginal and Torres Strait Islander mothers. <sup>29</sup> In contrast, only about 20% of all other Australian women were reported to smoke during pregnancy and this figure appears to be declining. <sup>20</sup>

Aboriginal and Torres Strait Islander children were exposed to nearly twice the amount of environmental tobacco smoke compared with non-Aboriginal and Torres Strait Islander children and were significantly more likely to live in a household with smokers (68.4% compared with 36.3% of non-Aboriginal and Torres Strait Islander children). Between 2004–05, 30.5% of Aboriginal and Torres Strait Islander children were exposed to regular indoor smokers compared with 10% of non-Aboriginal and Torres Strait Islander children (See *Table 1*).

#### Alcohol use

Alcohol use in pregnancy is associated with an increased risk of fetal alcohol syndrome and perinatal

	Indigenous children	Non-Indigenous children				
	aged 0–18	aged 0–18				
	%	%				
Does the regular smoker in your household smoke at home indoors? (a)						
No	37.6	26.1				
Yes	30.5	10.2				
Regular smoker in household	68.4	36.3				
No regular smoker	31.6	63.7				
Total	100.0	100.0				
Total number of children	217,815	4,802,303				
(a) Excludes not applicable, not asked (single-person household), not stated and not known.						

Table 1
Children aged zero to eighteen years: smoking status in households, 2004–05

Source: Adapted from ABS and AIHW Analysis of 2004–05 NATSIHS and 2004–05 National Health Survey.

**Proportion Indigenous Non-Indigenous** Excellent 30.0 40.3 Very good 34.4 38.3 Excellent/very good 64.5 78.6 Good 26.8 16.6 Fair 7.6 4.0 Poor 1.1 8.0 Fair/poor 8.7 4.8 100.0 **Total** 100.0 Note: Excludes persons for whom self-assessed health status was not stated.

Table 2
Self-assessed health status of people aged fifteen to eighteen years 2004–05

Source: AIHW analyses of 2004-05 National Aboriginal and Torres Strait Islander Health Survey

death. The Western Australian Aboriginal Child Health Survey reported that the mothers of an estimated 23% of Aboriginal children reported that they drank alcohol during their pregnancies. <sup>36</sup> Risky alcohol consumption has not abated for men and has increased for women.

Excessive alcohol consumption also accounted for the greatest proportion of the burden of disease and injury for young Aboriginal and Torres Strait Islander males (fifteen to thirty-four years) and the second highest proportion for young Aboriginal and Torres Strait Islander females (after intimate partner violence).<sup>36</sup>

#### Self-rated health

Self-rated health status provides an overall measure of a population's health based on an individual's personal perception of his or her own health. Health is recognised as having physical, mental, social and spiritual components, and measures of them go beyond more objective measures such as morbidity and mortality. Aboriginal and Torres Strait Islander teenagers aged between fifteen and eighteen years rated their health as consistently poorer than their non-Aboriginal and Torres Strait Islander counterparts (See *Table 2*).

## Perinatal health outcomes

#### **Births**

The recording of Indigenous births is likely to be an underestimate because the Aboriginal and Torres Strait Islander status of the parent is not always recorded or correctly recorded. In 2006, there were about 12,300 live births registered in Australia for which at least one parent was of Aboriginal and Torres Strait Islander origin; these accounted for about 5% of total births.<sup>37</sup> About one-third of these babies had both an Aboriginal and/or Torres Strait Islander mother and father, 41% had an Aboriginal and/orTorres Strait Islander mother and

non-Indigenous father, and 29% had a non-Indigenous mother and Indigenous father.<sup>17</sup> These percentages varied by state/territory (also reflecting ascertainment) between 39% of all babies in the Northern Territory, and 0.7% of all babies in Victoria. In 2006, the total fertility rate for Aboriginal and Torres Strait Islander mothers was 2.1 babies compared with 1.8 babies for non-Aboriginal and Torres Strait Islander mothers.<sup>17</sup>

In the period 2001–04, approximately 23% of Aboriginal and Torres Strait Islander females who gave birth were aged less than 20 years compared with about 4% of non-Aboriginal and Torres Strait Islander females.

The life expectancy at birth for Aboriginal and Torres Strait Islander babies born in the period 1996–2001 was estimated to be 59.4 years for males and 64.8 years for females compared with 76.6 years for all males and 82.0 years for all females. This represents an estimated difference of approximately seventeen years for both males and females.<sup>17</sup>

#### **Preterm births**

A baby born at a gestational age or length of pregnancy less than thirty-seven completed weeks is preterm. Preterm birth is associated with early health problems that cause considerable illness and a higher risk of death in newborn babies. In the period 2001–04, 14% of all babies born to Aboriginal and Torres Strait Islander women were born preterm, compared with 8% of babies born to non-Aboriginal and Torres Strait Islander women.<sup>37</sup>

## Birth weight

Babies born with a birth weight of less than 2500 grams are classified as low birth weight. Low birth weight may result from being born preterm or from poor fetal

Since the most powerful determinants of infant mortality are social and economic, death in infancy is a good indicator of the social progress of a society, country or group of people

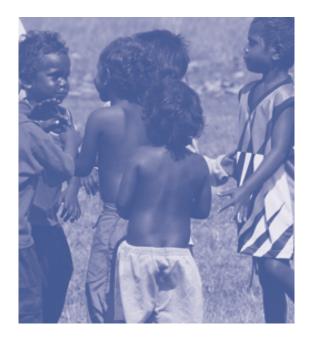


growth during pregnancy. Being born low birth weight increases an infant's chances of dying in the first year of life and of poor health outcomes throughout life.

During 2003–05, there were 3,601 low birth weight babies born to Aboriginal and Torres Strait Islander mothers, which represented 13% of all Aboriginal and Torres Strait Islander births. This was more than double the proportion of low birth weight babies born to non-Aboriginal and Torres Strait Islander mothers (6.1%).<sup>17</sup> Data from 1991–2004 show a significant increase in the rate of low birth weight babies born to Aboriginal and Torres Strait Islander mothers, from 11.2 to 12.1 per 100 live births (See *Figure 4*).

## **Breast feeding**

Breast feeding has many positive effects on survival, growth, development and the health of infants. There is strong evidence to support the protective effect of



Source: CRCAH-Cooperative Research Centre for Aboriginal Health, Darwin

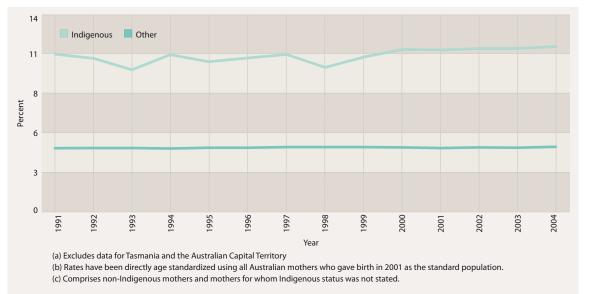


Figure 4
Rate of low birth weight
babies by Indigenous status
of mother 1991-2004

Source: AIHW National Perinatal Data Collection



Source: CRCAH-Cooperative Research Centre for Aboriginal Health, Darwin

breast feeding against conditions such as diarrhoea and respiratory infections. Breast feeding has also been shown to benefit children's growth, cognitive development and immunological functioning,<sup>38</sup> and also to offer a protective effect against Sudden Infant Death Syndrome (SIDS), asthma and other allergic diseases.<sup>39</sup> The National Aboriginal and Torres Strait Islander Health Survey in 2004–05 reported that approximately 79% of Aboriginal and Torres Strait Islander children living in non-remote areas had been breastfed compared with 88% of non-Aboriginal and Torres Strait Islander children. A higher proportion of non-Aboriginal and Torres Strait Islander than

Aboriginal and Torres Strait Islander children (aged zero to three years) had been fed for longer than twelve months (14% compared with 11%).<sup>27</sup> 85% of Aboriginal and Torres Strait Islander children aged between zero and three years living in remote areas and 75% living in non-remote areas were currently being or had been breastfed in 2004–05. The proportion of Aboriginal and Torres Strait Islander infants less than twelve months old living in remote areas who were being breastfed in 2004–05 was particularly high (85% of babies less than six months and 82% aged between six and twelve months).<sup>27</sup>

Table 3
Breastfeeding status,
Indigenous infants aged 0
to less than 6 months and
6 months to less than 12
months 2004–05

Source: ABS and AIHW analysis of 2004–05 NATSIHS

Breastfeeding status	Age 0-<6 months	Age 6-<12 months
Currently breastfeeding	61.2	46.5
Previously breastfed but not currently	26.2 <sup>(a)</sup>	42.17
Never breastfed	12.6 <sup>(a)</sup>	11.3 <sup>(a)</sup>
Total <sup>(b)</sup>	100.0	100.0
Total no. of infants	5,124	5,247

<sup>(</sup>a) Estimate has a relative standard error of between 25% and 50% and should be used with caution.

Table 4
Rates of fetal, neonatal and perinatal deaths by selected characteristics, 2006

Characteristic	Fetal deaths	Neonatal deaths (a) (b)	Perinatal deaths (a) (b)
Maternal status		Rate per 1000 births (c)	
Indigenous	11.4	7.1	20.7
Non-Indigenous	7.2	2.8	10.1

<sup>&</sup>lt;sup>(a)</sup> Numerators exclude neonatal deaths in NT. Denominators exclude live births in NT.

<sup>(</sup>b) Includes previously breastfed but current status not known, not stated and not known if breastfed.

<sup>(</sup>b) Except in WA, these may exclude neonatal deaths within 28 days of birth for babies transferred to another hospital or readmitted to hospital, and those dying at home.

<sup>(</sup>c) Fetal and perinatal death rates were calculated using all births (live births and fetal deaths). Neonatal death rates were calculated using all live births.

#### Perinatal and infant mortality

Since the most powerful determinants of infant mortality are social and economic, death in infancy is a good indicator of the social progress of a society, country or group of people. Many of the causes of infant death, such as infections, are potentially preventable; others, such as low birthweight or preterm birth can be treated with good health care and services.

#### Perinatal deaths

Neonatal deaths are deaths of live-born babies in the first 28 days of life. Perinatal death includes stillbirths and neonatal deaths. These deaths typically result from factors arising during pregnancy and childbirth. In 2006, Aboriginal and Torres Strait Islander babies were over two and a half times more likely to die in the neonatal period and nearly twice as likely to die in the perinatal period compared with non-Aboriginal and Torres Strait Islander babies (See *Table 4*).

#### Infant deaths

Infant deaths are deaths of live-born children before they reach their first birthday. For the period 2001–05, Aboriginal and Torres Strait Islander infants in Queensland, Western Australia, South Australia and the Northern Territory were two to three times more likely to die in infancy than non-Aboriginal and Torres Strait Islander infants. However, between 1998 (15.2 per 1000 live births) and 2006 (11.6 per 1000 live births), there have been significant decreases in the rates of Aboriginal and Torres Strait Islander infant deaths in Queensland, Western Australia, South Australia and the Northern Territory. These rates compared with rates of 5.1 per 1000 live births in 1998 and 4.2 per 1000 live births in 2006 for non-Aboriginal and Torres Strait Islander infants. The disparity between these two populations has also decreased over these years from a rate ration of 3.0 to 2.7, which represents a 30% decrease (See *Table 5*) (source AIHW analysis of the National Mortality Database, 2008).

Postneonatal death occurs after 28 days and before the first birthday. Data from Western Australia indicates that the post-neonatal death rate is higher than the neonatal death rate for Aboriginal and Torres Strait Islander infants, and the disparity between Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander post-neonatal mortality rates is increasing. This is a pattern found in less-developed countries.<sup>2</sup>

Between 1998–2006, an Aboriginal and Torres Strait Islander boy was 2½ times more likely to die in the

1998	1999	2000	2001	2002	2003	2004	2005	2006	Annual change (b)	% change over period (c)
				Indige	enous de	eaths pe	r 1,000 l	ve birth	S	
15.2	14.7	14.9	13.0	14.0	11.6	11.8	12.6	11.6	-0.5*	-24.9*
				Non-Ind	igenous	deaths	per 1,00	0 live bir	ths	
5.1	4.7	4.7	4.8	4.8	3.8	4.0	4.4	4.2	-0.1*	-17.8*
						Rate rati	O <sup>(d)</sup>			
3.0	3.2	3.1	2.7	3.0	3.1	3.0	2.9	2.7	0.0	-8.4
Rate difference (e)										
10.2	10.1	10.1	8.2	9.3	7.8	7.8	8.2	7.4	-0.4*	-28.5*

\* Represents results with statistically significant increases or decreases at the p < 0.05 level over the period 1998–2006.

Table 5 Infant mortality rates, rate ratios and rate differences, Qld, WA, SA and NT, 1998–2006<sup>(a)</sup>

Source: AIHW analysis of National Mortality Database

<sup>(</sup>a) Data exclude 90 registered infant deaths where Indigenous status was not stated over the period 1998–2006 in Queensland, Western Australia, South Australia and the Northern Territory combined.

<sup>(</sup>b) Average annual change in rates, rate ratios and rate differences determined using linear regression analysis.

<sup>(</sup>c) % change between 1998 and 2006 based on the average annual change over the period.

<sup>(</sup>d) Mortality rate for Indigenous infants divided by the mortality rate for non-Indigenous infants.

<sup>(</sup>e) Mortality rate for Indigenous infants minus the mortality rate for non-Indigenous infants.

first year of his life than a non-Aboriginal and Torres Strait Islander boy, and an Aboriginal and Torres Strait Islander girl was 3½ times more likely to die than a non-Aboriginal and Torres Strait Islander girl.<sup>17</sup>

#### Cause of Death

Between 2002–2006, the major causes of death for Aboriginal and Torres Strait Islander infants were conditions originating in the perinatal period (44%), SIDS (22%), congenital malformations (12%), respiratory diseases (8%), external causes (mainly accidents) (4%), and infectious and parasitic diseases (such as septicaemia, meningococcal infection and congenital syphilis) (4%) (See *Table 6*). The rate of deaths due to respiratory diseases and infectious and parasitic diseases was particularly high for Aboriginal and Torres Strait Islander infants, and was between five times higher (for infectious and parasitic diseases) and eleven times higher (for respiratory diseases) than non-Aboriginal and Torres Strait Islander infants.

Table 6
Causes of infant death by
Aboriginal and Torres Strait
Islander status, Queensland,
Western Australia, South
Australia and the Northern
Territory, 2002–06

Source: AIHW analysis of National Mortality Database

Cause of death	Indigenous	Non-Indigenous	Rate ratio		
	Deaths per 1,000 live births				
Certain conditions originating in the perinatal period (P00–P96)	5.7	2.1	2.7*		
Symptoms, signs, and abnormal clinical findings n.e.c. (R00-R99)	2.7	0.5	5.7*		
SIDS (R95)	1.1	0.2	5.4*		
Congenital malformations, deformations and chromosomal abnormalities (Q00–Q99)	1.5	1.0	1.5*		
Diseases of the respiratory system (J00–J99)	0.9	0.1	8.6*		
External causes (injury & poisoning) (V01–Y99)	0.5	0.1	3.8*		
Certain infectious and parasitic diseases (A00–B99)	0.3	0.1	4.2*		
Diseases of the circulatory system (I00–I99)	0.2	0.1	3.1*		
Other conditions(a)	0.5	0.3	1.8*		
Total	12.3	4.2	2.9*		

<sup>\*</sup> Represents results with statistically significant differences in the Indigenous/non-Indigenous comparisons at the p < 0.05 level.

Other conditions include: neoplasms (C00–D48); diseases of blood and blood-forming organs (D50–D89); endocrine, nutritional and metabolic diseases (E00–E89); mental and behavioural disorders (F00–F99); diseases of the nervous system (G00–G99); diseases of the eye and adnexa (H00–H59); diseases of the ear and mastoid process (H60–H95); diseases of the digestive system (K00–K93); diseases of the musculoskeletal system and connective tissues M00–M99); diseases of the genitourinary system N00–N99); and diseases of the skin and subcutaneous tissue (L00–L99).

Note: Data are reported for Queensland, Western Australia, South Australia and the Northern Territory only. These four states and territories are considered to have adequate levels of Indigenous identification in mortality data. They do not represent a quasi-Australian figure.

### Sudden Infant Death Syndrome (SIDS)

The rate of SIDS among the total Australian infant population has decreased significantly over the past two decades from 17.9 per 10,000 live births in the period 1980-90 to 11.5 per 10,000 live births in the period 1997-2002. However, these decreases have not been observed among the Indigenous population. Given the inaccuracies and lack of inclusion of Indigenousspecific information in statutory and administrative data-sets, there is no available national information describing the rates of Indigenous SIDS. However, a total population study that included all deaths that had occurred in Western Australia between 1980 and 2002, reported that the rate of SIDS among non-Aboriginal and Torres Strait Islander infants had decreased significantly over this period, from 1.3/1000 live births to 0.6/1000 live births. However, a similar decrease was not observed among Aboriginal and Torres Strait Islander infants: 4.9/1000 live births to 4.7/1000 live births over the same time period. This slower decrease among Aboriginal and Torres Strait Islander infants relative to non-Aboriginal and Torres Strait Islander infants resulted in an increase relative risk (RR= 7.9).3

There are a number of factors that are associated with an increased risk of SIDS, including sharing sleep surfaces, maternal smoking, infant exposure to environmental smoke, overcrowding in homes, prematurity and lack of breast feeding. These factors are proportionately more prevalent among the Indigenous population. It is therefore critical that well-resourced education campaigns led by Indigenous people are instigated in order to reduce these unexpectedly high rates of SIDS.

#### Childhood deaths

Child mortality rates should be interpreted with caution due to the small number of deaths each year of Aboriginal and Torres Strait Islander and other Australian children. The quality of death data is only acceptable in Western Australia, South Australia, the Northern Territory and Queensland (after 1998) (See

Table 7). Available data report that Aboriginal and Torres Strait Islander children are three times more likely to die in the first eighteen years of life compared with non-Aboriginal and Torres Strait Islander children. The disparities varied according to the age group: one to four years, rate ratio 2.8; five to twelve years, rate ratio 2.3; thirteen to eighteen years, rate ratio 2.8.

#### Deaths among children aged 1-4 years

For the period 2002–06, an Aboriginal and Torres Strait Islander boy aged one to four years was 2.6 times more likely to die than a non-Aboriginal and Torres Strait Islander boy. An Aboriginal and Torres Strait Islander girl was 2.9 times more likely to die than a non-Aboriginal and Torres Strait Islander girl.<sup>17</sup> There has been a statistically significant reduction in all-cause mortality rates, particularly in children aged less than five years in the Northern Territory and Western Australia<sup>2,40</sup>.

### Deaths among children aged 5-12 years

For the period 2002-06, an Aboriginal and Torres Strait Islander boy was 2.2 times more likely to die than a non-Aboriginal and Torres Strait Islander boy. For the same period an Aboriginal and Torres Strait Islander girl was 2.1 times more likely to die than a non-Aboriginal and Torres Strait Islander girl.

## Deaths among children aged 13-18 years

For the period 2002–06, an Aboriginal and Torres Strait Islander boy was 2.7 times more likely to die than a non-Aboriginal and Torres Strait Islander boy. For the same period an Aboriginal and Torres Strait Islander girl was three times more likely to die than a non-Aboriginal and Torres Strait Islander girl.

## Causes of deaths among children

For the period 2002–06, the death rate from external causes (such as transport accidents, accidental drowning, assault and intentional self-harm) was

		Indigenous	Non-Indigenous			
	Males	Females	All	Males	Females	All
			Deaths pe	er 100,000		
0	1,452.8	1,028.9	1,246.3	447.7	390.4	419.9
1-4	70.9	62.2	66.6	26.9	21.3	24.2
5–12	27.5	19.1	23.4	11.4	9.0	10.2
13–18	44.8	26.6	35.9	16.5	8.6	12.7
Total	97.1	67.9	82.8	31.2	23.5	27.5

Table 7

Deaths of children, age group and Indigenous status, Queensland, Western Australia, South Australia and the Northern Territory, 2002–06

Source: AIHW analyses of AIHW National Mortality Database



Source: CRCAH-Cooperative Research Centre for Aboriginal Health. Darwin

around three times higher for Aboriginal and Torres Strait Islander children (between six and eleven per 10,000 population) than for non-Aboriginal and Torres Strait Islander children (between one and three per 10,000 population) in Queensland, Western Australia, South Australia and the Northern Territory. Deaths due to accidental drowning continued to be prevalent among Aboriginal and Torres Strait Islander children. Aboriginal and Torres Strait Islander children also died from infectious and parasitic diseases and diseases

of the respiratory and circulatory system at three to six times the rate of non-Aboriginal and Torres Strait Islander children. Tables 8 and 9 show the main causes of death according to the International Classification of Diseases version 10 for children aged between zero and four (See *Table 8*) and for children aged between five and eighteen (See *Table 9*), highlighting the differences between the rates of death for Aboriginal and Torres Strait Islander children compared with non-Aboriginal and Torres Strait Islander children.

Table 8

Deaths of children aged
0-4 years, by main cause
of death and Indigenous
status, Queensland, Western
Australia, South Australia
and the Northern Territory,
2002–06

Source: AIHW analyses of AIHW National Mortality Database

	I	Indigenous	s	Non-Indigenous		
	Males	Females	All	Males	Females	All
			Deaths pe	er 100,000		
Certain conditions originating in the Perinatal period (P00–P99)	134.7	96.1	115.8	43.5	39.4	41.5
Symptoms, signs and abnormal findings n.e.c. (R00–R99)	71.7	48.6	60.4	12.6	9.2	11.0
Congenital malformations, deformations and chromosomal abnormalities (Q00–Q99)	35.8	31.6	33.8	22.5	19.3	20.9
External causes (injury & poisoning) (V01–Y98)	40.2	24.9	32.7	12.0	10.0	11.0
Diseases of the respiratory system (J00–J99)	26.1	17.0	21.6	3.1	2.9	3.0
Diseases of the nervous system (G00-G99)	10.9	11.3	11.1	3.9	3.5	3.7
Certain infectious and parasitic diseases (A00–B99)	8.7	10.2	9.4	2.5	2.0	2.2
Diseases of the circulatory system (I00–I99)	8.7	5.7	7.2	2.3	1.5	1.9
Other causes <sup>(a)</sup>	15.2	11.3	13.3	7.8	6.3	7.1
Total	351.9	256.5	305.2	110.1	94.1	102.3

<sup>(</sup>a) Other causes includes: neoplasms (COO–D48); diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism (D50–D89); endocrine, nutritional and metabolic diseases (E00–E89); mental and behavioural disorders (F00–F99); diseases of the eye and adnexa (H00–H59); diseases of the ear and mastoid process (H60–H95); diseases of the digestive system (K00–K93); diseases of the skin and subcutaneous tissue (L00–L99); diseases of the musculoskeletal system and connective tissue (M00–M99); and diseases of the genitourinary system (N00–N99).

There is evidence that improved access to primary healthcare can impede increasing preventable mortality rates. Such programs must be supported by well-constructed and well-resourced secondary prevention and health promotion programs



#### Injuries

Rates of injury mortality and hospital admission due to injury are substantially higher for Aboriginal and Torres Strait Islander Australians than for the Australian population as a whole. Children aged zero to fourteen years are known to be particularly vulnerable to injury, but very little is known about the nature and extent of injury to Indigenous children. Injury issues that confront children in Aboriginal and Torres Strait Islander communities are more complex

	Indigenous			Non-Indigenous		
	Males	Females	All	Males	Females	All
			Deaths pe	er 100,000		
External causes (injury and poisoning) (V01–Y98)	42.4	23.6	33.3	14.7	6.7	10.8
Symptoms, signs and abnormal findings n.e.c. (R00–R99)	4.8	1.7.	3.3	0.6	0.6	0.6
Diseases of the circulatory system (I00–I99)	3.6	2.5	3.1	0.8	0.4	0.6
Neoplasms (C00–D48)	3.2	2.5	2.9	2.8	2.8	2.8
Diseases of the nervous system (G00–G99)	2.4	2.1	2.3	1.5	0.9	1.2
Other causes (a)	4.8	5.5	5.1	2.6	2.2	2.4
Total	61.2	38.0	49.9	22.9	13.7	18.4

(a)Other causes includes: infectious and parasitic diseases (A00–B99); diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism (D50–D89); endocrine, nutritional and metabolic diseases (E00–E89); mental and behavioural disorders (F00–F99); diseases of the eye and adnexa (H00–H59); diseases of the ear and mastoid process (H60–H95); diseases of the respiratory system; diseases of the digestive system (K00–K93); diseases of the skin and subcutaneous tissue (L00–L99); diseases of the musculoskeletal system and connective tissue (M00–M99); diseases of the genitourinary system (N00–N99); pregnancy, childbirth and the puerperium (O00–O99); certain conditions originating in the perinatal period (P00–P96); and congenital malformations, deformations ad chromosomal abnormalities (Q00–Q99).

Table 9
Deaths of children aged
5–18 years, by main cause
of death and Indigenous
status, Queensland, Western
Australia, South Australia
and the Northern Territory,
2002–06

Source: AIHW analyses of AIHW National Mortality Database



Pictured: Darheio

than those commonly experienced within the general population, and are related to Aboriginal and Torres Strait Islander social disadvantage, poverty and general ill health. Aboriginal and Torres Strait Islander children may be put at risk through living in an overcrowded home environment, economic deprivation, high stress levels and recurring domestic violence.<sup>26</sup>

Between 2001 and 2003, Aboriginal and Torres Strait Islander children aged zero to fourteen years experienced a 2.5 times higher average injury mortality rate compared with non-Aboriginal and Torres Strait Islander children.<sup>41</sup> In 2004–05, Aboriginal and Torres Strait Islander children under four years were nearly 1.5 times more likely to be hospitalised as a result of injuries, poisoning and other external causes than non-Aboriginal and Torres Strait Islander children (See *Figure 6*).<sup>26</sup> Aboriginal and Torres Strait Islander children had a higher hospitalization rate for injuries from burns and scalds (approximately 2.3 times higher), assault and traffic-related pedestrian injury (two times higher) compared with other Australian children.<sup>41</sup>

#### Suicide and self-harm

Suicide is influenced by a complex set of factors as indicated by the significant differences that exist in suicidal behaviour not only between Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander populations, but also between different Indigenous communities. <sup>42</sup> These factors include the history of disposition, removal from family, discrimination, resilience, social capital and socioeconomic factors. <sup>26</sup> Evidence suggests that

Aboriginal and Torres Strait Islander suicide is most common among young men, while suicide attempts are reported to be more common among women. 43,44

Mental and behavioural disorders are often associated with an increased risk of self-harm, as is alcohol and substance abuse. Environmental risk factors have also been associated with a higher rate of suicide. Relevant family factors have included parents who are substance dependent, have been imprisoned or have violent tendencies, particularly if this translates into family violence. <sup>26</sup>

In the period 2001 to 2005, after taking into account the different age structures in the Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander populations, data from Queensland, Western Australia, South Australia and the Northern Territory reported that suicide rates among all Aboriginal and Torres Strait Islander males were significantly higher (between 32.3 and 84.9/100,000) than for non-Aboriginal and Torres Strait Islander males (between 17.0 and 25.8/100,000) and also higher for all Aboriginal and Torres Strait Islander females (between 6.2 and 21.0/100,000) compared with non-Aboriginal and Torres Strait Islander females (between 4.3 and 5.1/100,000).<sup>26</sup>

For Indigenous males aged 0–24 years, the agespecific rates were three times the corresponding agespecific rates for non-Indigenous males. The suicide rate for Indigenous females aged 0–24 years was five times the corresponding age-specific rates for non-Indigenous females.<sup>17</sup>

In 2005, suicide was the second leading cause of death (after transport accidents) for people aged 15–24 years, accounting for 22.2% of deaths in this age group.<sup>26</sup>

#### **Hospital admissions**

In 2005-06, Aboriginal and Torres Strait Islander infants were 1.4 times more likely to be admitted to hospital compared with non-Aboriginal and Torres Strait Islander infants. For skin diseases, respiratory conditions, and infectious and parasitic diseases Aboriginal and Torres Strait Islander infants were around three to four times more likely to be admitted to hospital than other infants. In 2005-06, Aboriginal and Torres Strait Islander children aged one to fourteen years were 1.3 times more likely to be admitted to hospital than other Australian children. Diseases of the respiratory system were the major cause of hospitalization for these Aboriginal and Torres Strait Islander children. 17 Most of the conditions resulting in Aboriginal and Torres Strait Islander infants and young children being admitted to hospital are related to poverty, housing and environmental conditions.26

#### **3.6 OTHER HEALTH CONDITIONS**

#### Long term health conditions in childhood

Similar proportions of Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander children had long-term health conditions, the main being diseases of the respiratory, ear and mastoid, eye and adnexa, skin and subcutaneous tissue and the nervous systems. There were similar percentages of respiratory morbidity in both populations in the years 2004-05. However, Aboriginal and Torres Strait Islander children were more likely to suffer from asthma (14% compared with 11%) and/or bronchitis (2% compared with 1%) and more likely to have ear/hearing problems especially partial deafness (5%

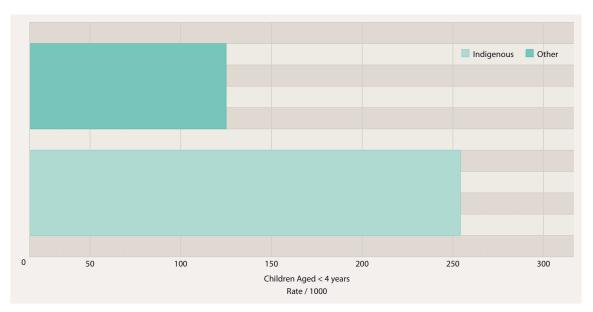


Figure 6
Rates of children
hospitalized for injuries,
2004-05

Source: SCRGSP 2007

compared with 1%) and /or otitis media (4% compared with 2%).

#### **Asthma**

Asthma is the second most common self-reported illness among Aboriginal and Torres Strait Islander Australians. According to the report *Asthma in Australia 2008* <sup>46</sup> when compared to the non-Aboriginal and Torres Strait Islander population Aboriginal people:

- have a higher prevalence of asthma, particularly among older people, children and those living in non-remote localities
- have a higher rate of mortality due to asthma
- · have higher rates of hospitalization for asthma
- are less likely to use inhaled corticosteroids for asthma, at least among children.

In the years 2004–05, the age-standardised prevalence of asthma for those who have ever been diagnosed was 24% (95% CI: 21.5–26.6) for Aboriginal and Torres Strait Islander children aged zero to seventeen years compared to 21.3 (95% CI: 19.9–22.7) for non-Aboriginal and Torres Strait Islander children. The age-standardised prevalence of current asthma in the same period was 13.5% (95% CI: 11.9–15.1) for Aboriginal and Torres Strait Islander children aged zero to seventeen years compared to 11.2% (95% CI: 10.1–12.3) for non-Aboriginal and Torres Strait Islander children.

Asthma in Australia 2008, also shows that Aboriginal and Torres Strait Islander infants aged up to one year have a higher prevalence of asthma when compared to non-Aboriginal and Torres Strait Islander infants. However, as diagnosis in this age group is uncertain, it is possible that these figures are inflated because it is not uncommon in this age group for other respiratory conditions, especially, bronchiolitis to be diagnosed as asthma. It is also well known that the Aboriginal and Torres Strait Islander population suffers significantly higher rates of bronchiolitis.<sup>46</sup>

## **Rheumatic fever**

Acute rheumatic fever and rheumatic heart disease are now rare in populations with good living conditions – optimal living conditions and minimal household overcrowding – and easy access to quality medical care (things that many Aboriginal and Torres Strait Islander people often lack). With this in mind, it is disturbing to note that in remote communities in the Northern Territory, 1–3% of the population has established rheumatic heart disease generally as a result of cumulative damage from repeated episodes of acute rheumatic fever. Rheumatic fever was commonly

seen in the non-Aboriginal and Torres Strait Islander child population in all Australian urban centres in the first half of the twentieth century. Today there are continuing high rates of acute rheumatic fever among Aboriginal and Torres Strait Islander children, largely as a result of overcrowding and poor living conditions and a very high level of exposure to group A streptococci infections.<sup>47</sup>

In a retrospective review from the Northern Territory there were 555 episodes of acute rheumatic fever in 367 people, of which 543 were episodes in 355 Aboriginal and Torres Strait Islander patients, nearly all from remote Aboriginal and Torres Strait Islander communities. None of the twelve non-Aboriginal and Torres Strait Islander patients had a recurrence, whereas 39.2% of the episodes in Aboriginal and Torres Strait Islander children were recurrent among 107 individuals with previously diagnosed rheumatic fever or rheumatic heart disease. 48

#### **Oral health**

The Australian Institute of Health and Welfare (AIHW) reports that a higher percentage of Aboriginal and Torres Strait Islander children had experienced dental caries than other Australian children at all ages between four and fourteen years, with the most affected being in socially disadvantaged groups and those living in rural / remote areas. Aboriginal and Torres Strait Islander children under five had almost one-and-a-half times the hospitalization rate for dental care as other Australian children, and the rate of these admissions increased with increasing remoteness. They also had consistently higher levels of dental caries in the deciduous or 'baby teeth' (extensive in many remote communities) and permanent dentition than their non-Aboriginal and Torres Strait Islander counterparts and the prevalence of caries is rising particularly in the deciduous dentition.49

#### Ear health

Aboriginal and Torres Strait Islander children are reported as having ear and hearing problems approximately twice as often as non-Indigenous children. This is due in part to high rates of otitis media (middle ear infection) among children in many Aboriginal and Torres Strait Islander communities.<sup>50</sup> Results of the 2004–05 National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) show that the prevalence of hearing loss / diseases of the ear was 10% for Aboriginal and Torres Strait Islander children aged zero to fourteen years, compared with only 3% of non-Indigenous children.<sup>27</sup> A recent study identified an association between a child's exposure to tobacco

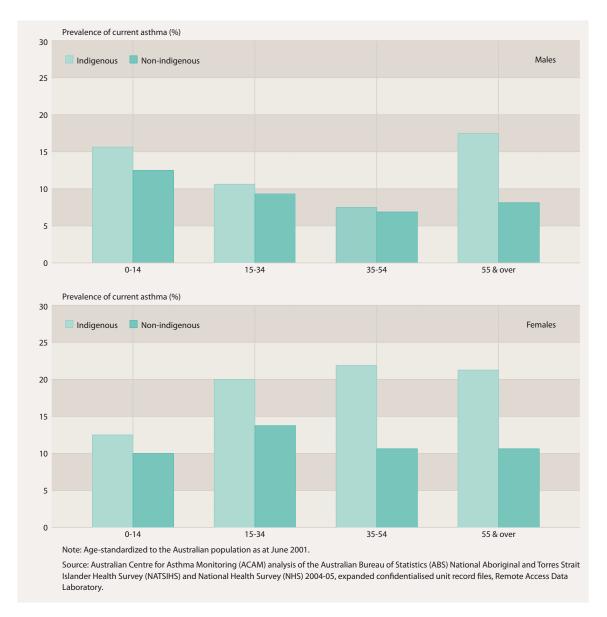


Figure 8
Prevalence of current
asthma by age, sex and
Indigenous status, 2004–05

Source: Asthma in Australia<sup>46</sup>

smoke in the home (and not attending organised childcare) and an increased risk of otitis media.<sup>51</sup>

#### Eye health

Trachoma is a disease of early childhood and if untreated leads to significant vision impairment and blindness. Trachoma is the most common cause of infectious blindness, with Australia being the only developed country to still have blinding endemic trachoma. A review of the National Aboriginal and Torres Strait Islander Eye Health Program in northern and western Australia in 2003 found prevalence of active trachoma (>20%) similar to those of thirty years ago. <sup>52</sup> Studies have identified a maximum age-specific infection in pre-school Aboriginal and Torres Strait Islander children, but there are also considerable rates of active trachoma into the teenage years. Studies have also identified that between 20%

and 30% of Indigenous children in rural and remote Australia have active trachoma. Trachoma can be treated by antibiotics and can be prevented through health promotion and education that highlights the importance of face washing and facial cleanliness and improved environments and health hardware.<sup>53</sup>

#### **Immunization**

There are varying estimates of the level of immunization coverage among Aboriginal and Torres Strait Islander children. Coverage varies from being much lower to being the same as non-Aboriginal and Torres Strait Islander children. In general, vaccination coverage tends to be higher among Aboriginal and Torres Strait Islander children living in remote areas compared with those living in non-remote areas. However, there are concerns as to the adequacies in data collection because estimates are drawn from a



Pictured: Hiarnz & Darheio

number of sources and different methods can be used to ascertain the level of coverage among Aboriginal and Torres Strait Islander children. Data suggests that Aboriginal and Torres Strait Islander at twelve months of age had lower vaccine coverage compared with non-Aboriginal and Torres Strait Islander children at the same age (82% compared with 91%), whereas at twenty-four months of age they had the same level of coverage as other Australian children (90.9% compared with 91.3%).<sup>54</sup>

## Mental health

There is a paucity of data to describe the mental health and wellbeing of Aboriginal and Torres Strait Islander children. The Western Australian Aboriginal Child Health Survey (WAACHS), conducted in 2001 and 2002, found that:

- 24% of Aboriginal and Torres Strait Islander children were at high risk of clinically significant emotional or behavioural difficulties compared with 15% of non-Aboriginal and Torres Strait Islander children.<sup>36</sup>
- more than one in five (22%) Aboriginal and Torres
   Strait Islander children aged zero to seventeen years
   were living in families where between seven and
   fourteen major life stress events had occurred in the
   twelve months prior to the survey.<sup>55</sup>
- the proportion of children at high risk of clinically significant emotional or behavioural problems was lowest in areas of extreme isolation.<sup>55</sup>

- stronger adherence to traditional culture and ways of life in extremely isolated areas may be a protective factor.<sup>55</sup>
- of the Aboriginal and Torres Strait Islander young people aged twelve to seventeen years who were surveyed, 9.0% of females and 4.1% of males had attempted suicide in the past twelve months.<sup>56</sup>
- the children of Aboriginal and Torres Strait Islander carers who had been forcibly separated from their natural families by a mission, the government or welfare were more than twice as likely to be at high risk of clinically significant emotional or behavioural difficulties.<sup>55</sup>

## Child abuse and neglect

The relationship between child abuse and neglect and child health and wellbeing is complex and related to the type, severity and duration of the abuse and neglect and to the context in which it occurs. As in non-Aboriginal and Torres Strait Islander communities, it is commonly believed that child abuse and neglect in Aboriginal and Torres Strait Islander communities are caused by a multitude of factors However, the Indigenous perspective usually places considerably more emphasis on the impact of the wider community and societal causal factors.<sup>57</sup> Memmot suggests these factors include: precipitating causes (one or more events triggering a violent episode); underlying factors (historical circumstances); and situational factors (such

as the combination of alcohol abuse, unemployment, and welfare dependency).

A number of prominent Indigenous spokespersons believe that present dysfunctional behaviour in some Indigenous communities, including the abuse and neglect of children, is grounded in unresolved grief associated with multiple layers of trauma that has spanned many generations. 58-60

The report, *Bringing Them Home* drew attention to the fact that violence may also be transmitted by omission. The past forced separation of Indigenous children from their families and communities has resulted in a loss of parenting skills and abilities<sup>12</sup>, thus increasing the likelihood of the involvement of child protection services in Aboriginal families.<sup>61</sup>

It is clear that Aboriginal and Torres Strait Islander children are significantly over-represented in most statutory child protection systems. Based on notifications (or reports) to child protection departments in Australia in 2001-02, 3,254 Aboriginal and Torres Strait Islander children under seventeen years had some form of abuse substantiated—that is, the statutory protection authority believed that abuse or neglect had occurred. 62 This rate of substantiation was on average 4.3 times higher (for all types of abuse) in the Aboriginal and Torres Strait Islander population than in the non-Aboriginal and Torres Strait Islander population. The rate varied widely between states, with Victoria and Western Australia having a substantiation rate nearly eight times higher for Aboriginal and Torres Strait Islander children than non-Aboriginal and Torres Strait Islander children.

Aboriginal and Torres Strait Islander children are six times more likely to be removed from their families than other Australian children<sup>63</sup>, a situation that has changed little since this problem was identified in 1979 at the First Aboriginal Child Survival Seminar.<sup>64</sup> Aboriginal and Torres Strait Islander children comprise 2.7% of children in Australia, yet constitute 20% of those placed in out-of-home care.<sup>61</sup>

## 3.7 ACCESS TO HEALTH CARE

There is very little information detailing issues of Aboriginal and Torres Strait Islander children's access to health care at a national level. The most comprehensive information available is at the Western Australian state level from the WAACHS.

The WAACHS survey found that Aboriginal children had fewer contacts with doctors when compared with non-Aboriginal and Torres Strait Islander children. This difference becomes greater the more isolated children are. The more isolated children were, the less likely they were to see a doctor and more

likely to see a nurse or Aboriginal Health Worker.<sup>65</sup> The survey also found that:

- Aboriginal and Torres Strait Islander children have a very low attendance for dental care
- Aboriginal and Torres Strait Islander children attended accident and emergency health care at similar rates to non-Aboriginal and Torres Strait Islander children, regardless of location
- Aboriginal and Torres Strait Islander children had a higher overall hospitalization rate compared to non-Aboriginal and Torres Strait Islander children. However, the reasons for admission were similar, with the most common causes of hospitalization for all children being respiratory illnesses, other infections and injuries
- the hospitalization rate for people who live in very remote areas of Australia is almost 50% higher than that for people living in major cities.<sup>65</sup>

#### **3.8 HEALTH EXPENDITURE**

Over one-quarter of Aboriginal and Torres Strait Islander peoples live in remote and very remote areas in Australia. 66 As such, and in order to experience the same level and quality of care as their Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander urban counterparts, an increase in health care expenditure per capita must occur.

In 2004-05, \$1.17 per person was spent on Aboriginal and Torres Strait Islander healthcare for every \$1.00 spent on the health of non-Aboriginal and Torres Strait Islander health. Average total health expenditure per Aboriginal and Torres Strait Islander person was \$4,718 compared with \$4,019 per person estimated for non-Aboriginal and Torres Strait Islander people. It was also estimated that \$2,304 million was expended on health care in 2004-05 for Aboriginal and Torres Strait Islander people. This was 2.8% of the total national expenditure on health services. Further, when compared to non-Aboriginal and Torres Strait Islander people, Aboriginal and Torres Strait Islander people used public hospital and community health services more, and used less medical, pharmaceutical, dental and other health services. However, accurate and consistent Aboriginal and Torres Strait Islander identification continues to be a major barrier to precise estimates of Aboriginal and Torres Strait Islander use of health care.66

#### **3.9 DATA LIMITATIONS**

Currently, Indigenous people are relatively invisible in global health statistics due to major deficiencies in the health data describing them. Such deficiencies have been acknowledged in New Zealand, <sup>67-69</sup> Canada and



the United States and in a number of Australian states and territories. These deficiencies are in part due to misclassification of Indigenous people; inconsistencies in the collection, sources, completeness and classifications in statutory<sup>(1)</sup> and administrative<sup>(2)</sup> data collections; and inconsistencies in analysis, interpretation and ownership of the data in each jurisdiction.

Prior to 1976, no Australian jurisdiction separately identified Aboriginal and Torres Strait Islander people in vital statistics or hospital-based collections. In 1984, the Australian Government initiated moves to identify all Aboriginal and Torres Strait Islander Australians in births and deaths data collections. By the end of 1997 all major vital statistics and hospital-based collections included the Aboriginal and Torres Strait Islander status of people who are born, die or are admitted to hospital in every state and territory. However, there is an acknowledged under-identification of Aboriginal and Torres Strait Islander people in statutory and administrative data collections due to a general lack of recognition of the importance of collecting accurate data, ineffective processes for the collection of data and the absence of mandates to ensure that accurate data are collected. Thus, the complete ascertainment of Aboriginal and Torres Strait Islander people is questionable. Those states where the ascertainment is of concern are Victoria, New South Wales, the Australian Capital Territory, Tasmania and Queensland (before 1998), which makes it impossible to provide a complete and accurate profile of the mortality of Australia's Aboriginal and Torres Strait Islander people.5

Mortality statistics are important indicators of a population's health, as they provide vital information on the prevalence of serious diseases and injuries. Studies of the trends in mortality and related statistics also demonstrate how the health status of a population is changing, and enable the effect of health policies,

services and interventions to be monitored and evaluated. The lack of ascertainment and accuracy in these collections is of great concern because mortality data is one of the most important ways of measuring community health. Important information about the patterns of illness and deaths for the community as a whole become available when details about the deaths in the community are disaggregated. The excess burden of mortality borne by young Aboriginal and Torres Strait Islander Australians, and the disparity in the rates of infant and childhood mortality that exists between Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander Australians, has been reported in the Northern Territory and in the two states (South Australia and Western Australia) that have accurate mortality data. Notwithstanding these limitations, the magnitude of

Notwithstanding these limitations, the magnitude of health disparities in Aboriginal and Torres Strait Islander child populations is concerning. Perhaps equally worrying is that these disparities have not reduced in recent years and, in many cases, are increasing.

#### 3.10 EXAMPLES OF POSITIVE INITIATIVES

The health status of Aboriginal and Torres Strait Islander people is significantly poorer than for Australians as a whole. However, there have been some improvements. Data indicates that the increase in death rates for many chronic diseases is slowing and that deaths due to infectious diseases have significantly declined. Improvements have been identified across all age groups, but are most dramatic in the under-five age group. These results show evidence of health gain and that interventions can make a difference. They demonstrate clearly that improved access to primary healthcare can impede increasing preventable mortality rates. Such programs must be supported by well-constructed

An Aboriginal and Torres Strait Islander boy was two-and-a-half times more likely to die in the first year of his life than a non-Aboriginal and Torres Strait Islander boy, and an Aboriginal and Torres Strait Islander girl was three-and-a-half times more likely to die than a non-Aboriginal and Torres Strait Islander girl.

<sup>(1)</sup> Statutory data are data that are regulated or imposed by or in conformity with laws passed. They include vital statistics data.

<sup>(2)</sup> Administrative data are data collected as part of the administrative process generally for audit purposes.

*Healthy for Life* is an Australian Government initiative that commenced during the 2005–06 budget cycle.

The four year program, with an allocated budget of A\$102.4 million, aims to improve the health of Aboriginal and Torres Strait Islander mothers, babies and children, improve the quality of life for people with a chronic condition, and over time, reduce the incidence of adult chronic disease.

The program is based strongly around the use of quality improvement principles, processes and tools to deliver primary maternal, infant and child health care. The first phase of the program has seen participating services analyze collected information about the child and maternal health and chronic disease service activity with the purpose of establishing baseline information.

This baseline information has been used to monitor progress in achieving objectives for improvement in maternal, infant and child health.

The objectives of *Healthy for Life* are to improve the:

- availability of child and maternal health care
- prevention, early detection and management of chronic disease
- long term health outcomes for Aboriginal and Torres Strait Islander Australians
- Aboriginal and Torres Strait Islander health workforce.

The expected short, medium and long term outcomes include:

#### Short to medium term outcomes (1-4 years)

- increase in first attendance for antenatal care in first trimester
- 10% increase per year of adult and child health checks, with associated plans for follow-up
- 30% improvement in best practice service delivery for people with chronic conditions.

## Longer term outcomes (5-10 years)

- increase in mean birth weight to within 200g of the non-Indigenous population
- decrease in incidence of low birth weight by 10%
- reduction in selected behavioural risk factors (eg smoking, harmful alcohol intake among others) in pregnancy by 10%
- 30% reduction in hospital admissions for chronic disease complications
- · 30% improvement in numbers of patients with intermediate health outcomes within acceptable range.

Text Box 1
Healthy for Life program

and well-resourced secondary prevention and health promotion programs.

Reliable total population data in some Australian states and territories provide an excellent resource in determining the patterns and trends of morbidity and mortality among Aboriginal and Torres Strait Islander people.

The authors of this paper have identified a couple of initiatives that have demonstrated that well-resourced, community-controlled and culturally appropriate and accessible programs can, and do, have a positive impact, and result in significant and sustained improvement in the health outcomes of Aboriginal

people. An important component of any health improvement program will be the ability to measure accurately the disparities and to track the impact that policies, strategies and interventions have on health outcomes and the reduction of health disparities.

## **Collection of data**

Text Box 1 provides a description of the program Healthy for Life. Importantly, this program will contribute not only to an improvement in Aboriginal and Torres Strait Islander health in the perinatal period and the early years, but also to the more accurate and complete collection of vital statistics data describing

- The primary source of data was the WA Maternal and Child Health Research Database which is a comprehensive linked total population data base including comprehensible information describing birth, death, hospitalizations and the health status for every child born in Western Australia.
- The other data sources include: The Registry of Births, Deaths and Marriages; autopsy case reports; reports of Coronial enquiries; forensic pathology reports; the Birth Defects Registry.
- The forensic and coronial documents for every death are reviewed and the information informs the classification of the death and coding of the cause of death.
- A rigorous validation process is undertaken to ensure objectivity and every classification and code is reviewed by three independent experts to ensure internal validity of the classifications.
- The databases is managed at the Telethon Institute for Child health research, Centre for Child Health Research, the University of Western Australia.
- The continuing collection, review and analysis of these data has been funded by the Western Australia government initially the Department for Community Development and more recently the Department of Child Protection.

Text Box 2
The Western Australian
Mortality Database, Infants,
Children and Young People

Pictured: Hiarnz



Aboriginal and Torres Strait Islander, maternal, infant and child health.

# The Western Australian Mortality Database, Infants, Children and Young People

This database includes comprehensive information describing the death and the context in which the death has occurred for every child born in Western Australia between 1980 and 2006. The data from this database have been rigorously analyzed, and the patterns and trends of mortality among Western Australian born infants, children and young people that have occurred in the last quarter of a century have been widely reported. The following information describes the structure and content of this database.

Particular focus has been on describing the change in the disparities existing among the Indigenous population when compared with the non-Indigenous population. These data have informed evidence-based policy, practice and health information and education initiatives, particularly the prevention of SIDS and the change in legislation to allow the fortification of flour with folate to assist in the prevention of Neural Tube Defects.

## 'Closing the Gap on Aboriginal and Torres Strait Islander disadvantage'

In 2007, the new Federal Government made a commitment to *Close the Gap* in Aboriginal and Torres Strait Islander disadvantage including disparities

- To close the life-expectancy gap between Aboriginal and Torres Strait Islander people and other Australians within a generation;
- To halve the mortality gap between Aboriginal and Torres Strait Islander children and other children under age five within a decade;
- To halve the gap in literacy and numeracy achievement between Aboriginal and Torres Strait Islander students and other students within a decade;
- To halve the gap in employment outcomes for Aboriginal and Torres Strait Islander people within a decade;
- To at least halve the gap in attainment at Year 12 schooling (or equivalent level) by 2020; and
- To provide all Aboriginal and Torres Strait Islander four year olds in remote communities with access to a quality preschool program within five years.
- Commonwealth of Australia, 2008 Statement by the honourable Jenny Macklin MP Minister for Families, Housing, Community Services and Indigenous Affairs. Closing the gap between Indigenous and non-Indigenous Australians.



Text Box 3
Closing the Gap on
Aboriginal and Torres Strait
Islander Disadvantage

that exist between the Aboriginal and Torres Strait Islander populations and other Australians in all the social determinants of health. The Close the Gap campaign, launched in 2007 was centred on two goals. The first being to drive existing Australian, state and territory government commitments targeted at ending Aboriginal and Torres Strait Islander health inequality with added accountable timeframes. The second being the development of a set of 'Close the Gap Indigenous Health Equality Targets'. In 2008, the Australian Government allocated \$AU 425.3 million in new funds in the 2008-09 Budget specifically addressing the Closing the Gap targets. The Australian Government has also agreed to an annual regimen of reporting the progress on reducing the gap of inequality. The threat to being able to measure the success or failure of the campaign lies with the ability to accurately measure progress to the targets set. Text Box 3 identifies the specific targets.

#### 3.11 CONCLUSION

'[T]he time is right for a global response to improve the health and well-being of Indigenous peoples' (Assembly of First Nations, Discussion Paper, p.40)<sup>70</sup>

Significant efforts and resources have been devoted to improving the health of Indigenous infants, children and young people in Australia, Canada, New Zealand and the United States of America over the past decade. There have been improvements in some educational and health outcomes for Indigenous children. However,

even in the face of these improvements, Indigenous children continue to fare worse than their non-Indigenous counterparts and disparities continue to exist among Indigenous populations. Many of these disparities reflect the historic, economic and social circumstances of Indigenous communities. These continuing and in some cases widening disparities, should challenge us all to do whatever is necessary and to commit whatever resources at whatever cost, to remedy the causes of Indigenous disadvantage.

Too often Indigenous people and their social conditions are invisible. Much better data and quality research on Indigenous health needs to be generated, but this must be with the specific agreement of Indigenous communities. This includes the need to take account of the Indigenous communities' holistic approaches to, and understandings of, health and well-being. Indigenous communities must be been actively involved in deciding how or what should be studied about them, and for what purpose. This is particularly important, considering that many political decisions are made on the basis of this research and often simplistic interpretations of data.<sup>70</sup>

Good health, education and social connectedness in childhood are fundamental to the development of human potential and to full participation in a democratic society. Improving the health and well being across all social determinants and reducing the disparities that currently exist for Indigenous children in our society is not an option, it is an imperative.

Improvements have been identified across all age groups among Aboriginal and Torres Strait Islander children, but are most dramatic in the under-five age group.

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## Health of Māori Children in Aotearoa / New Zealand

4.1 Introduction. This report is a background document that outlines Māori child health outcomes in Aotearoa / New Zealand. It contains an overview of the Māori population, a brief description of the health system in Aotearoa / New Zealand, a description of the collection and use of ethnicity data, an account of Māori children's health status, and an outline of the use of ethnicity data using sudden infant death syndrome as an example.

#### 4.2 MĀORI

Māori are the Indigenous peoples of Aotearoa / New Zealand. Prior to colonization Māori society was structured around kinship groups - whānau (families), hapū (sub-tribes) and iwi (tribes). The colonization of Aotearoa / New Zealand commenced in the late 1700's and progressed at a more rapid rate after the signing of the Treaty of Waitangi (the Treaty). The Treaty formalized the relationship between Māori and the British monarch and is sometimes referred to as the 'founding document' of New Zealand. It forms the basis of the relationship between Māori (the collective group) and the government of New Zealand (as the representative of the Monarch). There has been, and continues to be, considerable debate about the Treaty, its implementation, and its relevance to contemporary Aotearoa / New Zealand. Historical and contemporary claims regarding breaches of the Treaty are heard by the Waitangi Tribunal, which is able to make findings about alleged breaches and, where claims are upheld, recommend actions to address the breaches. The recommendations it makes to government are nonbinding, and the government and the group who made the claim then enter into negotiations in order to settle the grievance. Further detailed information about the colonization of Aotearoa / New Zealand, the Treaty,

and the Waitangi Tribunal may be found in Orange<sup>1</sup> and Walker<sup>2</sup>.

Each tribe occupies specific regions in Aotearoa. Post-colonial settlements (rural, towns, and cities) are contained within traditional tribal areas. For example, the greater Auckland region, which includes Auckland City and contains about one-third of the population of Aotearoa / New Zealand, is located within the tribal areas of the Ngāti Whātua and Tainui tribes. There are no reserves or reservations of the type found in Canada and the USA.

## **4.3 THE MĀORI POPULATION**

In the 2006 census 15% of the population reported Māori ethnicity – a total of 565,329 people. Just over half (52.8%) only identified Māori as their ethnic group, with the remainder identifying Māori and at least one other ethnic group.<sup>3</sup>

The Māori population is younger than the non-Māori population with a median age of 23 years for Māori and 36 years for the total population in 2006. In 2006, 35% of the Māori population were under 5 years of age, and 53% were less than 25 years of age. <sup>4</sup> Figure 1 presents the population pyramids for Māori and non-Māori, illustrating the younger age structure of Māori compared to the non-Māori population.

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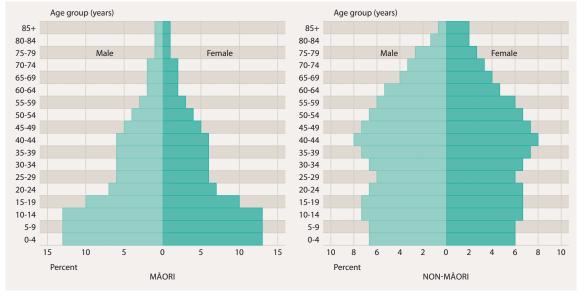


Figure 1
Age distributions of the Māori and non-Māori populations 2006

Source: Hauora: Māori Standards of Health IV

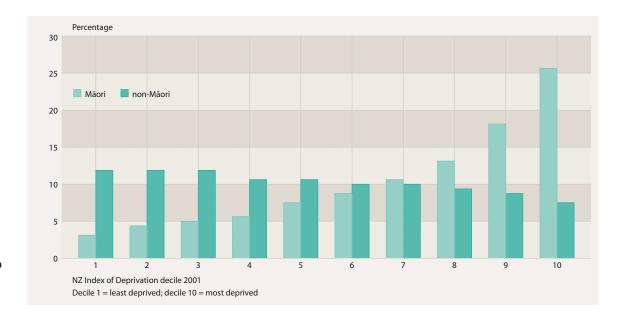


Figure 2
Distribution of deprivation by ethnicity 2006

Source: Ministry of Health

Māori women experience both the ethnic and the gender income gaps.<sup>5</sup> This is particularly important in relation to Māori children, as a substantial proportion of Māori children are living in households headed by a sole female adult.

The Māori population continues to grow and is predicted to account for 17% of the total population by 2021. The number of Māori children is expected to continue to increase, but will do so at a slower rate than seen in previous years. Predictions suggest that by 2021 the proportion of children in the Māori population will be smaller than it is currently.<sup>4</sup>

Māori are highly urbanized, and many live outside their tribal areas. In 2006, 84% of Māori lived in urban areas. The majority of Māori live in the North Island (87%) and about 25% of the Māori population live in the greater Auckland region.<sup>3</sup>

Just over 23% of Māori reported speaking more than one language in the 2006 population census. This percentage is consistent with the proportion of Māori adults who reported speaking Māori with some degree of proficiency in the 2006 Māori language survey.

An estimated 9,500 children attended Kohanga reo (Māori language immersion pre-schools) and over 26,000 Māori children attended Māori language medium schools in 2006.

## **4.4 SOCIAL AND ECONOMIC INDICATORS**

This section provides a brief overview of Māori socio-economic status, experience of the wider determinants of health, and an overview of the living standards experienced by Māori. These factors are vitally important in determining the health status of individuals and families, and are also important determinants of access to care and health outcomes. Māori are over-represented in indictors of deprivation and have poorer access to the social and economic factors that are important determinants of health.

#### Income

There is a persistent disparity between the incomes of Māori and non-Māori. The median annual income for Māori 15 years of age and over was \$NZ 20,900 in 2006 while that of non-Māori was \$NZ 24,400. The ethnic income gap is greater than the gender income gap. Māori women experience both the ethnic and the gender income gaps. This is particularly important in relation to Māori children, as a substantial proportion of Māori children are living in households headed by a sole female adult.

27% of Māori children live in poverty (defined as a household income below 60% of the median household income), as compared to 16% of NZ European children.<sup>5</sup>

## Deprivation

The New Zealand Index of Deprivation is a small area (neighbourhood) measure of deprivation. Small area deprivation is associated with both mortality and morbidity in Aotearoa / New Zealand. Using nine variables from the population census, the index assigns each census mesh block to a deprivation decile.

The least deprived decile is decile 1, and the most deprived is decile 10. Theoretically, ten percent of the population should reside in areas associated with each decile. However deprivation is not equally distributed across the population. In 2001 over half the Māori population lived in areas associated with the three most deprived deciles. However, less than one third of non-Māori lived in areas associated with those deciles. (See *Figure 2*)

#### **Education**

Evidence suggests that the education system continues to provide Māori students with lower quality education than that provided to non-Māori students. Māori children are more likely to leave school without a National Certificate of Educational Achievement (NCEA) qualification. Half (49%) of Māori students left school without this qualification in 2005, compared with 22% of non-Māori students. In tertiary education settings Māori are more likely to be studying for certificate level qualifications than for degrees.<sup>5</sup>

#### **Employment**

A higher proportion of the Māori population is unemployed with 7.6% of Māori and 2.6% of NZ European people aged 15 years of age or over unemployed in June 2007.

Māori who are employed are more likely to work in service industries and as machine operators and assemblers. Furthermore, there is evidence that Māori experience discrimination in getting a job, the type of jobs they are able to obtain, and the wages paid for a specific job.<sup>5</sup>

## Housing

Quality of housing is an important determinant of health. Māori are more likely to live in temporary or rental accommodation and to live in crowded houses.<sup>5</sup>

## **Living Standards**

The living standards experienced by children are significant determinants of a child's opportunities for healthy development. The Economic Living Standard Index (ELSI) incorporates data from a range of indicators and measures the living standards of family units across Aotearoa / New Zealand. In 2000 and 2004 the living standards for Māori were significantly lower than those of the total population. In 2004, 40% of Māori families were living in hardship, compared with 19% of European families.

#### Discrimination

The 2002/03 New Zealand Health Survey asked participants about their experience of ethnically motivated discrimination. Māori reported the highest prevalence of having 'ever' experienced discrimination in the health sector, work environment or when buying or renting housing. Overall, one third of Māori reported experiencing discrimination in any one of these settings. Furthermore, Māori were nearly ten times as likely to report experiencing discrimination in all three setting (4.5% compared with 0.5% of European participants). The reported experience of discrimination was significantly associated with adverse health outcomes in relation to self-rated health, physical functioning, mental health, being a current smoker, and reporting cardiovascular disease. <sup>6,7</sup>

## 4.5 THE HEALTH SECTOR IN AOTEAROA / NEW ZEALAND

The NZ Public Health and Disability Act (2000) provides for the public funding and provision of personal health services, public health services, and disability support services. The first two stated objectives of the Act are:

- (a) to achieve for New Zealanders -
  - (i) the improvement, promotion, and protection of their health:
  - (ii) the promotion of the inclusion and participation in society and independence of people with disabilities:
  - (iii) the best care or support for those in need of services.
- (b) to reduce health disparities by improving the health outcomes of Māori and other population groups.

The majority of health services in Aotearoa / New Zealand are publically funded, with private insurance accounting for a small part of health sector activity. Services in secondary and tertiary care are free. Primary care funding includes a contribution from the government but patients also contribute towards

Māori – the indigenous people of Aotearoa / New Zealand

- In 2006 about 15% of the population were Māori
- The Māori population is younger than the non-Māori population
- $\bullet$  In 2006 35% of the Māori population was under 5 years of age and 53% were under 25 years of age
- The Māori population is growing and is predicted to account for 17% of the population by 2021

#### Social and environmental determinants of health

- · Māori children are more likely to experience adverse social and environmental determinants of health
- 40% of Māori families live in hardship compared with 19% of European (White)
- 27% of Māori children live in poverty compared to 16% of European children
- Māori are more likely to live in crowded homes
- The education system fails to provide Māori children with the same quality of education as non-Māori
- Māori are more likely to report experiencing discrimination that other population groups in New Zealand

the cost of seeing a primary care doctor (user partcharges). Following the implementation of primary health care reforms in 2001 the level of government subsidy for primary care has increased, and the user part-charges have been reduced for a substantial proportion of the population. Health care to children under six years of age is typically free if the child attends the General Practitioner who usually provides their care. Routine childhood immunizations are free. Prescriptions attract a small charge – ranging from three to fifteen dollars per item if the drug is fully subsidized by the government. Prescriptions for medications that are not fully subsidized by the government have higher charges.

Māori health service providers (Māori providers) deliver primary health care and community health programmes to Māori who choose to access these services. The number of Māori providers increased substantially after the implementation of health sector reforms in 1991 - 1992, and there are now over 200 Māori providers. However, the majority of these services do not deliver primary medical care services. The majority of Māori receive care from 'mainstream' health services (i.e. not from Māori providers). About 14% of Māori participants in the 2002/03 New Zealand Health Survey reported using a Māori health provider in the twelve months prior to their interview<sup>8</sup>. More detailed accounts of Māori providers may be found in Crengle9; Crengle, Crampton & Woodward10 and Crengle, Lay-Yee & Davis11.

Specific strategies have been developed and implemented to assist the health sector to achieve the objectives of the NZ Public Health and Disability Act. He Korowai Oranga: Māori Health Strategy was published by the Ministry of Health in 2002. The strategy contains four pathways:

- Pathway 1 development of whānau, hapu, iwi and Māori communities
- Pathway 2 Māori participation in the health and disability sector

- Pathway 3 effective health and disability services
- Pathway 4 working across sectors.

Increasing Māori provider capacity and capability and developing the Māori health and disability workforces are included within Pathway 2. Pathway 3 includes addressing health inequalities for Māori; improving the effectiveness of 'mainstream' services in relation to Māori health; providing highest quality services; and improving Māori health information.

### **4.6 ETHNICITY DATA**

Improving Māori health status and reducing inequalities in health outcomes between Māori and non-Māori are key objectives for the New Zealand health sector.<sup>12, 13</sup> In order to achieve these objectives we must able to describe and monitor Māori health outcomes. This requires complete, accurate, reliable, and valid ethnicity data.

Prior to the 1986 census, for statistical purposes membership of the Māori population was based on a biological definition ('persons greater than half Māori blood', 'persons of half or more Māori blood'). In 1986 the biological definition of ethnicity used in the national census was replaced by a definition that was based on a social construct of ethnicity. However, ethnicity data relating to births and deaths continued to use the biological definition until 1995 when this was also replaced by the social definition.

The definition of ethnic group developed in 1988 by the Department of Statistics is still in use. According to this definition (Ministry of Health, 2004 pg.5) an ethnic group is:

A social group whose members:

- · share a sense of common origin
- claim a common and distinctive history and destiny
- possess one or more dimensions of collective cultural individuality
- feel a sense of unique collective solidarity.
   Each individual is able to nominate their ethnic affiliation(s) the ethnic group or groups which

they (or their child) belong to. That is, an individual's ethnic affiliation is self-identified, and is not limited to one ethnic group. Furthermore, an individual's ethnic affiliation may vary according to the situation, circumstances, or manner in which they are being asked their ethnicity, and may vary over time.

Although the definition of ethnicity has not been changed for twenty years there have been significant variations in the manner in which ethnicity data have been collected and used over those twenty years. These variations have adversely affected the accuracy, completeness, reliability and validity of (particularly Māori) ethnicity data. The utility of the data for comparison and time series analyses has also been compromised by regular changes to the ethnicity question and changes to methods used for classifying and using ethnicity data. 15-23

In recent years strategies such as workforce training and the development of ethnicity data protocols have been implemented in order to improve the collection and use of ethnicity data across the health sector. Recent evidence suggests that for the period 2001–04 differences in ethnicity counts between the census and mortality datasets are minimal but hospitalization and

cancer registration datasets continue to undercount the Māori ethnic group.<sup>24</sup> The completeness and accuracy of ethnicity data in primary care is poor and the differential misclassification of ethnicity in these databases results in under-enumeration of Māori and Pacific people.<sup>25-27</sup>

#### **4.7 CHILD HEALTH STATUS**

This section contains a brief overview of Māori child health outcomes. With few exceptions the data demonstrates significant disparities in health outcomes with Māori children experiencing worse outcomes than non-Māori children.

There are significant ethnic (and gender) differences in life expectancy at birth. A Māori male born in 2006 has a life expectancy of 71.2 years (78.8 years for non-Māori males) and Māori females can expect to live for 75.8 years (82.8 years for non-Māori females).<sup>28</sup>

Table 1 presents all-cause mortality rates by age group for children and young people aged 0–14 years. In each age group Māori experience higher mortality rates with the greatest disparity occurring in infants (under one year).

Age group	Māori rate	Non-Māori rate	Rate ratio	
	95% CI	95% CI	95% CI	
< 1 year	840.2	501.3	1.68	
	777.7 – 907.6	471.4 – 533.1	1.52 – 1.85	
1 – 4 years	40.9	30.1	1.36	
	34.2 – 48.8	26.6 – 34.1	1.09 – 1.69	
5 – 14 years	22.7	15.4	1.47	
	19.4 – 26.4	13.9 – 17.1	1.22 – 1.77	

Table 1
All-cause mortality rates
per 100,000, by age group
2000 – 2004

Source Hauora: Māori Standards of Health IV

Māori children face significant challenges to their opportunities to develop and realise their potential. Many of these challenges, such as socioeconomic disadvantage, poverty, and poorer outcomes from health services, are located within the structures, institutions, services, and the power relationships inherent in New Zealand society. The disparities

in health and social outcomes that are experienced by Māori children are breaches of the rights and protections afforded them by the United Nations Declaration of the Rights of the Child, Declaration on the Rights of Indigenous Peoples, Universal Declaration of Human Rights and the Treaty of Waitangi.

Cause of death	Māori		Non-l	Māori	Rate ratio				
	Rate	Rank	Rate	Rank					
Infants	under 1 year	(rate per 1,000	live births)						
Total: all causes	8.1		5.0		1.64*				
Perinatal conditions	2.8	1	2.5	1	1.1				
– Premature birth	1.3		0.7		1.76*				
Unknown causes	2.4	2	0.4	3	5.91*				
– Sudden infant death syndrome	2.0		0.4		5.66*				
Congenital anomalies	1.2	3	1.4	2	0.86				
Accidents	0.7	4	0.2	4	4.10*				
– Accidental suffocation in bed	0.5		0.1		4.27*				
Respiratory diseases	0.3	5	0.1	7	4.11*				
Child	ren ages 1 – 4	years (rate pe	r 100,000)						
Total: all causes	40.9		30.1		1.36*				
Accidents	18.1	1	9.8	1	1.88*				
Drowning	6.4		2.8		2.29*				
Pedestrian	4.4		2.4		1.80				
Motor vehicle (land)	3.7		1.4		2.54*				
Fires	2.3		0.7		3.23*				
Congenital anomalies	5.0	2	5.1	2	0.99				
Infectious diseases	3.7	3	2.5	5	1.45				
Meningococcal infection	3.0		1.2		2.49*				
Nervous system diseases	2.7	4	3.3	4	0.82				
Cancer	2.0	5=	3.6	3	0.55				
Homicide	2.0	5=	0.6	11	3.33*				
Childı	ren ages 5 – 14	l years (rate pe	er 100,000)						
Total: all causes	22.7		15.4		1.47*				
Accidents	9.8	1	5.9	1	1.66*				
Motor vehicle (land)	3.4		2.0		1.67*				
Pedestrian	1.8		1.0		1.81				
Drowning	1.7		0.7		2.40*				
Cancer	3.9	2	3.5	2	1.12				
Nervous system diseases	2.1	3	1.4	4	1.55				
Suicide	1.4	4	0.4	8	4.00*				
Congenital anomalies	1.3	5	1.8	3	0.69				
* indicates rate ratios are statistically	* indicates rate ratios are statistically significant at the 5% level								

Table 2
Major causes of death by age group 2000-04

Source Hauora: Māori Standards of Health IV

The leading causes of death vary by age and by ethnicity. *Table 2* presents leading causes of death by ethnicity for the age groups less than one year, one to four years, and five to fourteen years. Among infants the leading cause of death was 'perinatal conditions', and within this category premature birth was the commonest

cause of death for both Māori and non-Māori infants. Among Māori infants the second to fifth leading causes of death were: 'unknown causes' (primarily sudden infant death syndrome; SIDS); congenital anomalies, accidents (particularly accidental suffocation in bed); and respiratory diseases. Māori infant mortality rates

were significantly higher than non-Māori for premature birth, unknown causes, SIDS, accidents, accidental suffocation in bed, and respiratory diseases.

In the two older age groups accidents are the commonest cause of death for both Māori and non-Māori although Māori rates are significantly higher than non-Māori. In the one to four year age groups Māori also have significantly higher mortality rates from meningococcal disease and homicide. Mortality rates from accidents (especially motor vehicle accidents and drowning) and suicide are significantly higher among Māori children aged five to fourteen years compared with their non-Māori peers.

*Table 3* presents the leading causes of hospitalization for infants under one year, and children aged one to

four years, and five to fourteen years. The all-cause hospitalization rate for Māori infants was significantly lower than that of non-Māori infants, while the all-cause rates were significantly higher for Māori children aged one to four and five to fifteen years compared with their non-Māori peers.

The leading causes of hospitalization were the same in the two ethnic groups. In both ethnic groups live births was the most common reason for admission of infants under one year. However, Māori infant hospitalization rates for perinatal conditions (including premature birth) and congenital anomalies were significantly lower than those of non-Māori, while the hospitalization rate for respiratory disease was significantly higher for Māori infants.

Cause of Hospitalization	Māori		Non-Māori		Rate ratio
	Rate	Rank	Rate	Rank	
Inf	ants under 1 y	ear (rate per 1	00,000)		
Total: all causes	130764.6		161434.5		0.81*
Liveborn infants **	58338.0	1	71092.7	1	0.82*
Perinatal conditions	21958.5	2	36003.6	2	0.61*
– Premature birth	6393.9		7892.3		0.81*
Respiratory diseases	18853.6	3	9213.8	3	2.05*
Congenital anomalies	5203.2	4	7010.0	4	0.74*
Infectious diseases	4956.0	5	4778.7	5	1.04
	Children a	ges 1 – 4 year:	S		
Total: all causes	17634.5		16793.2		1.05*
Respiratory diseases	5094.3	1	4266.7	1	1.19*
Injury and poisoning	2227.6	2	2022.3	3	1.10*
Digestive system diseases	2003.1	3	1478.4	5	1.35*
Ear disease	1874.5	4	1748.7	4	1.07*
Infectious diseases	1666.9	5	2096.6	2	0.80*
	Children a	ges 5 – 14 yeaı	rs .		
Total: all causes	8189.8		7587.4		1.08*
Injury and poisoning	1850.3	1	1687.6	1	1.10*
Digestive system diseases	1079.8	2	959.3	2	1.13*
Respiratory diseases	1022.0	3	944.8	3	1.08*
Ear disease	950.5	4	523.7	5	1.81*
Symptoms and signs (unknown cause)	466.2	5	593.6	4	0.79*

\* Rate ratios are statistically significant at the 5% level



Table 3
Leading causes of public hospitalizations by age group 2000-04

Source Hauora: Māori Standards of Health IV

<sup>\*\*</sup> Liveborn infants do not include all live births. They are discharges with live birth recorded as the principle diagnosis. These rates use babies born in hospital as the numerator and intercensual estimates of the number of Māori and non-Māori babies as the denominator. They do not reflect the higher birth rates among Māori, where the rate is based on numbers of women giving birth.

The leading cause of hospitalizations for children aged one to four years, and for those aged five to fourteen were the same for the Māori and non-Māori ethnic groups, although the ranking varied.

Among children aged one to four years hospitalization rates for respiratory diseases, injury and poisoning, digestive system diseases, and ear diseases were all significantly higher for Māori than for non-Māori. However the Māori hospitalization rate for infectious diseases was significantly lower than that of non-Māori.

Among children aged five to fifteen years hospitalization rates for injury and poisoning, digestive system diseases, respiratory diseases, and ear diseases were all significantly higher for Māori than for non-Māori. However the Māori hospitalization rate for 'symptoms and signs (unknown cause)' was significantly lower than that of non-Māori.

Māori children are less likely to experience the benefits of preventive strategies such as routine childhood immunization. National data indicate that, in the 12 months to September 2008, fewer Māori children (68% of 24 month olds) had received their routine immunizations compared with 82% of NZ European children.<sup>29</sup> Disparities in access to immunization have

been documented for many years and reflect barriers to accessing these services. It is possible for health services to deliver effective immunization services to their communities and achieve near complete immunization coverage (Rachel Thomson personal communication). However, effective delivery such as this is the exception rather than the rule.

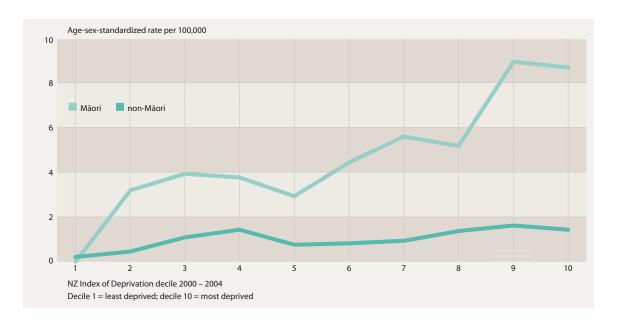
Other data suggests that Māori children are not served as well by primary care services. 'The Top 10 Report' on the health and wellbeing of children and young people aged 0 to 24 years in the Auckland and Waikato regions found that regional rates of potentially avoidable hospitalizations in 1999 were higher for the Māori and Pacific ethnic groups<sup>30</sup>.

Disparities in mortality and hospitalization rates are not simply due to differences in socioeconomic status between the Māori and non-Māori populations. Within each decile of the New Zealand Index of Deprivation age-standardized all-cause mortality rates are higher in the Māori than in the non-Māori population.

This pattern is evident in SIDS mortality. As seen in *Figure 3* Māori mortality rates from SIDS in deciles two through ten exceed that of non-Māori indicating that the differences in mortality are not due to differences in socioeconomic status alone.

Figure 3
Māori and non-Māori SIDS
mortality rates by NZ Index
of Deprivation decile
2000-2004

Source Hauora: Māori Standards of Health IV



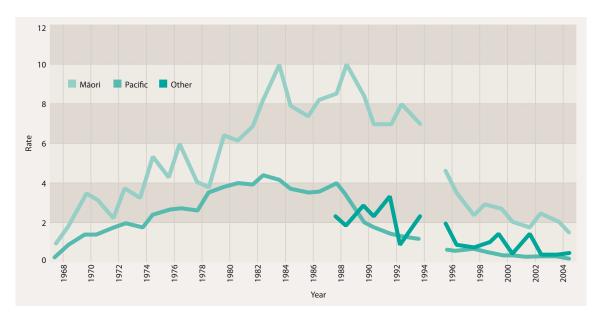




Figure 4 SIDS rates per 1000 live births, by ethnicity 1968-2005

Source: New Zealand Health Information Service, 2008

#### 4.8 USE OF ETHNICITY DATA - A CASE STUDY

This section briefly describes the use of ethnicity data for the monitoring of Māori SIDS.

Figure 4 presents SIDS mortality rates by ethnicity for the years 1968 – 2005. Pacific ethnic group data is only available from 1998 onwards. Direct comparisons between the years before 1995 and those after 1995 are difficult as the method for classifying ethnicity changed from the biological definition to the social definition in 1995. The effects of this change are most evident in the Māori ethnic group, which substantially increased in size. That is, there was a marked increase in the denominator for Māori and the apparent reduction in Māori SIDS rates between 1994 and 1996 is largely due to the increase in denominator rather than a 'true' reduction. Nevertheless, some general observations can be made. Māori SIDS rates have exceeded those of the 'Other' and Pacific ethnic groups in all years. From 1968 both the Māori and Other ethnic groups SIDS rates increased. The rate for Other ethnic group infants peaked at about 4 per 1000 live births in the years 1980 - 1988. The Māori SIDS rate peaked at 8 - 10 per 1000 live births in 1983 – 1993. As the SIDS rates increased, the Māori rate increased more rapidly resulting in a marked widening of the disparities between Māori and non-Māori infants.

The initial results of a major national study to identify the factors associated with SIDS were published in 1991<sup>31</sup>. The study identified four modifiable risk factors: prone sleeping position of baby, maternal smoking, absence of breast-feeding, and bed sharing. A major health promotion programme to reduce these risk factors was designed and implemented in 1991 – 1992. Although Māori

mortality was greater than non-Māori, the intervention was universally targeted and did not include Māori specific messages or mechanisms for implementing the programme in Māori communities. The Other ethnic group SIDS rate fell steadily over the years 1990 - 1994, while the Māori rate fluctuated between about 7 and 8 per 1000 live births, suggesting that the programme was more effective for the non-Māori community. Furthermore, as the non-Māori SIDS rate fell much faster than the Māori rate, the disparity between Māori and non-Māori increased markedly. Specific critique of the universal programme included that: the programme did not include appropriate and effective messages for Māori, did not consider appropriate mechanisms for disseminating the messages among the Māori community, and did not provide culturally acceptable alternatives for bed sharing - a common practice in the Māori community.

In 1994 a Māori SIDS prevention team was established and subsequently implemented a specific Māori SIDS prevention programme across the country. Māori SIDS rates have steadily fallen since 1995. It should be noted that while the data suggests that the Māori SIDS programme was more effective than the universal programme, we are unable to draw absolute conclusions that this was the case as the mortality data is ecologically derived rather than obtained from a specific outcome evaluation of the programme. It should also be noted that there is a yet to be answered question about whether the reduction in Māori SIDS is a 'real' reduction or is an apparent one arising from changes in the classification of the cause of death. The use of 'accidental suffocation in bed' as the cause of death has increased in recent years and is significantly

Improving Māori health status and reducing inequalities in health outcomes between Māori and non-Māori are key objectives for the New Zealand health sector. In order

to achieve these objectives we must able to describe and monitor Māori health outcomes. This requires complete, accurate, reliable, and valid ethnicity data.

#### Māori children's health

- The delivery of childhood immunizations is less effective for Māori children who have lower levels of immunisation coverage than European children
- Data about potentially avoidable hospitalizations suggest that provision of primary care services to Māori children could be improved
- All-cause mortality rates for Māori children under 1 year of age, aged 1-4 years and aged 5-14 years are significantly higher than those of non-Māori children
- For many conditions Māori hospitalization rates exceed those of non-Māori children

more common for Māori infants (see *Table 2*). Whether the use of 'accidental suffocation' instead of 'SIDS' accounts for all the apparent reduction in the Māori SIDS rate is yet to be determined. The final point to note is that although SIDS mortality rates for Māori and non-Māori have dropped, the disparity between Māori and non-Māori persists, and in the years 2000-2004 Māori were more than five times likely to die from SIDS than non-Māori<sup>22</sup>.

#### **4.9 CONCLUSION**

This paper has provided a brief overview of indigenous (Māori) child health in Aotearoa / New Zealand.

Māori children face significant challenges to their opportunities to develop and realize their potential.

Many of these challenges, such as socioeconomic disadvantage, poverty, and poorer outcomes from health services, are located within the structures, institutions, services, and the power relationships inherent in New Zealand society. The disparities in health and social outcomes that are experienced by Māori children are breaches of the rights and protections afforded them by the United Nations Declaration of the Rights of Indigenous Peoples, Universal Declaration of Human Rights and the Treaty of Waitangi.

Improving health and social outcomes for Māori children requires us to collect accurate, complete, reliable, and valid ethnicity data. In addition to reporting these outcomes for Māori children, we must also compare them with the most advantaged children in our society.



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### **Health of Indigenous Children in the United States**

5.1 Introduction. The United States population spends more on health care than any other country in the world. <sup>1-3</sup> And yet, as a whole, the health status of the United States' population lags behind citizens of other industrial nations who spend less on health care. As of 2006, the US was 30th in life expectancy of 30 developed counties. <sup>4</sup> Research shows that not all Americans have equivalent life expectancy. Some studies report that the gap between the highest and lowest life expectancies for a race and geographic combination in the United States is over 35 years. <sup>5,6</sup>

Indigenous people in the United States are among those in the US with the lowest life expectancy.<sup>7</sup> One contributor to the poor health status of Indigenous people in the US is infant mortality. Infant mortality is regarded as an important indicator of a nation's health and social well-being. Some Indigenous groups in the US experience the highest infant mortality rates in the country.

This chapter discusses briefly a number of key issues, including infant mortality, which affects the health of Indigenous children in the United States. In addition, this chapter provides a brief overview of the Indigenous people of the United States and their health status, highlights some lesser known social determinates of health, presents available data on the health of Indigenous children, and describes some major difficulties with the data collected on and for Indigenous people in the country. Finally, this chapter presents a successful strategy to address a number of key challenges; Indigenous epidemiology centers.



In this publication, the Indigenous people of the United States are defined as populations who:

- Have Pre-Invasion/Pre-Colonial Historical Continuity on Territory
- Are Considered Distinct from those Now Prevailing in Territories
- Are in Their Present Form, Non-Dominant Sectors of Society
- Are Determined to Preserve, Develop and Transmit Ancestral Territories and Ethnic Identity to Future Generations

Although many members of these Indigenous communities refer to themselves using traditional names, the United States refers to members of these groups as American Indians, Alaska Natives and Native Hawaiians (AIANNH). There are over 562 federally recognized American Indian and Alaska Native Tribes and many more petitioning and working towards for Federal Recognition or Sovereignty, including Native Hawaiians. The Indigenous peoples of the United States have diverse histories and rich cultures.

According to the most recent US Census in 2000, 4.3 million people, or 1.5% of the total US population, reported that they were American Indian or Alaska Native.<sup>8</sup> Native Hawaiians makes up approximately 0.1% of the US population, and currently numbers 401,000 people. Residing on traditional home lands or

on reservations/homesteads is an important measure for Indigenous communities in the US because many of the resources and services provided to these populations are available only in these areas. While having access to such lands may be equated with greater access to targeted services, for various reasons, both by force and by choice, many Indigenous people have relocated to urban areas or relocated completely off island. An example of such a Diaspora is revealed in the fact that over 67% of American Indians/Alaska Natives (AIAN) and 43% of Native Hawaiians (NH) reside off reservation or off island.8

Similar to other nations, the Indigenous people of the USA suffer grave health concerns.

- AI/AN/NH have lower educational levels and higher unemployment rates AI/AN/NH population is a younger population. Median age AIAN 28.0 years, NH 32 years, compared to 35.3 years for the US All Races.
- Life expectancy for AI/AN 74.5 years (compared to US Population 77.8)
- Diseases of the heart, malignant neoplasm, unintentional injuries, diabetes mellitus, and cerebrovascular disease are the five leading causes of Indian deaths (2002–04).
- Native Hawaiians also have a higher rate of death and disability due to stroke and cerebrovascular conditions than other populations (mortality rate of 58 per 100,000).



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Table 1
Socioeconomic
Characteristics Among
American Indians/Alaska
Natives/Native Hawaiians,
2000

Source: 2000 US Census

	Nationwide Populations		
	AIAN	NH	General
Socioeconomic Characteristics	%	%	%
Income in 1999 below poverty level	22.0	14.6	12.4
Children (age<15) below poverty level	7.5	5.3	3.7
Older than 25 years with a high school diploma or GED	70.9	84.0	80.4
Older than 25 years with 4 year college degree	11.5	10.0	24.4
Reported Disability (5 to 15 years)	2.0	1.6	1.0
Reported Disability (16+ years)         23.5         15.4         18.3			18.3
AIAN=American Indian/Alaska Native; NH= Native Hawaiian			

Accurate health information is essential to effectively address and eliminate current health disparities

- Between age 36 and 64, Native Hawaiians have a rate of diabetes that is over twice that of other populations (79 vs. 34 per 1000).
- Native Hawaiian females have the highest mortality rate from lung, liver, pancreatic, breast, cervical, uterine, stomach, and rectal cancer.

#### **5.3 SOCIAL DETERMINATES OF HEALTH**

Table 1 presents a number of socioeconomic characteristics of the AIANNH population which play a central role influencing health outcomes of Indigenous people in the US These social determinates of health have an effect on the US Indigenous population similar to what is seen in the other countries outlined in this report. Poverty, limited educational attainment, and unemployment are all factors that influence health. AIANNH children are exposed to these determinates and the results are seen in the resultant health disparities.

Previous country sections of this report, as well as numerous studies, have outlined and described the effects of poverty, unemployment, and limited education on health. Therefore, to build on that knowledge and discussion, this section of the report will highlight two social determinates of health mentioned less frequently, but have a grave impact Indigenous communities.

#### **Historical Trauma**

The psychosocial and anthropologic concepts of 'intergenerational trauma' and 'historical trauma' began evolving in the 1960s and 1970s as descriptive research terms after having studied the residual effects experienced by the offspring of World War II Holocaust victims. Historical trauma has since been defined as a cumulative emotional and psychological wounding over the lifespan and across generations, emanating from massive group trauma. Scholars have

examined and applied the effects of historical trauma on Indigenous people. Contemporary symptoms of depression, posttraumatic stress disorder (PTSD) and grief have been attributed to historical trauma.

#### **Loss of Traditional Diet**

One of the most crucial, yet still insufficiently emphasized social determinate of health is the loss of traditional foods. In many cultures food is held sacred. Often times, there are many direct links to food and the creation beliefs. An example of this spiritual relationship can be seen in the Hawaiian creation story:

The taro, or kalo plant originated when the son of Wakea (Sky Father) and his daughter Hoʻohokukalani was born lifeless and deformed like the gnarled root of a plant. The grieving parents buried the baby, but the next day a taro plant sprouted from the grave, which Wakea named Haloa-naka. When the second son of Wakea and Hoʻohokukalani was born, they named him Haloa, because he was the younger brother of taro, from whom all Hawaiians descended. Haloa, first-born man, was to respect and to look after his older brother forever more. In return, the elder Haloa-naka, would always sustain and nourish him and his descendants.

The spiritual connection between food and man in many societies is not a coincidence. For survival purposes, societies were completely dependent on the food they were able to grow and harvest. They chose food products that would ensure their ability to survive and thrive. In the example of the Hawaiian diet, the taro plant, mentioned above, was the major staple of the diet. They considered the plant akin to a god, and believed they ingested his power when they consumed the plant. In addition to strong cultural and spiritual ties to the food source, taro is a nutritional food source.

It is rich in calcium, riboflavin, iron and thiamine, has no cholesterol and almost no fat, and is also used as a medicinal preparation for many ailments.

The social costs resulting from a loss of traditional diet present themselves at both the individual and societal level. Initial costs to the individual begin with the shift from consumption of healthier, traditional foods to the consumption of foods of lower nutritional value. It has been observed globally that when changes in dietary consumption such as these occur, there is a profound increase in dietrelated chronic diseases such as obesity, coronary heart disease, diabetes, high blood cholesterol levels, stroke, etc. These poor health outcomes have the potential of limiting employment opportunities for those individuals where the disease state results in a reduced capacity for work or left the person with physical limitations at performing work. Consequently, reduced employability has an obvious negative consequence on income and social status.

In addition to these individual impacts, there are also a number of societal consequences whenever there is a loss of access to a traditional diet. For example, nutrition transition, especially among Indigenous peoples, has been noted to result in a grave loss of cultural and spiritual connection to traditional food. The very food that has for centuries served as the spiritual, cultural, and physical lifeblood of Indigenous people the world around has suddenly become unavailable or 'unsafe' to consume. This, in turn, lends to the potential demise of those customs and traditions associated with traditional foods. Other challenges to society include rising health care costs due to diet-related diseases. This is especially pronounced when the abandoning of native diets with its inherent

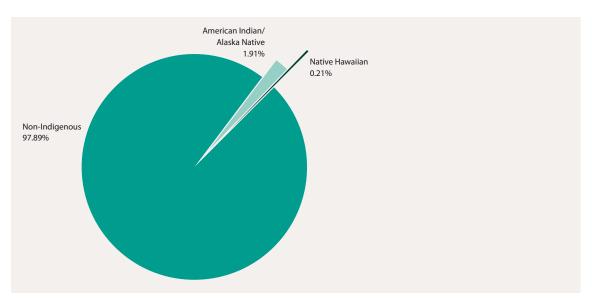


Figure 1
US Children – Ages 0–14
Source: 2000 US Census

protective benefits is substituted for foods with highfat and high-sugar content which can lead to those predictable poor health outcomes. While this is a global phenomenon, government agencies of many countries are ill-equipped and poorly educated to effectively address the resultant increase in costs in health care. In addition, national productivity (i.e. industrial) decreases when work days and school days are missed due to diet-related chronic diseases.

## 5.4 HEALTH OF INDIGENOUS CHILDREN OF THE USA

In the United States there are approximately 1,274,000 American Indian/Alaska Native/Native Hawaiian children between the ages of 0–14. These Indigenous children comprise roughly 2.1% of the total 0–14 age group and more than 25% of the Indigenous population.

The health status of these children mirrors that of their preceding generations, in that there are grave health disparities. A number of key areas of disparities are highlighted within this report.

#### **Infant Mortality**

Infant mortality is one of the most reliable indicators of a nation's health and social well-being. The United States ranked 26th among thirty developed countries in terms of infant mortality rate in 2000 and recent data suggest that the rate of decline in the national infant mortality rate has stabilized. However, for some Indigenous communities in the US, disparities in infant mortality persist and in some instances have even worsened. All of this while proportional risk factors to infant mortality (e.g., rates of low-birth weight) continued to increase. 12-15

Among Indigenous populations in the US, Native Hawaiians experience the highest infant and neonatal mortality rates.<sup>15, 16</sup> American Indians/Alaska Natives also experience high infant mortality rates.<sup>14</sup>

Table 2
Mortality rate per 1,000 live births

Source: CDC, National Center for Health Statistics (NCHS).

Race of mother	Infant	Neonatal	Postneonatal
All races	7.0	4.7	2.3
White	5.8	3.9	1.9
American Indian/Alaska Native	8.6	4.6	4.0
Native Hawaiian	9.6	5.6	4.0



Disease patterns and health disparities among this heterogeneous population have been associated with poverty, limited access to health care services, and cultural dislocation. Much of the research on infant mortality among American Indians/Alaska Natives has focused on Sudden Infant Death Syndrome (SIDS).<sup>14</sup>

Although little is known and documented related to the direct causes of infant mortality, one surveillance project, the Pregnancy Risk Assessment Monitoring System (PRAMS), conducted by the US Centers for Disease Control and Prevention (CDC) as well as state health departments, aim to collect population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. *Table 3* shows a number of key factors associated with poor health and infant mortality for American Indians and Alaska Natives. Comparable data on Native Hawaiians is not available at this time.

*Table 4* shows the mortality rate for AIAN children by age group. Data for Native Hawaiian children is not yet available.

#### Hospitalization

Hospitalization data specific to AIANNH populations is very limited. Many of the complexities related to data

interpretation results from the non-uniformity of health service delivery in the US The US is the only western industrialized nation that relies on for-profit private insurance agencies to fund the cost of health care for a majority of the US population.<sup>17</sup> This has lead to a crisis-level lack of adequate access to health care in the United States for some 45 million people.<sup>18</sup>

Although limited, some hospitalization data is available for American Indians/Alaska Natives. Hospitalization rates for injury among AI/ANs have been published for the Indian Health Service (IHS) service population, but these analyses have not specifically focused on children (IHS). Furthermore, these analyses have used IHS hospital discharge data and may miss AI/AN patients who receive hospital care outside of the IHS system, especially if the payer is other than the IHS. State hospital discharge registries represent another potential source of data for surveillance of hospitalizations, but many do not contain racial or ethnic identification data. If they do, the potential also exists for racial misclassification.<sup>13</sup>

The most widely used source of information on hospitalization is National Hospital Discharge Survey (NHDS). Conducted annually by the National Center for Health Statistics, NHDS collects medical and

		Nationwide	Populations	
	Α	IAN	General	
	%	95% CI	%	95% CI
Poor Birth	Outcomes/Risk Fa	actors (1991-2000	))	
Low birth weight (<2,500 grams)	6.6	(6.5-6.7)	7.4	(7.4-7.4)
Premature birth	12.1*	(12.0-12.3)	11.1	(11.0-11.1)
Mother's age <18	8.2*	(8.2-8.3)	4.8	(4.8-4.9)
Mother unmarried	57.4*	(57.2-57.7)	31.9	(31.9-31.9)
Received late or no prenatal care	7.3*	(7.2-7.4)	3.0	(3.0-3.0)
Smoked during pregnancy	21.1*	(21.0-21.3)	14.3	(14.3-14.3)
Alcohol use during pregnancy	0.3	(0.3-0.4)	0.3	(0.3-0.3)
Factors Associ	ciated with Infant	Deaths (1995-20	00)	
Mother unmarried	65.6	(62.1-69.1)	47.2	(46.9-47.5)
Low birth weight (<2,500 grams)	49.7	(46.7-52.8)	65.2	(64.8-65.6)
Premature birth	50.1	(46.9-53.6)	64.5	(64.1-64.9)
Smoked during pregnancy	29.8	(27.3-32.5)	19.5	(19.3-19.7)
Mother's age <18	10.2	(8.9-11.6)	7.6	(7.4-7.7)
Alcohol use during pregnancy	7.4	(6.2-8.9)	2.3	(2.2-2.4)
Received late or no prenatal care	7.1	(5.9-8.4)	2.7	(2.6-2.7)

Table 3
Poor Birth Outcomes/
Risk Factors and Factors
Associated with Infant
Death Among American
Indians/Alaska Natives

\*Significantly higher for AIAN compared to the general population

	AIAN		All Races Combined	
	Rate per 100,000	95% CI	Rate per 100,000	95% CI
	Less tha	an 1 Year		
All Causes	782.17	(753.49, 811.7)	715.11	(712.15,718.08)
Congen malfrm/defrm/chrm abn	147.72	(135.41, 160.87)	140.85	(139.54, 142.17)
Accidents and external causes	41.24	(34.87, 48.46)	22.84	(22.31, 23.37)
Influenza and pneumonia	22.95	(18.27, 28.47)	7.57	(7.26, 7.88)
Diseases of heart	19.46	(15.17, 24.59)	13	(12.6, 13.4)
Assault (homicide)	16.2	(12.31, 20.92)	8.3	(7.98, 8.62)
	Age	e 1-4		
All Causes	47.53	(44.19, 51.07)	32.79	(32.47, 33.11)
Accidents and external causes	19.25	(17.15, 21.55)	11.62	(11.43, 11.81)
Assault (homicide)	4.07	(3.14, 5.2)	2.49	(2.40, 2.58)
Congen malfrm/defrm/chrm abn	3.96	(3.04, 5.07)	3.4	(3.30, 3.50)
	Age	e 5-9		
All Causes	47.53	(44.19, 51.07)	32.79	(32.47, 33.11)
Malignant neoplasm (MNP)	19.25	(17.15, 21.55)	11.62	(11.43, 11.81)
Assault (homicide)	4.07	(3.14, 5.2)	2.49	(2.4, 2.58)
Accidents and external causes	3.96	(3.04, 5.07)	3.4	(3.3, 3.5)
Age 10-14				
All Causes	24.11	(22.16, 26.19)	20.11	(19.89, 20.32)
Accidents and external causes	12.44	(11.05, 13.95)	7.9	(7.76, 8.04)
Intent self-harm (suicide)	2.4	(1.82, 3.12)	1.35	(1.29, 1.41)
Assault (homicide)	1.2	(0.8, 1.74)	1.13	(1.08, 1.18)
CI=confidence interval				

Table 4

American Indians/Alaska

Natives Children Mortality

demographic information from a sample of inpatient discharge records selected from a national probability sample of non-Federal, short-stay hospitals. The data serve as a basis for calculating statistics on hospital inpatient utilization in the United States.

Race is not reported in about 18% of NHDS records since data on race are not reported by many hospitals due to the omission of a race field on hospital discharge reporting forms.<sup>19</sup> More hospitals have automated their discharge systems in recent years and are currently using a form which does not require race reporting.

Because population based, hospitalization data for US Indigenous children is not available at this time, a special focus highlighting areas of concern is included for this report.

Limitations in the health population data make it nearly impossible for communities

#### Injury

Injuries are a leading cause of childhood morbidity and mortality throughout the world. Although there have been substantial declines in the rates of death from injuries among children in developed nations, it still remains the principal threat to the health and welfare of children and adolescents. American Indians and Alaska Natives (AI/ANs) have higher rates of injury morbidity and mortality than all other races.<sup>20</sup> In addition, AI/AN children experience higher rates of morbidity and mortality from unintentional injuries than do other US children. The 881 injury deaths to AI children between 1992 and 1994 translate to an overall rate of 52.3 deaths per 100,000 children per year. This rate is nearly twice the US rate of 28.3 per 100,000 children for all races (1993).<sup>21, 22</sup>

to advocate for resources to create culturally appropriate care

A particularly revealing study which examined hospitalizations for AIAN youth provides an analysis highlighting one area of health disparities existing in the US<sup>23</sup> In this analysis, a total of 694 hospitalizations for injury were identified for AI/AN youth and 29,048 were identified for all races. *Table 5* presents findings from this study. In summary, AI/AN children experience a disproportional rate of hospitalizations due to injury and therefore more efforts to reduce injury are critical for this population.

#### Diarrhea

For 2000–04, diarrhea-associated hospitalization rates were similar for AI/AN children versus US children <5 years of age (65.9 and 79.3 of 10,000, respectively).<sup>24, 25</sup> However, the rate among AI/AN infants was nearly twice the rate among US infants (262.6 and 154.7 of 10,000, respectively). The rate of diarrhea-associated outpatient visits among AI/AN children was higher than for US children (2,255.4 versus 1,647.9 of 10,000, respectively), as a result of the high rate among AI/AN infants compared with US infants (6,103.5 and 2,956.3 of 10,000, respectively).<sup>26</sup> Understanding the causes of these disparities among AIAN infants is an important endeavour to undertake.

#### **Otitis Media**

Otitis media (OM) is one of the most common and costly health problems that affect children younger than five years in the United States.<sup>27, 28</sup> Approximately half of US children have an episode of OM before their first birthday, and nine out of ten children have an episode by five years of age.<sup>29</sup> Studies report the rates of OM-associated hospitalization were significantly higher for AI/AN children than for all US children 1,542 vs. 1,021 per 100,000 children/y. 30 As with OM-associated outpatient visits, much of the disparity in OM hospitalization rates was attributed to the difference among infants (1994–1996 rates: 5,643 vs. 2,440 per 100,000 infants/y, 823 vs. 665 per 100,000 1-to 4-year-olds/y).

#### **5.5 CRITICAL AREAS OF FOCUS**

#### Type 2 Diabetes Mellitus

Type 2 diabetes mellitus is a new morbidity trend amongst children and adolescents.<sup>31-34</sup> For pediatric patients, it is an ominous risk indicator for the earlier onset of cardiovascular disease, retinopathy, nephropathy, and neuropathy, along with its increased morbidity/mortality risks of impaired quality of life and premature death.31 The emergence of type 2 diabetes mellitus in young people is believed to be associated with overall decreased physical activity and poorer nutrition; negative factors which are ubiquitous in modern society. However, not all populations are equally affected. American Indian/Alaska Native (AI/ AN) children in the United States have a higher rate of this disease than do children of other ethnicities.<sup>35</sup> Rates and disease patterns in the population provide evidence that this is also a growing concern for Native Hawaiian children. In US children, the prevalence of type 2 diabetes mellitus is expected to exceed that of type 1 diabetes mellitus within 10 years. There is an undeniable need for additional research, primary and secondary prevention efforts, and evidence-based treatment for youth at risk for type 2 diabetes mellitus, paying special attention to AIANNH children.

#### **Sudden Infant Death Syndrome (SIDS)**

The Back to Sleep campaign, lead by the National Institute for Child Health and Human Development (NICHD) has resulted in an overall decline in SIDS rates of about 50%. While the decline has occurred in all segments of the population, it has been less in American Indian and Alaska Native (AI/AN) communities. A recent report showed that AI/AN infants were still almost three times more likely to die from SIDS as white infants, and the rates are particularly high in Alaska and the Northwest and Northern Plains of the continental United States. 21, 36

Studies have been conducted to investigate causes for regional differences. One study conducted in the

	Rate	Incidence Rate	95% CI
Hospitalization for Injuries – Discharges	507/100,000	1.30	1.20, 1.40
Motor Vehicle		1.73	1.49, 1.40
Falls		0.95	0.79, 1.15
Poisonings		1.20	0.80, 1.78
Fire		2.35	1.42, 3.87
Cl=confidence interval			

Table 5
Youth Hospitalizations
Resulting from Injury
Among American Indians/
Alaska Natives



Aberdeen area found that binge drinking (five or more drinks at a time) during the mother's first trimester of pregnancy made it eight times more likely that her infant would die of SIDS.<sup>36</sup> Any maternal alcohol use during the periconceptional period (three months before pregnancy or during the first trimester) was associated with a six-fold increased risk of SIDS. The study also found that infants were more likely to die of SIDS if they wore two or more layers of clothing while they slept.<sup>36</sup>

#### **5.6 CHALLENGES IN DATA COLLECTION**

Local, state and federal public health institutions routinely develop, coordinate, and maintain surveillance systems for the US populations; however, major gaps exist for Indigenous communities. Although various departments of health collect data which might include Indigenous populations, it is atypical for the surveillance data to be disaggregated or separately analyzed for the population. The occurrence of sub-analysis and/or the availability of this data vary

between the different health departments. Federal public health institutions may conduct national surveys (through state agencies) which provide national and state data for monitoring various health indices. However, small population numbers, low response rates, and the lack of dis-aggregation for analyses are some examples of why such analyses have failed to be forthcoming. This continues to be one of the ongoing challenges faced.

One solution to this data survey discrepancy is to perform sub-population oversampling. Unfortunately, this requires additional financing and consequently may not be frequently considered or incorporated.

Until recently, no national data was available on the health of Native Hawaiians. Data was only collected for the aggregate population group, Asian/Pacific Islanders (Asian/PI). Asian/PI encompasses many distinct cultures and as a consequence, the disparities affecting NH become invisible under this system. Current efforts to describe the health of NH are challenged due to sample size limitations and under counting. As

An example of successful strategies employed in the U.S. Indigenous communities are the creation and establishment of the Tribal Epidemiology Centers.



more government agencies adopt and implement the new Federal data collection guidelines on race which specifically identifies NH separately from the larger Asian category, more data will be available and the health status of the now identifiable sub-population can be measured and monitored with greater accuracy.

Recent literature provides strong evidence of how essential accurate health information is in effectively identifying and eliminating current health disparities. Limited or inaccurate population health data is a core problem for Indigenous communities. Data is needed to create culturally appropriate health programs, identify areas of need, and for advocating on behalf of the community. Such efforts could redress the health disparities and would result in improved access and affordability of health care. Inaccuracies and deficiencies in the health population data due to misclassification and aggregation make it nearly impossible for subpopulation groups to advocate for resources to create culturally appropriate care essential to address health needs.

## 5.7 COMMUNITY-BASED STRATEGIES AND SOLUTIONS

In recent years, the Indigenous communities of the US have expressed interest in increasing their understanding, capacity in effective use, and control over health data for the purposes of developing programs and in forming policy. Indigenous communities express a clear understanding of the value of data, and especially of high quality data, as a tool for making better program and funding decisions that will have demonstrated benefits for their community members. This insight and strategy is tremendously important for any program wishing to strengthen and expand its use of health data.

An example of successful strategies employed by Indigenous communities within the US is seen in the creation and establishment of the Tribal Epidemiology Centers. Funded by the Indian Health Service, Tribal Epidemiology Centers are community or Tribal-based organizations that plan, coordinate, and perform essential public health services necessary to address

the health deficiencies specific to AIAN. In 2009, the Native Hawaiian health organization, Papa Ola Lokahi, announced the establishment of its own Indigenous epidemiology center.

Effectively addressing the health and wellness of the US Indigenous populations demands a greater accountability with sound planning and development. Central to this effort is consistent, specific, and standardized data collection and the utilization of that information which addresses all factors affecting Indigenous health. Indigenous epidemiology centers manage public health information systems, investigate diseases of concern, manage disease prevention programs, and coordinate activities with other public health authorities. The Indigenous epidemiology centers focus on collaboration with existing public health entities and filling gaps in the public health system where Indigenous populations' needs might otherwise go unnoticed.

#### **5.8 CONCLUSION**

In reviewing data for this chapter, a number of challenges were raised, particularly since no prior report has detailed health issues facing American Indians, Alaska Natives, and Native Hawaiian children collectively. A key challenge was the availability of quality data for all Indigenous children in the United States. Thus, data which highlighted or reported the health of the United States Indigenous people was limited; only subsections of the people were highlighted, data was regional, or the data excluded a substantial proportion of the population (e.g. off-reserve populations and non-federally recognized people). Unfortunately, the special and unique relationship formalized between the US government and the nation's first and original people does not ensure systematic, standardized, and comprehensive monitoring of health. This negligence, whether intended or unintended, has serious deleterious effects on the Indigenous children in the US, as many health issues may go unmonitored and unmeasured. Without careful attention and prioritization of Indigenous children in the US, many will continue to suffer grave disparities.



Indigenous epidemiology centers manage public health information systems, investigate diseases of concern, manage disease prevention programs, and coordinate activities with other public health authorities

Despite the limitations of low quality data, findings show that Indigenous children of the US carry a disproportionate weight of the burden of poor health in the country and efforts must be made to improve their health status. In a nation as wealthy as the United States, children should always have access to health care. Timely access to culturally sensitive and high quality health care is central to improving the health of Indigenous children.

In addition to the health challenges which could be resolved by access to quality health care, a number of health issues faced by Indigenous children could be addressed through support services to families. Social determinants of health such as poverty, employment, and education can have a greater impact on health then access to health care.

Most importantly, efforts must be made to support the resurgence of Indigenous culture, language, and traditions. Resiliency of traditional practices, access to traditional foods, and the resurgence of Native languages help to address the effects of colonization. Local community based solutions which support traditional practises, coupled with community based solutions to monitor progress towards improving health (i.e. Indigenous epidemiology centers) will enrich the lives of Indigenous people in the United States, resulting in improved quality of life for Indigenous children.

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# Indigenous Child Health Stakeholder's Meeting — Discussion and Recommendations

6.1 Introduction.. The chapter presents a summary of findings from discussion groups held with key First Nations, Inuit, and Métis child health stakeholders in Canada and the international authors. The summary is derived from *The Health of Indigenous Children: Health Assessment in Action Meeting* held at St. Michael's Hospital, Toronto, Canada, on May 30th, 2008. This important meeting brought together a diverse mix of twenty-one health professionals, policy makers, community representatives, analysts and researchers working in the field of Indigenous children's health from Canada, New Zealand, Australia, and the United States. (Participants are listed in Appendix A). Discussion topics included: identification of key health issues; best practice ideas; and policy approaches. This summary is a reflection of the stakeholders enthusiasm and passion for improving Indigenous children's health in both a Canadian and international context.



#### **6.2 PROCESS**

#### **Presentations**

At the meeting, Canadian and international authors shared their knowledge with stakeholders on current Indigenous child health assessment information and best practices from each presenter's home country. Presentations focused on commonly used children's health measures as well as Indigenous-specific measures where available. Please refer to previous chapters for more in-depth accounts of Indigenous children's health assessment in individual countries.

#### **Group Activities and Feedback**

Following the presentations, those at the meeting participated in two discussion group activities. The first activity involved small group discussions. The second activity was a large group discussion involving everyone in attendance. Following the meeting, all the priorities and recommendations identified and discussed were summarized and provided to participants via email for review and clarification. This final report summary incorporates that additional feedback.

#### **Group Activity 1**

Participants were organized into three groups: First Nations, Inuit, and Métis. Each group brainstormed ideas, provided insights and developed a list of:

Community autonomy and selfdetermination do not necessarily need to be incompatible with using other western tools for accurate data collection

- (a) key health status inequities and / or issues facing Indigenous children (First Nations, Inuit and Métis respectively)
- (b) priority areas for Indigenous children's health assessment and response

The groups then presented the lists they had generated to the larger group. These lists were later arranged by the chapter authors into the following broad theme groups: Social Concerns; Health Concerns; and Health Service Delivery Concerns.

#### **Group Activity 2**

Following the first group activity, a larger group discussion took place to identify:

- (a) Indigenous child health assessment and response issues that cut across First Nations, Inuit, and Métis groups
- (b) best practice ideas for Indigenous children's health assessment and response
- (c) policy approaches to Indigenous children's health assessment and response (i.e. balancing the right to be counted, OCAP (ownership, control, access and possession of information), Indigenous right to participate in governance and management of health data, and the rights of children)

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#### **6.3 GROUP ACTIVITY 1**

Table 1

Small Group One – First Nations		
Inequities / Priorities	Additional comments from flipcharts / mini-group presentations	
Social Concerns		
1. Poverty		
2. Housing		
3. Education	<ul> <li>Lack of access to quality on-reserve education</li> <li>Difficulty accessing off-reserve education</li> <li>Post and secondary retention rates</li> <li>Sustainable costs</li> </ul>	
4. Food security		
5. Child welfare	– Family violence; foster care; abuse	
6. Environmentally related impacts	<ul> <li>Environmental contamination and some cancers linked to child health</li> </ul>	
7. Experiences of racism	<ul> <li>Interpersonal &amp; institutional (systemic) racism affecting accessibility to services</li> </ul>	
Healt	h Concerns	
1. Oral health	<ul> <li>Access to fluoridation in water; access to receive treatment (anesthetic waiting lists)</li> </ul>	
2. Obesity	<ul> <li>Links to other chronic conditions including diabetes / hypertension</li> </ul>	
3. Cervical Cancer Screening* (see below)	– Implications of HPV vaccinations	
<ul><li>4. Special needs:</li><li>Autism</li><li>Fetal Alcohol Syndrome</li></ul>	<ul> <li>Stereotypes and stigma associated with labeling and the potential for this to impact service accessibility</li> </ul>	
5. Hearing (Otitis Media)		
Health Service Delivery Concerns		
<ul><li>1. Lack of coordinated care</li><li>Multiple visits with different care providers / specialists</li></ul>	- Need for a harmonization of services	
	Other	
1. * Scope of the proposed Report	<ul> <li>- * Clarification required re: 'just' Child health - or Child and Maternal Health?</li> <li>Need to note linkages between these.</li> </ul>	

Small Cray	na Tura I lauria	
Small Group Two – Inuit  Additional comments from flipcharts /		
Inequities / Priorities	mini-group presentations	
Social	Concerns	
<ul> <li>1. Schooling</li> <li>Quality of education/curriculum</li> <li>Workforce</li> <li>Historical family experiences</li> <li>Pre-school and Day Care needs (especially with economic development drive)</li> </ul>	<ul> <li>Workforce/Human Resources (across sectors; Inuit capacity; retention)</li> <li>Increase Aboriginal Head Start programs.         Making the system work better for Inuit children – improving retention in Education     </li> <li>Second languages and bilingualism</li> <li>Balancing women in the workforce and the needs of their children</li> </ul>	
<ul><li>2. Housing</li><li>Quality of housing</li><li>Overcrowded housing</li><li>Health impacts of poor housing</li></ul>	<ul> <li>Respiratory illnesses and infectious diseases</li> <li>Reduced schooling</li> <li>Social impacts</li> <li>How do Inuit access quality housing?</li> </ul>	
Food Security     Multifaceted	<ul> <li>Traditional economy: hunter / gathering / fishing and how to preserve this</li> <li>Implications of foods and their links to oral health</li> <li>Links between workforce and being able to access oral health</li> </ul>	
4. Exposure to violence		
Health	Concerns	
1. Mental Health		
2. Suicide	<ul><li>Suicide awareness</li></ul>	
	Delivery Concerns	
1. Lack of child-centered care	Limited access to healthcare/doctors	
<ul><li>2. Lack of data</li><li>'Next to nothing'</li><li>Limited mortality information</li><li>Data use and accessibility</li></ul>	<ul> <li>Establish data protocols with researcher accountability; researchers need to return information back to the community</li> <li>Include statistics on resilience outcomes from 'on the land' programs etc.</li> <li>Data to reflect regions and communities as well as 'national' (total Inuit) population</li> </ul>	
0	ther	
Nurturing intra-cultural resilience and wellbeing	<ul><li>Inuit traditional values:</li><li>On the Land &amp;'Country Food'</li></ul>	

Table 2

Small Group Three – Métis		
Inequities / Priorities	Additional comments from flipcharts / mini-group presentations	
<ul> <li>1. Health Status Inequities are unclear because of:</li> <li>lack of ability to measure</li> <li>lack of consistent terminology</li> <li>Data is required to provide reasons as to why these events occur</li> </ul>	<ul> <li>Currently no baseline data records / measurements for infant health exist – so difficult to paint an accurate &amp; ongoing picture of Métis health or to plan more appropriate health service delivery</li> <li>Cross-jurisdictional challenges</li> <li>Communities to identify the health and wellbeing indicators that are relevant to them:         <ul> <li>interpreted in context (community norms &amp; mores could be reflected within these indicators)</li> <li>Community to be involved as a Data Working Group &amp; provide input on a 'Data Dictionary'</li> </ul> </li> </ul>	
Social	Concerns	
1. Racial discrimination	<ul> <li>Lateral violence is an issue that is often articulated by Métis and can be more common and destructiv than within First Nation Communities</li> <li>Discrimination exists within families, between communities as well as from other Aboriginal communities</li> </ul>	
2. Kinship / Family	<ul> <li>Acceptance of heritage or lack of recognition, generational effects of abuse may be present due to a number of factors not excluding residential school experience</li> <li>Domestic violence, 'parenting' knowledge &amp; strategies</li> </ul>	
3. Food security		
4. Housing security		
Health	Concerns	
<ol> <li>Infant mortality – reproductive health</li> <li>Mental wellbeing</li> </ol>	<ul> <li>Pre-conception and pre-natal</li> </ul>	
3. Mobility	<ul> <li>Highly mobile population intra and intergenerational mobility thus difficult to identify actual numbers, and deliver programs when population is often in flux</li> </ul>	
Health Service	Delivery Concerns	
1. Pre-natal care		

Table 3

#### **6.4 GROUP ACTIVITY 2**

## A) Cross-Cutting Indigenous Children's Health and Health Assessment Issues and Priorities

As evident from Group Activity 1, many of the issues affecting the health of Indigenous children are cross-cutting for First Nations, Inuit and Métis populations. Some similarities / commonalities were also identified and shared with the Canadian stakeholders by international guest speakers from New Zealand, Australia and the USA. Although the following cross-cutting areas of concern were identified as priority areas, they are not listed in any hierarchy. It is also acknowledged that these issues are not seen as occurring in isolation from one another, but rather are undoubtedly inter-related.

#### Social Concerns

- Poverty
- Housing
- Education / Schooling
- · Food Security
- Child Welfare / Exposure to Violence
- Racial discrimination as a determinant of health affecting access to services and quality of care in services

#### Health Concerns

- · Oral health
- Hearing health
- Diabetes, Obesity & other chronic diseases
- · Respiratory & other infectious diseases
- · Mental health

#### Health Service Delivery Concerns

- Lack of child-centered care
- · Lack of coordinated care

#### Health Status Inequities and IMR

- Health status inequities for Indigenous children are currently unclear because of the inability to accurately measure them
- Need for the development and/or improvement of both data collection and data sharing protocols in a manner that is respectful and ensures cultural safety for Aboriginal groups

#### B) Best practice ideas

Best practice ideas generated from discussions at the meeting reflected the concept of 'Practice Partnerships'. This included more consultation, engagement and involvement amongst researchers, public health practitioners and Aboriginal communities. This would

provide communities with the time and space to identify, utilize and then apply health data products to benefit their children. Most importantly, practice partnerships would foster increased opportunities for engaging with and drawing on the expertise of Aboriginal community leaders. This was seen as a fundamental and necessary for establishing trust and negotiating ownership of data for Aboriginal communities.

In the spirit of best practice partnerships and in light of Canada's colonial history, it was identified that community autonomy and self-determination do not necessarily need to be incompatible with using other 'western' tools for accurate data collection. Participants recognized that attempts to achieve a balance in this sense must account for the differences in historical perspectives and experiences of First Nations, Inuit and Métis. Understanding these differences when informing best practice and policy initiatives is important, for it avoids the mentality of 'a one size fits all' approach to Aboriginal issues. As such, it reduces the social fallacy of Aboriginal essentialism and promotes a space for recognizing and celebrating the diversity of First Nations, Inuit, and Métis in Canada.

Participants highlighted that action was required to strengthen and increase the capacity for Indigenous communities to identify issues and address inequities in relation to data collection (or lack thereof) which continue to have huge impacts on the health of Aboriginal children. This action is important because current data sets are skewing (underestimating / misrepresenting) infant and child morbidity and mortality rates for our children. Again, the notion of best practice and sustainable partnerships was raised as one way for reducing the chance of data misuse or misinterpretation. This would be seen in practice as advocating for community representatives, public health data practitioners, and other stakeholders to work together. One example of this discussed at the meeting came from the SOGC (Society of Obstetricians and Gynecologists of Canada). The SOGC stated their strong interest in collaborating with Aboriginal groups, noting that addressing Indigenous maternal and child health data problems and discrepancies could greatly contribute to the improvement of Indigenous children's health.

Some Aboriginal community representatives also identified that there was a mismatch between what academic institutions recognized as 'research' and what Aboriginal communities 'need' as 'action' and 'deliverables'. As a result, best practice would need to take account of research and data collection approaches that incorporate the *timely* needs and desires of the

There is currently a mismatch between what academic institutions recognize as research and what Aboriginal communities need as action and deliverables

community, so that research and data collection translates into tangible outcomes and benefits for Aboriginal communities. Part of this best practice process would involve increasing the capacity for Aboriginal communities and researchers to have their community based health research approaches (as CIHR guidelines for research involving Aboriginal peoples advocate) recognized and funded accordingly for ongoing sustainability.

#### C) Policy Approaches

A central theme to the meeting discussions was the development of balanced policy and practice approaches to the collection of Indigenous child infant mortality and morbidity data in Canada. These approaches call for the need to balance the right to be counted, with OCAP Indigenous right to participate in governance and management of health data, and the overarching rights of children.

Policy and practice considerations discussed at the meeting reflected the complexities associated with orchestrating and implementing initiatives aimed at improving Indigenous children's health. Having no standardized data collection methods, little statistical data readily available to accurately identify health status inequalities (or even where they stem from in relation

to Indigenous infant and child morbidity and mortality rates), is in itself a major public health issue; arguably one that speaks to colonization and many of its ongoing guises. As Aboriginal people we can not, nor should we, ignore the power dynamics inherent at a functioning social systems level between non-Aboriginal and Aboriginal Canada - for it is these power relationships that shape and determine what is socially 'significant' and worth 'measuring' in terms of health status inequities. One thing we can say with certainty is that our meeting and the discussions generated demonstrated the shared commitment to improving the health of Aboriginal children in Canada - for they are our future. Having established our dedication to improving the health of Aboriginal children, the next obstacle to overcome is how we work together with diverse Aboriginal communities to achieve improved health outcomes for our children.

As any good healer knows, before you can begin to treat it helps if you can first identify the poisons. One major concern at the moment is that we do not have an accurate picture of Indigenous child health status. Thus, we are unaware of the specific 'poisons' we are dealing with. Any policy or best practice designed to change this lack of knowledge will therefore need to be well informed and be able to engage community support.

Any policy and practice initiatives formulated that consider the rights of children, the right to be counted, and the rights of Aboriginal communities to participate in the governance and management of their health data will have a host of complex questions that must be addressed. Due to the social, political, economic, and health ramifications we should ask ourselves: 'What are the costs associated with opting out of census in terms of political repercussions and funding? What will be the repercussions of this on smaller Aboriginal groups being able to run their own data systems independently? How does this sit with vital statistical information?'

To help navigate our way through some of these complex questions in relation to our approaches to policy and practice in the area of Indigenous child health data collection, participants at our meeting shared their ideas in relation to both policy concepts / ideas, as well as actual policy strategies.

#### Policy Concepts / Ideas

Policy concepts that emerged from our meeting were heavily focused on establishing policies and practices that support the preservation and protection of Indigenous OCAP (Ownership, Control, Access, Possession) principles. This would include reserving the right for Aboriginal groups to collect data for themselves and operationalize this for themselves - without necessarily having to share this data with other Aboriginal groups. This reflects that some Aboriginal groups may prefer not to share data with other Aboriginal groups in an 'overarching' macro-Aboriginal health agenda and this should be respected. This raises an important implication for policy formulation in terms of avoiding a 'one size fits all' approach. Flexibility and scope for maneuverability in relation to tailoring policy approaches that are applicable to specific Aboriginal groups will therefore be necessary. This does not mean that individual Aboriginal communities and groups are not interested in the collection of data for improving child and maternal health. It also doesn't mean that all Aboriginal groups/communities agree with OCAP principles.

Flexibility in policy and practice approaches is also necessary in light of some Aboriginal groups' strong belief that if an issue within their community needs to be 'studied' then they themselves should be the ones initiating this study first. Help would be sought from outside the community only if it is required. This stands in stark contrast to historical policy and practice initiatives that view Aboriginal community health issues through a western frame, dictating from the 'outside', 'What is needed'. In this instance, these

Aboriginal groups follow the concept of *initiating*, *controlling*, and having *ownership* over research data and research practice.

Different experiences for different Aboriginal groups however, may not necessarily mean that different truths and perspectives are incompatible. For instance, Métis people have been completely ignored in the collection of health status data, and this in itself is a major health status inequity. Some communities, including Métis, have not been funded for infrastructure around health or other socially related data collection. In a practical sense, the notion of integrating Indigenous and Western knowledge when developing policies aimed at working with Aboriginal communities would need to involve Aboriginal communities taking a pro-active approach in the research/data collection process. This will help to identify the health and wellbeing indicators that are relevant to each communities needs. In so doing, community norms and mores would be reflected in those indicators. Our strength and creativity as Aboriginal people affords us the ability to identify the scope and potential opportunities for us to explore avenues for improving our children's health, whilst at the same time respecting diversity between and within Aboriginal groups and our sovereign right to participate in the implementation and sharing of our children's health data.

#### **Policy Strategies**

One key policy strategy that emerged through our discussions included being respectful of the ownership and use of data. Developing partnerships and protocols for the sharing of information between Aboriginal groups and data collection agencies is therefore a major priority. So too is respecting that data from multiple sources may be conflicting or contradictory. Again, this is where knowledge sharing between Aboriginal groups and researchers can help to clarify data and what data means.

Additionally, the meeting discussions addressed the need for communities and researchers to work together in lobbying as advocates for improvements in children's health and to use community lobbying platforms to drive and inform policy on the issue of data collection, ownership and sharing agreements. Appropriate policy was identified as a critical and crucial step in the development of data collection. The use of culturally meaningful marketing strategies was identified as an important policy strategy to give communities a better understanding of how data collection initiatives can help us to provide better services and improve the health of children in Aboriginal communities.





### **Concluding Remarks**

## **Finding Strength in Numbers**

Eighteen months ago Health Canada approached me to write this report. Although enthusiastic about the task at the time, I did not anticipate the broad scope and new depths of knowledge about Indigenous children's health that this project has generated. The quality and comprehensiveness of this final product is rooted in a fundamental commitment by all of the writers and participant stakeholders to the health and wellbeing of Indigenous children not only in this generation, but for many generations to come. Action to ensure that Indigenous children begin to experience the same levels of prosperity, environmental nurturance, access to health services and wellbeing that most non-Indigenous children take for granted in our relatively affluent countries is long overdue.

In Canada, jurisdictional complexities are often used as an excuse for double standards in Indigenous/ non-Indigenous health assessment and response. Commonly, the argument is between the provinces/ territories and the federal government as to who holds the responsibility for Indigenous health and public health assessment and service. Unfortunately, more often than not, the argument is not clearly resolved and there is a resultant lack of action. It is First Nations, Inuit, and Métis children who end up experiencing avoidable suffering as a result of these stalemates. It is one of the causes of the deficiencies in Indigenous child health assessment data in Canada, and also results in significant challenges in access to care. For example, in 2005 a chronically ill and disabled First Nations child by the name of Jordan River Anderson died in a Winnipeg hospital, far away from his family and

home community in northern Manitoba, because the federal and provincial government argued for over two years over which government would be responsible for the cost of his home health care. In response to this situation, Jordan's Principle, a child first approach to resolving jurisdictional disputes within and between the federal and provincial/territorial governments¹ was developed as a private members bill and unanimously approved by federal parliament. Jordan's Principle requires that the government of first contact pays for the service to the child without delay or disruption. Although it is now legislated, Jordan's Principle has yet to be implemented.

This report provides a convincing example of the value that can be added by forming partnerships and working across jurisdictions - locally, regionally, nationally, and internationally. Collaborating internationally in the production of this report has provided an opportunity for the authors to highlight the Indigenous child health disparities that exist in each of our countries and also identify a number of crosscutting issues. The report is crafted as a reference and advocacy tool for Indigenous child health stakeholders committed to ensuring the prosperity, environmental nurturance and well being of Indigenous children around the world. Hopefully these stakeholders will similarly find "strength in numbers" both through mutual collaboration and the figures shared in the preceding chapters and with this renewed energy continue to press for the policy actions required to address Indigenous children's health disparities at home and abroad.

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<sup>1</sup> http://www.fncfcs.com/docs/ JordansPrincipleFactSheet.pdf





### **Appendix A**

## **Stakeholder Meeting Participants**

Indigenous Children's Health Report Stakeholder Meeting Friday May 30th, 2008 St. Michael's Hospital

Please note that attendants' participation at the stakeholder meeting does not indicate an endorsement from their respective organizations for the information contained in this report. We acknowledge with thanks their time and contributions to the engaging discussions that took place.

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