# CHILDREN AND YOUTH IN CARE: An Epidemiological Review of Mortality, British Columbia, April 1974 to March 2000

A Technical Report of the Office of the Provincial Health Officer

In Cooperation with the Ministry for Children and Families, the B.C. Children's Commission, and the B.C. Vital Statistics Agency



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### 1. Summary

### A. Comparisons of Children and Youth in Care (CYIC) with the B.C. Child Population.

- Children living with severe disabilities are proportionately over-represented in the CYIC caseload, relative to the provincial child population.
- All CYIC, regardless of functional ability, had higher mortality rates for All Causes than the provincial child population, and particularly so for Natural Causes in CYIC living with a physical disability.
- Those CYIC living with a physical disability comprised 12.9% of the CYIC caseload, but experienced 52.7% of the deaths of CYIC.
- Those CYIC living with a physical disability had a much higher mortality (statistically significant) due to All Causes and Natural Causes, relative to functionally average CYIC, but an apparently higher mortality due to External Causes was not statistically significant.
- Those CYIC living with an intellectual and/or behavioural disability did not have an increased mortality rate in comparison with the functionally average CYIC, for All Causes, Natural Causes, or External Causes.
- The CYIC population differs from the provincial child population in age composition, with relatively fewer younger children (ages 0-4 and 5-14 years) and more older children (ages 15-18 years).
- The age composition of the CYIC population has changed significantly over time, with a proportionate increase in younger children (ages 0-4 and 5-14 years) and a decrease in older children (ages 15-18 years), such that the CYIC age composition has gradually become more like that of the provincial child population.
- There were statistically significant differences in All Causes mortality between age groups in the CYIC population, highest in ages 0-4 years, and lowest in ages 5-14 years. This pattern of

Comparative Demographic Characteristics, CYIC and Provincial Child Population, B.C., 1985/86 to 1999/00

Frovincial Clind Fobulation, B.C., 1965/66 to 1999/66			
Characteristic	Percent of Individuals		
Characteristic	CYIC	B.C. Child Population	
Age 0-4 5-14 15-18	16.3 44.5 39.3	26.1 52.7 21.2	
Gender Male Female	51.5 48.5	51.3 48.7	
Ethnicity* Aboriginal Non-Aboriginal	32.4 67.6	5.7 94.3	
Functional Status** Mild or Moderate Disability Severe Disability Average/No Disability/Not Recorded***	33.5 18.3 48.2	7.9 0.4 91.7	

mortality was similar to, but greater than, the mortality of the provincial child population.

- The mortality of CYIC was significantly higher than that of the provincial child population in all age groups for both Natural and External Causes.
- There was a statistically significant higher mortality of CYIC ages 0-4 years for Natural Causes, and ages 15-18 years for External Causes, a pattern which was similar to the provincial child population.
- The cumulative age-specific mortality rates for CYIC exceeded that of the provincial child population for both genders, for each age group, and for Natural, External, and All Causes, with the only exception being males aged 5-14 years for External Causes, where the mortality rates were similar for CYIC and the provincial child population.
- The cumulative All Causes mortality for CYIC did not differ significantly by gender for all ages (0-18 years), ages 0-4 years, or ages 15-18 years, however, there was a statistically significant higher mortality for female CYIC ages 5-14 years.
- There was no statistically significant difference by gender in the cumulative Natural Causes or External Causes mortality for CYIC for all ages (0-18 years) or any of the age groups concerned.
- Aboriginal children are over-represented in the CYIC caseload relative to the general provincial child population.

Comparative Mortality Experience, CYIC and Provincial Child Population, B.C., 1985/86 to 1999/00

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Characteristic or Indicator	C,	B.C. Child	
Characteristic of Indicator	Deaths	Rate*	Population Rate**
Age			
0-4	95	53.2	14.7
5-14	49	10.1	1.7
15-18	82	19.1	6.0
Total	226	22.5	6.0
Gender			
Male	122	23.1	7.1
Female	104	22.6	5.0
Total	226	22.5	6.0
Ethnicity***			
Aboriginal	77	22.9	11.3
Non-Aboriginal	149	22.3	4.7
Total	226	22.5	5.1
Functional Status****			
Physical Disability	78	94.0	
Intellectual/Behavioural Disability	21	8.4	
Not Recorded	8	15.6	
Functionally Average	41	15.8	
Total	148	23.0	6.6
Cause of Death			
Natural Causes	144	18.3	4.2
External Causes	82	5.5	1.8
Total*****	226	22.5	6.0

The ethnicity characteristic "Aboriginal" in the B.C. child population refers only to Status Indian children. Data for Status Indians is for 1990 only. See Chapter 8 for definition of Aboriginal CVIC.

For the B.C. child population, disability in HAI. S (1991) defined as any restriction or tack of ability to perform an activity in the manner or within the range considered normal for a human being, not fully corrected by a technical aid and lasting or expected to last six month. Includes mobility agility, seeing, hearing, speaking, and emotionally scychaiter disability or development delay. For C.Y.C. includes physical, intellectual, and/or behavioural disability, as determined by child's Social Worker.

For the purpose of this comparison, the data on those C.Y.C with a "not recorded" functional ability were merged with the data on clients recorded as functionally average.

All CYIC rates are Age-Standardized (Indirect) Per 10,000, except for age group (Age-Specific Rates Per 10,000) and severe disability (Crude Rates Per 10,000). Except for Age-Specific Rates, all rates for B.C. Child Population are Age-Standardized (Direct) Rates Per 10,000. The ethnicity characteristic "Aboriginal" in the B.C. child population refers only to Status Indian children. Data not available prior to 1991 for Status Indians, so the data for both the B.C. child population and Status Indian child population are limited to the period 1991 to 2000. See Chapter 8 for definition of Aboriginal CYIC. Disability data evailable for 1986/897 to 1995/66 only. See Chapter 5 for definitions. "As the CYIC rates are indirectly standardized, the total is not the exact sum of both groups of causes.

- Aboriginal children in the CYIC caseload proportionally exceeded non-Aboriginals for ages 0-4 and 5-14 years, but were proportionately less for ages 15-18 years.
- The All Causes mortality for Aboriginal CYIC was higher for ages 15-18, and was higher for non-Aboriginals for ages 5-14 years (both statistically significant),
- The differences in All Causes mortality for ages 0-4 years and all ages (0-18 years) between Aboriginal and non-Aboriginal CYIC were not statistically significant.
- The cumulative mortality differences in Aboriginal and non-Aboriginal CYIC for Natural Causes and External Causes were not statistically significant.
- The only statistically significant gender difference by Aboriginal status was the higher External Causes mortality in Aboriginal males compared to non-Aboriginal males. The equivalent CYIC female differences for External Causes were not statistically significant, nor were differences by Aboriginal Status and gender for Natural Causes.

Major comparative data are summarized in the tables above.

### **B.** Time Trend of CYIC Mortality

- The declining CYIC mortality trend occurred during a time of declining mortality in the provincial child population, with the relative mortality of CYIC in comparison with the provincial child population not changing significantly over time.
- The proportion of CYIC as a percentage of the provincial child population has changed over time, ranging from 1.22% in the mid-1970s, to 0.70% in the early 1990s, then increasing to 1.04% by the late 1990s.
- There was no correlation between CYIC mortality rates and the proportion of CYIC as a percentage of the provincial child population.
- The CYIC crude mortality trend increased from the mid-1970s to the early 1980s (statistically significant), followed by a declining trend through to the late 1990s (statistically significant).
- The CYIC age-standardized mortality rate declined from the mid-1980s to the late 1990s (statistically significant).

- The age-standardized mortality for CYIC was consistently higher than the mortality in the provincial child and Status Indian child populations, both of which also had a statistically significant decline in mortality from the mid-1980s (or early 1990s for Status Indian children) to the late 1990s.
- There was no statistically significant time trend in the CYIC mortality rates for any of the individual age groups studied, although the all ages (0-18 years) mortality showed a statistically significant decline as indicated above.
- The All Causes and Natural Causes mortality rates for CYIC females showed a statistically significant declining trend for the period 1985/86 to 1999/00, while there was no statistically significant change in the mortality trend for CYIC males, and
- The External Causes mortality rates for both CYIC males and females showed no statistically significant change in trend for the period 1985/86 to 1999/00.

The mortality rate time trends are summarized in the following table.

### Summary of Major Mortality Rate Trend Indicators, CYIC, B.C.

Time Period	CYIC Group	Mortality Rate Indicator	Causes of Death	p Value*
Indicators with Increasi	ng Mortality Tren	nd (statistically significant)		
• 1974/75 to 1982/83	Total	Crude	All Causes	0.003
Indicators with Decreas	ing Mortality Tre	nd (statistically significant	)	
• 1983/84 to 1999/00         Total         Crude         All Causes           • 1985/86 to 1999/00         Total         Crude         All Causes           • 1985/86 to 1999/00         Total         Age-Standardized         All Causes           • 1985/86 to 1999/00         Female         Age-Standardized         All Causes           • 1985/86 to 1999/00         Total         Age-Standardized         Natural Causes           • 1985/86 to 1999/00         Female         Age-Standardized         Natural Causes			0.005 0.029 0.018 0.046 0.037 0.010	
Indicators with No Char	ge in Mortality 1	Frend (not statistically sign	ificant)	
• 1985/86 to 1999/00 • 1985/86 to 1999/00	Male Male Total Male Female Age 0-4 Age 5-14 Age 15-18	Age-Standardized Age-Standardized Age-Standardized Age-Standardized Age-Standardized Age-Specific Age-Specific Age-Specific	All Causes Natural Causes External Causes External Causes External Causes All Causes All Causes All Causes	0.120 0.164 0.120 0.190 0.190 0.218 0.120 0.141

 $<sup>^\</sup>star\,$  Mann-Kendall test, statistical significance at p  $\leq 0.05$ 

### C. The Leading Causes of Death for CYIC

Data showing the 10 leading causes of CYIC death are summarized in the table below, in descending order of frequency. Each of these causes in CYIC was significantly higher than the provincial child population average.

Also shown are total deaths by Natural, External, and All Causes. For most comparisons the differences were not statistically significant, either because the differences were minor, or the differences were greater but the numbers were too small.

Summary of Client Characteristics Associated with Significantly Higher Mortality Rates\* for the Leading Causes of CYIC Deaths, B.C., 1985/86 to 1999/00

Leading Cause by Rank	Age		All Ages	
Leading Cause by Kank	Group	Gender	Ethnic Status	Functional Ability**
Congenital Anomalies     SIDS     Motor Vehicle Traffic Accidents***     Suicide     Diseases of the Nervous System     Accidental Poisoning***     Diseases of the Respiratory System     Homicide     Infectious Diseases****	0-4 Infants 15-18 - - 15-18 - - 0-4	-	- Aboriginal - - - - - - -	
Natural Causes External Causes All Causes	0-4 15-18 0-4	- - -	-	Physical Disability - Physical Disability

<sup>\*</sup> Mortality difference was statistically significant (95% Confidence Intervals), or in the case of SIDS, infants are the only age group affected.

### D. Comparison of CYIC Mortality in B.C. With Other Jurisdictions

- The general pattern of proportionate mortality of CYIC in B.C. is not unusual in relation to the other three jurisdictions, for both Natural and External Causes, which contribute to approximately 2/3 and 1/3 of the deaths, respectively.
- Disabled CYIC in the Alberta study were represented in the caseload to a similar extent as in B.C. (about 20%), and had made a similar contribution to CYIC mortality (about 50%), mostly to Natural Causes.

### E. Recommendations

In summary, the recommendations to improve the understanding of the mortality experience and health status of CYIC are to:

- Establish an ongoing means of epidemiological mortality analysis,
- Establish a minimum dataset for such an epidemiological analysis, including cause of death, age, sex, and Aboriginal status,
- Use the calendar year-end CYIC deaths and caseload statistics for calculating agestandardized (indirect) mortality rates, and
- Give further consideration as to how best to assess the mortality of Aboriginal CYIC,

- Assess the feasibility of re-introducing and maintaining a standard coding of the functional status of CYIC,
- Assess the feasibility of introducing a standard diagnostic coding of medical conditions to CYIC records using the ICD-10 coding system,
- Give consideration to using additional data to obtain a more complete assessment of the mortality experience and health status of CYIC, including other data in MIS-SWS, the Looking After Children system, the Children's Commission information system, the Ministry of Health and BCVSA information systems, other government information systems, and other cultural information.

Functional ability data available only for 1986/87 to 1995/96, insufficient data by individual cause of death.
Ages 15-18 is significantly higher than ages 5-14 only.

<sup>\*\*\*\*</sup> Ages 0-4 is significantly higher than ages 15-18 only.

### 2. Introduction

The role of the **Provincial Health Officer** was redefined by legislation in 1994 to report independently to the Minister of Health and directly to the public on health issues. This includes the production of an Annual Report on the health of British Columbians, which in 1997 consisted of a Feature Report on Child Health, entitled "The Health and Well-being of British Columbia's Children".

While primarily concerned with the general interests of all children in the province, this report also addressed the societal interest in the health status of a particularly vulnerable group of children -- Children and Youth in Care (CYIC).

If a family is unable to care for a child, the child welfare authorities may temporarily or permanently assume responsibility for the child, by authority of the *Child, Family and Community Services Act*.

Children who require this custody, care, or guardianship, come into the care of the Ministry for Children and Families, and are referred to in the <u>Act</u> as "children in care". The term "children and youth in care" is used in this study, as many of these individuals are youth aged 13 to 18 years.

Children come into care for a variety of reasons. Protection may be required due to abuse or neglect, parents may be absent or unable to care for their child, or the child may require medical or other special care.

In his 1997 Annual Report, the Provincial Health Officer noted that an analysis of more complete information on the health status of CYIC could assist in monitoring future progress in improving their health, and provide a means by which their mortality experience and other health outcomes could be evaluated over time.

# Some specific recommendations by the Provincial Health Officer concerning the health and welfare of CYIC included the following:

- Develop strategies to address the factors underlying the inequities in children's health status: inequalities in income, social status, housing, and other aspects of daily life.
- In addition, address the special needs of atrisk groups, in particular, Aboriginal children, children in low-income families, and Children and Youth in Care.

- Continue to improve provincial information about Aboriginal children, Children and Youth in Care, and other vulnerable groups of children. Data definitions and categories should be compatible with other systems designed to track health and disease in the total child population.
- The Ministry for Children and Families should develop data and information systems to track health outcomes, including hospitalizations and deaths, for all children who are or have been in-care.

### **Project Objectives**

At this time, provincial information systems do not yet produce comprehensive statistics about the health and well being of CYIC. However, using available data, it is possible to study the deaths of CYIC as a group, and to compare their experience to that of the British Columbia (B.C.) child population.

# Accordingly, the objectives of this mortality review were:

- To document and describe the mortality of CYIC in comparison to the general child population in the province, including an examination of possible risk factors,
- To establish a scientifically valid set of baseline data that could serve as a means to evaluate progress in reducing the mortality of CYIC, and
- To provide knowledge about significant causes of death for CYIC, as a guide to the development of specific strategies to improve their health.

It is expected that the information in this report may be of interest primarily to health and social services practitioners, administrators, policy makers, and researchers.

### **Project Participants**

This report was prepared by a project team consisting of staff in the Office of the Provincial Health Officer, the Population Health Surveillance and Epidemiology Branch, and the B.C. Vital Statistics Agency, Ministry of Health.

Key partners in the project were the Ministry for Children and Families, and the Children's Commission.

While acknowledging this valuable assistance with appreciation, the project team assumes full responsibility for the methodology, findings, and interpretation of the study.

The Ministry for Children and Families (MCF) provides child protection services under the legislative authority of the *Child, Family and* Community Service Act. The Ministry was established on September 26, 1996, partly in response to recommendations by the Gove Inquiry into Child Protection\* and the report of Cynthia Morton, Transition Commissioner for Child and Youth Services.\*\*

This new Ministry integrated child and family services from the Ministries of Health, Education, Social Services, Attorney General, and Women's Equality. In addition to child protection\*\*\*, these services include adoption, child and youth mental health services, addiction services, services for children and youth with special needs, specialized multi-disciplinary child and family prevention and early support programs, youth justice services, child care programs, and community living services for adults with developmental disabilities.

Also created in 1996 following the Gove Inquiry, the Children's Commission has a mandate to:\*\*\*\*

review all deaths of children in B.C., and investigate those which the commission decides require investigation to determine the adequacy of services or examine public health or policy issues,

- review and investigate critical injuries sustained by CYIC,
- make recommendations concerning deaths or critical injuries investigated if the commission considers this will enhance the safety and protection of other children,
- hear and resolve complaints made to the commission about breaches of the rights of CYIC and decisions made about designated services to children by MCF,
- set standards for the internal review of complaints about provision of services to children by MCF, and monitor adherence to those standards.
- review plans of care for children in continuing custody of MCF, and ensure these plans meet legislative and policy standards, and
- inform the people of B.C. about the state of the province's child- and family-serving system, and invite public comment on the commission's work.

The B.C. Vital Statistics Agency (BCVSA) of the Ministry of Health is responsible for registering vital events (births, deaths, and marriages) in the province, and for providing services and products related to vital statistics.

The methodology and limitations are described in the next section.

Thomas Gove, Matthew's Story: Report of the Gove Inquiry into Child Protection, Vancouver, B.C.: 1995.

<sup>\*\*</sup> Cynthia Morton, <u>British Columbia's Child. Youth and Family Serving System. Recommendations for Change</u>, 1996.

\*\*\* Prior to the establishment of the Ministry for Children and Families, CYIC were clients of the former Ministry of Social Services. These children are aged under 19 years, also referred to in this paper as children aged 0-18 years.

\*\*\*\* Children's Commission, <u>Annual Report</u>, 1999: 6.

### 3. Methodology and Limitations

### **Methods**

The child and youth clients of MCF can be placed into two basic groupings: either CYIC or family support (FS) clients. The CYIC group is under the full responsibility of MCF, which provides substitute parenting for individual children (the clients), when they are unable to live with their families. The FS group includes whole families (the clients), who receive various supportive services from MCF, while the children continue to live with their family under full parental/guardian responsibility.

This distinction according to client service category has implications for data availability, as MCF has extensive documentation on CYIC, including reports of serious occurrences such as death. However, in the case of FS clients, all children associated with the family or all serious occurrences to children in the family, may not necessarily be known to or documented by MCF to the same detailed extent. This is because services, whether periodic or continuing, could be directed primarily to the support of a specific family member, e.g., an autistic child; therefore, the death of that child or of a sibling due to circumstances unrelated to those services may not necessarily be reported to nor recorded by MCF.

Thus, any past mortality records or caseload statistics available on FS clients would be of variable and unknown completeness, and hence, would be unsuitable for epidemiological analysis without extensive further research beyond the scope of this study. This is not a criticism of the MCF information system, as it was developed for the purpose of supporting service delivery to clients, not for the conduct of epidemiological studies. Accordingly, this review focused only on the CYIC clients of MCF, for whom MCF was fully responsible as substitute parent/guardian, and for whom more complete information was available.

However, a challenge for the study was the fact that CYIC are not a uniform group of children with the same characteristics and risks. While some children were in care through an agreement with their parents, the majority were in care as the result of a court order. These children and youth are in the care and guardianship of MCF for a variety of reasons which pre-date admission to the CYIC program, including being severely disabled, having a chronic medical condition, experiencing psychological or emotional trauma, or being socio-economically disadvantaged.\*

Recent experience\*\* indicates that 39% of CYIC came into care because they suffered neglect, physical and/or emotional harm, or sexual abuse.

There were 41% of CYIC who entered care because their parents abandoned them or were unwilling or unable to care for them. Because of their earlier life with their parents, many of these children also have emotional and behavioural problems. A further 12% of CYIC came into care because they had emotional, behavioural, physical, or developmental needs that their parents could not meet. The remaining 8% were in care for a variety of other reasons.

Many CYIC are of Aboriginal heritage or are living with a disability, hence this review attempted to take these particular client characteristics into consideration, along with gender and age, to the extent possible with available data. The study involved an analysis of mortality statistics only, and did not include an examination of individual client health status, personal circumstances, or health service utilization.

An epidemiological study of mortality rate comparisons requires the determination of a case definition and the population at risk, to obtain both numerator and denominator. In accordance with the intended focus of the project, the case definition (numerator) was defined as "any CYIC whose reason for discharge from care was recorded as being deceased". Outside the scope of this study were any child deaths which may have occurred either before admission to or after discharge from the CYIC program.

A general assessment of the validity and reliability of the CYIC caseload statistics was undertaken at the beginning of the project (see Appendix A). It was concluded that the CYIC caseload statistics based on the March 31st year-end provided a satisfactory estimate of person-years in care. Thus, the population at risk (denominator) was defined as "the number of individuals recorded in the MCF information system as being in the current CYIC caseload as of March 31st in each year".

Mortality comparisons were made between CYIC and the provincial child population, taking age and gender into consideration. Lack of specific comparable data on the provincial child population precluded comparisons of such other important factors as disability, socio-economic, or Aboriginal status, as explained in later sections of the report. For the period 1974/75 to 1984/85, only crude mortality rates (0-18 years) could be calculated due to the lack of age-related data on CYIC. However, the available data allowed more detailed calculations to be done for the period 1985/86 to 1999/00.

<sup>\*</sup> In B.C., approximately 60% of CYIC come from families on Income Assistance (Children's Commission, 1999 Annual Report: 27). For the B.C. child population, there are almost 9% of children ages 0-18 years who live in a family or alone while receiving basic B.C. benefits (BC STATS, 17 Apr 00).

\* Personal communication, W. Matheson, Ministry for Children and Families.

The mortality of CYIC was assessed by age-standardizing, but due to small numbers, the indirect method was used for calculating rates\* and Standardized Mortality Ratios (SMRs) over the 15-year time period to 1999/00. The mortality trend for the B.C. child population and Status Indian children was assessed with age-standardized rates using the direct method.

Age-standardization calculations were based primarily on age groups 0-4, 5-14, and 15-18 years, as there were very few deaths in some cells if smaller age groupings were used.\*\* The 1991 B.C. child population was used as the standard population for all age-standardization calculations. Statistical tests for trends and differences are indicated where used in specific sections of the paper.

### **Data Sources**

The information presented in this report was derived from operational databases and files maintained by MCF and BCVSA. Access to the names of individual CYIC and their records was limited to the staff of those agencies whose usual duties involved working with such confidential information. The project team worked with linked non-identified data provided by those agency staff.

Data on CYIC deaths and caseloads were compiled by two time periods, based on relative ease of access to data through annual reports or electronic information systems:

- 1974/75 to 1984/85: For this 11-year period, data from annual reports were limited to the number of CYIC deaths per year and the March 31<sup>st</sup> year-end caseload statistics. Data on age, gender, and Aboriginal status were not available, nor was the cause of death during this period. Individual death certificates could not be identified, and hence, the project team was unable to independently verify either the occurrence or cause of death. Accordingly, these data limitations restricted the analysis for this period to annual crude mortality rates and overall caseload statistics.
- 1985/86 to 1999/00: For this 15-year period, more detailed CYIC caseload data were available. These included age-related data, which enabled the calculation of age-standardized mortality rates, as well as data on gender and Aboriginal status. Functional status data were also available for 10 years of this period. Information system improvements during this period included the availability of month-end caseload counts for each month since January 1990, which also became available by age group since April 1992.

Mortality data on the general B.C. child population were provided by BCVSA from the provincial mortality database by calendar-year. Population estimates (as of July 1) were based on the national Census for Census years, and as estimated by BC STATS of the Ministry of Finance and Corporate Relations for inter-Census years.

### **Data Verification**

Individual CYIC since 1985/86 who were recorded as dying while in care were identified in the MCF electronic information system by MCF staff. The following steps were taken to verify the occurrence of death and to determine the cause:

- (1) The MCF list of deceased CYIC was matched to death certificates by BCVSA staff, to obtain the officially recorded date and cause of death.
- (2) Children who had been in care in the month of death or the previous month were identified in the BCVSA mortality registry\*\*\*. The dates of death and of discharge were reviewed manually in the CYIC master files by MCF staff, to search for any additional cases in which the date of death preceded the date of discharge.
- (3) As a final step, the MCF list of deceased CYIC for 1997 forward was cross-matched with child death records in the Children's Commission by the staff of both agencies, to ensure the completeness and consistency of the mortality data for the project.

This process identified a total of 226 CYIC who died while in care over the 15-year period 1985/86 to 1999/00, of whom two lacked death certificates in BCVSA. Further investigation determined that these individuals had died (due to natural causes) while temporarily outside of B.C., thus, the deaths would have been registered in the jurisdiction of occurrence. As the MCF master files contained sufficient information about the chronic illness of these children to assign a probable cause of death, these two cases were included in the study.

### Limitations

Before describing the results, it is important to acknowledge certain important limitations in this study of mortality in CYIC:

(1) For the period 1985/86 to 1999/00, with two exceptions as described above, the underlying cause of death was taken as recorded in the BCVSA mortality registry.\*\*\*\* These data are subject to the agency's internal review process for consistency in coding practice and routine updating, including information from coronor's reports. However, there was no additional attempt by the project team to verify the accuracy of the medical diagnosis. So, while the recorded diagnosis of the cause of death is believed to be adequate for the purposes of this study, it is possible that the recorded cause of death for some CYIC was not the actual cause of death.

<sup>\*</sup> R. Anderson and H. Rosenberg, "Age Standardization of Death Rates: Implementation of the Year 2000 Standard", National Vital Statistics Reports, Vol. 47, No. 3, October 7, 1998: 13.
The indirect method is preferred for rates based on small numbers as it reduces the degree of annual fluctuation. The methodology used to calculate the indirect standardized rate involved taking the ratio of observed the expected deaths (SMP) for CVIC for a clipp used and multiplying by the crude mortality rate for the standard population.

taking the ratio of observed to expected deaths (SMR) for CYIC for a given year, and multiplying by the crude mortality rate for the standard population.

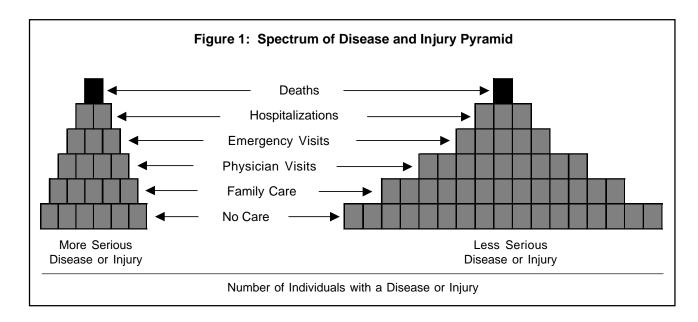
\*\* The only exceptions were SMR calculations for SIDS, Perinatal Causes, and Suicide, which used age groupings relevant to those causes.

<sup>\*\*\*</sup> This process was part of a test of the feasibility of matching CYIC data with health records. Personal communication, W. Warburton, Ministry of Social Development and Economic Security.
\*\*\*\* The underlying cause of death is (a) the disease or injury which initiated the train of events leading directly to death, or (b) the circumstance of the accident or violence which produced the fatal injury. WHO, ICD 1975, 9th Revision: 763.

- (2) For the earlier period 1974/75 to 1984/85, identifying data were not readily available to verify either the occurrence or cause of death in the BCVSA mortality registry. The accuracy of the early paper record system in documenting CYIC deaths in annual reports is unknown, however, the project team found no reason to doubt the completeness of these data. While not necessarily evidence of completeness, it was noted that the annual number and rate of recorded deaths during this early period was generally greater than was reported in the later period.
- (3) While electronic information system crossmatching was used where possible to verify the occurrence of CYIC deaths in the later period 1985/86 to 1999/00, it is possible that some CYIC deaths recorded on MCF paper files could have been omitted from the electronic information system. However, relatively few inconsistencies were found in the database matching processes, the majority of which had the effect of over-estimating mortality, e.g., child recorded to be discharged as deceased when the discharged child was alive, duplicate records of the deceased child under different names or in different time periods. Moreover, the data reviewed in this project, although covering a longer time period, were not inconsistent with data reported by the Gove Inquiry.\* Therefore, the project team believes that the theoretical possibility of the unrecording of CYIC deaths is unlikely to be a major source of error in this study.
- (4) The health status of a population (or a group such as CYIC) cannot be completely described or assessed by an analysis of mortality alone. Those individuals dying of a condition are usually less numerous than, and not necessarily representative of, all individuals with the condition, as is illustrated by the pyramid model below. The size of the base of the

- pyramid is indirectly related to the seriousness of the health problem as a cause of death. As mortality represents the tip of the iceberg, any detailed analysis of health problems should also include episodes of hospitalization, medical care, and other significant events, in relation to the characteristics of members of the population, matters which were outside of the scope of this study.
- (5) The CYIC caseload consists primarily of children who by legislation become clients because there was reason to believe that they were at risk. Currently, CYIC comprise approximately 1% of the provincial child population, but this proportion has varied over time between 0.7% and 1.22%. If for any reason there has been a change in the underlying "risk mix" of CYIC over time, that change could affect the mortality rate and consequent assessment of their mortality trend over time. Hence, caution is needed in interpreting any apparent trends over time.
- (6) Since an epidemiological comparison of CYIC with a similar group of children who are not CYIC was not possible in this study, the only comparison which could be made was with the general provincial child population, taking age and gender into consideration. Thus, the mortality comparisons in this study provide an estimate of the degree of the mortality gap between CYIC and the provincial child population. However, this does not imply that it should be or could be possible for the mortality of CYIC to be similar to the mortality of the general child population.\*\*
- (7) In addition, there were some specific limitations regarding the completeness and accuracy of data on the functional ability of CYIC, which are described in detail in that section of the report.

The next sections contain the study findings.

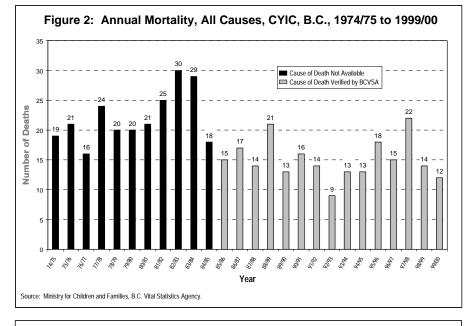


<sup>\*</sup> Gove Thomas, ibid

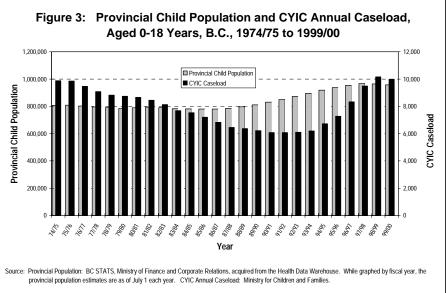
<sup>\*\*</sup> While absurd to consider, in theory the only way that CYIC mortality could be similar to that of the B.C. child population, would be if CYIC were chosen so as to be representative of the provincial child population, through a random sample stratified by age, gender, Aboriginal status, disability status, and geographic area of residence.

### 4. The Long Term CYIC Caseload and Mortality Trend

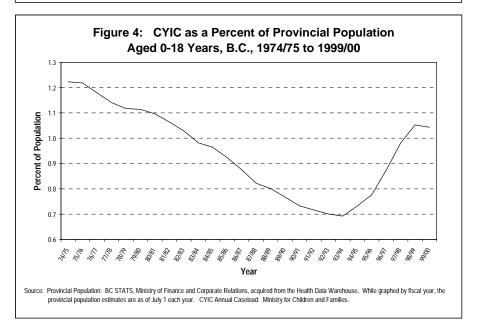
The mortality experience as evidenced by the number of deceased CYIC for each year during the 26-year period 1974/75 to 1999/00 is shown in Figure 2. The pattern is characterized by considerable annual fluctuation, which is to be expected with rare events. The number of deaths ranged from nine in 1992/93 to 30 in 1982/83. There were 243 deaths in the first 11 years (an average of 22.1 per annum), and 226 deaths in the last 15 years (an average of 15.1 per annum).



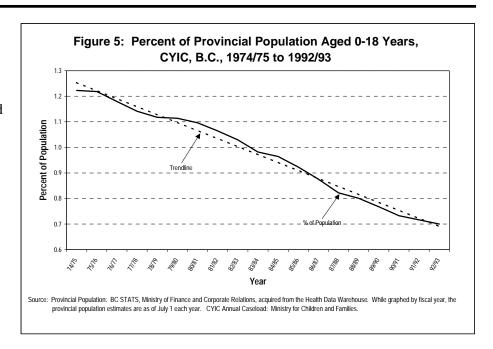
In assessing the mortality trend, it should be noted that the annual year-end CYIC caseload has changed over time. Using approximate numbers, the caseload declined from 9,900 cases in the mid-1970s to 6,100 during the early 1990s (a decrease of 40%). It then increased to 10,000 in the late 1990s (an increase of 65%), to a level which was similar to that in the mid-1970s (see Figure 3).



Putting this change into context, the provincial child population was relatively stable around 800,000 from the mid-1970s to the late 1980s, then gradually increased to a peak of 966,500 by the late 1990s. an increase of 20% over the last ten years. The CYIC caseload comprised 1.22% of the provincial child population in the mid-1970s, declined to 0.70% in the early 1990s, then rose to 1.05% by 1998/99, with a slight decrease to 1.04% in 1999/00 (see Figure 4).



As the lowest proportion of CYIC to the provincial child population was in the early 1990s, the data were graphed by early 19-year and later 7-year periods. Regression analysis\* found a downward trend (averaging 2.4% per year) in the early period and an upward trend (averaging 8.4% per year) in the later period, both of which were statistically significant (see Figures 5, 6, and accompanying table).



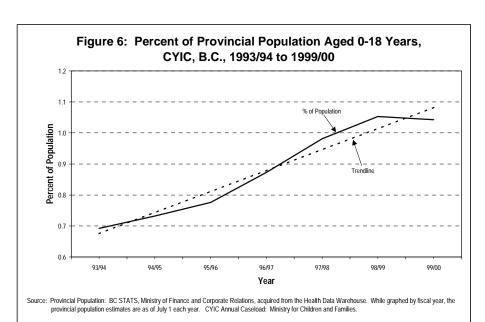
Over the long term, this changing trend in the CYIC caseload as a proportion of the provincial child population could be due to a variety of influences, such as changes in the number of children requiring care, changes in the eligibility criteria for being placed into care, changes in child abuse reporting, socio-economic changes, legislative changes, or program changes. Other than noting the change in caseload numbers, and where possible, general client demographic characteristics, it was beyond the scope of this study to determine the causes for these caseload changes.

Time Trends in CYIC Caseload as a Percentage of the Provincial Child Population, B.C.

Time Period	Trend (Slope)	p Value*
1974/75 to 1992/93	decreasing	<0.001
1993/94 to 1999/00	increasing	<0.001

<sup>\*</sup> Regression Analysis.

Given the lack of detailed data prior to 1985/86, the 26-year mortality trend for CYIC could only be assessed by the crude mortality rate, which considers deaths for All Causes, without regard to age or other factors. Since age influences the risk of mortality, this crude or "not adjusted for age" mortality rate is not sensitive to changes in the age-structure of a population over time, nor to differences in the agestructure between populations. Accordingly, it must be interpreted with caution when comparing mortality time trends for the same population or for mortality comparison between populations.

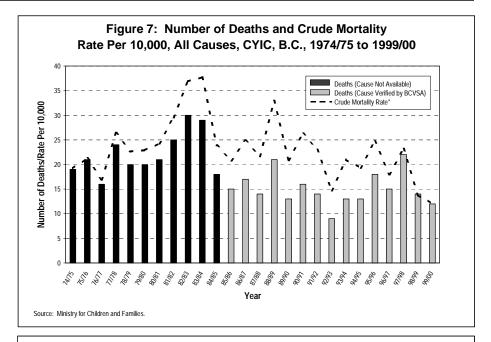


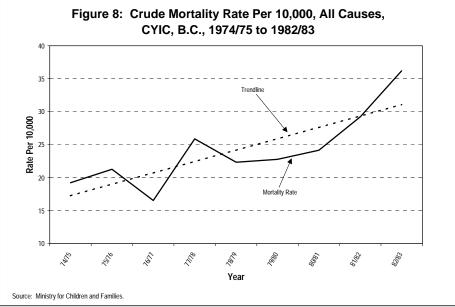
<sup>\*</sup> In this study, regression analysis refers to a linear time-series analysis using sum of least squares, Microsoft® Excel 97 SR-2 (statistical significance at p≤0.05).

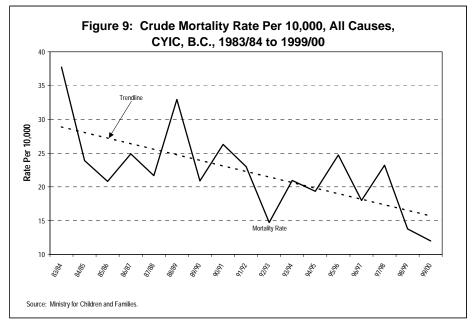
The crude mortality rate for CYIC demonstrated considerable annual fluctuation, as expected with rare events. The rate approximately doubled from the mid-1970s to the peak years in the early 1980s, then trended downwards in the 1990s, to its lowest level in 1999/00 (see Figure 7). The time trend for the entire 26-year period showed no significant change when assessed with the Mann-Kendall test.\* As the mortality rate peaked around 37 per 10,000 in the early 1980s, the rates were graphed by early 9-year and later 17-year periods.

A statistically significant upward trend was found in the early period, followed by a statistically significant downward trend in the later period (see Figures 8, 9, and accompanying table). However, as noted above, the crude mortality rate is a less precise indicator because age is not taken into account. The more accurate technique involves agestandardizing the mortality rate, which adjusts for age structure by holding the age effect constant over time for a given population or between different populations.

Therefore, annual agestandardized mortality rates and Standardized Mortality Ratios (SMR) were calculated for CYIC, as permitted by available data for the period 1985/86 to 1999/00, and are shown along with CYIC crude rates in Figure 10. As examined in more detail in a later section of the report, the CYIC caseload has had relatively fewer of the youngest children (the age group with highest mortality risk) than the provincial child population, which results in the CYIC age-standardized mortality rate being higher than the crude rate.







<sup>\*</sup> Hollander and Wolfe, Nonparametric Statistical Methods, John Wiley, New York, 1999. The Mann-Kendall test was designed to assess trends with fluctuating rates (statistical significance at p≤0.05).

However, both methods of calculating CYIC mortality rates yielded similar results, with significant downward trends. The CYIC mortality was higher than that of the provincial child population and the Status Indian child population (see Figures 10, 11, and accompanying table). The SMR is a ratio\* which in this case compares the mortality of CYIC to the

provincial child population; i.e., for CYIC relative to the provincial child population, an SMR of 1.0 means a similar mortality, an SMR less than 1.0 means a lower mortality, and an SMR greater than 1.0 means a higher mortality.

Over the last 15 years, while the mortality rate for CYIC has been declining, their SMR has displayed a fluctuating annual pattern with no trend (the 95% confidence intervals for each year overlapping the confidence intervals for all other years, data not shown). Thus, while both the CYIC and provincial child population mortality have declined, the CYIC mortality gap relative to the provincial child population mortality has not significantly changed over time.

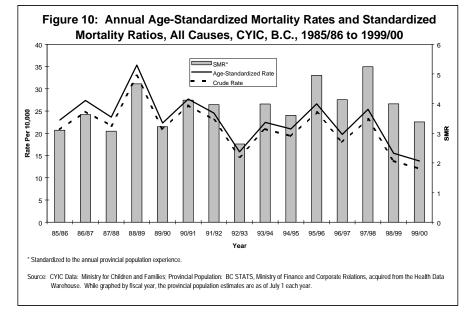
This finding is consistent with the mandate of the CYIC program, in that the caseload is comprised of children believed to be at high risk, and hence, for any interval of time, CYIC would be expected to have a higher mortality than the provincial child population.

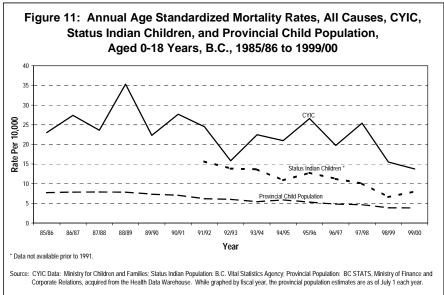
Moreover, the finding that mortality gains in the CYIC population are being achieved more slowly than for the provincial child population is also consistent with the fact that CYIC are at high risk. While both the provincial child population and provincial Status Indian child populations had significantly declining mortality, the Status Indian child mortality gap with the provincial child population has narrowed over time.

# Time Trends in Crude Mortality Rates, CYIC, All Causes, B.C.

Time Period	Trend (Slope)	p Value*
1974/75 to 1982/83	increasing	0.003
1983/84 to 1999/00	decreasing	0.005

<sup>\*</sup> Mann-Kendall Test





Time Trends in Mortality, All Causes, CYIC, Status Indian Children, and Provincial Child Population, B.C., 1985/86 to 1999/00

C	p Value		lue
Group	Trend (Slope)	Regression Analysis	Mann-Kendall Test
CYIC Crude Rates CYIC Age-Standardized Rates CYIC SMR Status Indian Children ASMR* Provincial Child Population ASMR	decreasing decreasing no change decreasing decreasing	- - - <0.001 <0.001	0.029 0.018 0.084 - -

<sup>\*</sup> Data not available prior to 1991.

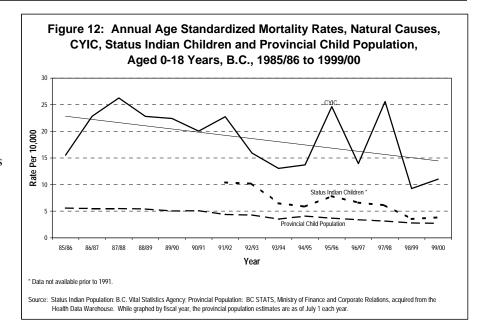
<sup>\*</sup>The annual number of observed deaths in CYIC divided by the annual number of expected deaths in CYIC, with the expected deaths being a theoretical calculation based on the age-specific mortality experience of the provincial child population being applied to the number of children in each age group of the CYIC caseload.

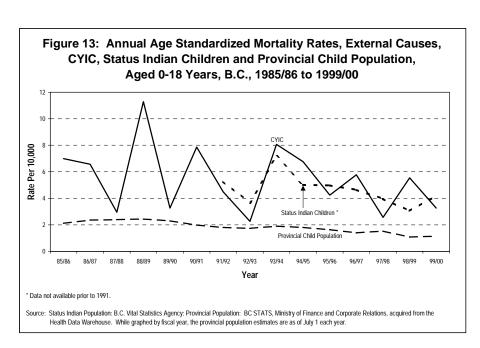
In keeping with usual practice, the causes of death were broadly categorized into:

- Natural Causes deaths due to illness, whether of known or unknown cause, and
- External Causes deaths due to an injury-causing event, whether intentional or unintentional.

Beginning with Natural Causes, the age-standardized mortality rates for CYIC, Status Indian children, and the provincial child population are graphed in Figure 12. The mortality rates for CYIC were higher and showed more fluctuation, however, there was a statistically significant declining trend. The rates for provincial children and the Status Indian child population also showed statistically significant declines (see accompanying table). The mortality gap for Natural Causes between Status Indian children and the provincial child populations has almost closed over the last two years.

For External Causes, the higher CYIC and Status Indian child mortality rates were similar, with no significant change in trend, although the rates for CYIC showed more annual fluctuation (see Figure 13 and accompanying table). The declining provincial child population rates were statistically significant, but a substantial mortality gap remains between the provincial child and Status Indian child populations.





Time Trends in Mortality, Natural and External Causes, CYIC, Status Indian Children, and Provincial Child Population, B.C., 1985/86 to 1999/00

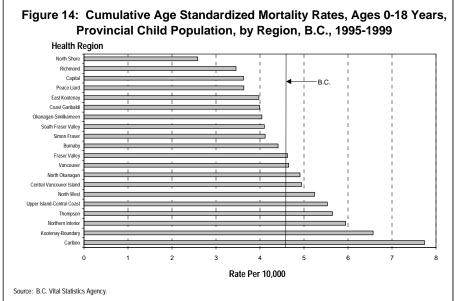
Crown	Trand (Slane)	p Va	lue
Group	Trend (Slope)	Regression Analysis	Mann-Kendall Test
CYIC Natural Causes External Causes	decreasing no trend	-	<b>0.037</b> 0.120
Status Indian Children* Natural Causes External Causes	decreasing no trend	<b>0.002</b> 0.173	-
Provincial Child Population Natural Causes External Causes	decreasing decreasing	<0.001 <0.001	-

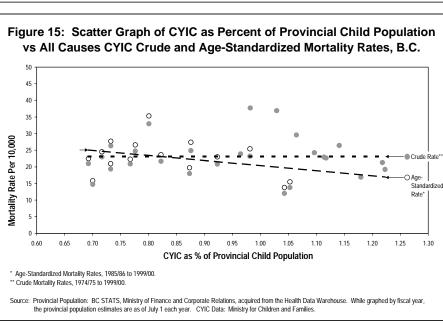
<sup>\*</sup> Data not available prior to 1991.

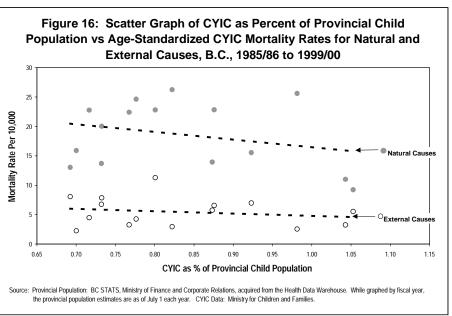
While sufficient long-term data were not available to assess regional differences in CYIC mortality, such data were available for the provincial child population (see Figure 14). Cumulative mortality rates varied almost 3-fold between the lowest and highest regions. While there were some exceptions, the metropolitan areas generally had lower rates, and the northern areas had higher rates, a similar pattern to that of many other health status indicators.

Returning to the issue of the changing caseload, and without speculating on the actual cause(s) of the changes in caseload numbers, it is important to acknowledge any changes in client characteristics over time, for any potential influence on the risk of mortality to CYIC, in either direction. For example, if there was a small core of "highest risk" clients who remained in care for a prolonged period, while a larger group of "moderate risk" clients were present in variable numbers over time, the calculated mortality rates could be negatively correlated (inversely associated) with the annual CYIC caseload as a proportion of the provincial child population, other things being equal.

To assess this possible association in a very general way, scatter graphs were developed to plot CYIC mortality against the proportion of CYIC in the provincial child population (see Figures 15, 16, and accompanying table). Whether viewing the entire 26-year time frame with All Causes crude mortality rates or the latest 15-year period with age-standardized mortality rates, the data show no association between these variables, with low R<sup>2</sup> values. There was also no association found for Natural and External Causes mortality when assessed separately for the last 15 years.







While the mortality rate trends could be associated with an unknown underlying change in the client mix of mortality risks in the CYIC caseload, these data are suggestive (although not conclusive) that the recent decline in mortality is a real phenomenon, not an artifact of the increasing caseload.

In summary, this analysis of the long-term CYIC mortality pattern observed that:

- (a) The CYIC crude mortality trend increased from the mid-1970s to the early 1980s (statistically significant), followed by a declining trend through to the late 1990s (statistically significant).
- (b) The CYIC age-standardized mortality rate declined from the mid-1980s to the late 1990s (statistically significant).
- (c) The age-standardized mortality for CYIC was consistently higher than the mortality in the provincial child and Status Indian child populations, both of which also had a statistically significant decline in mortality from the mid-1980s (or early 1990s for Status Indian children) to the late 1990s.

Statistical Significance of Correlation Between CYIC as Percent of B.C. Child Population vs CYIC Mortality Rates, B.C.

Time Period	Cause of Death	R²	p Value*
1974/75 to 1999/00** 1985/86 to 1999/00 1985/86 to 1999/00 1985/86 to 1999/00	All Causes	<0.001	0.999
	All Causes	0.114	0.218
	Natural Causes	0.078	0.312
	External Causes	0.037	0.491

- Mann-Kendall Test.
- \*\* Crude Mortality Rate for this time period, Age-Standardized Mortality Rates for other indicators in table.
- (d) The declining CYIC mortality trend occurred during a time of declining mortality in the provincial child population, with the relative mortality of CYIC in comparison with the provincial child population not changing significantly over time.
- (e) The proportion of CYIC as a percentage of the provincial child population has changed over time, ranging from 1.22% in the mid-1970s, to 0.70% in the early 1990s, then increasing to 1.04% by the late 1990s.
- (f) There was no correlation between CYIC mortality rates and the proportion of CYIC as a percentage of the provincial child population.

The next section examines CYIC mortality by functional status.

### 5. The Association Between Functional Status and Mortality

During the period 1986/87 to 1995/96, the MCF information system included the functional status of most CYIC, as determined by the child's Social Worker, who assessed the child as functioning at an average, mild/moderately disabled, or severely disabled level, in each of three functional areas (physical, intellectual, and behavioural).

While further comments are contained in Appendix A, it should be noted that:
(1) ratings may have been subject to significant intra- and inter-observer variability,
(2) ratings may not always have been accurately recorded, and
(3) ratings were not subject to verification or systematic updating.\*

Although the obtaining of this information was not mandatory, functional status was recorded for 92% of CYIC during this 10-year period. The functional status of CYIC can be broadly compared with the disability status of the provincial child population, using data from the national Health and Activity Limitation Survey (HALS) of 1991 (see Figure 17 and accompanying table).

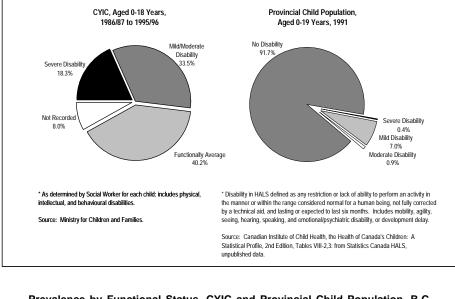


Figure 17: Proportionate Functional Status\* in One or More Areas,

CYIC and Provincial Child Population, B.C.

Prevalence by Functional Status, CYIC and Provincial Child Population, B.C.

	Percent of	Ratio of	
Functional Status*	CYIC**	All B.C. Children***	CYIC : All B.C. Children
Mild/Moderate Disability Severe Disability Average/No Disability/Not Recorded****	33.5 18.3 48.2	7.9 0.4 91.7	4.2 45.8 0.5
Total	100.0	100.0	-

- \* Includes physical, intellectual, and/or behavioural disability.
- \*\* Aged 0-18 years, 1986/87 to 1995/96.
- \*\*\* Aged 0-19 years, 1991.

While acknowledging differences in age groupings and methodology, both approaches included physical, intellectual, and behavioural disabilities. Accordingly, the project team believed that a very general comparison of the prevalence of disability between CYIC and the provincial child population would be both reasonable and informative.

This comparison showed that children with disabilities were greatly over-represented in the CYIC caseload. Severely disabled children were prevalent in the CYIC caseload at a level approximately 45-fold higher than their prevalence in the provincial child population, while children with less severe disabilities were prevalent in the CYIC caseload at a level approximately four-fold higher than their prevalence in the provincial child population.

On visual inspection of the list of deceased CYIC by functional status, it was clear that CYIC recorded as living with a severe physical disability, irrespective of the presence of a co-existing intellectual or behavioural disability, were over-represented among deceased clients. It was also noted that very few deaths occurred in CYIC recorded as living with either an intellectual or behavioural disability, without a physical disability.

Accordingly, it was decided that the mortality analysis would compare CYIC based primarily on their recorded functional status in the following groupings\*\*:

- (a) those recorded with a predominant physical disability,
  - severe physical disability, with or without an intellectual/behavioural disability of any level,
  - mild/moderate physical disability, with or without a mild/moderate intellectual/behavioural disability,
  - including any child with an ICD diagnosis of ICD 343/344 or ICD 740-759, regardless of recorded functional ability,
  - excluding any child who died of SIDS, regardless of recorded functional ability;
- (b) those with a predominant intellectual/behavioural disability,
  - severe intellectual/behavioural disability, with or without a mild/moderate physical disability,

<sup>\*\*\*\*</sup> In this table, the data on CYIC with a "not recorded" functional ability were included with those recorded as functionally average, which has a slight conservative influence on the comparison. (Excluding the "not recorded" data would increase the ratio of CYIC: All B.C. Children to 49.8 for the Severe Disability Category.)

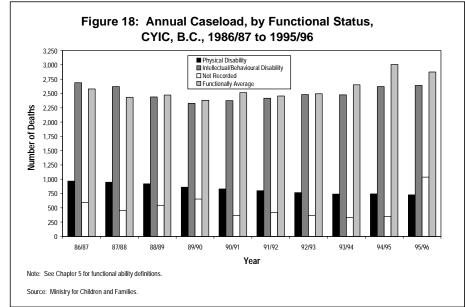
<sup>\*</sup> Personal communication, W. Matheson, Ministry for Children and Families.

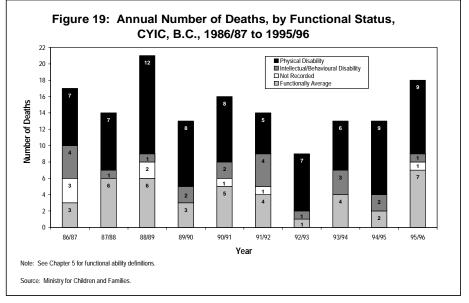
<sup>\*\*</sup> For further explanation of rationale, see end of this chapter.

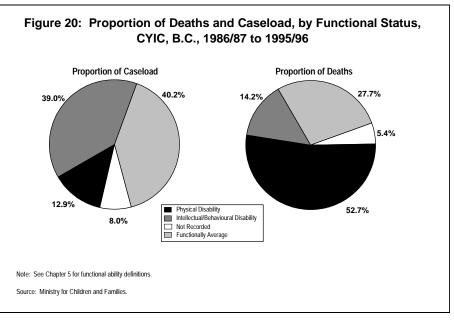
- mild/moderate intellectual/ behavioural disability without a physical disability of any level,
- excluding any child who died of ICD 343/344, ICD 740-759, or SIDS, regardless of functional ability;
- (c) those with an unknown functional status,
  - functional status was not recorded,
  - excluding any child who died of ICD 343/344, ICD 740-759, or SIDS;
- (d) those with an average functional ability,
  - average functional status,
  - including any child who died of SIDS, regardless of recorded functional ability,
  - excluding any child who died of ICD 343/344 or ICD 740-759, regardless of recorded functional ability.

The annual CYIC caseload and mortality statistics by functional ability are shown in Figures 18 to 20. Most of the CYIC caseload, in approximately equal numbers, were recorded as being functionally average (40.2%) or living with an intellectual/behavioural disability (39.0%). Physically disabled CYIC (12.9%) gradually decreased over time, however, the numbers of CYIC with functional ability not recorded showed more annual fluctuation, and almost tripled in the last year when the recording of disability status was discontinued.\*

The annual number of deaths by functional status showed considerable fluctuation due to small numbers, and it is possible that misclassification or nonclassification of some CYIC may have affected the picture somewhat. Nevertheless, having observed that the estimated prevalence of severe disability in CYIC far exceeded that in the general child population, and noting that physically disabled CYIC appeared to experience more deaths than other CYIC, the mortality pattern by functional ability was examined further.







<sup>\*</sup>During 1995/96, there was a gradual monthly reduction in the level of completion of some data fields in the information system, which coincidentally occurred during a time of major changes, including preparation for a new information system rating health and behavioural issues rather than functional ability, regional hearings of the Gove Inquiry, and an increase in the CYIC caseload Personal communication, W. Matheson, Ministry for Children and Families.

It was found that CYIC living with a physical disability comprised only 12.9% of the caseload, but experienced 52.7% of the deaths. The other more numerous groups contributed proportionately much less to CYIC mortality. Given the limitations of the data and a relatively short timeframe (nine complete years, plus the final year during which the recording of functional status was discontinued), it was decided that the mortality data would only be analyzed on a cumulative basis.

Cumulative crude mortality rates\* were calculated for All Causes in the above table. The mortality of each group can be seen in comparison to the mortality rate of those CYIC recorded as being functionally average, 15.8 per 10,000 (95% C.I. of 11.3 to 21.6). Those CYIC living with a physical disability had a significantly higher mortality, 94.0 per 10,000 (95% C.I. of 74.2 to 117.5), while the intellectual/ behavioural disability group had a mortality which was not significantly different than the functionally average group, 8.4 per 10,000 (95% C.I. of 5.2 to 12.8).

About 70% of the deaths due to Natural Causes occurred to CYIC with a physical disability, with about 25% occurring to the functionally average group. About one-third each of the deaths due to External Causes occurred to CYIC recorded as having an intellectual/behavioural disability and functionally average CYIC (see Figure 21). The mortality for each category of causes was again compared by functional ability and to the provincial child population (see Figure 22 and accompanying tables on next page). These mortality comparisons indicated that all CYIC, including the functionally average group, had a much higher mortality than the provincial child population for both Natural and External Causes, with the exception of the intellectual/ behavioural and not recorded groupings for External Causes.\*\*

Cumulative Crude Mortality Rates due to All Causes, by Functional Status, CYIC, B.C., 1986/87 to 1995/96

CYIC Group	Number of Deaths	Rate Per 10,000	95% C.I.*
Intellectual and/or Behavioural Disability Physical Disability Not Recorded Average	21 <b>78</b> 8 41	8.4 <b>94.0</b> 15.6 15.8	5.2 to 12.8 <b>74.2 to 117.5</b> 6.7 to 30.8 11.3 to 21.6
All CYIC	148	23.0	19.5 to 27.1

Note: See Chapter 5 for functional ability definitions

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, Neuroepidemiology 2: 257-265 (1983).

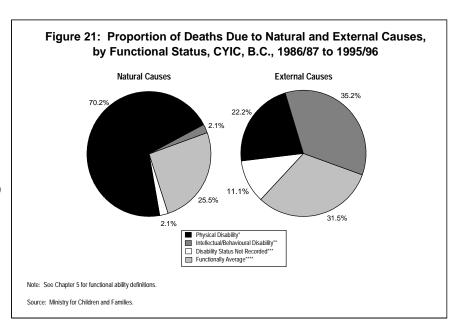


Figure 22: Cumulative Crude Mortality Rates, Natural and External Causes. by Functional Status, CYIC, and Provincial Child Population, B.C., 1986/87 to 1995/96 Intellectual/Behavioural Disability Physical Disability Not Recorded All CYIC ■ External Causes B.C. Child Population 15 20 25 35 40 45 75 Rate Per 10,000 Note: See Chapter 5 for functional ability definitions Source: Ministry for Children and Families

<sup>\*</sup> While age-standardized mortality rates are preferred, crude rates were used in this comparison due to relative ease of data access. This is not believed to be a serious limitation in view of the magnitude of the differences.

magnitude of the differences.

\*\* Comparable mortality data by disability category were not available for the provincial child population.

The most important finding was that for Natural Causes, CYIC living with a physical disability had a significantly higher mortality than the functionally average group. There were few deaths due to Natural Causes in CYIC living with an intellectual/ behavioural disability. However, this could be due to the categorization system used in this study (which was more likely to place a CYIC with multiple disabilities into the physically disabled group), or it could be a data problem. Nonetheless, it seems unusual that there were not more Natural Causes deaths to CYIC living with an intellectual/ behavioural disability, as was the case with the functionally average group, which had a similar number of children in the caseload (approximately 25,000).

While it may have been anticipated that problems with judgement could have resulted in CYIC with an intellectual and/or

behavioural disability being at higher risk of injury mortality than the functionally average, the next important finding was that for External Causes, their mortality was not significantly different than the functionally average group. While the physically disabled group's mortality appeared to be higher, the difference was not statistically significant.

As previously indicated, CYIC had their functional ability assessed by their social worker, and their status recorded in the MCF information system for the years 1986/87 to 1995/96. The prevalence of severe disability as recorded in CYIC was 18.3%, as compared to 0.4% in the general provincial child population, a 45-fold difference in prevalence. However, the functional status data have some particular limitations which do not apply to other basic CYIC data in the MCF information system. The accuracy of the recorded functional ability rating for CYIC is unknown, and 8% of CYIC had an unrecorded disability status. This raises the question of whether inaccurate or incomplete data could have influenced the calculated mortality comparisons by functional ability.

While the accuracy of the disability assessment of the CYIC caseload could not be verified directly, the calculated crude mortality rate for physically disabled CYIC was very high. Hence, it seems unlikely that many CYIC of average functionality were inappropriately categorized as being physically disabled, as misclassification of that type would have

# Cumulative Crude Mortality Rates due to Natural Causes, by Functional Status, CYIC, B.C., 1986/87 to 1995/96

CYIC Group	Number of Deaths	Rate Per 10,000	95% C.I.*
Intellectual and/or Behavioural Disability Physical Disability Not Recorded Average	2 <b>66</b> 2 24	0.8 <b>79.5</b> 3.9 9.3	0.1 to 2.9 <b>61.5 to 101.0</b> 0.5 to 14.1 5.9 to 13.8
All CYIC	94	14.6	11.8 to 17.8

Note: See Chapter 5 for functional ability definitions

## Cumulative Crude Mortality Rates due to External Causes, by Functional Status, CYIC, B.C., 1986/87 to 1995/96

CYIC Group	Number of Deaths	Rate Per 10,000	95% C.I.*
Intellectual and/or Behavioural Disability Physical Disability Not Recorded Average	19 12 6 17	7.6 14.5 11.7 6.6	4.6 to 11.8 7.5 to 25.3 4.3 to 25.6 3.8 to 10.5
All CYIC	54	8.4	6.3 to 10.9

Note: See Chapter 5 for functional ability definitions.

the effect of lowering the calculated mortality rate for physically disabled CYIC. However, visual inspection of the data found that some infants who died of SIDS were categorized as physically disabled, which would have the effect of raising the mortality rate of the physically disabled CYIC.

The reverse type of misclassification was assessed to some extent by examining deaths due to Natural Causes in those CYIC recorded as other than physically disabled. These deaths occurred to children who were either categorized as functionally average or whose functional status was not recorded. Visual inspection of the data found that indeed some of the deaths for these children were chronic disabling conditions similar to the conditions causing deaths due to Natural Causes in the physically disabled group. This would have the effect of over-estimating mortality in the functionally average group and underestimating mortality in the physically disabled group.

Therefore, the project team "reassigned" the functional status of certain deceased CYIC for selected causes of death, in order to improve the accuracy of the analysis.\* While it would have been preferable to make similar adjustments to the caseload statistics where warranted, this was not possible. Therefore, it must be acknowledged that the true mortality rate for each of these CYIC functional status groups, could be higher or lower than as presented in this report.

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, Neuroepidemiology 2: 257-265 (1983).

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, Neuroepidemiology 2: 257-265 (1983).

<sup>\*</sup>These changes primarily involved: (a) Reassigning some CYIC who died of SIDS from a Physical Disability or Not Recorded category to Functionally Average (because by definition, SIDS occurs to an otherwise healthy infant once other more definitive causes have been excluded); (b) Reassigning some CYIC who died of a chronic disabling condition, from being Functionally Average or Not Recorded, to Physically Disabled, e.g., Congenital Anomalies (ICD 740-759) and Neurological System Disease (ICD 343/344), including such conditions as cerebral palsy with quadriplegia, muscular dystrophy, microcephaly, hydrocephalus, congenital anomalies of heart, etc. To some extent these changes were off-setting.

Having noted the limitations of the data portraying functional ability of CYIC, the data were adequate to conservatively demonstrate that:

- (a) Children living with severe disabilities were proportionately over-represented in the CYIC caseload, relative to the provincial child population;
- (b) All CYIC, regardless of functional ability, had higher mortality rates for All Causes than the provincial child population, and particularly so for Natural Causes in CYIC living with a physical disability;
- (c) Those CYIC living with a physical disability comprised 12.9% of the CYIC caseload, but experienced 52.7% of the deaths of CYIC;

- (d) Those CYIC living with a physical disability had a much higher mortality (statistically significant) due to All Causes and Natural Causes, relative to functionally average CYIC, but an apparently higher mortality due to External Causes was not statistically significant;
- (e) Those CYIC living with an intellectual and/ or behavioural disability did not have an increased mortality rate in comparison with the functionally average CYIC, for All Causes, Natural Causes, or External Causes.

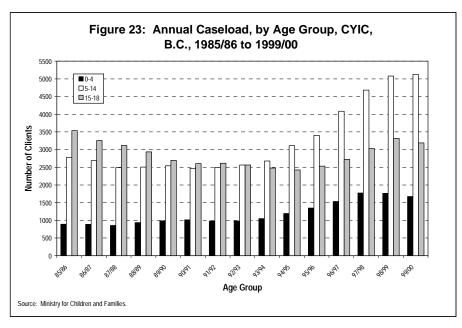
In the next section, the CYIC mortality will be examined further with regard to other characteristics, which will allow the inclusion of data for the longer period 1985/86 to 1999/00.

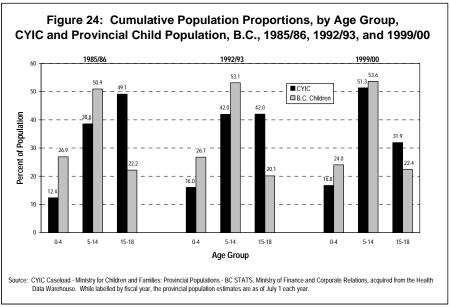
### 6. The Association Between Age and Mortality

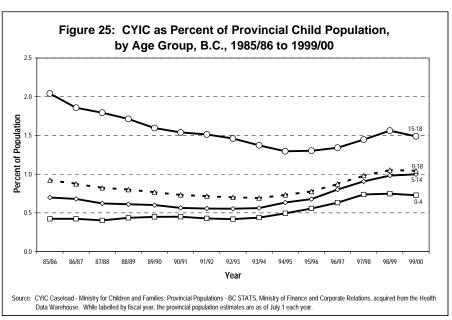
As age is a demographic variable with an important influence on mortality, the age structure of the CYIC caseload was examined over time (see Figure 23). The numbers of CYIC ages 0-4 and 5-14 years were fairly stable from the mid-1980s to the mid-1990s, at which point they began to increase. Ages 15-18 years were the most numerous in the late 1980s, but more CYIC were in ages 5-14 years by 1993/94.

Next, the age structure of the CYIC caseload was compared to that of the provincial child population, with ages 0-4 years being relatively underrepresented, while age group 15-18 years was relatively over-represented in CYIC (see Figure 24). The age structure of the CYIC caseload has varied over time, with a proportional decrease in age group 15-18 years, and a proportional increase in the younger age groups. Thus over time, the age structure of the CYIC caseload has gradually changed to be closer to that of the provincial child population, whose age structure has been relatively more stable during this period.

The proportion of CYIC as a percent of the provincial child population has changed over time, with ages 15-18 years being proportionally the highest (while declining), and ages 0-4 years being the lowest (and increasing). Ages 5-14 years had an intermediate position, but has also been increasing as a proportion of the provincial child population, and was similar to the all ages (0-18 years) proportion by 1999/00 (see Figure 25). As described above, this change was also reflected in the increasing numbers of CYIC aged 5-14 years, an age cohort which is greater than the 0-4 and 15-18 year cohorts.







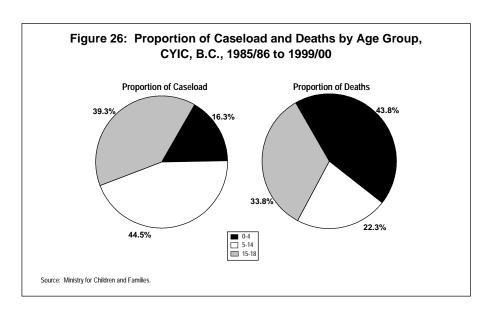
Time series analysis of the changing proportion of CYIC as a percent of the provincial child population found that the upward trend for the youngest age groups (0-4 and 5-14 years) was statistically significant, while the proportion of clients in age group 15-18 years had a statistically significant downward trend (see accompanying table).

Significance of Time Trends, CYIC as a Proportion of the Provincial Child Population, by Age Group,
B.C., 1985/86 to 1999/00

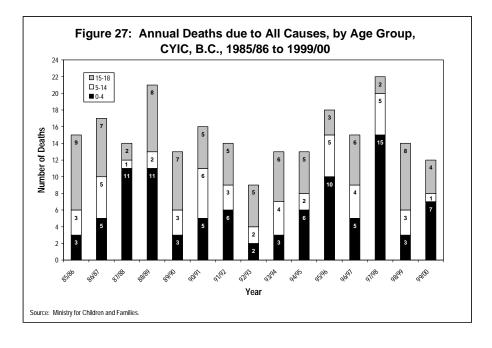
Age Group	Trend (Slope)	p Value*
0-4	increasing	<0.001
5-14	increasing	0.006
15-18	decreasing	<0.001

<sup>\*</sup> Regression analysis.

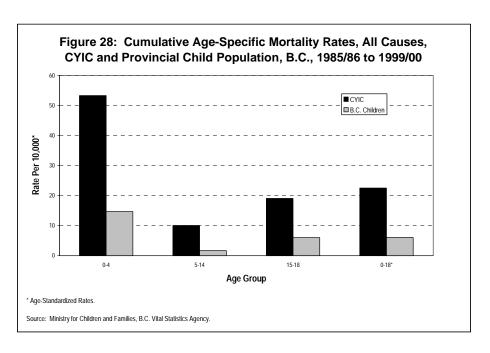
Relative to their proportion in the caseload (16.3%), CYIC ages 0-4 years experienced a much higher proportion of the CYIC deaths (44%) than the other age groups. Conversely, the proportion of deaths in ages 5-14 years (22.0%) and ages 15-18 years (34.1%) were less than their proportions in the caseload (44.5% and 39.3%, respectively), as shown in Figure 26.



The number of deaths of CYIC by age group were characterized by considerable fluctuation from year to year. The annual range of deaths was 2 to 15 for ages 0-4 years, 1 to 5 for ages 5-14 years, and 2 to 9 for ages 15-18 years (see Figure 27).



On comparing the cumulative CYIC mortality by age group for the period 1985/86 to 1999/00, ages 0-4 years had the highest mortality rate, followed by ages 15-18 and 5-14 years. This overall pattern of age-specific CYIC mortality rates was similar to that of the provincial child population, however, the mortality rates for CYIC were significantly higher in all age groups (see Figure 28 and accompanying table).



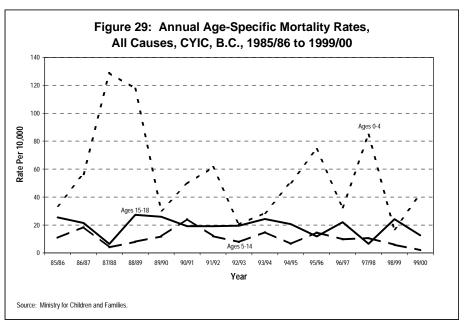
Statistical testing of differences in the age-specific mortality rates of CYIC found the rates for each age group differed significantly from each other age group.

#### Cumulative Age-Specific Mortality Rates, All Causes, CYIC and Provincial Child Population, B.C., 1985/86 to 1999/00

	4.55		CYIC B.C.		Rate Ratio	
	Age Group	Rate Per 10,000	95% C.I.*	Rate Per 10,000	CYIC:B.C.	95% C.I.*
	0-4 5-14 15-18	53.2 10.1 19.1	43.1 to 65.0 7.4 to 13.3 15.2 to 23.6	14.7 1.7 6.0	3.62 6.04 3.18	2.93 to 4.42 4.45 to 7.97 2.53 to 3.95
ſ	0-18**	22.5	19.7 to 25.7	6.0	3.82	3.35 to 4.36

- \* Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios,
- Neuroepidemiology 2: 257-265 (1983).
  \*\* Age-Standardized.

The annual CYIC age-specific mortality rates showed a relatively flat trend for ages 5-14 and 15-18 years, with moderate annual fluctuation, while ages 0-4 years exhibited extreme annual fluctuation (see Figure 29).



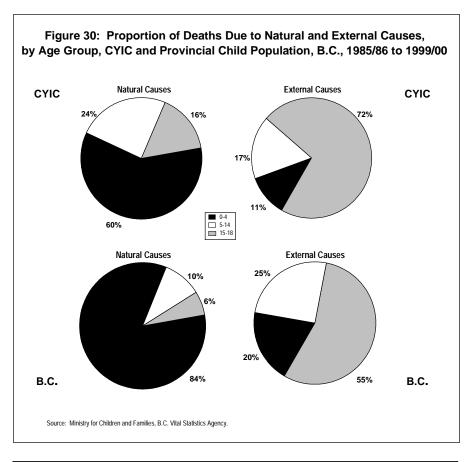
However, there was no statistically significant change in the mortality trend for any individual CYIC age group over this time, although all ages (0-18 years) had a statistically significant declining trend because pooling the data provided more power (see accompanying table).

Significance of Time Trends, Age-Specific Mortality Rates, CYIC, B.C., 1985/86 to 1999/00

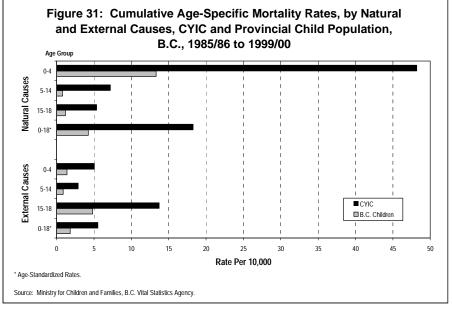
Age Group	Trend (Slope)	p Value*
0-4 5-14 15-18	no change no change no change	0.218 0.120 0.141
0-18**	decreasing	0.018

<sup>\*</sup> Mann-Kendall Test.

The proportions of deaths by Natural and External Causes are shown in Figure 30, with the highest proportion of CYIC deaths for Natural Causes (60%) occurring in ages 0-4, and for External Causes (72%) in ages 15-18 years. This compares with the provincial child population in which the highest proportion of deaths for Natural Causes (84%) also occurred in ages 0-4 years\*, and for External Causes (55%) in ages 15-18 years.



Cumulative age-specific mortality rates for CYIC are shown in Figure 31, with comparisons to the provincial child population. The overall pattern of age-specific mortality was similar for CYIC and the provincial child population, with the CYIC rates being higher in all age groups for both groups of causes.



<sup>\*</sup>The higher proportion of B.C. child deaths in this age group is primarily due to the effect of perinatal mortality, which is rare in CYIC.

<sup>\*\*</sup> Age-Standardized.

The mortality rates of CYIC aged 0-4 years for Natural Causes and aged 15-18 years for External Causes were significantly higher than the other age groups of CYIC (see accompanying table).

Age-Specific Mortality Rates, Natural and External Causes, CYIC and Provincial Child Population, B.C., 1985/86 to 1999/00

B.O., 1000/00 to 1000/00					
		CYIC B.		Ra	te Ratio
Age Group	Rate Per 10,000	95% C.I.*	Rate Per 10,000	CYIC:B.C.	95% C.I.*
Natural Causes 0-4 5-14 15-18	<b>48.2</b> 7.2 5.3	38.6 to 60.0 5.0 to 10.0 3.4 to 8.0	13.3 0.8 1.2	3.62 9.15 4.55	2.90 to 4.49 6.38 to 12.72 2.88 to 6.82
0-18**	18.3	15.5 to 21.6	4.2	4.32	3.66 to 5.10
External Causes 0-4 5-14 15-18	5.0 2.9 <b>13.7</b>	2.3 to 9.6 1.6 to 4.8 10.4 to 17.7	1.4 0.9 4.8	3.65 3.26 2.85	1.67 to 6.93 1.78 to 5.48 2.17 to 3.68
0-18**	5.5	4.4 to 6.8	1.8	3.04	2.42 to 3.77

Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, <u>Neuroepidemiology</u> 2: 257-265 (1983).

In summary, the age-related data on CYIC indicate that:

- (a) The CYIC population differs from the provincial child population in age composition, with relatively fewer younger children (ages 0-4 and 5-14 years) and more older children (ages 15-18 years).
- (b) The age composition of the CYIC population has changed significantly over time, with a proportionate increase in younger children (ages 0-4 and 5-14 years) and a decrease in older children (ages 15-18 years), such that the CYIC age composition has gradually become more like that of the provincial child population.
- (c) There were statistically significant differences in All Causes mortality between age groups in the CYIC population, highest in ages 0-4 years, and lowest in ages 5-14 years. This pattern of mortality was similar to, but greater than, the mortality of the provincial child population.

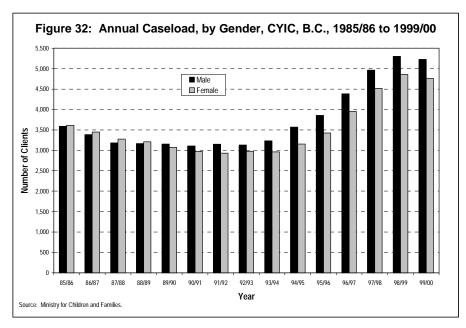
- (d) There was no statistically significant time trend in the CYIC mortality rates for any of these individual age groups studied, although the all ages (0-18 years) mortality showed a statistically significant decline as indicated above.
- (e) The mortality of CYIC was significantly higher than that of the provincial child population in all age groups for both Natural and External Causes.
- (f) There was a statistically significant higher mortality of CYIC ages 0-4 years for Natural Causes, and ages 15-18 years for External Causes, a pattern which was similar to the provincial child population.

The association between gender and mortality will be considered next.

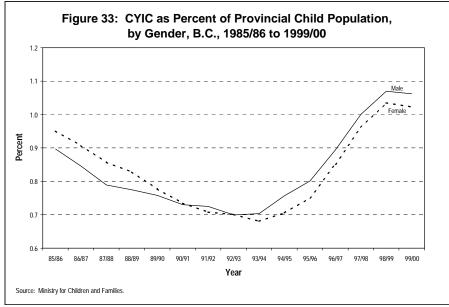
<sup>\*\*</sup> Age-Standardized

### 7. The Association Between Gender and Mortality

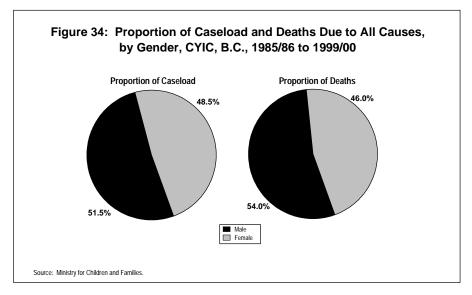
As with the provincial child population, the number of male CYIC has generally exceeded the number of females over time, with the exception of the late 1980s for CYIC (see Figure 32). As noted in the previous section, this change was associated with a decline in the numbers of CYIC aged 15-18 years, and an increase in younger children in the caseload.\*



Next, the gender balance of CYIC relative to the provincial child population was compared over time (see Figure 33). The proportion of CYIC as a percent of the provincial child population declined for both genders until the early 1990s, then rose until the late 1990s. The relative decline was slightly greater for female CYIC, and the subsequent rise was slightly greater for male CYIC, as reflected in the gender balance in the caseload (see Figure 32).

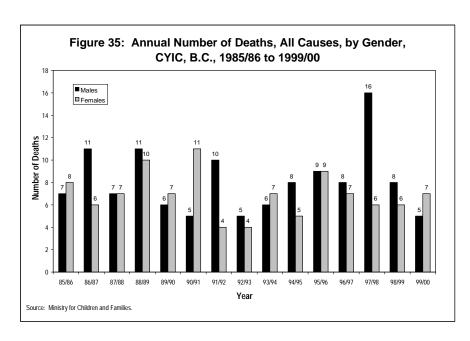


Relative to their proportion in the caseload (51.5%), males experienced a slightly higher proportion of the CYIC deaths (54.0%) than females (see Figure 34).

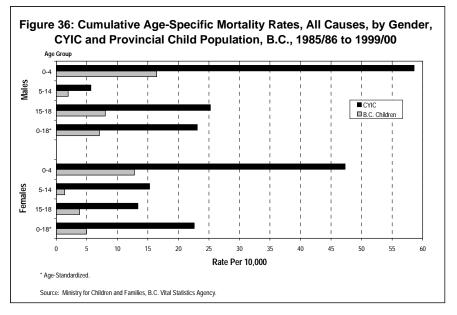


<sup>\*</sup> Although these data are not displayed by age group, males exceeded females in ages 0-4 and 5-14 years, and females exceeded males in ages 15-18 years.

The annual number of deaths of CYIC by gender are shown in Figure 35, with the pattern for both males and females showing fluctuation due to small numbers.\* There were 122 deaths of males, ranging from 5 to 16 per year, with an annual average of 8.1. There were 104 deaths of females, ranging from 4 to 11 per year, with an annual average of 6.9.



A comparison of CYIC with the B.C. child population using cumulative age-specific mortality rates and rate ratios by gender, showed that CYIC mortality was significantly higher than the provincial child population mortality in all age groups for both genders (see Figure 36 and accompanying table).



The male mortality was higher than female in each age group in both populations, except for ages 5-14 years in CYIC, where there was a statistically significant higher female mortality rate.\*\* There were no statistically significant gender differences in CYIC mortality between the other age groups or for all ages (0-18 years).

### Cumulative Gender and Age-Specific Mortality, All Causes, CYIC and Provincial Child Population, B.C., 1985/86 to 1999/00

B.C., 1963/66 to 1999/66					
	CYIC		B.C.	Rat	e Ratio
Age Group	Rate Per 10,000	95% C.I.*	Rate Per 10,000	CYIC:B.C.	95% C.I.*
<u>Males</u> 0-4 5-14 15-18	58.6 5.7 25.3	44.0 to 76.2 3.2 to 9.4 18.8 to 33.1	16.4 1.9 8.0	3.57 2.92 3.15	2.68 to 4.64 1.64 to 4.82 2.34 to 4.12
0-18**	23.1	19.3 to 27.7	7.1	3.27	2.73 to 3.92
Females 0-4 5-14 15-18	47.3 <b>15.3</b> 13.4	33.8 to 64.3 10.6 to 21.4 9.0 to 19.1	12.8 1.4 3.8	3.70 11.09 3.50	2.64 to 5.03 7.68 to 15.52 2.36 to 5.00
0-18**	22.6	18.5 to 27.5	5.0	4.56	3.74 to 5.55

Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, Neuroepidemiology 2: 257-265 (1983).

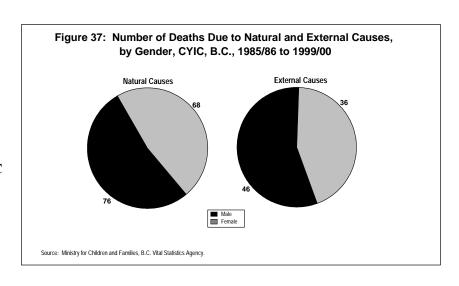
Age-Standardized

The number of male deaths in 1997/98 was much higher than in other years, associated with the chance occurrence of an above average number of deaths due to certain Natural Causes (SIDS,

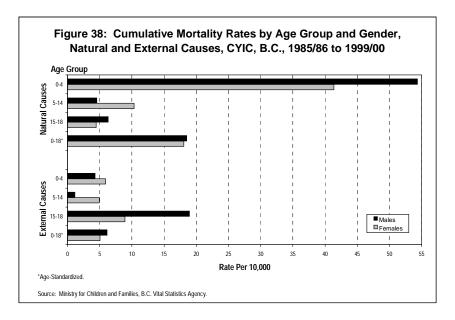
Congenital Anomalies, and Neurological Conditions).

Cas shown in Figure 38, the CYIC female mortality was higher than males for both Natural and External Causes, although with smaller numbers the difference was not statistically significant for either group of causes.

Gender differences by Natural and External Causes were examined next (see Figure 37). The number of deaths of male CYIC slightly exceeded females for both groups of causes. Apparent gender differences were seen in some age groups, however, none of the CYIC age-specific mortality differences between genders were statistically significant (see Figure 38).



The CYIC mortality rates exceeded the provincial child population rates for both groups of causes for both genders in all age groups, except for males aged 5-14 years for External Causes, where the rates were similar (see accompanying tables).



Cumulative Gender and Age-Specific Mortality, Natural Causes, CYIC and Provincial Child Population, B.C., 1985/86 to 1999/00

	CYIC		B.C.	Rat	e Ratio
Age Group	Rate Per 10,000	95% C.I.*	Rate Per 10,000	CYIC:B.C.	95% C.I.*
Males 0-4 5-14 15-18	54.3 4.5 6.3	40.3 to 71.2 2.3 to 7.9 3.4 to 10.8	14.9 0.8 1.4	3.66 5.88 4.61	2.71 to 4.79 3.04 to 10.30 2.45 to 7.88
0-18**	18.5	14.6 to 23.1	4.7	3.97	3.13 to 4.96
Females 0-4 5-14 15-18	41.4 10.3 4.5	28.8 to 57.5 6.6 to 15.5 2.1 to 8.2	11.6 0.8 1.0	3.56 12.91 4.60	2.48 to 4.95 8.19 to 19.37 2.21 to 8.46
0-18**	18.1	14.0 to 22.9	3.7	4.82	3.75 to 6.12

Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, <u>Neuroepidemiology</u> 2: 257-265 (1983). \* Age-Standardized.

Cumulative Gender and Age-Specific Mortality, External Causes, CYIC and Provincial Child Population, B.C., 1985/86 to 1999/00

-,					
	CYIC		B.C.	Rat	e Ratio
Age Group	Rate Per 10,000	95% C.I.*	Rate Per 10,000	CYIC:B.C.	95% C.I.*
Males 0-4 5-14 15-18	4.3 1.1 18.9	1.2 to 10.9 0.2 to 3.3 13.5 to 26.0	1.6 1.2 6.7	2.72 0.97 2.85	2.04 to 3.54 0.54 to 1.60 2.12 to 3.73
0-18**	6.1	4.5 to 8.2	2.4	2.57	2.14 to 3.08
Females 0-4 5-14 15-18	5.9 4.9 8.9	1.9 to 13.8 2.5 to 8.8 5.5 to 13.7	1.2 0.6 2.9	4.97 8.56 3.12	3.55 to 6.76 5.93 to 11.99 2.11 to 4.47
0-18**	5.1	3.5 to 7.0	1.2	4.19	3.44 to 5.10

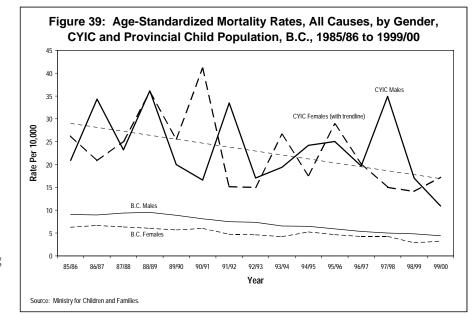
Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, <u>Neuroepidemiology</u> 2: 257-265 (1983).
 \*\* Age-Standardized.

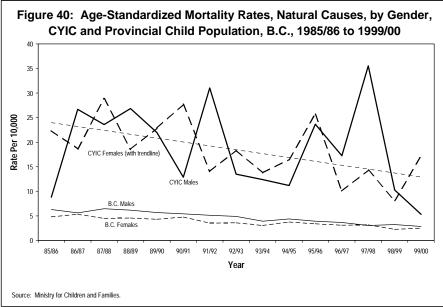
For All Causes, the annual mortality rates are shown in Figure 39, and as is the case with Natural and External Causes, there is considerable fluctuation in CYIC rates due to small numbers. The declining mortality trend in female CYIC was statistically significant (see following table), however, there was no statistically significant change in the male CYIC mortality trend over time. The mortality for the provincial child population showed a statistically significant declining trend in both males and females.

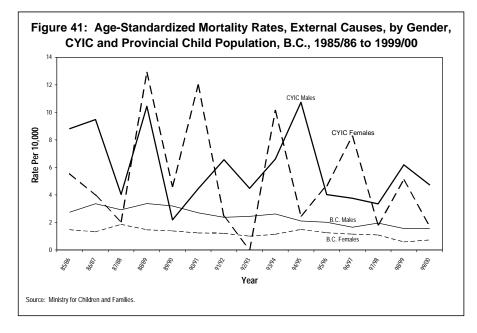
For Natural Causes, the annual mortality rates for female CYIC showed a declining trend (see Figure 40 and following table), which was statistically significant. However, there was no statistically significant change in the male CYIC mortality trend over time. The mortality for the provincial child population showed a statistically significant declining trend in both males

For External Causes, there was no statistically significant change in the CYIC mortality trend over time in either gender (see Figure 41 and following table). The mortality for the provincial child population showed a statistically significant declining trend in both males and females.

and females.







Statistical Significance of Time Trends, Age-Standardized Mortality Rates, by Gender, CYIC and Provincial Child Population, B.C., 1985/86 to 1999/00

Gender	Cause of Death	Trend (Slope)	p Value*
CYIC Male	Natural Causes External Causes All Causes	no change no change no change	0.164 0.190 0.120
CYIC Female	Natural Causes External Causes All Causes	declining no change declining	0.010 0.190 0.046
B.C. Male	Natural Causes External Causes All Causes	declining declining declining	<0.001 <0.001 <0.001
B.C. Female	Natural Causes External Causes All Causes	declining declining declining	<0.001 0.001 <0.001

<sup>\*</sup> Mann-Kendall Test for CYIC, regression analysis for B.C. children.

In summary, the examination of the mortality pattern of CYIC by gender indicated that:

(a) The cumulative age-specific mortality rates for CYIC exceeded that of the provincial child population for both genders, for each age group, and for Natural, External, and All Causes, with the only exception being males aged 5-14 years for External Causes, where the mortality rates were similar for CYIC and the provincial child population,

- (b) The cumulative All Causes mortality for CYIC did not differ significantly by gender for all ages (0-18 years), ages 0-4 years, or ages 15-18 years, however, there was a statistically significant higher mortality for female CYIC ages 5-14 years,
- (c) There was no statistically significant difference by gender in the cumulative Natural Causes mortality for CYIC for all ages (0-18 years) or any of the age groups,
- (d) The All Causes and Natural Causes mortality rates for CYIC females showed a statistically significant declining trend for the period 1985/86 to 1999/00, while there was no statistically significant change in the mortality trend for CYIC males, and
- (e) The External Causes mortality rates for both CYIC males and females showed no statistically significant change in trend for the period 1985/86 to 1999/00.

The association between Aboriginal status and mortality will be considered in the next section.

### 8. The Association Between Aboriginal Status and Mortality

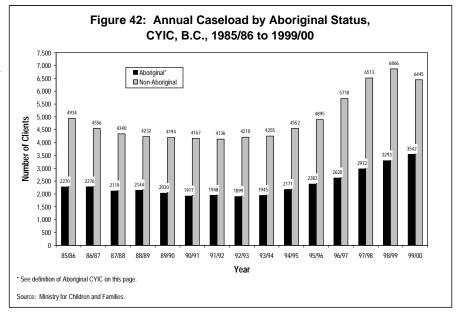
Information on the Aboriginal status of CYIC has been collected since 1985/86. In the *Child, Family and Community Service Act* (1996), an Aboriginal child is a child:

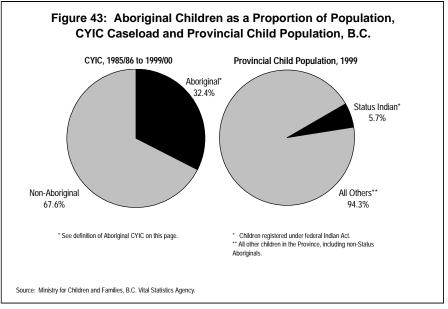
- who is registered under the *Indian Act* (Canada),
- who has a biological parent who is registered under the *Indian Act* (Canada),
- who is under 12 years of age, and has a biological parent who is of Aboriginal ancestry and considers himself or herself to be Aboriginal, or
- who is 12 years of age or over, is of Aboriginal ancestry and considers himself or herself to be Aboriginal.

While the new legislative definition (1996) is essentially similar to the former policy definition (1991)\*, it is believed that the new Act may have heightened awareness of social issues concerning Aboriginal children/youth and their families, including the nature of needed child protection services, which may have resulted in an increase in the number of Aboriginal CYIC in recent years. Another contributing factor may be that more Status Indian families are living off reserve, perhaps highlighting child protection concerns upon moving to dominant culture communities.\*\*

It is also possible that some children could be Aboriginal without their heritage being recorded in the information system, which could have the effect of under-estimating the number of Aboriginal children in the CYIC caseload. This indeed appears to be possible as discussed in more detail in Appendix A. Because of uncertainty concerning the completeness of the identification of Aboriginal children among deceased CYIC and in the CYIC caseload, mortality time trends were not calculated, and caution is warranted in interpreting any apparent differences between Aboriginal and non-Aboriginal CYIC in the cumulative comparisons in this study.

In making comparisons with the provincial child population, it is only possible to obtain data on Status





Indians in the province. Comparable provincial population estimates and mortality statistics for Non-Status Aboriginal people are not available, which results in the under-estimation of Aboriginal children in the provincial child population. Status Indian children comprised approximately 5.7% of the B.C. child population in 1999.\*\*\*

Based on available MCF statistics, Aboriginal children have comprised approximately 32% of the CYIC caseload over the period 1985/86 to 1999/00 (see Figure 43), an estimate which may be conservative as noted in Appendix A. Even though the data are not equivalent due to the above-stated differences in definition, it seems reasonable to conclude that Aboriginal children are proportionately over-represented in the CYIC caseload.

<sup>\*</sup> Prior to November 1996, these CYIC were defined in policy (1991) to be Native when at least one of the following criteria applied: a) the child is registered or may be entitled to be registered under the *Indian Act*; b) one or both of the child's parents or guardians are registered, reinstated or are entitled to be registered under the *Indian Act*; c) one or both of the child's parents is of aboriginal origin and considers himself, herself or themselves to be Native or Metis; d) a child who is 12 years old or older is of aboriginal origin and considers himself or herself to be Native or Metis. Personal communication, W. Matheson, Ministry for Children and Families.

<sup>\*\*</sup> Personal Communication, L. Foster and W. Matheson, Ministry for Children and Families

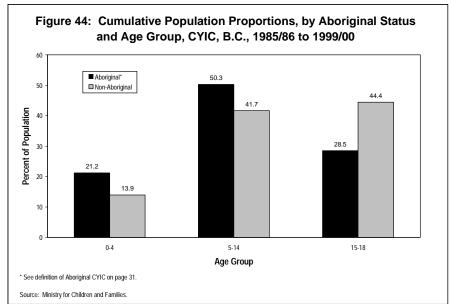
<sup>\*\*\*</sup> B.C. Vital Statistics Agency, Unpublished data, January 2001.

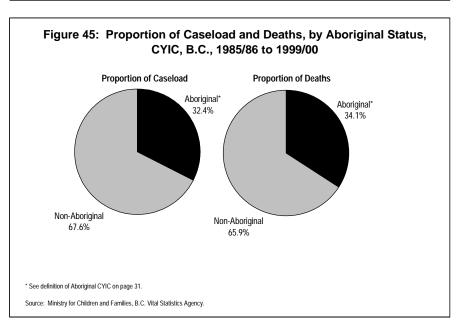
As mortality risk is related to age, it is important to consider the age structure of the Aboriginal and non-Aboriginal CYIC groups (see Figure 44). The pattern shows that age groups 0-4 and 5-14 years have a higher proportion of Aboriginal CYIC, while age group 15-18 years has a lower proportion (see accompanying table). However, if some Aboriginal CYIC have been incorrectly recorded as being non-Aboriginal, the true differences in the age structure of these groups may be greater than shown here for ages 0-4 and 5-14 years, and less for ages 15-18 years.

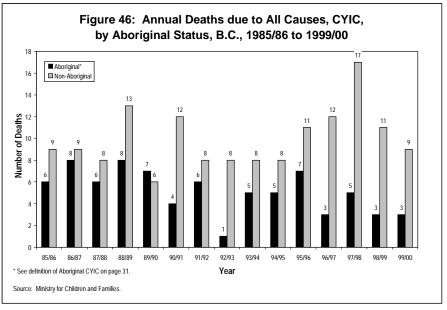
Given their relatively high presence in the CYIC caseload, the general provincial mortality experience of Aboriginal people is important to consider in this review. In a recent report\*, BCVSA reported that Status Indians had 2.3-fold higher infant mortality rates and 1.8-fold higher age-standardized mortality rates (children and adults combined), as compared to other provincial residents.

Accordingly, it could be expected that Aboriginal children in the CYIC caseload could influence the overall CYIC mortality experience, due to their relatively high proportions in the CYIC caseload, and their higher underlying risk of mortality as members of the general Aboriginal community in the province.

However, the overall cumulative mortality experience for Aboriginal and non-Aboriginal CYIC appears to be similar, with Aboriginal CYIC comprising 32.4% of the caseload and experiencing 34.1% of the deaths of CYIC (see Figure 45). The annual number of deaths for CYIC by Aboriginal status is shown in Figure 46. While there appeared to be a relative decline in the number of Aboriginal CYIC deaths in recent years, their true mortality trend is uncertain due to the possible under-estimation of Aboriginal children in the CYIC caseload.\*\*





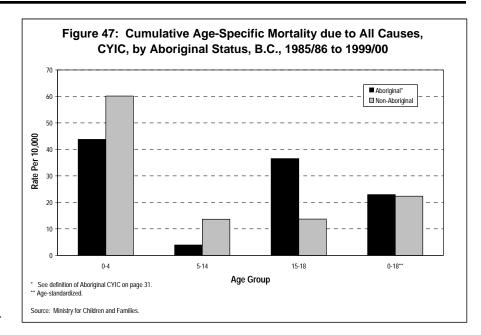


<sup>\*</sup> B.C. Vital Statistics Agency, Analysis of Health Statistics for Status Indians in British Columbia 1991-1998, January 2000.

<sup>\*\*</sup> In this study, a death of a CYIC was considered to be Aboriginal if the child was identified as being Aboriginal by in the MCF information system, or if the child was identified as being Status Indian by BCVSA. As the updating is ongoing, these data are subject to change over time.

A comparison of cumulative mortality by Aboriginal status is shown in Figure 47, using both age-specific and agestandardized rates. On statistical testing, there was no significant difference in mortality by Aboriginal status for all ages (0-18 years) and 0-4 years. However, the mortality in ages 5-14 years was significantly higher for non-Aboriginal CYIC, and the mortality for ages 15-18 years was significantly higher for Aboriginal CYIC (see accompanying table).

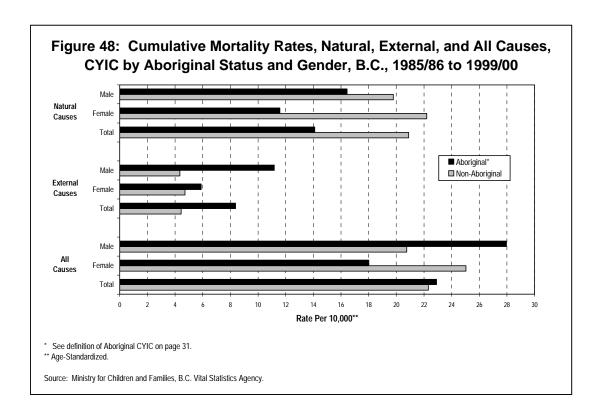
The Natural Causes mortality rates appeared to be higher for non-Aboriginal CYIC (both males and females), and **External Causes mortality** appeared to be higher for Aboriginal CYIC (both males and females), as shown in Figure 48. However, the only statistically significant gender difference was the higher External Causes mortality for Aboriginal CYIC males compared to non-Aboriginals (see accompanying tables on next page).



Cumulative Age-Specific Mortality, All Causes, CYIC, by Aboriginal Status, B.C., 1985/86 to 1999/00

Ago Croup	Aboriginal*		Non-Aboriginal		
Age Group	Rate Per 10,000	95% C.I.**	Rate Per 10,000	95% C.I.**	
0-4 5-14 15-18	43.8 3.9 <b>36.5</b>	30.1 to 61.3 1.6 to 8.1 <b>25.7 to 50.4</b>	60.2 <b>13.6</b> 13.7	46.1 to 77.0 <b>9.8 to 18.4</b> 10.0 to 18.3	
0-18***	22.9	18.1 to 28.6	22.3	18.9 to 26.3	

- \* See definition of Aboriginal CYIC on page 31.
- \*\* Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, Neuroepidemiology 2: 257-265 (1983).
- ^^ Age-Standardized



#### Cumulative Mortality Rates, CYIC by Aboriginal Status and Gender, B.C., 1985/86 to 1999/00

	Abori	ginal*	Non-Aboriginal		
Cause	Rate Per 10,000***	95% C.I.**	Rate Per 10,000***	95% C.I.**	
<u>Male</u> Natural External	16.4 <b>11.2</b>	10.7 to 24.2 <b>7.0 to 16.9</b>	19.8 4.4	14.6 to 26.1 2.8 to 6.5	
All	28.0	20.6 to 37.2	20.8	16.3 to 26.1	
<u>Female</u> Natural External	11.6 5.9	6.7 to 18.5 3.0 to 10.3	22.2 4.7	16.5 to 29.1 3.0 to 7.0	
All	18.0	12.1 to 25.9	25.0	19.7 to 31.3	

- See definition of Aboriginal CYIC on page 31.
- \*\* Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, Neuroepidemiology 2: 257-265 (1983)
- \*\*\* Age-Standardized.

Cumulative Mortality Rates, CYIC by Aboriginal Status, B.C., 1985/86 to 1999/00

	Abori	ginal*	Non-Aboriginal		
Cause Rate Per 10,000		95% C.I.**	Rate Per 10,000	95% C.I.**	
Natural External	14.1 8.4	10.2 to 19.0 5.8 to 11.7	20.9 4.4	17.1 to 25.5 3.3 to 5.9	
Total***	22.9	18.1 to 28.6	22.3	18.9 to 26.3	

- \* See definition of Aboriginal CYIC on page 31.
- \*\* Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, Neuroepidemiology 2: 257-265 (1983).
   \*\*\* Age-Standardized.

In summary, while acknowledging that Aboriginal children may be underestimated in the MCF information system, thus requiring caution in interpreting these results, the current data show that:

- (a) Aboriginal children are over-represented in the CYIC caseload relative to the general provincial child population;
- (b) Aboriginal children in the CYIC caseload proportionally exceeded non-Aboriginals for ages 0-4 and 5-14 years, but were proportionately less for ages 15-18 years;
- (c) The All Causes mortality for Aboriginal CYIC was higher for ages 15-18, and was higher for non-Aboriginals for ages 5-14 years (both statistically significant);
- (d) The differences in All Causes mortality for ages 0-4 years and all ages (0-18 years) between Aboriginal and non-Aboriginal CYIC were not statistically significant;

- (e) The cumulative mortality differences in Aboriginal and non-Aboriginal CYIC for Natural Causes and External Causes were not statistically significant;
- (f) The only statistically significant gender difference by Aboriginal status was the higher External Causes mortality in Aboriginal males compared to non-Aboriginal males. The equivalent CYIC female differences for External Causes were not statistically significant, nor were differences by Aboriginal status and gender for Natural Causes.

The next section will examine specific causes of death in more detail.

## 9. A Description of CYIC Mortality by Cause of Death

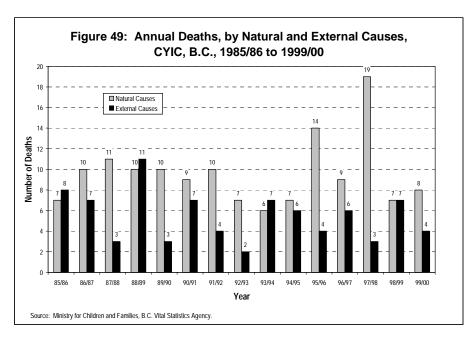
There were 226 deaths of CYIC over the period 1985/86 to 1999/00, of which 144 were due to Natural Causes (almost 2/3 of all deaths), and 82 were due to External Causes (over 1/3 of all deaths). For Natural Causes, the annual range was 6 to 19 deaths, averaging 9.6 per year. For External Causes, the annual range was 2 to 11 deaths, averaging 5.5 per year (see Figure 49).

In order to compare the mortality of CYIC and the provincial child population by cause of death, cumulative Standardized Mortality Ratios (SMRs) were used.

However, this estimation of the mortality gap does not imply that it should be possible for the mortality of

CYIC, as a vulnerable high-risk group, to be similar to the mortality of the provincial child population. The following description of the relative mortality experience of CYIC includes "expected" and "excess" mortality estimates in quotation marks, to emphasize the theoretical nature of these calculations.

The cumulative mortality of CYIC due to Natural and External Causes, as measured by the SMR, is shown in the accompanying tables, together with the observed deaths, "expected" deaths, and "excess" deaths. For each cause of death, by definition the provincial child comparison value is SMR = 1.00, with the SMR for CYIC being a comparison of their



cumulative mortality experience relative to the provincial child mortality experience, during the entire period 1985/86 to 1999/00.

Those Natural Causes in which the SMR for CYIC was significantly higher than the provincial child mortality were Congenital Anomalies, Sudden Infant Death Syndrome (SIDS), Diseases of the Nervous System, Diseases of the Respiratory System, Infectious Diseases, Cancer, Other Natural Causes, and Unknown Causes. Natural Causes with an SMR for CYIC which was not significantly different than the provincial child mortality were Certain Perinatal Conditions\* and Diseases of the Circulatory System.

Mortality Due to Natural Causes, Cumulative Standardized Mortality Ratios, CYIC, B.C., 1985/86 to 1999/00

Cause of Death (ICD)	Standardized Mortality Ratio	95% Confidence	Number of Deaths Over 15 Years**			
0	(SMR)	Intervals (C.I.)*	Observed	"Expected"	"Excess"	
Congenital Anomalies (740-759)	5.45	3.91 to 7.41	41	7.5	33.5	
SIDS (798.0)***	7.84	5.26 to 11.30	29	3.7	25.3	
Diseases of the Nervous System (320-389)	10.80	6.50 to 16.85	19	1.8	17.2	
Other Natural Causes****	7.04	4.09 to 11.26	17	2.4	14.6	
Diseases of the Respiratory System (560-519)	6.88	3.15 to 13.07	9	1.3	7.7	
Infectious Diseases (001-139)	9.06	3.91 to 17.86	8	0.9	7.1	
Cancer (140-208)	2.44	1.05 to 4.81	8	3.3	4.7	
Certain Perinatal Conditions (760-779)***	0.85	0.34 to 1.75	7	8.2	(1.2)	
Unknown Causes (799.9)	5.62	1.53 to 14.39	4	0.7	3.3	
Diseases of the Circulatory System (390-459)	1.68	0.20 to 5.89	2	1.2	0.8	
All Natural Causes	4.41	3.73 to 5.21	144	32.6	111.4	

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, Neuroepidemiology 2: 257-265 (1983).

<sup>\*\*</sup> Totals for "expected" and "excess" deaths do not equal sum of column due to rounding, and because the SMR for All Natural Causes includes all age groups for "expected" deaths due to SIDS and Certain Perinatal Conditions.

<sup>\*\*\*</sup> The SMR calculations for these conditions of infancy were based on the age group <1 year.

<sup>\*\*\*\*</sup> All other Natural Causes not specifically listed in this table.

<sup>\*</sup>The majority of deaths in B.C. due to this cause occur to infants <7 days old. It would be extremely unlikely for a seriously ill infant of this age, who would be receiving hospital treatment, to be taken into care. Personal communication, W. Matheson, Ministry for Children and Families.

Those External Causes with an SMR significantly higher than the provincial child mortality were Motor Vehicle Traffic Accidents, Suicide, Accidental Poisoning, Homicide, and Other External Causes.

Those External Causes with an SMR which was not significantly different from the provincial child mortality were Drowning, Falls, Other Transport Accidents, and Fire/Burns.

Mortality Due to External Causes, Cumulative Standardized Mortality Ratios, CYIC, B.C., 1985/86 to 1999/00

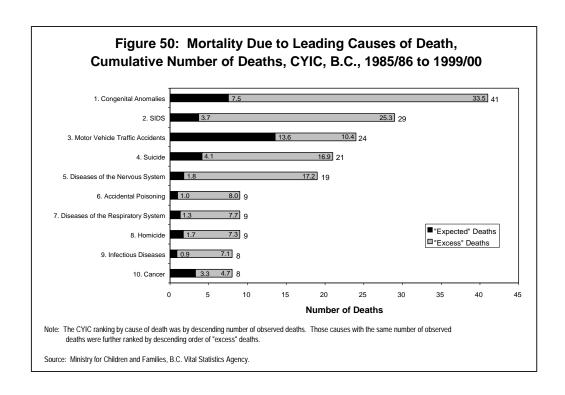
Cause of Death (ICD)	Standardized Mortality Ratio 95% Confidence		Number of Deaths Over 15 Years**			
	(SMR)	Intervals (C.I.)*	Observed	"Expected"	"Excess"	
Motor Vehicle Traffic (E810-819)	1.77	1.13 to 2.64	24	13.6	10.4	
Suicide (E950-959)	5.09	3.15 to 7.78	21	4.1	16.9	
Accidental Poisoning (E850-869)	9.40	4.31 to 17.86	9	1.0	8.0	
Homicide (E960-969)	5.23	2.39 to 9.93	9	1.7	7.3	
Other External Causes***	3.16	1.27 to 6.50	7	2.2	4.8	
Drowning (E830-832,910)	2.03	0.55 to 5.19	4	2.0	2.0	
Falls (E880-888)	3.70	0.76 to 10.81	3	0.8	2.2	
Other Transport (E800-807,826-848)	2.50	0.51 to 7.29	3	1.2	1.8	
Fire/Burns (E890-899,924)	2.30	0.28 to 8.30	2	0.9	1.1	
All External Causes	2.99	2.37 to 3.70	82	27.4	54.6	

Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, <u>Neuroepidemiology</u> 2: 257-265 (1983). Totals for "expected" and "excess" deaths may not equal sum of column due to rounding.

## The Ten Leading Causes of Death

The ten most frequent specific causes of death which were significantly increased in CYIC are shown in rank order in Figure 50 and accompanying table, with the corresponding rank for the provincial child population included for comparison.

Most of the leading CYIC causes of death had higher ranks than the provincial child population. The ten leading causes of CYIC death accounted for 78% of observed and 83% of "excess" deaths, and accordingly have been emphasized in this paper.



<sup>\*\*\*</sup> All other External Causes not specifically listed in this table.

The only cause with the same rank for both CYIC and the provincial child population was Motor Vehicle Traffic Accidents (#3). The highest ranked provincial child cause was Certain Perinatal Causes (#1), which is not even on the list of ten leading

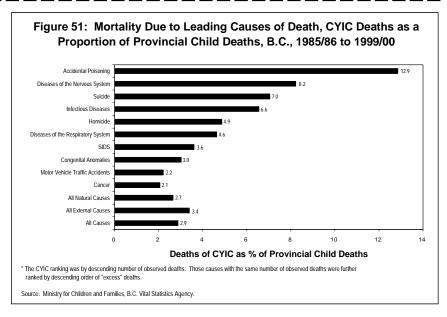
causes for CYIC. In order to put the entire 15-year period of CYIC experience into perspective, the average annual number of deaths by leading cause was listed in the table below, by observed, "expected", and "excess" deaths.

Mortality Due to Leading Causes of Death, Average Annual Deaths, CYIC, B.C., 1985/86 to 1999/00

CYIC	B.C.			Annual Average Number of Deaths Over 15 Years***				
Rank*	Rank**	Cause of Death (ICD)	SMR	% of Observed	Observed	"Expected"	"Excess"	% of "Excess"
1	2	Congenital Anomalies	5.45	18.1	2.73	0.50	2.23	20.2
2	4	SIDS	7.84	12.8	1.93	0.25	1.69	15.3
3	3	Motor Vehicle Traffic Accidents	1.77	10.6	1.60	0.90	0.70	6.3
4	6	Suicide	5.09	9.3	1.40	0.28	1.12	10.2
5	7	Diseases of the Nervous System	10.80	8.4	1.27	0.12	1.15	10.4
6	17	Accidental Poisoning	9.40	4.0	0.60	0.06	0.54	4.8
7	9	Diseases of the Respiratory System	6.88	4.0	0.60	0.09	0.51	4.6
8	10	Homicide	5.23	4.0	0.60	0.11	0.49	4.4
9	15	Infectious Diseases	9.06	3.5	0.53	0.06	0.47	4.3
10	5	Cancer	2.44	3.5	0.53	0.22	0.32	2.8
Subtotal	Subtotal - 10 Leading Causes		-	78.3	11.80	2.59	9.21	83.3
Other Ca	auses Not I	Listed Above	-	21.7	3.27	1.39	1.88	17.0
All Caus	All Causes		3.76	100	15.07	4.01	11.06	100
All Natur	All Natural Causes 4.41 63.7 9.60 2.18 7.42		7.42	67.1				
All Exter	nal Causes		2.99	36.3	5.47	1.83	3.64	32.9

The CYIC ranking was by descending number of observed deaths. Those causes with the same number of observed deaths were further ranked by descending order of "excess" deaths

However, many of the average annual differences were very small, with fractional estimates due to the rarity of some causes. Another way to look at the mortality experience of CYIC is by the proportion of all provincial child deaths which have occurred to CYIC for each of the leading causes. Over the entire 15-year period, CYIC deaths comprised 2.9% of all deaths to children in B.C., with the highest percentage of CYIC deaths by cause being Accidental Poisoning (12.9%), Diseases of the Nervous System (8.2%), Suicide (7.0%), Infectious Diseases (6.6%), and Homicide (4.9%), as shown in Figure 51.



Following are more detailed descriptions for each of the ten leading causes of CYIC death, beginning with the most common cause. Again, it should be emphasized that the general nature of an epidemiological study of the causes of death of CYIC cannot be regarded as an indication that these children did not receive competent and **appropriate care,** as: (1) these vulnerable children were at risk for medical or social reasons prior to coming into care, and (2) this study only assessed the mortality experience of CYIC as a group, without considering the individual circumstances of any child who died. For each leading cause of death, the mortality pattern was assessed by age, gender, and Aboriginal status.

The previously noted data quality issues mean that the mortality comparisons by Aboriginal status must be interpreted with caution, as the true Aboriginal or non-Aboriginal mortality rates for CYIC could be higher or lower than is reported here. Data on functional status were not included in this section, due to data quality issues, very small numbers in many cells, and a time frame of only 10 years. **Finally, a general limitation in** comparing mortality differences by age, gender, and Aboriginal status for the leading causes is that the small numbers involved with these rare events resulted in many of the apparent differences not attaining statistical significance.

The other of the ten provincial leading causes of child death not listed above are Certain Perinatal Causes (#1) and Drowning (#8).

Totals for "expected" and "excess" deaths and % of "excess" deaths do not equal sum of column due to rounding, and because the SMR for All Natural Causes includes all age groups for "expected" deaths due to SIDS

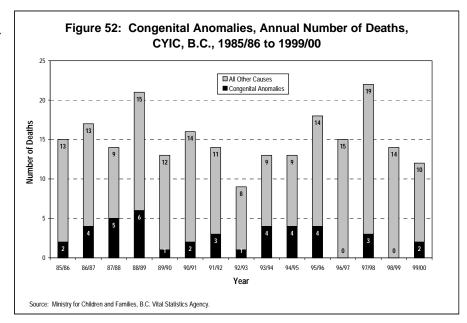
## (1) Congenital Anomalies

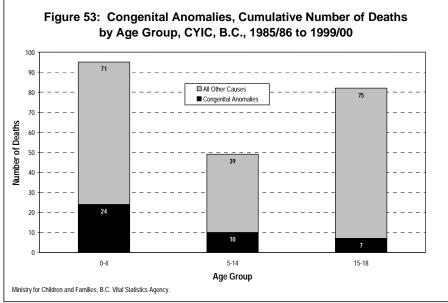
The leading cause of CYIC death, Congenital Anomalies (or birth defects), are physical conditions which are present at the time of birth. These may be inherited (genetic) or arise during the pregnancy, and are major causes of disability and death in the provincial child population.

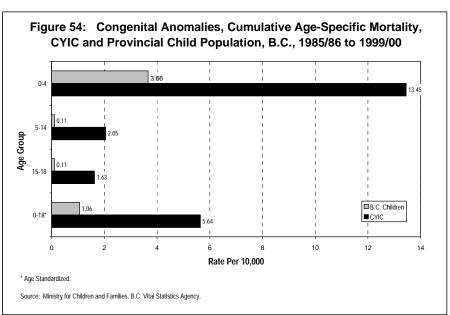
As children living with a severe disability are over-represented in the CYIC caseload, an increased mortality due to Congenital Anomalies would not be unexpected. Children with such conditions are medically fragile, and the more serious of these disorders have high case fatality rates.

For this cause of death, the annual range was 0-6 deaths, averaging 2.7 per annum, for a total of 41 deaths (see Figure 52). The SMR was 5.45 and it was estimated that over the entire 15-year period, 33.5 (or 2.23 per annum) of the deaths (82%) were in "excess" of what would have been expected based on the provincial child population experience. The number of deaths in the latest five-year period was less than in each of the previous five-year periods.

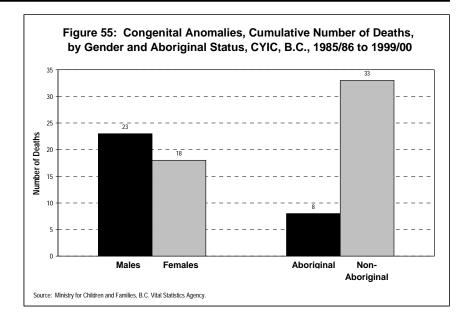
Deaths of CYIC comprised 3.0% of all provincial child deaths due to this cause. The majority of CYIC deaths (59%) occurred in ages 0-4 years, which also had the highest mortality rate (statistically significant). The CYIC age-specific mortality pattern was similar to the provincial child pattern, but CYIC rates were much higher in all age groups (see Figures 53 and 54).



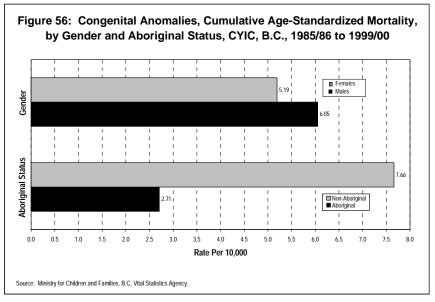




There were 23 deaths in CYIC males and 18 in females, While the male mortality rate appeared to be higher, the difference was not statistically significant.



The higher mortality for non-Aboriginal CYIC was also not statistically significant (see Figures 55, 56, and accompanying table). The B.C. Vital Statistics Agency found no difference in mortality due to Congenital Anomalies on comparing Status Indians (all ages) with other provincial residents. \*



In summary, the only characteristic of CYIC associated with a statistically significant higher rate of mortality was being in age group 0-4 years. Mortality differences by gender and Aboriginal status were not statistically significant.

Congenital Anomalies, Cumulative Mortality Rates for CYIC, B.C., 1985/86 to 1999/00

CYIC Group	Rate Per	95% C.I.*
·	10,000	
<u>Age</u> 0-4 5-14 15-18	<b>13.45</b> 2.05 1.63	<b>8.62 to 20.04</b> 0.90 to 3.78 0.65 to 3.35
<u>Gender</u> ** Male Female	6.05 5.19	3.84 to 9.07 3.08 to 8.21
Aboriginal Status** Aboriginal Non-Aboriginal	2.71 7.66	1.17 to 5.33 5.27 to 10.73
Total**	5.64	4.03 to 7.68

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios,

Neuroepidemiology 2: 257-265 (1983).

<sup>\*\*</sup> Age-Standardized Rates

<sup>\*</sup>B.C. Vital Statistics Agency, Analysis of Health Statistics for Status Indians in British Columbia 1991-1998, January 2000: 51.

The largest group of conditions causing death (37%) was disabling conditions of the central nervous system. The next largest category of deaths (22%) involved structural defects in the heart.

Chromosomal anomalies and gastrointestinal anomalies were respectively associated with 12% and 10% of the deaths, and another 20% were due to a variety of other anomalies. Details are included in the following table:

Cumulative Deaths Due to Congenital Anomalies, CYIC, B.C., 1985/86 to 1999/00

ICD	Cause of Death	No. of Deaths	% of Deaths
741-742 741.0 742.1 742.2 742.3 742.9	Spina Bifida and Other Congenital Anomalies of the Nervous System Spina bifida with hydrocephalus Microcephalus Reduction deformity of brain Congenital hydrocephalus Unspecified anomalies of nervous system Subtotal	1 4 3 4 3	37
<b>745-746</b> 745.2 745.6 746.9	Congenital Anomalies of the Heart Tetralogy of Fallot Endocardial cushion defects Unspecified anomalies of heart Subtotal	3 1 5	22
<b>758</b> 758.0 758.1 758.2 758.9	Chromosomal Anomalies Down's syndrome (trisomy 21) Patau's syndrome (trisomy 13) Edward's syndrome (trysomy 18) Anomaly of unspecified chromosome	2 1 1 1	12
	Subtotal	5	
<b>750-751</b> 750.4 751.5 751.6 751.8	Congenital Anomalies of Gastrointestinal System Other specified anomalies of esophagus Other anomalies of intestine Anomalies of gall bladder, bile ducts, and liver Other specified anomalies of digestive system	1 1 1	10
	Subtotal	4	
Other 740-759 748 753 754 759	Other Congenital Anomalies Congenital anomalies of respiratory system Congenital anomalies of urinary system Certain congenital musculoskeletal deformities Other and unspecified anomalies	1 2 1 4	20
All 740-759	Subtotal  Total Congenital Anomalies	8 41	100*

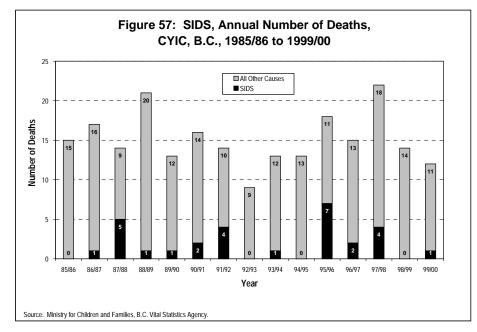
<sup>\*</sup> Sum of groupings may not equal 100 due to rounding. Source: Ministry for Children and Families, BC Vital Statistics Agency.

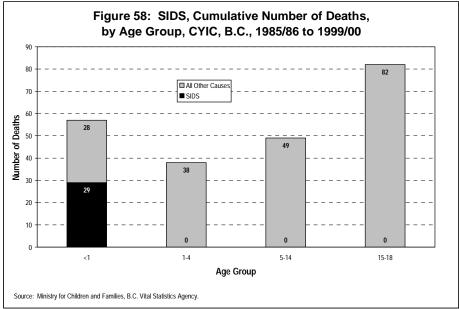
## (2) Sudden Infant Death Syndrome (SIDS)

SIDS refers to the sudden and unexpected death of an apparently healthy infant under one year of age, which remains unexplained after all known and possible causes have been ruled out through autopsy, death scene investigation, and review of the medical history.\*

For this sporadic cause of death, the annual range was 0-7 deaths, averaging 1.9 per annum, for a total of 29 deaths (see Figure 57). The SMR was 7.84, and it was estimated that over the entire 15-year period, 25.3 (or 1.69 per annum) of the deaths (87%) were in "excess" of what would have been theoretically expected, based on the provincial child population experience.

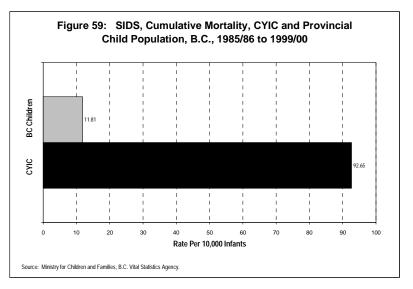
Deaths of CYIC comprised 3.6% of all provincial child deaths due to this cause. The CYIC mortality rate was much higher than the provincial child rate (see Figures 58 and 59). As shown in the table below, SIDS is by far the most common cause of infant deaths (51%) in CYIC, and exceeds the comparable proportion (19%) for the provincial child population.





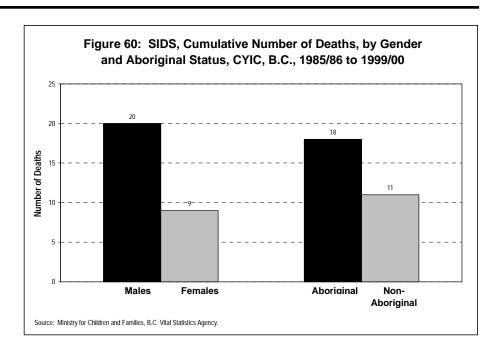
Infant Deaths, Proportionate Mortality by Major Causes, CYIC and Provincial Child Population, B.C., 1985/86 to 1999/00

1 opulation, b.o., 1303/00 to 1333/00				
	% of Infant Deaths			
Cause of Death	CYIC	B.C. Child Population		
SIDS Congenital Anomalies Perinatal Causes All Other Causes	51 19 12 18	19 26 42 13		
Total	100	100		

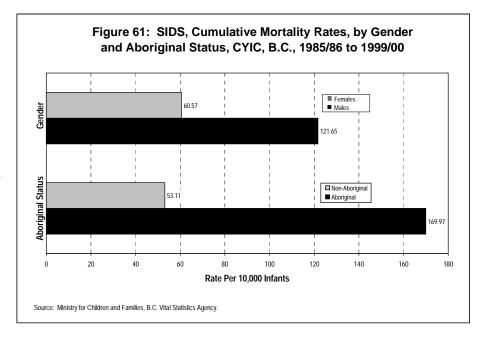


<sup>\*</sup>Bureau of Reproductive and Child Health, Health Canada, September 1999.

There were 20 deaths in CYIC males and 9 in females. While the male mortality appeared to be higher than that of females, the difference was not statistically significant. The mortality for Aboriginal CYIC (18 deaths) was over three times higher than for Non-Aboriginals (11 deaths), and the difference in mortality rates was statistically significant (see Figures 60, 61, and accompanying table).



The higher SIDS mortality for Aboriginal CYIC is consistent with reported data indicating that the SIDS rate for the Status Indian infant population is over six times higher than that of all other infants in the provincial child population.\*



In summary, the only characteristic of CYIC infants associated with a statistically significant higher risk of mortality due to SIDS was being of Aboriginal heritage. Mortality differences by gender were not statistically significant.

SIDS, Cumulative Mortality Rates for CYIC,

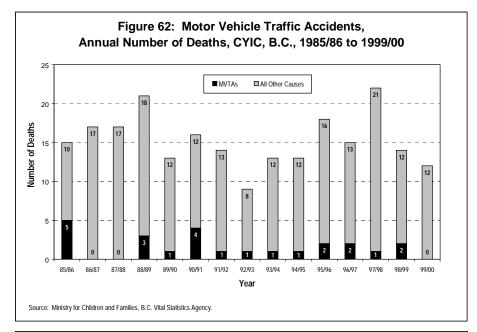
B.O., 1303/00 to 1333/00					
CYIC Group	Rate Per 10,000 Infants	95% C.I.*			
<u>Gender</u> Male Female	121.65 60.57	74.33 to 187.35 27.74 to 115.07			
Aboriginal Status Aboriginal Non-Aboriginal	<b>169.97</b> 53.11	<b>100.79 to 268.56</b> 26.50 to 95.07			
Total	92.65	62.08 to 133.42			

Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, Neuroepidemiology 2: 257-265 (1983).

<sup>\*</sup> B.C. Vital Statistics Agency, Analysis of Health Statistics for Status Indians in British Columbia 1991-1998, January 2000: 34.

## (3) Motor Vehicle Traffic Accidents (MVTAs)

For this cause of death, the annual range was 0-5 deaths, averaging 1.6 per annum, for a total of 24 deaths (see Figure 62). The SMR was 1.77, and it was estimated that over the entire 15-year period, 10.4 (or 0.70 per annum) of the deaths (43%) were in "excess" of what would have been theoretically expected based on the provincial child population experience.



The annual range has varied from 0-2 deaths in recent years, less than the maximum in previous years. Deaths of CYIC comprised 2.2% of all provincial child deaths due to this cause.

Figure 63: Motor Vehicle Traffic Accidents, Cumulative Number of Deaths, by Age Group, CYIC, B.C., 1985/86 to 1999/00

The street of Deaths, by Age Group, CYIC, B.C., 1985/86 to 1999/00

The street of Deaths, by Age Group, CYIC, B.C., 1985/86 to 1999/00

The street of Deaths, by Age Group, CYIC, B.C., 1985/86 to 1999/00

The street of Deaths, by Age Group, CYIC, B.C., 1985/86 to 1999/00

The street of Deaths, by Age Group, CYIC, B.C., 1985/86 to 1999/00

The street of Deaths, by Age Group, CYIC, B.C., 1985/86 to 1999/00

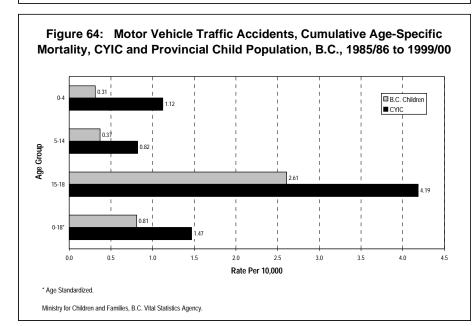
The street of Deaths, by Age Group, CYIC, B.C., 1985/86 to 1999/00

The street of Deaths, by Age Group, CYIC, B.C., 1985/86 to 1999/00

The street of Deaths, by Age Group and Deaths, by Age Group

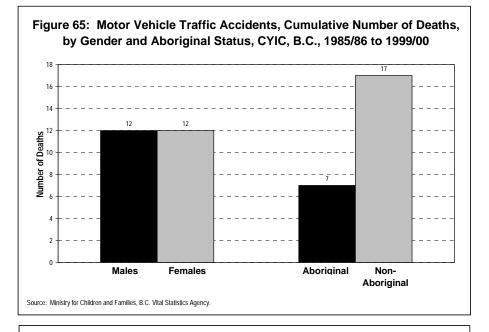
Source: Ministry for Children and Families, B.C. Vital Statistics Agency.

There have generally been one or two deaths per year in recent years, with higher and lower numbers in some earlier years. The majority of deaths (75%) occurred in age group 15-18 years, which also had the highest mortality rate.

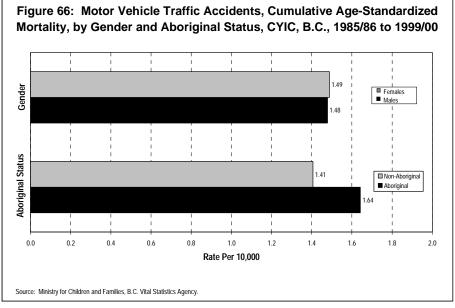


However, only the mortality difference between age groups 5-14 and 15-18 years was statistically significant. The CYIC mortality rates were higher than the provincial child mortality rates in all age groups (see Figures 63 and 64).

There were 12 deaths in male CYIC and 12 in females, with 7 deaths to Aboriginal and 17 to Non-Aboriginal CYIC.



The mortality differences by gender and Aboriginal status were not statistically significant (see Figures 65, 66, and accompanying table).



In summary, the only characteristic of CYIC associated with a significantly higher rate of mortality was being in age group 15-18 years (as compared to age group 5-14 years). Mortality differences by gender and Aboriginal status were not statistically significant.

Motor Vehicle Traffic Accidents, Cumulative Mortality Rates for CYIC, B.C., 1985/86 to 1999/00

CYIC Group	Rate Per 10,000	95% C.I.*	
<u>Age</u> 0-4 5-14 15-18	1.12 0.82 <b>4.19</b>	0.14 to 4.05 0.22 to 2.10 <b>2.48 to 6.61</b>	
Gender** Male Female	1.48 1.49	0.76 to 2.59 0.77 to 2.60	
Aboriginal Status** Aboriginal Non-Aboriginal	1.64 1.41	0.66 to 3.38 0.82 to 2.25	
Total**	1.47	0.94 to 2.19	

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, Neuroepidemiology 2: 257-265 (1983).

<sup>\*\*</sup> Age-Standardized Rates

The category of MVTA associated with the most deaths (38%) was loss of control without collision on the highway. The second largest category (21%) was MVTA involving the death of a pedestrian. Next most common (17%) was MVTA involving collision with another motor vehicle stopped on the highway.

Another 6 deaths occurred due to a variety of other types of accidents. Regarding the fatal non-pedestrian situations, 6 CYIC were drivers (of which 1 was a motorcyclist), 9 were passengers, and 4 were unspecified. Details are included in the following tables:

## Non-Pedestrian Deaths by Vehicle Type and Driving Status, CYIC, B.C., 1985/86 to 1999/00

Time of Vahiala	Persons in Vehicle					
Type of Vehicle	Driver	Passenger	Unspecified	Total		
Non-Motorcycle MV Motorcycle Unspecified	5 1 -	7 - 2	- - 4	12 1 6		
Total	6	9	4	19		

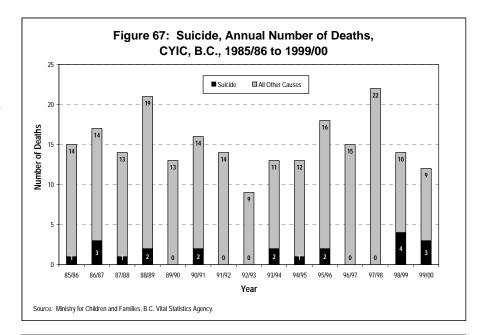
#### Cumulative Deaths due to Motor Vehicle Traffic Accidents, CYIC, B.C., 1985/86 to 1999/00

ICD	Cause of Death	No. of Deaths	% of Deaths
E816	MVTA Due to Loss of Control, Without Collision on Highway		
E816.0	Driver of non-motorcycle MV	2	
E816.1	Passenger of non-motorcycle MV	2	38
E816.2	Motorcyclist	1	
E816.9	Unspecified person	4	
	Subtotal	9	
E814	MVTA Involving Collision with Pedestrian		
E814.7	Pedestrian	5	21
	Subtotal	5	
E812	Other MVTA Involving Collision with Another MV Stopped on Highway		
E812.0	Driver of non-motorcycle MV in collision with other MV	1	17
E812.1	Passenger in non-motorcycle MV	3	
	Subtotal	4	
Other E810-819 E811 E813	Other MVTA  MV re-entrant collision with another MV (passenger)  Passenger in MV in collision with other MV (non-	1	
E815	motorcycle) Other MVTA involving collision on highway (driver of	1	25
2010	non-motorcycle MV)	2	
E819.1	MVTA of unspecified nature (passenger)	2	
	Subtotal	6	
All 810-819	Total Motor Vehicle Traffic Accidents	24	100*

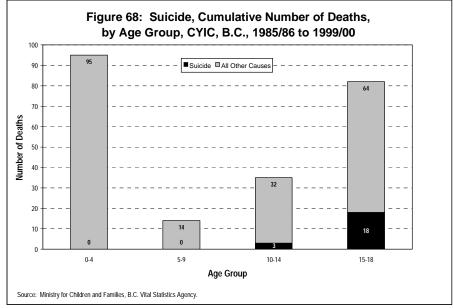
<sup>\*</sup> Sum of groupings may not equal 100 due to rounding. Source: Ministry for Children and Families, BC Vital Statistics Agency.

## (4) Suicide

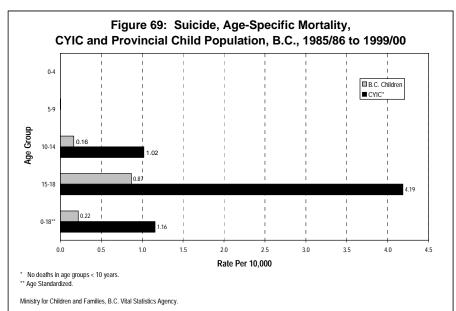
For this sporadic cause of death, the annual range was 0-4 deaths, averaging 1.4 per annum, for a total of 21 deaths (see Figure 67). The SMR was 5.09, and it was estimated that over the entire 15-year period, 16.9 (or 1.12 per annum) of the deaths (80%) were in "excess" of what would be theoretically expected based on the provincial child population experience.



There were more deaths in the latest five-year period (particularly the last two years) than in previous periods. Deaths of CYIC comprised 7.0% of all provincial child deaths due to this cause.

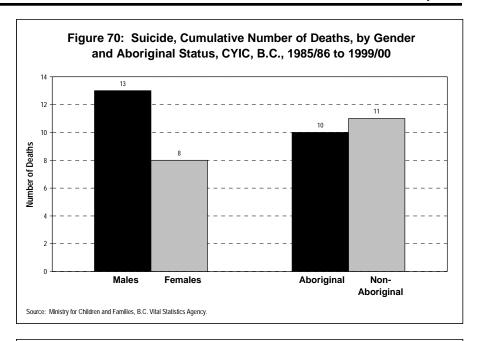


The majority of the deaths (86%) occurred in age group 15-18 years. The remainder were in age group 10-14 years, with the youngest two cases being age 13 years (see Figure 68).

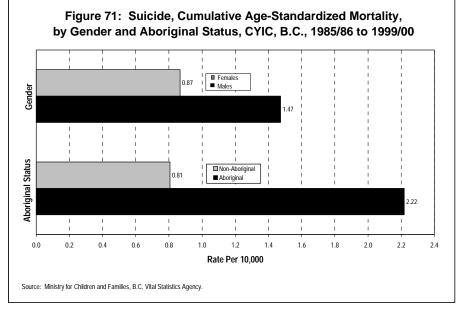


The CYIC mortality for both of these age groups was higher than the provincial average. The difference in CYIC mortality between ages 10-14 years and 15-18 years was not statistically significant (see Figure 69).

There were 13 male and 8 female CYIC deaths. The male mortality rate appeared to be higher, but the difference was not statistically significant. While the Aboriginal CYIC mortality appeared to be higher than for non-Aboriginals, the difference was not statistically significant (see figures 70, 71, and accompanying table).



This compares with an almost three-fold higher mortality due to suicide for the Status Indian population (all ages) as compared to other residents in the province.\*



In summary, CYIC mortality differences by age, gender, and Aboriginal status were not statistically significant.

Suicide, Cumulative Mortality Rates for CYIC, B.C., 1985/86 to 1999/00

CYIC Group	Rate Per 10,000	95% C.I.*
<u>Age</u> 10-14 15-18	1.02 4.19	0.21 to 2.98 2.48 to 6.61
<u>Gender</u> ** Male Female	1.47 0.87	0.78 to 2.52 0.37 to 1.71
Aboriginal Status** Aboriginal Non-Aboriginal	2.22 0.81	1.06 to 4.08 0.40 to 1.44
Total**	1.16	0.72 to 1.77

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and

Ratios, Neuroepidemiology 2: 257-265 (1983).

<sup>\*\*</sup> Age-Standardized Rates

<sup>\*</sup> B.C. Vital Statistics Agency, Analysis of Health Statistics for Status Indians in British Columbia 1991-1998, January 2000: 56.

The most common method of suicide (57%) was by hanging. Next most common (19%) was jumping from a high place or other means, with the remaining 5 deaths caused by firearms or drugs. Details are included in the following table:

Cumulative Deaths Due to Suicide, CYIC, B.C., 1985/86 to 1999/00

ICD	Cause of Death	No. of Deaths	% of Deaths
E953	Suicide and Self-inflicted Injury by Hanging, Strangulation, and Suffocation	12	57
E953.0	Hanging Subtotal	12	31
E957-958  E957.1  E958.0  E958.8	Suicide and Self-inflicted Injury by Jumping from a High Place or Other Means Jumping from other man made structure Jumping or lying before moving object Other specified means	2 1 1	19
	Subtotal	4	
<b>E955</b> E955.4	Suicide and Self-inflicted Injury by Firearms and Explosives Other and unspecified firearm	3	14
	Subtotal	3	
<b>E950</b> E950.3 E950.4	Suicide and Self-inflicted Poisoning by Solid or Liquid Substance Tranquilizers and psychotropic agents Other specified drugs and medicaments	1 1	10
	Subtotal	2	
All E950-959	Total Suicide and Self-inflicted Injury	21	100*

<sup>\*</sup> Sum of groupings may not equal 100 due to rounding. Source: Ministry for Children and Families, BC Vital Statistics Agency.

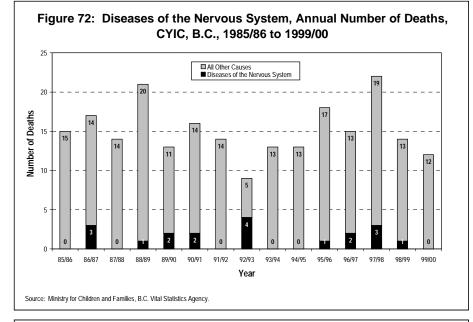
## (5) Diseases of the Nervous System

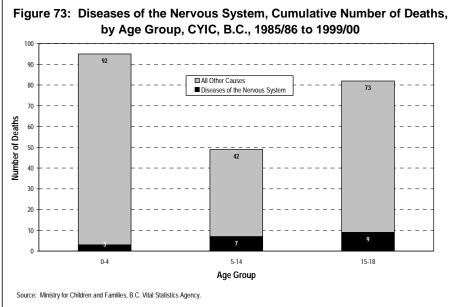
As acquired causes of illness resulting in severe physical disability, many of these neurological conditions would have been apparent at birth or during early childhood. For this sporadic cause of death, the annual range was 0-4 deaths, averaging 1.3 per annum, for a total of 19 deaths (see Figure 72).

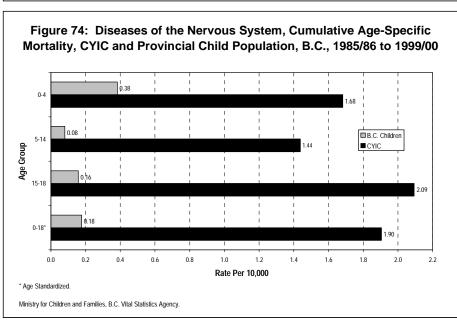
As children with a severe disability are over-represented in the CYIC caseload, an increased mortality due to Diseases of the Nervous System would not be unexpected. Children with such conditions are medically fragile, and the more serious of these disorders have high case fatality rates.

The SMR was 10.80, and it was estimated that over the entire 15-year period, 17.2 (or 1.15 per annum) of these deaths (91%) were in "excess" of what would have been theoretically expected, based on the provincial child population experience.

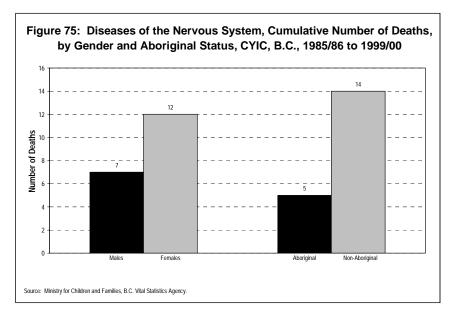
Deaths of CYIC comprised 8.2% of all provincial child deaths due to this cause. The majority of the deaths (47%) occurred in ages 15-18 years, however, none of the CYIC age-specific mortality differences were statistically significant. The mortality for CYIC was much higher than the provincial average for all age groups (see Figures 73 and 74).



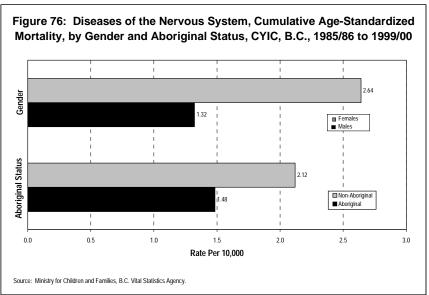




There were 7 male and 12 female deaths, however, the apparent higher female mortality was not statistically significant.



The mortality for non-Aboriginal CYIC appeared to be slightly higher than for Aboriginals, but the difference was not statistically significant (see Figures 75, 76, and accompanying table). The mortality for this cause of death for Status Indians (all ages) was only slightly higher than for other residents of the province.\*



In summary, CYIC mortality differences by age, gender, and Aboriginal status were not statistically significant.

#### Diseases of the Nervous System, Cumulative Mortality Rates for CYIC, B.C., 1985/86 to 1999/00

CYIC Group	Rate Per 10,000	95% C.I.*
Age 0-4 5-14 15-18	1.68 1.44 2.09	0.35 to 4.91 0.58 to 2.96 0.96 to 3.98
<u>Gender</u> ** Male Female	1.32 2.64	0.53 to 2.72 1.37 to 4.62
Aboriginal Status** Aboriginal Non-Aboriginal	1.48 2.12	0.48 to 3.46 1.16 to 3.56
Total**	1.90	1.15 to 2.97

Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and

Ratios Neuroepidemiology 2: 257-265 (1983).
\*\* Age-Standardized Rates.

<sup>\*</sup> B.C. Vital Statistics Agency, Analysis of Health Statistics for Status Indians in British Columbia 1991-1998, January 2000: 60-61.

The largest group of conditions causing death (53%) was cerebral palsy and other paralytic syndromes. The next largest group (21%) was epilepsy. Another 5 deaths were due to various other neurological disorders. Details are included in the following table:

# Cumulative Deaths Due to Diseases of the Nervous System, CYIC, B.C., 1985/86 to 1999/00

ICD	Cause of Death	No. of Deaths	% of Deaths
343/344	Infantile Cerebral Palsy and Other Paralytic Syndromes		
343.2	Quadraplegia due to cerebral palsy	3	
343.9	Unspecified cerebral palsy	5	53
344.0	Quadraplegia unspecified	2	
	Subtotal	10	
345	Epilepsy		
345.3	Status epilepticus	1	
345.9	Unspecified epilepsy	3	21
	Subtotal	4	
Other 320-389	Other Disorders of Nervous System		
326	Late effects of intracranial abscess/pyogenic		
	infection	1	
331	Other cerebral degenerations	1	
334	Spinocerebellar disease	1	26
349	Other and unspecified disorders	1	
359	Muscular dystrophies and other myopathies	1	
	Subtotal	5	
All 320-389	Total Diseases of the Nervous System	19	100*

<sup>\*</sup> Sum of groupings may not equal 100 due to rounding. Source: Ministry for Children and Families, BC Vital Statistics Agency.

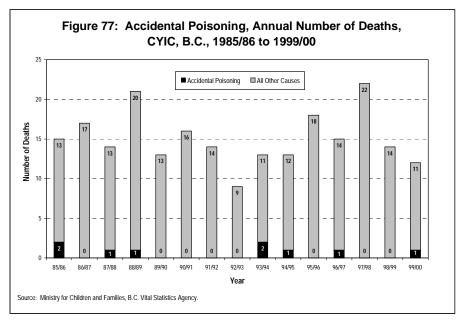
## (6) Accidental Poisoning

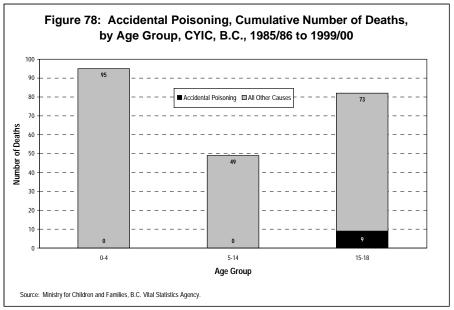
For this sporadic cause of death, the annual range was 0-2 deaths, averaging 0.6 per annum, for a total of 9 deaths (see Figure 77). Deaths due to this cause were less frequent in the last 5-year period than in the previous 5-year periods.

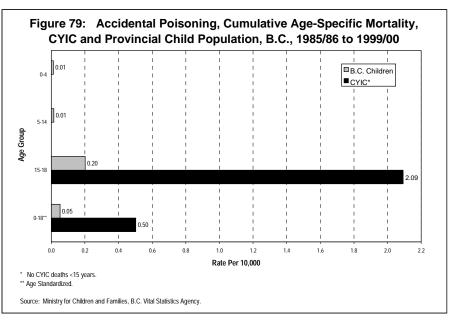
The SMR was 9.40, and it was estimated that over the entire 15-year period, 8.0 (or 0.54 per annum) of the deaths (89%) were in "excess" of what would have been theoretically expected based on the provincial child population experience.

Deaths to CYIC comprised 12.9% of all provincial child deaths due to this cause. All of the CYIC deaths occurred in age group 15-18 years, but because of small numbers, the only statistically significant comparison was with ages 5-14 years.

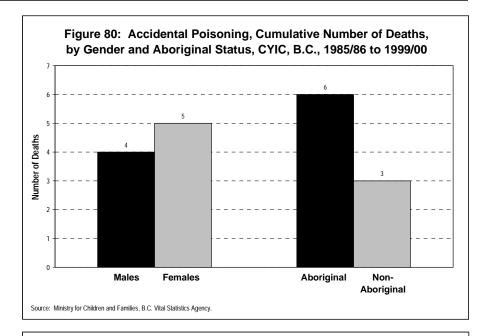
The CYIC mortality rate was much higher than for the provincial child population for ages 15-18 years (see Figures 78 and 79).



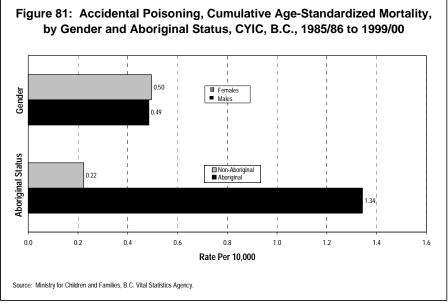




There were no CYIC gender differences in mortality, with 5 female and 4 male deaths. Aboriginal CYIC mortality appeared to be higher than for non-Aboriginals, but the difference was not statistically significant (see Figures 80, 81, and accompanying table).



The accidental poisoning mortality for Status Indians (all ages) was over four times higher than for other residents of the province.\*



In summary, the only characteristic of CYIC associated with a statistically significant higher rate of mortality was being in age group 15-18 years (as compared to ages 5-14 years). Mortality differences by gender and Aboriginal status were not statistically significant.

Accidental Poisoning, Cumulative Mortality Rates for CYIC, B.C., 1985/86 to 1999/00

101 CTIC, B.C., 1903/00 to 1999/00		
CYIC Group	Rate Per 10,000	95% C.I.*
Age 0-4 5-14 15-18	0.00 0.00 <b>2.09</b>	0.00 to 1.68 0.00 to 0.62 <b>0.96 to 3.98</b>
<u>Gender</u> ** Male Female	0.50 0.49	0.13 to 1.24 0.16 to 1.15
Aboriginal Status** Aboriginal Non-Aboriginal	1.34 0.22	0.49 to 2.93 0.05 to 0.65
Total**	0.50	0.23 to 0.95

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, <u>Neuroepidemiology</u> 2: 257-265 (1983).

<sup>\*\*</sup> Age-Standardized Rates.

<sup>\*</sup> B.C. Vital Statistics Agency, Analysis of Health Statistics for Status Indians in British Columbia 1991-1998, January 2000: 56.

Of the 9 deaths due to accidental poisonings, 7 were associated with drug overdose, and 2 with other toxic substances, as shown in the accompanying table:

Cumulative Deaths Due to Accidental Poisoning, CYIC, B.C., 1985/86 to 1999/00

ICD	Cause of Death	No. of Deaths	% of Deaths
E850-858	Accidental Poisoning by Drugs, Medicaments, and Biologicals		
E850.0	Opiates and related narcotics	2	
E853.0	Tranquilizers	2	78
E858.8	Opiate and cocaine	1	10
E858.9	Unspecified drugs	2	
	Subtotal	7	
E860-869	Accidental Poisoning by Other Solid and Liquid Substances, Gases and Vapours		
E862.1	Accidental poisoning by petroleum fuels and cleaners	1	22
E869.9	Accidental poisoning by unspecified gases and vapours	1	
	Subtotal	2	
All E850-869	Total Accidental Poisonings	9	100*

<sup>\*</sup> Sum of groupings may not equal 100 due to rounding. Source: Ministry for Children and Families, BC Vital Statistics Agency.

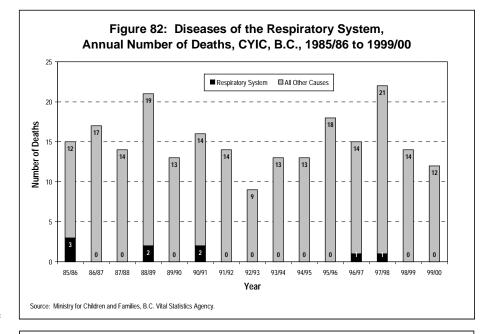
#### (7) Diseases of the Respiratory System

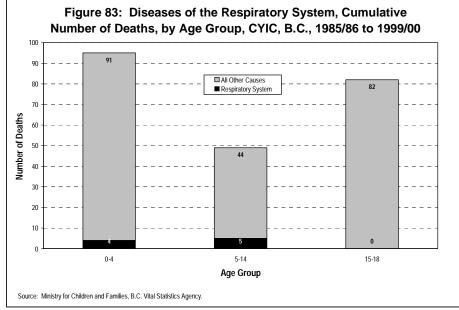
For this sporadic cause of death, the annual range was 0-3 deaths, averaging 0.6 per annum, for a total of 9 deaths (see Figure 82). Deaths due to this cause have become less frequent over time.

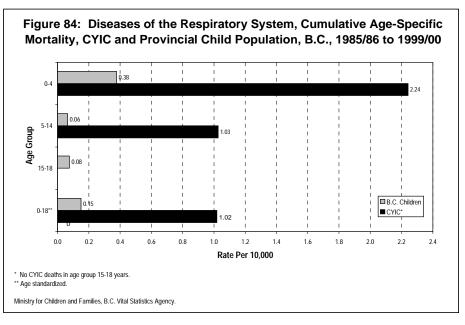
The SMR was 6.88, and it was estimated that over the entire 15-year period, 7.7 (or 0.51 per annum) of these deaths (86%) were in "excess" of what would have been theoretically expected, based on the provincial child population experience.

Deaths of CYIC comprised 4.6% of all provincial child deaths due to this cause. Three of the deaths involved chronic respiratory conditions, which may have occurred to children with a physical disability who would have been medically fragile in the later stages of their illness.

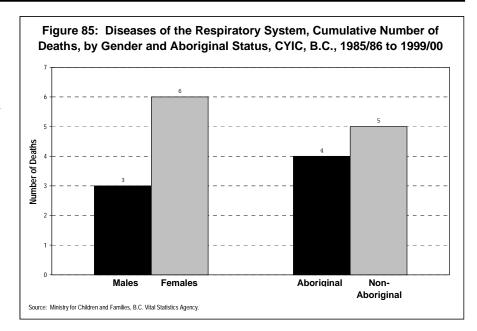
While 5 of the deaths (56%) occurred in the 5-14 age group, the 0-4 age group appeared to have the highest mortality (not statistically significant). There were no deaths in ages 15-18 years, but for the younger age groups, CYIC had a much higher mortality than the provincial child population (see Figures 83 and 84).



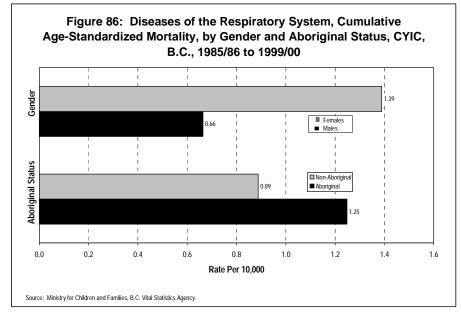




There were 6 female and 3 male deaths, but the apparently higher female mortality was not statistically significant. The mortality for Aboriginal CYIC appeared to be slightly higher than for non-Aboriginals, but the difference was not statistically significant (see Figures 89, 90, and accompanying table).



The mortality for this cause in the Status Indian population (all ages) was slightly higher than for other residents in the province.\*



In summary, CYIC mortality differences by age, gender, and Aboriginal status were not statistically significant.

Diseases of the Respiratory System, Cumulative Mortality Rates for CYIC, B.C., 1985/86 to 1999/00

CYIC Group	Rate Per 10,000	95% C.I.*
<u>Age</u> 0-4 5-14 15-18	2.24 1.03 0.00	0.61 to 5.74 0.33 to 2.39 0.00 to 0.70
<u>Gender</u> ** Male Female	0.66 1.39	0.14 to 1.94 0.51 to 3.03
Aboriginal Status** Aboriginal Non-Aboriginal	1.25 0.89	0.34 to 3.19 0.29 to 2.07
Total**	1.02	0.47 to 1.94

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and

Ratios, Neuroepidemiology 2: 257-265 (1983).

\*\* Age-Standardized Rates.

<sup>\*</sup>B.C. Vital Statistics Agency, Analysis of Health Statistics for Status Indians in British Columbia 1991-1998, January 2000: 50.

As to specific cause, there were 6 deaths (67%) due to respiratory infections (ICD 466, 480-487, and 510). There were 3 deaths involving chronic conditions, 2 deaths due to Asthma, and another one due to unspecified chronic respiratory disease. Details are included in the following table:

## Cumulative Deaths Due to Diseases of the Respiratory System, CYIC, B.C., 1985/86 to 1999/00

ICD	Cause of Death	No. of Deaths	% of Deaths
<b>480-487</b> 480 485 486	Pneumonia and Influenza Viral pneumonia Bronchopneumonia unspecified organism Pneumonia unspecified organism	2 1 1	44
	Subtotal	4	
<b>493</b> 493.9	Asthma Asthma unspecified	2	22
	Subtotal	2	
Other 460-519 466 510 519	Other Disease of the Respiratory System Acute bronchitis and bronchiolitis Empyema Unspecified chronic respiratory disease	1 1 1	33
	Subtotal	3	
All 460-519	Total Diseases of the Respiratory System	9	100*

\*Sum of groupings may not equal 100 due to rounding.

Source: Ministry for Children and Families, BC Vital Statistics Agency.

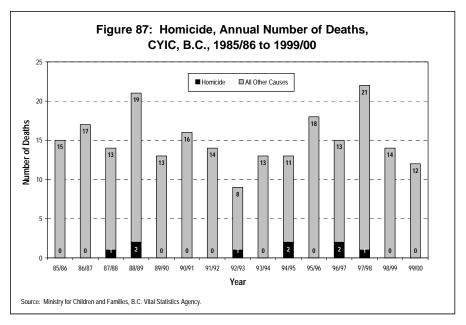
## (8) Homicide

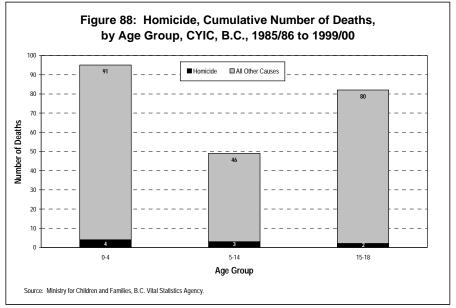
For this cause of death, the annual range was 0-2 deaths, averaging 0.6 per annum, for a total of 9 deaths (see Figure 87). These deaths occurred sporadically, with 3 recorded in each 5-year period.

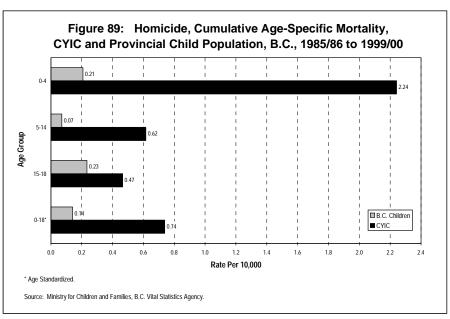
The SMR was 5.23, and it was estimated that over the entire 15-year period, 7.3 (or 0.49 per annum) of the deaths (81%) were in "excess" of what would have been expected based on the provincial child population experience.

Deaths of CYIC comprised 4.9% of all provincial child deaths due to this cause. Almost one-half of the CYIC deaths (4) occurred in age group 0-4 years, which also appeared to have the highest mortality rate.

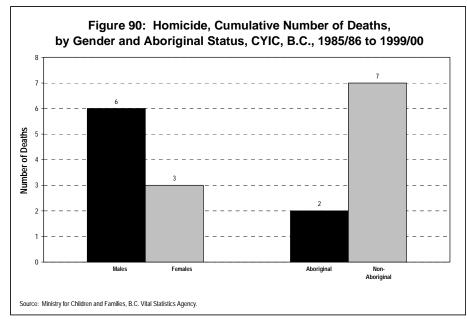
None of the differences in CYIC age-specific mortality rates were statistically significant, and CYIC had a higher mortality than the provincial child population for all age groups (see Figures 88 and 89).







There were 6 male and 3 female deaths, but the apparently higher male mortality was not statistically significant. Aboriginal CYIC mortality appeared to be lower than for non-Aboriginals, but the difference was not statistically significant (see Figures 90, 91, and accompanying table).



There was a four-fold higher mortality due to homicide for Status Indians (all ages) as compared to other residents in the province.\*



In summary, CYIC mortality differences by age, gender, and Aboriginal status were not statistically significant.

Homicide, Cumulative Mortality Rates for CYIC, B.C., 1985/86 to 1999/00

D.O., 1303/00 to 1333/00		
CYIC Group	Rate Per 10,000	95% C.I.*
<u>Age</u> 0-4 5-14 15-18	2.24 0.62 0.47	0.61 to 5.74 0.13 to 1.80 0.06 to 1.68
<u>Gender</u> ** Male Female	0.94 0.52	0.35 to 2.06 0.11 to 1.53
Aboriginal Status** Aboriginal Non-Aboriginal	0.54 0.82	0.07 to 1.96 0.33 to 1.70
Total**	0.74	0.34 to 1.40

Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and

Ratios, Neuroepidemiology 2: 257-265 (1983).

\* Age-Standardized Rates.

<sup>\*</sup>B.C. Vital Statistics Agency, Analysis of Health Statistics for Status Indians in British Columbia 1991-1998, January 2000: 58.

As to specific cause of death, there were 2 deaths each due to firearms and sharp instruments, and another 5 deaths due to a variety of other means. Details are included in the following table:

Cumulative Deaths Due to Homicide, CYIC, B.C., 1985/86 to 1999/00

ICD	Cause of Death	No. of Deaths	% of Deaths
<b>E968</b> E968.0 E968.9	Assault by Other and Unspecified Means Assault by fire Assault by unspecified means	1 2	33
	Subtotal	3	
<b>E965</b> E965.2 E965.4	Assault by Firearms and Explosives Assault by hunting rifle Assault by other and unspecified firearm	1 1	22
	Subtotal	2	
E966	Assault by Cutting and Piercing Instrument	2	20
	Subtotal	2	22
Other E960-969 E960.0 E969	Other Homicide Unarmed fight or brawl Late effects of injury purposely inflicted by other person	1	22
	Subtotal	2	
All E960-969	Total Homicide	9	100*

<sup>\*</sup> Sum of groupings may not equal 100 due to rounding. Source: Ministry for Children and Families, BC Vital Statistics Agency.

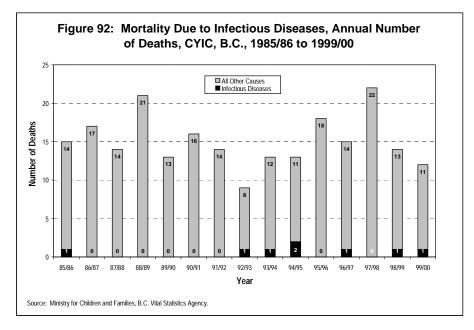
### (9) Infectious Diseases

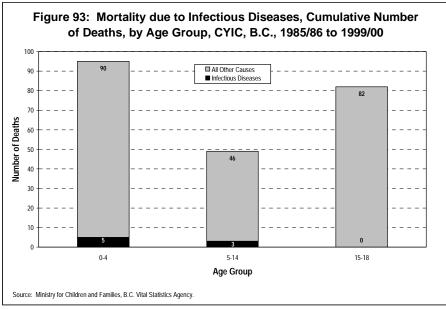
For this sporadic cause of death, the annual range was 0-2 deaths, averaging 0.53 per annum, for a total of 8 deaths (see Figure 92). Deaths were more common in recent than in past years.

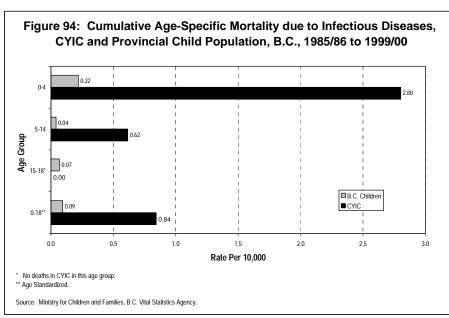
The SMR was 9.06, and it was estimated that over the entire 15-year period, 7.1 (or 0.47 per annum) of the deaths (89%) were in "excess" of what would have been theoretically expected based on the provincial child population experience.

Deaths of CYIC comprised 6.6% of provincial child deaths due to this cause. The majority of the deaths occurred in the youngest age group, which had the highest age-specific mortality (see figures 93 and 94).

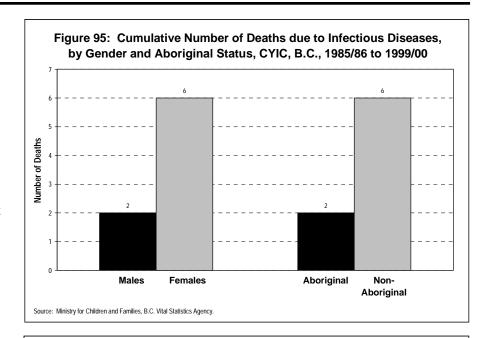
There were no deaths in ages 15-18 years, but otherwise CYIC had a higher mortality than the provincial child population for the other age groups. The only mortality difference by age which was statistically significant was that the mortality for ages 0-4 years was higher than for ages 15-18 years.



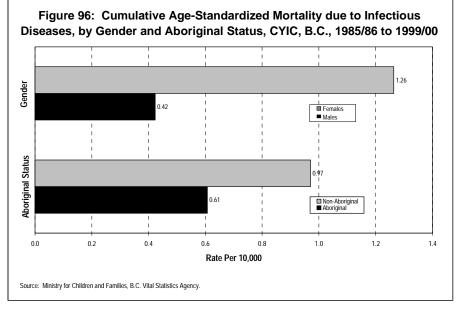




There were 6 female and 2 male CYIC deaths, but the apparently higher female mortality was not statistically significant. Non-Aboriginal CYIC appeared to have a higher mortality than Aboriginals, but the difference was not statistically significant (see Figures 95, 96, and accompanying table).



The Status Indian population (all ages) had more than twice the infectious disease mortality than other residents of the province.\*



In summary, the only characteristic of CYIC associated with a statistically significant higher rate of mortality was being in age group 0-4 years (as compared to 15-18 years). Mortality differences by gender and Aboriginal status were not statistically significant.

Infectious Diseases, Cumulative Mortality Rates for CYIC, B.C., 1985/86 to 1999/00

CYIC Group	Rate Per 10,000	95% C.I.*
Age 0-4 5-14 15-18	<b>2.80</b> 0.62 0.00	<b>0.91 to 6.53</b> 0.31 to 1.80 0.00 to 0.70
<u>Gender</u> ** Male Female	0.42 1.26	0.05 to 1.53 0.46 to 2.76
Aboriginal Status** Aboriginal Non-Aboriginal	0.61 0.97	0.07 to 2.19 0.36 to 2.12
Total**	0.84	0.36 to 1.66

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and

Ratios, Neuroepidemiology 2: 257-265 (1983).

\*\* Age-Standardized Rates.

<sup>\*</sup>B.C. Vital Statistics Agency, Analysis of Health Statistics for Status Indians in British Columbia 1991-1998, January 2000: 44.

As to cause of death, the largest group of conditions (50%) was septicemia, and the next largest group (25%) was HIV-related deaths. The remaining deaths (2) were due to other infections. Details are included in the following table:

#### Cumulative Deaths Due to Infectious Disease, CYIC, B.C., 1985/86 to 1999/00

ICD	Cause of Death	No. of Deaths	% of Deaths
<b>038</b> 038.9 038.9	Septicemia Streptococcal septicemia Unspecified septicemia	1 3	50
	Subtotal	4	
<b>042</b> 042.1 042.9	AIDS HIV infection with other specified infections AIDS with or without other conditions	1 1	25
	Subtotal	2	
Other 001-139 008 052	Other Infectious Diseases Intestinal infections due to other organisms Chickenpox	1 1	25
	Subtotal	2	
All 001-139	Total Infectious Diseases	8	100*

<sup>\*</sup> Sum of groupings may not equal 100 due to rounding. Source: Ministry for Children and Families, BC Vital Statistics Agency.

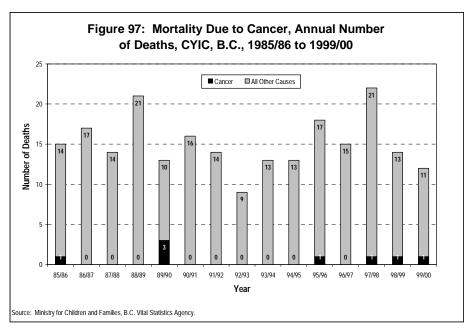
### (10) Cancer

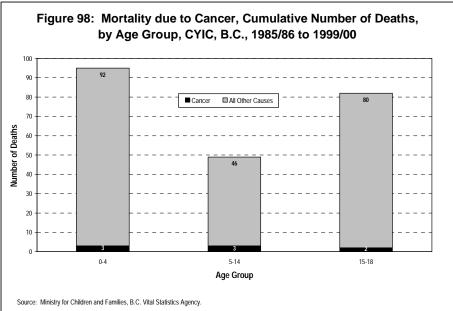
For this sporadic cause of death, the focus was on malignant disease (ICD 140-208). The annual range was 0-3 deaths, averaging 0.53 per annum, for a total of 8 deaths (see Figure 97).

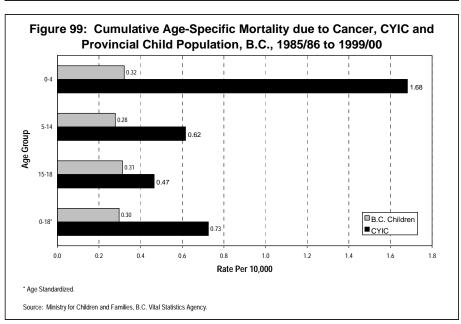
The SMR was 2.44, and it was estimated that over the entire 15-year period, 4.7 (or 0.32 per annum) of these deaths (59%) were in excess of what would have been theoretically expected based on the provincial child population experience.

Deaths of CYIC comprised 2.1% of all provincial child deaths due to this cause. The deaths occurred in all age groups, at rates which were higher than the provincial child rates. These children would have been medically fragile, with significant disability in the later stages of their illness.

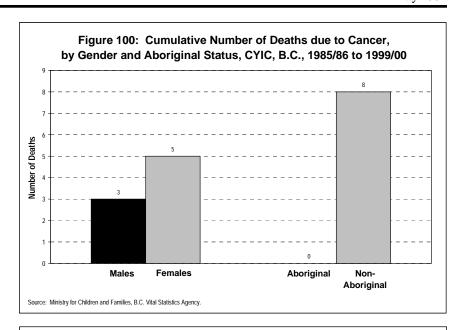
The highest mortality rate for CYIC appeared to be in age group 0-4 years, however, none of the age-specific mortality differences were statistically significant (see Figures 98 and 99).



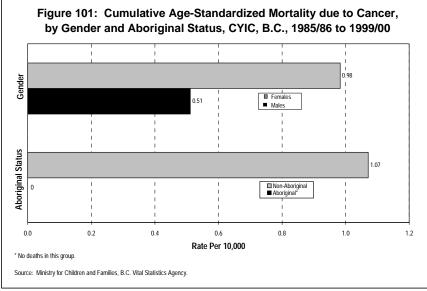




There were 5 female and 3 male deaths, but the apparently higher female mortality was not statistically significant. There were no deaths recorded among Aboriginal CYIC, although because of small numbers this difference was not statistically significant.



In the Status Indian population (all ages), cancer mortality was slightly higher than for other residents of the province.\*



In summary, CYIC mortality differences by age, gender, and Aboriginal status were not statistically significant.

Mortality due to Cancer, Cumulative Mortality Rates for CYIC, B.C., 1985/86 to 1999/00

tor CYIC, B.C., 1985/86 to 1999/00				
CYIC Group	Rate Per 10,000	95% C.I.*		
<u>Age</u> 0-4 5-14 15-18	1.68 0.62 0.47	0.35 to 4.91 0.13 to 1.80 0.06 to 1.68		
<u>Gender</u> ** Male Female	0.51 0.98	0.11 to 1.49 0.32 to 2.29		
Aboriginal Status** Aboriginal Non-Aboriginal	0.00 1.07	0.00 to 0.84 0.46 to 2.11		
Total**	0.73	0.31 to 1.43		

<sup>\*</sup> Schoenberg, Bruce S., Calculating Confidence Intervals for Rates and Ratios, <u>Neuroepidemiology</u> 2: 257-265 (1983).

<sup>\*\*</sup> Age-Standardized Rates.

<sup>\*</sup>B.C. Vital Statistics Agency, Analysis of Health Statistics for Status Indians in British Columbia 1991-1998, January 2000: 71.

As evident in the table below, most cancers (88%) involved the blood-forming and lymphatic systems, the most common types of cancer in children.

Cumulative Deaths Due to Cancer, CYIC, B.C., 1985/86 to 1999/00

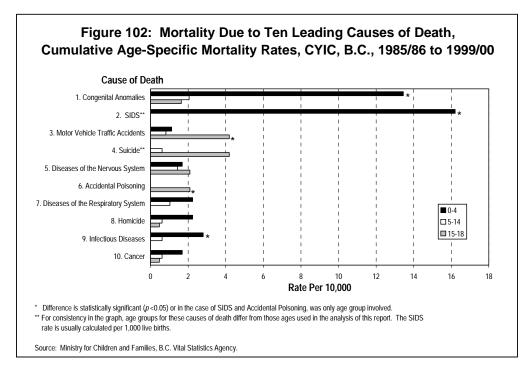
ICD	Cause of Death	No. of Deaths	% of Deaths
200-208	Lymphatic and Haemotapoietic Cancers		
200.8	Reticulolymphosarcoma	1	
202.8	Lymphoma	1	
204.0	Lymphoid leukemia (acute)	1	
205.0	Myeloid leukemia (acute)	1	88
208.0	Acute leukemia of unspecified cell type	1	
208.9	Unspecified leumekia of unspecified cell type	2	
	Subtotal	7	
Other 140-208	Other Cancers		
194.0	Adrenal gland	1	13
	Subtotal	1	
All 140-208	Total Cancer	8	100*

<sup>\*</sup> Sum of groupings may not equal 100 due to rounding. Source: Ministry for Children and Families, BC Vital Statistics Agency.

## The Leading Causes of Death in Summary

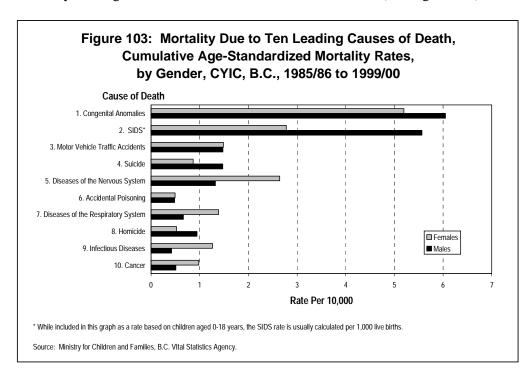
The higher CYIC mortality rate for ages 0-4 years was statistically significant for Congenital Anomalies and Infectious Diseases. For SIDS, infancy was the only age group affected. Ages 0-4 years also appeared to have the highest mortality rates for Diseases of the Respiratory System, Homicide, and Cancer, but the differences were not statistically significant.

The higher mortality rate for ages 15-18 years was statistically significant for Motor Vehicle Traffic Accidents and Accidental Poisoning. While the mortality rates for Suicide and Diseases of the Nervous System appeared to be higher in ages 15-18 years, the differences were not statistically significant (see Figure 102).



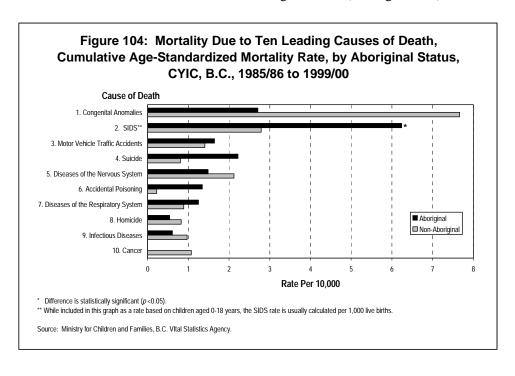
Both genders of CYIC had the same mortality rates for Motor Vehicle Traffic Accidents and Accidental Poisoning. The male mortality was higher for Congenital Anomalies, SIDS, Suicide, and Homicide, but the differences were not statistically significant. The female mortality was higher for Diseases of the

Nervous System, Diseases of the Respiratory System, Infectious Diseases, and Cancer, but these differences were also not statistically significant. Thus, none of the gender differences were statistically significant for any of the leading causes of death (see Figure 103).



The higher SIDS mortality for Aboriginal CYIC was statistically significant, but the higher Aboriginal rates were not statistically significant for Motor Vehicle Traffic Accidents, Suicide, Accidental Poisoning, and Diseases of the Respiratory System.

The mortality for non-Aboriginal CYIC appeared to be higher for Congenital Anomalies, Diseases of the Nervous System, Homicide, Infectious Diseases, and Cancer, but the differences were not statistically significant. (see Figure 104).



### 10. Comparisons with Other Jurisdictions

While a comparison of B.C. with other jurisdictions was an objective of this study, only three general reports on CYIC mortality could be located, based on studies in Alberta, Ontario, and California. While the results of these studies are summarized in this report, it should be emphasized that valid comparisons of CYIC mortality in B.C. with these other areas cannot be made, and accordingly, conclusions cannot be drawn from any apparent differences.

The lack of comparability is due in part to differences in research methodology, but also because of possible variations in:

- the demographic characteristics of the population,
- the nature of the underlying population health and social risks to children.
- the number and distribution of children exposed to high risks,
- the nature of the child protection legislation,
- the nature of the child abuse/neglect reporting system,
- the nature and operation of the child protection services,
- the nature, availability, and utilization of other social and health services to children and families,
- the nature and operation of coroner's services,
- the nature and operation of information systems for child protection and vital statistics.
- the time periods of the studies.

The following illustrate how factors could influence CYIC mortality in a jurisdiction. Both the underlying population demographics and CYIC caseload composition can differ substantially between jurisdictions:

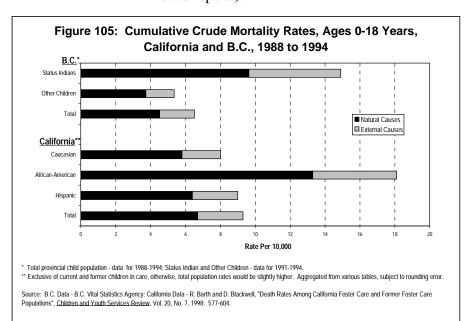
(a) Beginning with the general population demographics of a jurisdiction, Barth and Blackwell (1998) presented crude mortality rates by major ethnic group and categories of major causes for the general child population under age 19 years in California\* (exclusive of deaths occurring to current and former foster children), which are presented together with data from the B.C. population (see Figure 105).

The overall B.C. child mortality was slightly lower than the lowest of the California groups (Caucasians), while the higher B.C. Status Indian child mortality was somewhat less than the highest of the California groups (African American children). California's African American children had a higher Natural Causes mortality than B.C. Status Indian children, while both groups had a similar mortality for External Causes.

These data are not directly comparable because:

- the calculations involved crude rates,
- the B.C. data for Status Indians and Other Children omitted the years 1988 to 1990, and
- the California population data were exclusive of the current and former CYIC caseload, while the CYIC caseload was included in the B.C. child population data.

This limited review of child population mortality between B.C. and California was sufficient to indicate that a direct comparison of CYIC mortality may not be valid (notwithstanding any other possible differences between jurisdictions), given differences in the demographics of the underlying population. (Similar data were not available in the Ontario or Alberta reports).



<sup>\*</sup> R. Barth and D. Blackwell, "Death Rates Among California Foster Care and Former Foster Care Populations", Children and Youth Services Review, Vol. 20, No. 7, 1998: 577-604.

(b) To illustrate the next interjurisdictional difference that could have an influence on CYIC mortality comparisons, a report on child welfare service by Trocme et al (1999) documented the caseload trend for CYIC in Ontario\* from 1971 to 1998, which is presented together with caseload data from B.C. (see Figure 106). These data appear to show that the proportion of CYIC in Ontario as a percent of the provincial child population was consistently lower than in B.C.

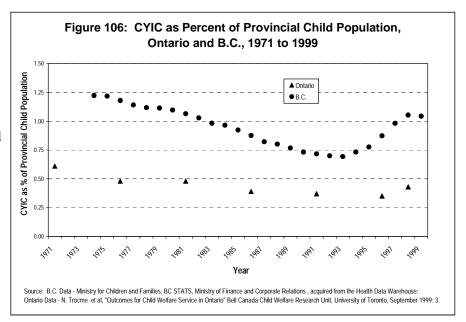
However, upon further inquiry, it was learned that child protection legislation differed between the provinces, including such issues as client age and consent of

youth concerning eligibility to be a CYIC.\*\* These differences could contribute to a relatively lower proportion of older teen-aged CYIC in Ontario relative to B.C., which would render invalid any overall CYIC mortality comparisons. While agestandardization would help to some extent with this issue, there could still be differences in the risk profiles of in-care youth in each jurisdiction.

### Key elements of the methodology of the three CYIC mortality studies from other jurisdictions are briefly described as follows:

1. The **Alberta** study\*\*\* by Thompson and Newman (1995) followed a cohort of over 20,000 children-in-care (assigned child welfare status) during the period January 1 to December 31, 1980. The follow-up period continued for each child until December 31, 1987, or the death of the child, whichever came first. Deaths were ascertained by computerized record linkage with the provincial vital statistics agency, supplemented by information in child welfare files. (It was acknowledged that any deaths occurring outside of Alberta may not have been completely ascertained.)

Denominators were calculated for both time in-care and not-in-care, using person-years of follow-up by age group and disability status. Expected deaths by cause were determined using the experience of the Alberta child population, which together with the observed deaths in the CYIC cohort, allowed a calculation of Standardized Mortality Ratios (SMR). The Alberta CYIC mortality was assessed by handicapped status, primarily severe mental retardation and/or physical disability, affecting 19.6% of clients in Alberta (similar to the B.C. severely disabled CYIC estimate of 18.3%). The other children in Alberta became CYIC due to abuse/ neglect. Comparisons of mortality by Aboriginal heritage were not included.



Mortality was compared with the provincial child population for major Natural and External Causes. Comparisons by Aboriginal heritage were not included. There were 182 deaths in the entire cohort, which included children less than 18 years of age who died while in care, children less than 18 years of age who died after being discharged from care, and young adults from 18-25 years of age who had been in care in 1980. The mortality results for 134 children who were CYIC at the time of death were reported by handicapped status, as follows:

SMRs by Selected Causes of Death for Handicapped and Neglected/Abused Children with Child Welfare Status, Alberta, 1980 Cohort

	SMR		
Cause (ICD-9 code)	Handicapped	Neglected/ Abused	
Neoplasms (140-239)	7.64*	0.31	
Respiratory (460-519)	47.89*	3.46*	
Congenital (740-759)	7.84*	0.72	
Motor Vehicle (E810-819)	0.19	0.98	
Suicide (E950-959)	0.53	2.98*	
Homicide (E960-969)	0.00	4.32*	
Above Natural Causes	14.35	1.02	
Above External Causes	0.27	1.68	
All Above Causes	5.40	1.44	

<sup>\*</sup> x2>10.83, p<0.001

For various reasons noted above, CYIC mortality cannot be compared between Alberta and B.C., including the SMR being based on different standard populations, different study time periods, the single year cohort versus cumulative caseload approach, and possible legislative or other differences. In both provinces, the handicapped/severely disabled CYIC had a much higher risk of mortality due to Natural Causes. The neglected/abused CYIC in Alberta had a higher mortality due to External Causes, as did CYIC of average functional ability in B.C.

N. Trocme et al., "Outcomes for Child Welfare Service in Ontario" Bell Canada Child Welfare Research Unit, University of Toronto, September 1999: 3. Personal communication, Wayne Matheson, Ministry for Children and Families.
A. Thompson and S. Newman, "Mortality in a Child Welfare Population: Implications for Policy", Child Welfare, Vol. LXXIV, #4, July/August 1995: 843-857.

On ranking the causes of death in order, it is noted that Respiratory Diseases and Suicide are ranked highest in Alberta, while Congenital Anomalies and SIDS occupy the highest positions in B.C. (see table below). It was also noted that SIDS and Nervous System disease, which were the 2nd and 5th leading causes in B.C., were not on the Alberta list. In the case of SIDS, this could be because the Alberta study followed a single year cohort over time, and in the case of Nervous System disease, because of the rarity of this cause of death.

Leading Causes of Death by Rank Order, CYIC in Alberta and B.C.

Rank	Cause of Death		
Kank	Alberta	B.C.	
1	Respiratory System Diseases	Congenital Anomalies	
2	Suicide	SIDS	
3	Congenital Anomalies	MVTA	
4	MVTA	Suicide	
5	Neoplasms	Nervous System Diseases	
6	Homicide	Accidental Poisoning	
7	N/A	Respiratory System Diseases	
8	N/A	Homicide	
9	N/A	Infectious Diseases	
10	N/A	Cancer	

Another difference was that Motor Vehicle Traffic Accident deaths, although ranked 3rd/4th, had a SMR which was not increased for CYIC in Alberta, but which was increased in B.C. However there were 22 MVTA deaths in CYIC in Alberta over 8 years (2.8 per year) and 24 deaths in B.C. over 15 years (1.6 per year), so the low SMR due to MVTAs in Alberta CYIC may have in part reflected a high underlying mortality rate in the provincial child population.

Not withstanding the fact that direct comparisons cannot be made between B.C. and Alberta, there are some general similarities: in both provinces, almost 20% of CYIC had a severe disabling condition. This small group experienced about half of the overall CYIC mortality, mostly due to Natural Causes. The other 80% of CYIC who were not disabled also experienced about half of the overall mortality, mostly due to External Causes.

2. The **Ontario** study\* surveyed the 55 Children's Aid Societies in the province for deaths occurring to children known to the societies during 1994 and 1995. Over this two-year period, a total of 100 deaths were reported, of which 31 occurred to CYIC and 69 to other children known to the societies. In 1995, the societies provided services to 150,000 children and youth, and substitute care to 20,800 CYIC. Specific causes of death were determined by the Coroner's Office, and categorized by major causes of death.

The report acknowledged difficulties in conducting the research due to limited or unavailable provincial statistics on these children at that time. There was no computerized record linkage mentioned in the report, nor was a centralized client database available. The report provided counts of deaths of all children known to the societies, and it was not possible to disaggregate data for CYIC from all tables. A denominator based on caseload statistics or person-years was not developed, and nor were mortality rates or SMRs available. There was no comparison with the Ontario child population, nor were there analyses by disability status or Aboriginal heritage.

Some of the mortality data on CYIC from the Ontario report are summarized in the table below, by major causes of death:

Deaths of CYIC, Ontario, 1994 to 1995

Cause of Death	CYIC		
Cause of Death	Number	Percent	
SIDS Other Diseases	3 18	10 58	
Natural Causes	21	68	
Suicide Homicide Other Injuries	5 0 5	16 0 16	
External Causes	10	32	
All Causes	31	100	

The Ontario numbers are too small to allow comparisons of proportionate mortality by specific cause, however, a general similarity with B.C. is noted, in that for both jurisdictions approximately 2/3 of deaths were due to Natural Causes, and 1/3 were due to External Causes.

3. The **California** study by Barth and Blackwell (1998) utilized data in the California Children's Services Archive, which contained data on over 233,000 children in foster care during the period 1988 to 1994. After matching these data with death certificate data from the state Department of Health Services, deaths were determined for current and former foster children, and all other children (nonclients) in the state.

After a subsequent verification process, the authors made a conservative mortality estimate of 690 deaths to current foster children and 321 deaths to former foster children.\*\* Denominators consisted of person-years for both current and former foster children, which allowed crude mortality rates to be calculated. Major ethnic groups were studied based on having adequate numbers in the data, which included Caucasians, African Americans, and Hispanics. (Excluded due to small numbers were American Indians and Asians.) As was the case with B.C., all age groups of California foster children had higher mortality rates than the state (non-client) child population (see Figure 107).

<sup>\*</sup> Ontario Child Mortality Task Force, Final Report, 1997.

<sup>\*\*</sup> Their estimate was "conservative" due to difficulties in ascertaining current or former foster child deaths which may have occurred out of state.

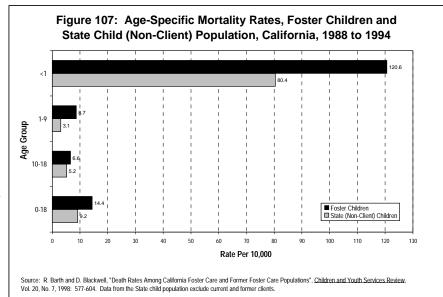
Caucasians had the lowest mortality, and African Americans the highest mortality, for both Natural and External Causes, for both foster children and the state (non-client) population. Furthermore, for African Americans the Natural Causes mortality was very high for foster children and almost as high for the state (nonclient) child population. External Causes mortality was higher in African American foster children than for any other client group, but state (non-client) African American children had an even higher mortality (see Figure 108).

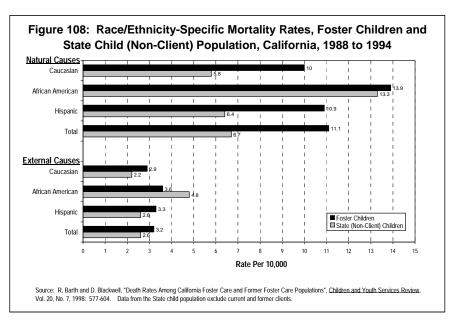
While not directly comparable, this study showed that California had less of a disparity between foster children and state child (nonclient) mortality than B.C., which could have been influenced by child protection program or other service differences, or by the fact that the state (non-client) crude mortality rate was higher than in B.C. (see Figure 105).

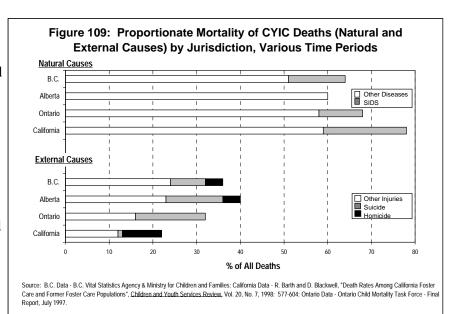
While contrasting these other jurisdictions with B.C., there were too many different variables which could influence mortality in the CYIC and provincial/state populations to allow valid direct comparisons. However, the proportionate mortality comparison shows some general similarities in causes of death, while avoiding absolute mortality comparisons (see Figure 109).

In summary, the comparison with other areas was limited to these basic findings:

- (1) The general pattern of proportionate mortality of CYIC in B.C. is not unusual in relation to the other three jurisdictions, for both Natural and External Causes, which contribute to approximately 2/3 and 1/3 of the deaths, respectively,
- (2) Disabled CYIC in the Alberta study were represented in the caseload to a similar extent as in B.C. (about 20%), and had made a similar contribution to CYIC mortality (about 50%), mostly to Natural Causes.







## 11. Options for Enhancing the Mortality Study

The objectives of this epidemiological study were: to document and describe the mortality of CYIC in comparison to the general child population in the province, including an examination of possible risk factors; to establish a scientifically valid set of baseline data that could serve as a means to evaluate progress in reducing the mortality of CYIC; and to provide knowledge about significant causes of death for CYIC, as a guide to the development of specific strategies to improve their health.

An epidemiological study cannot provide a detailed analysis of why and how an individual CYIC died or what could have been done to prevent the death. That assessment is obtained through the separate and independent child fatality reviews conducted by the responsible authorities, the B.C. Coroner's Service, the Director of Child Protection in MCF, and the B.C. Children's Commission. The following discussion and recommendations focus on opportunities to improve the description of CYIC mortality (and ultimately health status) through epidemiological analysis, which could complement the reviews performed by the agencies responsible for the health and welfare of these children.

This epidemiological analysis described long-term trends and patterns of mortality for CYIC, with comparisons to the provincial child population. The small number of deaths of CYIC meant that trends had to be assessed over a long time period (placing annual fluctuation into perspective), and by combining multiple years of data, for analysis by age, gender, Aboriginal status, cause of death, and for some years, by functional status. While the small numbers made it difficult to identify and describe trends and patterns in CYIC mortality in a detailed way, it may become easier in the future as more years of data and additional types of data become available for use.

# Issues Related to Current Epidemiological Approach

Since this was the first attempt at such an analysis in the province, some useful methods were identified, while some outstanding issues remain.

- The use of the year-end CYIC caseload statistics as a denominator appeared to be a stable measure over time, particularly for age, gender, and overall caseload. In subsequent analyses, this denominator should be re-evaluated for its continued stability, particularly during times of changing caseloads.
- The indirect age standardization method minimized the fluctuations in rates due to small numbers of events, making it easier to identify trends in the data. This basic technique could be used for consistency in subsequent analyses, especially if, as in previous years, the age structure of the CYIC caseload changes over time and/or diverges from the provincial child population age structure. Consideration could be given to whether other more sophisticated statistical techniques could contribute to the future analysis of these data.
- There appeared to be a need for improved quality of data in the CYIC caseload statistics regarding the

identification of Aboriginal children, which limited the scope of the study to a comparison of cumulative mortality rates by Aboriginal heritage. Further analysis of mortality trends by Aboriginal heritage could be considered in the future once these apparent inconsistencies have been resolved.

- The definition of Aboriginal children in the CYIC caseload, which includes both Status and Non-Status Aboriginals, differs from that of the provincial population, where only Status Indians are identified. Further study would be required to enable mortality comparisons between Aboriginal CYIC and the provincial Aboriginal child population. Key issues include defining the Aboriginal population in a consistent way, or understanding how different definitions impact mortality statistics, issues which were beyond the scope of this study.
- While this study used available fiscal year statistics for CYIC mortality, it would be preferable to analyze CYIC mortality by calendar year for the sake of consistency with data collected by the BCVSA, the Children's Commission, and other jurisdictions.

#### Other Information on CYIC

Mortality statistics provide a very limited view of health status. To obtain a more complete picture of health status, a similar epidemiological approach could be applied to other outcomes such as episodes of illness, the presence of ongoing health and social problems, or positive measures of health and development. The availability of consistent standard data over adequate time periods would be necessary to enable these other analyses to be undertaken.

What other sources of information might allow a more detailed description of CYIC and thus allow a more complete description of their mortality experience? In the current study, a list of identified deceased CYIC was provided to the BCVSA to verify the official cause of death. The study team were provided with the date of birth, date of death, sex, Aboriginal status, and underlying cause of death, and for some of the years, data on functional status were also available.

Other dimensions could include information on any other factors which could influence death as an outcome, e.g., health determinants such as illness, education, housing, income level, social supports, family status, etc. Some of these data may be directly available, while other information may be accessible only through record linkage. Not all of this information may be readily available for each CYIC; either it may not have been collected, or if collected, it may not be linkable to CYIC records.

The following table describes some additional information which could be used to describe CYIC, the care they receive, and the results or outcomes in terms of their health and well-being. The latter should not be interpreted as being solely attributable to the in-care experience, as the current health status of the child results from an interaction of many factors, both before and after coming into care.

#### Information About Children and Youth in Care\*

Demographics	The In-Care Experience	Examples of Outcomes/Results
• Age	Age when coming into care	Growth and Development
Gender	Reason for coming into care	<ul><li>Physical growth and nutritional status</li><li>Motor and social development</li></ul>
Birth weight	Services/treatments provided	Language and cognitive development     Emotional maturity
Gestational Age	Settings, e.g., foster care, group home, residential	Safety and security
• Ethnicity ( <i>Aboriginal</i> )	Cultural placement matching	Abuse and maltreatment
Disability status	Length of time in care	Critical injuries
Health conditions, e.g., Fetal Alcohol Syndrome	Number of placement changes	Learning • School Readiness
Location of residence	Reason for discharge	<ul><li>Attitudes towards learning</li><li>Assessment scores</li></ul>
Family background		<ul><li> Grade to grade transition</li><li> School completion</li></ul>
Socio-economic status of family and neighbourhood		Social engagement and responsibility  Connections with family and school  Community involvement  Contacts with criminal justice system
Comparison groups  • B.C. population age 0-18  • Status Indians age 0-18		Health behaviours  Tobacco, alcohol, drug use  Physical activity Safety practices
		Health problems  Illness episodes, e.g., hospitalizations Emotional and behavioural problems
		Death • Cause • Preventability (from fatality reviews)

<sup>\*</sup> The data listed in italics were the most readily available, and accordingly were used in this study.

### **Existing MCF Information Systems**

The most obvious source of additional information to explore are other administrative files containing data on CYIC. Some possible dimensions for analysis include the length of time in-care, the number of times the client has moved in and out of care, or the geographic location of CYIC clients.

While the area of residence of the CYIC who died was available for this study, an analysis of regional differences was not performed because of the small numbers involved, and inconsistencies in regional CYIC caseload statistics due to shifting administrative boundaries over time. If it is possible to aggregate the CYIC caseload to regions that are stable over long periods of time, it may be possible to assess regional differences. Consideration could be given to such comparisons as urban vs rural, by health jurisdiction (Regional Health Boards, Community Health Services Societies), or by Aboriginal status.

The Management Information System - Social Work System (MIS-SWS) is the new information system used for CYIC. It contains much detail, including the situation which prompted being brought into care, the events of the care episode, and circumstances of the conclusion of the care episode. Some of the data in MIS-SWS may provide other dimensions along which to analyze mortality.

The Looking After Children collection of integrated documentation tools may also offer opportunities for

analysis. Looking After Children is a recently initiated child-centred approach to case planning which is designed to assess needs and achieve better outcomes for CYIC, based on the premise that good parenting contributes to better outcomes. One of the documentation tools is the Assessment and Action Record, which was developed to assess the needs of and facilitate case planning for CYIC. The child or youth is assessed across seven developmental dimensions (health, education, identity, family and social relationships, social presentation, emotional and behavioural development, and self care skills), according to individual age group.

The designation of functional status on CYIC records for the period 1986/87 to 1995/96 allowed analysis of mortality according to the type of disability. The recording of functional status was discontinued in 1995/96, and the current information system does not have this type of indicator. This analysis demonstrated a very much higher risk of death for physically disabled CYIC, which contributed significantly to the overall elevated mortality rate of CYIC due to Natural Causes. Providing that the previously mentioned issues related to the past disability data could be avoided, the re-introduction of a standardized disability assessment could be considered to describe differences along this dimension, and to record the diagnosis of any important chronic or ongoing health problem (e.g., congenital anomalies, neurological conditions, Fetal Alcohol Syndrome).

# **Existing Ministry of Health Information Systems**

Ministry of Health administrative information systems could provide data on CYIC interactions with health services. It would be possible to link CYIC to records in these information systems by using the Personal Health Number (PHN), or when the PHN is not available, by using a probablistic match that uses name, birth date, sex, etc. to link CYIC with their health records. The information systems include the Morbidity (hospitalization) database, the Medical Services Plan (MSP) database, and Vital Statistics databases.

The Morbidity database contains details of hospitalizations, including diagnoses, procedures performed, length of stay, and resource intensity weighting (RIW). Using these data, it would be possible to build a history of hospitalization for CYIC prior to coming into care, which may identify preexisting conditions or significant prior events such as injuries. This could have explanatory value when examining individual death records, or provide additional dimensions along which to analyze mortality data. As hospital admissions are more frequent than deaths, an analysis of hospitalization data would capture more events, thus reducing data fluctuation due to small numbers, and enabling a more stable and complete picture of the health status of CYIC. As hospitalization data are available annually, these data are primarily useful for supplementing the historical mortality record.

The MSP database contains details of funded services provided to CYIC. These services may be medical, laboratory, radiological, or non-medical (e.g., chiropractic, physiotherapy, etc.). MSP records contain diagnostic information as well as fee-item codes that describe the service provided. While not as rich in detail nor as accurate diagnostically as the hospitalization data, the MSP data may contribute to an understanding of the illness/injury experience of CYIC, including events prior to hospitalization or death. The advantage of these data is currency; as MSP payments are made on a biweekly basis, it is possible to obtain these data shortly after the event occurs. This may allow tracking of MSP services for current CYIC, and perhaps, the identification of particular critical events which put CYIC at a higher risk of serious injury, illness, or death.

As described above, information regarding the cause of death was extracted from the BCVSA mortality database. The BCVSA also maintains a birth database and the Health Status Registry. The birth database records information concerning the birth event (e.g., age of mother, gestational age, birth weight, Apgar and ICD-coded maternal, perinatal, and congenital conditions, etc.). The Health Status Registry records information on individuals with congenital anomalies and other disabilities. Both of these information systems could provide details of possible risk factors which might affect mortality. Linking records in these databases could be done in a similar way to the death records.

The above options for linking data on CYIC to other sources of information would be relatively straightforward due to the availability of the PHN, and the high probability that the CYIC database will match with other MCF information systems, BCVSA information systems, and other Ministry of Health information systems.

# **Existing Children's Commission Information System**

The Children's Commission Tracking System includes information about each child fatality. The information collected to fulfil the Children's Commission's mandate to investigate child injuries and deaths could be very useful in providing further details on the overall CYIC mortality experience. Because of the small numbers of CYIC deaths, it may be relatively easy to link such information in Children's Commission databases.

### **Options for Other Sources of Information**

Further options for linking with other types of information located in other government ministries may be more difficult due to the lack of a common identifier for CYIC. Other types of information may include educational records, income assistance records, and criminal justice records.

Educational records relating to school graduation, standardized test results, and behavioural problems or learning disabilities might offer additional dimensions for analysis. A project to look at such educational outcomes is underway and involves the Children's Commission, the Ministry for Children and Families, and the Ministry of Education.

Income assistance records may show differences in risks for those families receiving income assistance and those that do not. Finally, criminal justice records may provide insights into risk differences between those who have committed offences and those who have not.

There may also be opportunities to identify and study records of the natural parents to look for patterns within these same categories that show familial risks. Accessing this information would involve record linkage using name, sex, and birth date. The linkage results may not attain complete matches, but may still provide meaningful results.

Research and evaluation projects could assess the feasibility of these linkages and value of the information gained. If value was demonstrated, mechanisms to collect these data could be established to provide data on an ongoing basis.

#### Recommendations

The following recommendations deal with the methods employed in this study, and options for enhancement using modified methods or additional data.

1. Establish an Ongoing Means of Epidemiological Mortality Analysis: It is recommended that CYIC mortality be analyzed epidemiologically on a continuing basis to incorporate future years of data. The responsibility for this analysis should rest with an appropriate authority with the expertise and resources to maintain this function.

2. Establish a Minimum Data Set: Basic epidemiological analysis concerns the characteristics of person, place, and time, and how these characteristics might be used to assess events such as death, illness, or injury. It is recommended that the minimum set of data elements used to perform an epidemiological analysis of mortality be the following: age, sex, Aboriginal status, and cause of death, and if possible in the future, functional status, and coding of pre-existing medical conditions.

While age and sex were clearly defined and readily available, there were differences in the definition of Aboriginal Status in CYIC and the provincial population, and apparent inconsistencies in the identification of Aboriginal children in the CYIC database. Other than recognizing the potential impact of these issues on the mortality analysis, resolving the issues was beyond the scope of this study.

As a significant proportion of CYIC are Aboriginal, it is recommended that further consideration be given to how best to assess mortality in this group. A partial answer may be to use BCVSA files to confirm Status Indian identity in both CYIC death and caseload statistics, thereby providing numerator and denominator for CYIC who are Status Indians, and allowing comparisons with the provincial Status Indian child population. However, small numbers could make analysis and interpretation difficult, and an appropriate approach to non-Status Aboriginal CYIC would still be required.

It is recommended that the feasibility be assessed of re-introducing a standard coding of functional status to replace that which was in place for the period 1986/87 to 1995/96. Functional status proved to be a very important factor because of the association between physical disability and mortality, and in a future analysis would require the re-establishment of a standard functional ability assessment. Disability assignments could be supported by other information captured in MIS-SWS and Looking After Children, and it would be important to ensure both the validity and reliability of this information over time.

It is recommended that the feasibility be assessed of using standard diagnostic coding of medical conditions using the ICD-10 coding system. As an addition to the minimum data set, it would be very helpful to analyze the data in terms of pre-existing medical conditions coded in a systematic way. Many of these conditions may be directly or indirectly related to the cause of death, and would indicate a pre-existing risk. This standard coding could be applied where appropriate in both MIS-SWS and Looking After Children.

**3. Review and Refine Methodology**: It is recommended that CYIC deaths and caseload statistics based on calendar year-end be used for calculating rates. The use of the year-end caseload as denominator for the calculation of rates appeared

to be a reliable proxy for client-years. However, if there is a significant change in the nature of the caseload in future years, it may be necessary to use an aggregate annual person-year estimate for a denominator. The calendar year-end would have the advantage of being consistent with BCVSA and the Children's Commission.

It is recommended that age standardization be used in calculating rates for CYIC, as it removes the effect of a changing age structure in the CYIC caseload over time or differences in age-structure between CYIC and the provincial comparison population. The indirect calculation method used in this study (as compared to the direct method), reduces somewhat the fluctuation in rates from year to year, as occurs with rare events.

# 4. Consider Using an Epidemiological Approach With Other CYIC Variables and Outcomes:

- MIS-SWS: Review the contents of the MIS-SWS for a limited number of deceased CYIC.
   Determine if patterns exist among the dimensions included (Child Protection Finding, Child Protection Priority, Health/Behaviour Issues, Reason for Service) or any other data elements in MIS-SWS. Analyze mortality data for any identified groupings.
- Looking After Children: Determine the extent of the coverage of the newly implemented Looking After Children assessment tools for CYIC, review the data content, and assess the potential for electronic capture of data which could be useful in a future mortality or health study of CYIC.
- Children's Commission Information System: Review the information system of the Children's Commission to assess the potential contribution of the data to epidemiological analysis of CYIC health status and mortality experience.
- Ministry of Health Data: Review the Ministry of Health hospitalization, MSP, and BCVSA birth and Health Status Registry data for a limited number of CYIC deaths. Evaluation should include an assessment of the value of the data as it contributes to mortality analysis, as well as the feasibility of retrieving the data from the various databases.
- Other Government Information: Review other government information systems data (education, criminal justice, income assistance) for a limited number of CYIC deaths. This work\* has already been initiated, but evaluation should include an assessment of the value of the data to epidemiological analysis, as well as the feasibility of retrieving the data from the various databases.

<sup>\*</sup> Personal Communication, W. Mitic, Children's Commission

• Other Cultural Information: As the B.C. population becomes more culturally diverse, another option may be to assess the value and feasibility of capturing information on the cultural heritage and immigration or refugee status of CYIC and their families.

In summary, the recommendations to improve the understanding of the mortality experience and health status of CYIC are to:

- (a) Establish an ongoing means of epidemiological mortality analysis,
- (b) Establish a minimum dataset for such an epidemiological analysis, including cause of death, age, sex, and Aboriginal status,
- (c) Give further consideration as to how best to assess the mortality of Aboriginal CYIC,
- (d) Assess the feasibility of re-introducing and maintaining a standard coding of the functional status of CYIC,

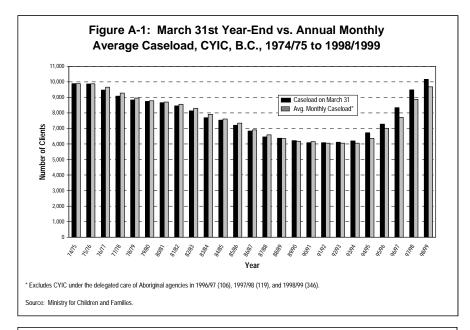
- (e) Assess the feasibility of introducing a standard diagnostic coding of medical conditions to CYIC records using the ICD-10 coding system,
- (f) Use calendar year-end for CYIC deaths and caseload statistics for calculating agestandardized (indirect) mortality rates, and
- (g) Give consideration to using additional data to obtain a more complete assessment of the mortality experience and health status of CYIC, including other data in MIS-SWS, the Looking After Children system, the Children's Commission information system, the Ministry of Health and BCVSA information systems, other government information systems, and other cultural information.

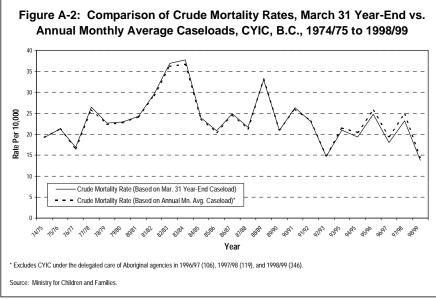
### **APPENDIX A: An Assessment of CYIC Caseload Statistics**

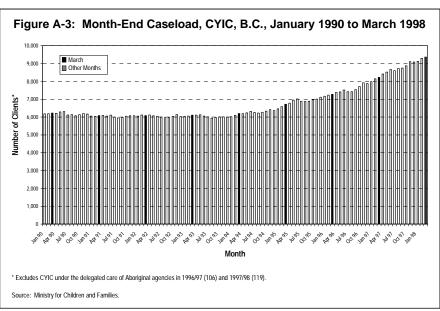
The initial aspect of client data to assess was a comparison of the annual monthly average versus the March 31st year-end caseload statistics for use as a denominator (see Figure A-1). The annual monthly average caseload counts were higher during an initial period of declining caseloads (1974/75 to 1987/88), both were about the same during a period of fairly stable caseloads (1988/89 to 1992/93), after which the March 31<sup>st</sup> year-end counts were higher during the recent period of increasing caseloads (1992/93 to 1998/99).

In order to compare the effect on mortality rate calculations for each of these approaches to estimating a denominator for the CYIC population, crude mortality rates are displayed in Figure A-2. As indicated, there is little practical difference between the two approaches, with the mortality rates based on March 31st year-end statistics being slightly higher in the earlier years (during a time of declining caseloads), and slightly lower in the later years (during a time of increasing caseloads). As the March 31st year-end statistics included additional data on such client characteristics as age, gender, functional status, and aboriginal status, these data were the obvious preference for this study.

Having shown that the choice between these two denominators had a minimal impact on the calculation of crude mortality rates, the next question was whether the March 31st yearend statistics provided a valid indicator of the CYIC client population during the year, or could substantial variation from month-to-month be obscured? To assess this question, monthend caseload data were available since January 1990 (see Figure A-3). The pattern shows no evidence of instability, as the total caseload varied only slightly from month to month, with a gradual increasing trend beginning in the spring of 1994.



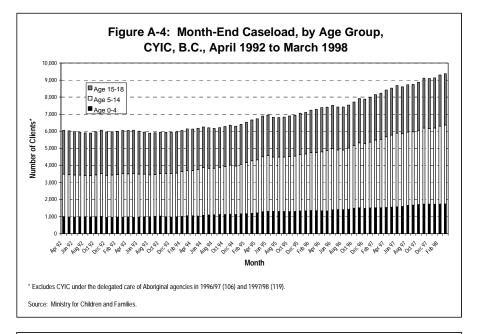


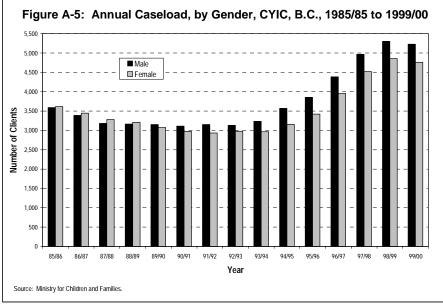


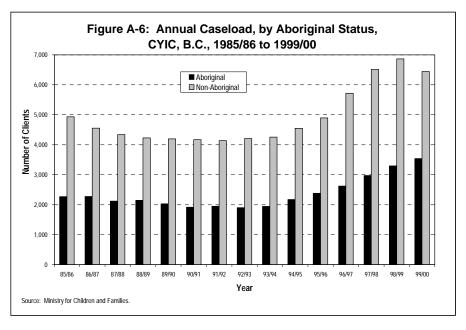
While the overall monthly caseload trend had a fairly smooth pattern, could these All Ages data be obscuring major changes by age group? Monthly data by age group were available since April 1992 (see Figure A-4). Again the data show a fairly smooth trend for each age group over time, with no evidence of instability. Ages 15-18 years were numerically fairly stable, but showed a decrease in proportion over time. Ages 0-4 and 5-14 years showed both an actual and proportionate increase, however, these changes were very gradual. Furthermore, the pattern for March, the year-end point, was not unusual in comparison to other months.

Gender was the next CYIC characteristic examined for evidence of instability (see Figure A-5). The pattern showed a gradual change over time, with girls slightly exceeding boys in the first four years, and boys slightly exceeding girls in the last 11 years. For 1999/00, the CYIC male/female ratio was 52.3/47.7, compared to the provincial ratio of 51.4/48.6, indicating a slight overrepresentation of boys and under-representation of girls in the CYIC caseload.

The next CYIC characteristic examined was Aboriginal heritage, based on the definition\* used by MCF, as shown in Figure A-6. Again the pattern appeared to be fairly stable over time. As discussed in the body of this report, aboriginal children are over-represented among CYIC in relation to the provincial child population, but it is also possible that the heritage of some Aboriginal CYIC was not recorded in the MCF information system and hence they could be under-estimated in the CYIC caseload.







<sup>\*</sup> See definition in Chapter 8

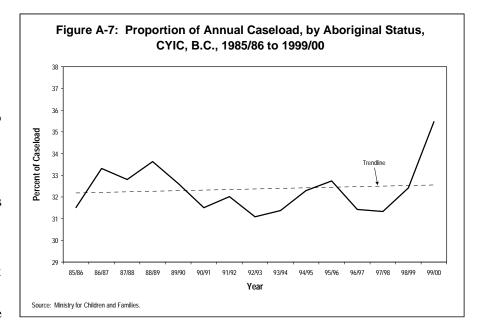
On examining the caseload statistics by Aboriginal status over time, the latest year appeared to be unusual. Aboriginal CYIC increased in number and proportion, while non-Aboriginal CYIC decreased, changes not seen to the same extent in previous years. In order to explore this apparent inconsistency, MCF staff arranged a cross-match of all active CYIC records with BCVSA records on Status Indian children, as of September 1997 and December 2000.

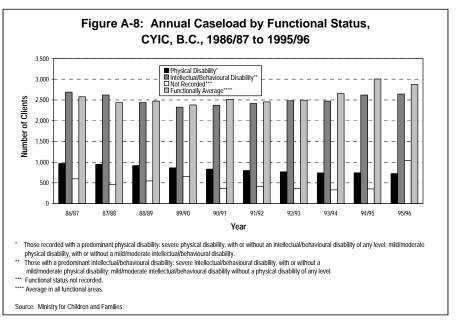
After a preliminary assessment of a random sample of records from this cross-matching process, which because of time constraints could not involve the more lengthy steps of final verification with regional staff, it was generally estimated from these limited data that 38 to 40% of CYIC could be Aboriginal in those years.\* While not necessarily representative of all CYIC records in those years or in other years in the period 1985/86 to 1999/00, these preliminary results suggested that:

- (1) Aboriginal children may be under-estimated in the current CYIC caseload statistics, and
- (2) the degree to which Aboriginal children were under-estimated may vary over time.

As the problem appeared to be more complex than could be readily assessed and corrected in the immediate future, it was decided that an analysis of time trends based on Aboriginal status could be unreliable, and therefore these data were only used for cumulative comparisons, and interpreted with caution.

Finally, caseload statistics based on functional status were examined, together with the list of deceased CYIC by functional status. The MCF information system contained client data aggregated by functional disability status (mild/moderate, severe, average, not recorded), in each of three functional areas (physical, intellectual, behavioural), which results in 12 possible combinations of functional ability rating for each CYIC. As deaths to all CYIC numbered 148 for the 10-year period 1986/87 to 1995/96, ranging from 9 to





21 per annum, there would be difficulties with "small numbers" on both an annual and cumulative basis, if the analysis included all 12 possible combinations. On inspecting the list of deceased CYIC, it was obvious that CYIC recorded as living with a physical disability were highly represented among the deceased children. The causes of death for these physically disabled CYIC were primarily due to a variety of severe medical problems, whether the child was rated as mildly/moderately or severely physically disabled.

On learning that the MCF information system may not always have had on record a current functional status rating for each CYIC, and that the functional status rating was not subject to verification\*\*, it appeared that the recorded distinction between mild/moderate and severe disability could be unreliable, so these two categories were collapsed together (see Figure A-8).

<sup>\*</sup> Personal Communication, M. Wright, Ministry for Children and Families.

<sup>\*\*</sup> Personal Communication, W. Matheson, Ministry for Children and Families.

There were very few deaths to CYIC living with only an intellectual and/or behavioural disability rating, so that these two categories were also collapsed together. Furthermore, as CYIC were rated in each of the three functional areas, a hierarchical approach was needed, so the final choice of categories was collapsed into:

- (a) Those recorded with a predominant physical disability,
  - severe physical disability, with or without an intellectual/behavioural disability of any level,
  - mild/moderate physical disability, with or without a mild/moderate intellectual/ behavioural disability,
- (b) Those with a predominant intellectual/behavioural disability.
  - severe intellectual/behavioural disability, with or without a mild/moderate physical disability,
  - mild/moderate intellectual/behavioural disability without a physical disability of any level,
- (c) Average in all functional areas, and
- (d) Functional status not recorded.

The number of children recorded as having an intellectual/behavioural disability varied slightly over time, and CYIC with a physical disability rating showed a gradual decrease over time. The category with the most variability over time was the CYIC with disability status "Not Recorded". This group gradually decreased over time with annual fluctuation until the last year, when it abruptly tripled, in association with the implementation of a new information system.

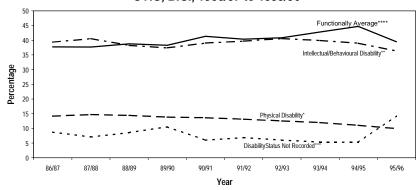
As the "Not Recorded" group comprised a variable proportion of all CYIC over time, and given the small numbers, it was decided that an analysis of time trends based on functional ability may be unreliable, hence these data were only used for cumulative comparisons.

In summary, other than for functional ability and Aboriginal status, the pattern of the variables considered above, while subject to some gradual change and minor variation, showed a caseload which has gradually evolved over time. There is no evidence of abrupt alterations in the case mix of clients, within the limits of the data examined on major demographic variables.

Other than for functional ability and Aboriginal status, this review found no indication or suggestion of unreliability or inconsistency in the pattern of March 31st year-end statistics describing the CYIC client population. Nor was there any evidence that the CYIC client population is subject to extreme variability, either monthly or annually, which would suggest that the March 31st year-end statistics may not be representative of the overall fiscal year caseload experience.

However, a theoretical concern remained that even with a fairly smooth pattern of gradual change as shown in month-end statistics, is it possible (although perhaps, not operationally probable) that month-end statistics

Figure A-9: Annual Caseload Percentage by Functional Status, CYIC, B.C., 1986/87 to 1995/96



- Those recorded with a predominant physical disability: severe physical disability, with or without an intellectual/behavioural disability of any level; mild/moderate
- physical disability, with or without a mild/moderate intellectual/behavioural disability.

  Those with a predominant intellectual/behavioural disability: severe intellectual/behavioural disability, with or without a mild/moderate physical disability; mild/moderate intellectual/behavioural disability without a physical disability of any level Functional status not recorded.
- \*\*\*\* Average in all functional areas

Source: Ministry for Children and Families

could obscure intra-month variation? Could additional clients be admitted after the beginning of a month and then discharged before month-end, hence, not appearing in the month-end statistics?

If this were to happen, it could mean that while CYIC deaths (the numerator) would be captured in the information system, their actual recorded contribution to the CYIC caseload (the denominator) would be missing in month-end statistics. Thus, the mortality rate calculation could be skewed upward due to the "smaller" denominator, thereby exaggerating the calculated mortality rate for CYIC clients.

To assess this possibility, a further check was made which involved an examination of the length of stay of each individual CYIC client, which was possible only beginning in 1997/98, using the enhanced capability of the new information system in MCF. During this year there were a total of 13,926 individual CYIC clients on record, each of whom was a client for part or all of the year. The number of client-months was counted for each individual client, to determine the total number of client-months, and hence, client-years.

Number of Clients/Client Years, Duration of Stay in Months, CYIC, BC, 1997/98

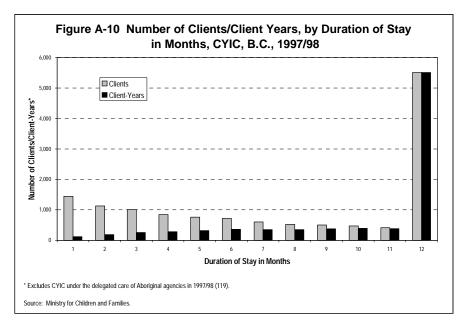
Duration in Months	Number of Clients*	Percent of Clients	Client- Months	Client- Years	Percent of Client- Years
1	1,441	10.3	1,441	120	1.4
2	1,127	8.1	2,254	188	2.1
3	1,012	7.3	3,036	253	2.9
4	844	6.1	3,376	281	3.2
5	762	5.5	3,810	318	3.6
6	719	5.2	4,314	360	4.1
7	599	4.3	4,193	349	3.9
8	527	3.8	4,216	351	4.0
9	500	3.6	4,500	375	4.2
10	473	3.4	4,730	394	4.4
11	414	3.0	4,554	380	4.3
12	5,508	39.6	66,096	5,508	62.1
Total	13,926	100.0	106,520	8,877	100.0

\* Excludes CYIC under the delegated care of Aboriginal agencies in 1997/98 (119).

Source: Ministry for Children and Families

This calculation showed that 13,926 clients contributed a total of 8,877 client-years during that year (see above table and Figure A-10).

During 1997/98, the monthly caseload statistics varied from 8,411 (on April 30<sup>th</sup>) to 9,366 (on March 31<sup>st</sup>), a gradual increase with minor monthly fluctuation, as shown in the accompanying table. The annual monthly average was 8,878. These data indicate that month-end statistics do not appear to obscure intramonth variation in caseload, as the monthly average caseload of 8,878 clients and the client-year estimate of 8,877 based on length of stay data are essentially identical in value. If there had been significant intra-month admission and discharge of clients, the client-year estimate should have greatly exceeded the monthly average caseload, which it clearly did not.



As indicated in Figure A-10, the CYIC population is comprised of two broad groups. The smaller group of 5,508 clients was in-care for 12 months during 1997/98. (Some clients may also have been in-care during the previous year or years, but that is not necessary to consider here.) The larger group of 8,418 clients was in care during 1997/98 for less than 12 months, with a range of 1 to 11 months, averaging 4.8 months per client. (Some of these clients may also have been in-care during the previous year, but that also is not necessary to consider here.)

This raises the final methodological issue to be addressed, whether the denominator should include every child ever in-care during the year, such that each child would be counted and weighted the same, regardless of length of stay. The implication to the denominator is as follows: the smaller group of 5,508 long-stay clients contributed 5,508 client-years to the population, whereas the larger group of 8,418 short-stay clients contributed only 3,369 client-years to the population during the year.

Expressing the same information proportionately, the 40% of clients who were long-stay accounted for 62% of client-years, while the other 60% of clients who were short-stay accounted for 38% of client-years. On methodological grounds this approach was rejected, as this "duration of stay unweighted" definition of denominator would not match the definition of numerator, which was each death occurring to a child who was a CYIC client at the time of death.

The definition of numerator includes only deaths occurring to a child while in-care. Thus, for the denominator to match the numerator, it would have to include only the contribution of each child to the CYIC client population for that portion of the year actually spent in-care. Therefore, the use of client-years rather than total number of individual clients during the year as a population denominator, was deemed to be a more valid representation of the caseload, given the variation

Month-End CYIC Caseload Statistics, BC, 1997/98

Month-End	Number of Clients*
April	8,441
May	8,524
June	8,673
July	8,600
August	8,723
September	8,745
October	8,876
November	9,106
December	9,090
January	9,128
February	9,296
March	9,366
Annual Monthly Average	8,878

\* Excludes CYIC under the delegated care of Aboriginal agencies in 1997/98 (119).

Source: Ministry for Children and Families.

in length of stay. However, a calculation of clientyears was only conducted for 1997/98, not for the earlier years in the study.

In summary, the CYIC caseload statistics, based on a reasonable and practicable assessment of available data on CYIC clients, were believed to be satisfactory for the purpose of this epidemiological study. As no single parameter could provide a definitive assessment, a variety of client characteristics were considered. While there were some changes in the caseload, the changes were gradual and evolved over time.

Therefore, on reviewing the caseload data, and, on considering the information together as a whole, the CYIC statistics based on the March 31<sup>st</sup> year-end demonstrated sufficient validity and reliability to enable the mortality rate calculations required for this study. The only major data quality issues found were related to functional status and Aboriginal status, hence the use of those data was limited to cumulative mortality comparisons, due to being less complete, accurate, and reliable than other CYIC data elements.