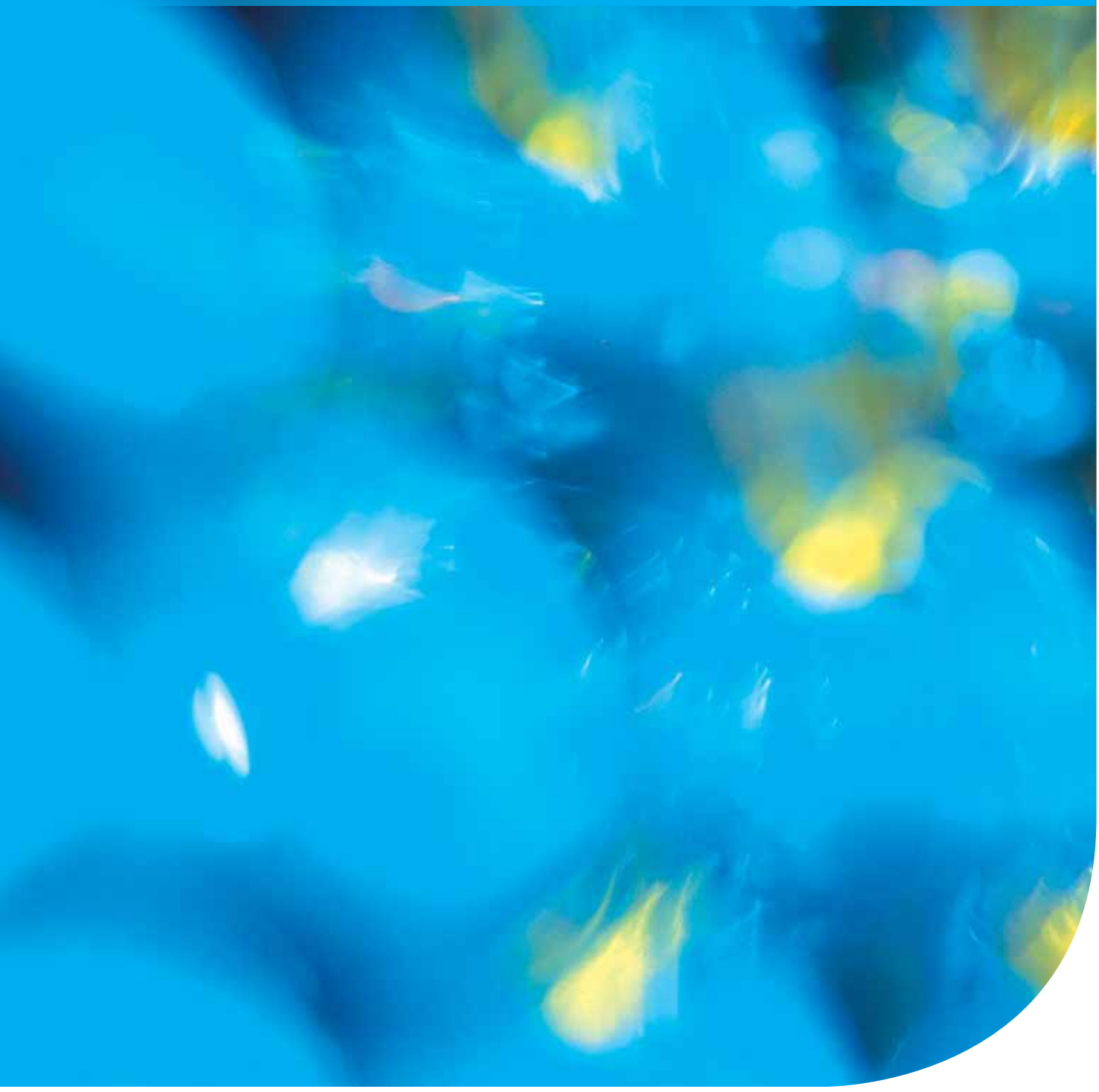
ACT Children & Young People
Death Review Committee

ANNUAL REPORT 2012–13



ACT Children & Young People
Death Review Committee

LETTER OF TRANSMISSION

The Minister for Disability, Children and Young People
ACT Legislative Assembly
London Circuit
Canberra ACT 2601

Dear Minister

I am pleased to present you with the second annual report of the ACT Children and Young People Death Review Committee. The report has been prepared in accordance with Section 727S of the *Children and Young People Act 2008*.

While the report is in relation to 2012–13, it also presents information for the 2008–09 to 2012–13 financial years and fulfils the Committee's statutory obligations.

Yours sincerely

Dr Penny Gregory
Chair
31 October 2013

The ACT Children and Young People Death Review Committee is established under the *Children and Young People ACT 2008*

GPO Box 158 Canberra City ACT 2601
t 02 6205 2949 | **e** childdeathcommittee@act.gov.au

Enquiries about this publication should be directed to:
Secretariat, ACT Children and Young People Death Review Committee, GPO Box 158, Canberra City ACT 2601
e childdeathcommittee@act.gov.au **t** 02 6205 2949

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ACT Government

FOREWORD

This is the second annual report of the Australian Capital Territory (ACT) Children and Young People Death Review Committee (the Committee) and my first as Chair of the Committee.

In April 2013, Dr Judith Gibbs, the inaugural Chair of the Committee, resigned from the role for personal reasons and I was appointed as Chair on 11 June 2013 for a three-year term. Dr Gibbs led the Committee during the hard work of establishment, particularly in its first year of operation, and the Committee and I extend our grateful thanks to her for the valuable guidance and generous time she gave to the Committee's work.

This report concerns 105 children and young people who normally lived in the ACT and died in either the ACT or NSW between 1 July 2008 and 30 June 2013. The death of any child or young person is a tragedy and, on behalf of the members of the Committee, I would like to extend our sincere condolences to the families, friends and communities who knew and loved the children and young people who died.

In last year's report, the first for the Committee, broad demographic trends were reported for the three financial years from 2009–10 to 2011–12. This year we are able to provide more detailed information covering the five years from 2008–09 to 2012–13. This includes additional information about whether those children and young people were known to Care and Protection Services, Youth Justice Services or ACT Policing prior to the dates of their deaths. Information is also provided about the socioeconomic status of the children and young people who died.

The Committee has made great progress in developing its methodology and approach for conducting reviews into the individual deaths of children and young people and these reviews will commence in the near future. How the Committee will communicate what it learns in a way that respects the right to privacy of the child, young person and their family, while ensuring the findings can inform the community in the future, will be a critical task for the Committee.

In the year ahead, the Committee looks forward to involving itself in activities that will ensure it meets its goal of becoming one of the leading bodies in the ACT for helping to prevent or reduce the likelihood of the death of children and young people.

Finally, I would like to thank the members of the Committee, the support staff and the many people consulted in the ACT for the support given to the Committee throughout 2012–13.

Dr Penny Gregory
Chair
ACT Children and Young People Death Review Committee

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EXECUTIVE SUMMARY

The ACT Children and Young People Death Review Committee (the Committee) was established in the ACT with Committee members appointed in January 2012. The Committee is required to report annually to the Minister and this is the Committee's second annual report.

Activities of the Committee 2012–13

The Committee has met on a number of occasions throughout 2012–13 and has been involved in a number of activities. The Committee's first member from the education sector was appointed during the year and attended their first meeting in April 2013. A full-time Senior Research and Review Officer was also appointed and commenced in January 2013.

The Committee receives demographic information from the ACT Registry of Births, Deaths and Marriages (ACT BDM) on the deaths of children and young people that occur in the ACT and information from the NSW Registry of Births, Deaths and Marriages (NSW BDM) on the deaths of those children and young people who normally live in the ACT but died in NSW. With regard to the latter group, the decision to initially focus on obtaining information from NSW was based on the assumption that the majority of deaths that occurred outside the ACT of children and young people who normally live in the ACT were likely to have occurred in NSW. The ACT is located in close proximity to NSW and a substantial segment of the ACT population regularly uses NSW health services and holiday destinations.

The Committee has also started to obtain additional information about the circumstances surrounding the deaths of children and young people from the Office for Children, Youth and Family Support (OCYFS), ACT Health, ACT Policing and the National Coronial Information System (NCIS). Agreements are now in place with the OCYFS and the NCIS allowing the Committee to regularly obtain information. Work is continuing with the Office of the Coroner and it is anticipated that this protocol will be finalised in the near future.

The ACT is fortunate that a relatively small number of deaths of children and young people occur each year. This small number, together with the size of the ACT, in terms of both geography and population, means the Committee must pay particular attention to the way it reports its information. The Committee has continued to prioritise the ongoing challenge of honouring the right to privacy of all children, young people and their family members cited in this report while ensuring that the community will be able to learn from the circumstances of their deaths.

During 2012–13 the Committee made significant progress in developing its working arrangements for undertaking individual reviews and developed its methodology and approach. To assist in completing these reviews, the Committee has included in its protocols with the Office of the Coroner and the OCYFS the ability to access comprehensive case files as considered necessary by the Committee.

The Committee has continued to progress its work in developing a new register and has developed its business requirements for any future register. The Committee is currently in the final stages of formalising the information fields it would like the register to include.

The Committee has started to explore the best method for coding cause of death using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) to ensure that any coding recorded on the register is accurate.

The Committee's website has now been established at www.childdeathcommittee.act.gov.au. The website contains information about the Committee's functions, membership and publications, along with links to interstate child death review bodies and relevant ACT agencies and support services. Media coverage related to the Committee in the past year occurred following the tabling of the Committee's first annual report in 2012 and the appointment of a new Chair in 2013.

The Committee continues to be a member of the Australian and New Zealand Child Death Review and Prevention Group (ANZCDR&PG) and was represented at its annual meeting held in Melbourne in February 2013. The Committee was also represented at the Third Australasian Conference on Child Death Inquiries and Reviews held in Sydney in November 2012.

Child deaths in the ACT, July 2008–June 2013

To ensure that the privacy of individual children, young people and their families is protected, the Committee has agreed that it will not report data for an individual year. The numbers of deaths are so small in some cases that this may lead to unintentional disclosure of information. In this report, a five-year period covering the financial years 2008–09 to 2012–13 has been aggregated. Fortunately, only small numbers of deaths of children and young people occur in the ACT each year. However, these small numbers can lead to significant variations in the numbers of deaths and the rates of death per age group each year. This variation means there needs to be a focus on numbers over an extended period of time, rather than drawing conclusions from one year of data. The Committee's future annual reports will also provide information covering five-year periods to allow for the identification of trends.

During this reporting period there were 155 deaths recorded on the children and young people deaths register. Of these deaths, 115 are of children or young people who normally live in the ACT and 10 of these are awaiting coroner findings and will be included in subsequent reports when cases are finalised by the Committee.

Accordingly, this report provides information on 105 children and young people who normally live in the ACT and whose deaths occurred in the ACT or NSW in the five-year period from 1 July 2008 to 30 June 2013.

The major findings contained in this report with respect to all 105 ACT children and young people deaths are:

- sixty-two deaths were of male children and young people (59.0%)
- forty-seven deaths occurred in the neonatal period (under 28 days) (44.8%)
- sixty-three deaths were of children less than 1 year old (includes neonatal deaths) (60.0%)
- sixty-four deaths were due to medical causes (61.0%)
- eighty-one deaths occurred in a hospital (77.1%)
- six children and young people who died identified as Aboriginal (5.7%)
- twenty-nine deaths were subject to a coronial inquiry (27.6%)
- twenty-two children and young people who died and/or their siblings were known to Care and Protection Services in the three years before the child or young person's death (20.9%)
- seven children and young people were the subject of intervention by Care and Protection Services at the time of their death (6.7%)
- none of the children and young people who died were known to Youth Justice Services
- twenty-three children and young people who died and/or their families were known to ACT Policing (21.9%), and of these, fifteen were only known as a result of the death incident (65.2%).

Usual residents of other jurisdictions who died in the ACT

In the five years from 1 July 2008 to 30 June 2013, a number of children and young people who normally lived in NSW, and less than five children and young people who normally lived in Victoria, died in the ACT. There were no deaths recorded in the ACT of children and young people who normally lived in any of the other Australian states or the Northern Territory.

Future directions for the Committee

The Committee's priority over the next 12 months is to continue to work towards being one of the leading bodies in the ACT in helping to prevent or reduce the likelihood of the death of children and young people. To do this, the Committee has identified a number of goals it would like to achieve, including:

- commencing the review of deaths of individual children and young people
- forming a communications sub-group to examine how best to reach out to the ACT community in the future
- continuing work on the report on the deaths of children and young people in the ACT for the period from 1 January 2004 and including data for a 10-year period from 1 January 2004 to 31 December 2013
- making an informed decision about whether to develop its own register or purchase another child death review body's register
- finalising arrangements for including ICD-10 coding in the new register
- commencing discussions with other Australian states and the Northern Territory about the possibility of obtaining information about the deaths that occur outside of the ACT of children and young people that normally live in the ACT
- considering how best to communicate what it is learning from conducting individual reviews and the implications for government policy and service provision in a sensitive way that honours the right to privacy of all children, young people and their families
- providing relevant information to other jurisdictions as requested and when this sharing of information will not impact on the Committee's responsibilities set out under the *Children and Young People Act 2008* (the Act)
- continuing to be a member of the ANZCDR&PG and attending any relevant meetings and conferences.
- identifying any legislative amendments required and working with government and the Legislative Assembly to address these.

CHAPTER 1 THE ACT CHILDREN AND YOUNG PEOPLE DEATH REVIEW COMMITTEE

Role of the Committee

The Committee was established in January 2012 under Chapter 19A of the Act as an independent multi-sectoral Ministerial Committee. It was formed to help reduce preventable deaths of children and young people in the ACT by reviewing all deaths of children and young people that occur in the ACT, as well as those deaths of ACT children and young people that occur outside of the ACT. Included within the legislation is a particular focus for the Committee to review the deaths of children and young people who were known to the Care and Protection Service (CPS) of the OCYFS. Section 727S(c)(ii) states that the Committee must report about the patterns or trends (if any) identified in relation to the deaths of children and young people who, within three years before his or her death were, or had a sibling who was, the subject of a Child Protection Report.

The Committee promotes critical reflection about the circumstances and risk factors associated with the deaths of children and young people and aims to provide the ACT Government with a way to examine the current provision of medical, educational, cultural, legal, youth justice, community and welfare services available to children and young people.

In the future, the Committee expects to make recommendations to the ACT Government about policies and service provision that could improve the quality of these services. These findings and recommendations will be reported publicly in future reports.

Background of the Committee

The proposal for an ACT Children and Young People Death Review Team was first raised in 1999 by the Children's Services Council. At that time, similar Child Death Review Teams had already been established in NSW and Victoria.

In 2004 the proposal for a Committee received further support from recommendations in the review undertaken by Ms Cheryl Vardon. This review focused on the safety of children in care and the management of Child Protection Services in the ACT. The review report '*The Territory as Parent: Review of the Safety of Children in Care in the ACT and of ACT Child Protection Management*' (known as the Vardon Report) was published in May 2004 and recommended that a child death review committee be established within a Commission for Children and Young People and that the Commissioner should chair the Committee. The report recommended that there should be a review of each child's death for all children and young people who died when in the care of Family Services (now known as CPS) and/or when the Chief Executive had parental responsibility for the child and/or when the child was known to Family Services. These reviews would be carried out by an external reviewer and be provided to the Child Death Review Committee for consideration.

The government at that time agreed in principle with these recommendations. However, the Commission for Children and Young People had yet to be established and a decision as to the most appropriate location of a Child Death Review Committee was postponed.

In 2004 ACT Health established a model for a Child Death Review Team. This team relied on the powers of the ACT Chief Health Officer, under the *Public Health Act 1997*, to review child deaths from 1992 to 2003. The ACT Chief Health Officer chaired the Child Death Review Team whose membership was multidisciplinary and included those with a wide range of work expertise and experience. In June 2006, the Child Death Review Team published their work in a report entitled *'Review of ACT Child Deaths 1992–2003'*. The report examined general issues and trends and identified the need for appropriate legislation to guide the operation of an ongoing child death review mechanism. It did not report on individual child deaths.

In 2006 the ACT Government commissioned a study about intervention in the lives of children who had died or nearly died and who at some time in their lives were known to CPS (known as the Murray-Mackie Study). This independent study was undertaken by experts, Ms Gwenn Murray and Mr Craig Mackie, and its findings were reported to the then Department of Disability, Housing and Community Services (now known as the Community Services Directorate).

In September 2006 the then Minister for Disability and Community Services tabled the government's response to the study, entitled *'Recommendations from the Murray-Mackie Study into the Deaths and Near Deaths of Children Known to Care and Protection and the Government Response'*, in the ACT Legislative Assembly. The recommendations of this study reiterated the recommendation made in the Vardon Report relating to a Child Death Review Committee. The then government agreed to implement this recommendation and to consider joint ACT Health and CPS clinical reviews of children who had died and who were known to both agencies prior to their deaths.

In January 2009 a memorandum of understanding was signed by ACT Health and the then Department of Disability, Housing and Community Services, including the OCYFS. This memorandum of understanding established a joint case review by the ACT Clinical Audit Committee of clients known to both ACT Health and CPS. When a review follows the death of a child known to CPS, the Clinical Audit Committee can make recommendations for systemic improvements involving individual agencies and in relation to collaborative practice between ACT Health Services and CPS. In a small number of cases, CPS has engaged an independent external reviewer to examine a death and produce a report.

In August 2010 Ms Meredith Hunter, MLA proposed amendments to the Act enabling the establishment of an ACT Children and Young People Death Review Committee. The proposed independent committee would complement and draw on existing review mechanisms, such as the ACT Office of the Coroner, the Clinical Audit Committee within ACT Health and any external or internal review process instigated by the then Department of Disability, Housing and Community Services. However, the role of the proposed committee would be fundamentally different and would mean, for the first time, a child death review mechanism specifically relating to the review of deaths of ACT children and young people would be enshrined in legislation.

The Bill and proposed government amendments were debated in the ACT Legislative Assembly and a final Bill was passed on 9 March 2011. These provisions became operational on 18 September 2011. The ACT Children and Young People Child Death Review Committee was established in accordance with the provisions contained in Chapter 19A of the Act. The first Committee meeting was held on 2 March 2012.

Functions of the Committee

The functions of the Committee as set out under Section 727B of the Act are:

a to keep a register of deaths of children and young people under part 19A.3

b to identify patterns and trends in relation to the deaths of children and young people

c to undertake research that aims to help prevent or reduce the likelihood of the death of children and young people

d to identify areas requiring further research, by the Committee or another entity, that arise from the identified patterns and trends in relation to the deaths of children and young people

e to make recommendations about legislation, policies, practices and services for implementation by the Territory and non-government bodies to help prevent or reduce the likelihood of the death of children and young people

f to monitor the implementation of the Committee's recommendations

g to report to the Minister under part 19A.4

h to carry out any other function given to the Committee under this chapter.

Register

The Committee is required to develop and maintain a register of all deaths of children and young people that occur in the ACT and the deaths that occur outside of the ACT of children and young people who normally live in the ACT.[1] The register must include the information provided under section 727N(2) of the Act, namely:

- the cause of death of the child or young person
- the age of the child or young person
- the sex of the child or young person
- whether the child or young person is Aboriginal and/or Torres Strait Islander
- whether, within three years before his or her death, the child or young person, or a sibling of the child or young person, was the subject of a Child Protection Report
- anything else prescribed by regulation.

The register may contain any other demographic data available to the Committee and any other information about a child or young person or the circumstances of the child or young person's death that the Committee considers relevant to exercising its reporting functions and anything else the Committee considers relevant.[2]

To ensure the Committee complies with the above requirements, it is currently keeping an interim register of the deaths of children and young people that occur in the ACT and the deaths that occur outside the ACT of children and young people who normally live in the ACT. The information contained in this interim register will be migrated into any future register developed by the Committee.

The Committee has continued to progress its work in developing a new register and has developed its business requirements for any future register. The Committee is currently in the final stages of formalising the information fields it would like the register to include. The selection of information fields is a vital stage of the planning process as the information fields selected will dictate the information obtained and recorded in relation to each death of a child or young person. The Queensland Commission for Children and Young People and Child Guardian, in particular its Child Death Review Team, has provided significant support and advice during this planning and development phase.

It is anticipated any future register will allow the Committee to:

- record information about the death of a child or young person
- update and maintain information recorded about a child or young person's death
- provide for quality assurance
- analyse and report on the information contained within the register
- support and record individual reviews completed by the Committee
- store any recommendations made by the Committee
- monitor any recommendations made.

The Committee has been considering the benefits of either developing its own register or purchasing an already developed register and enhancing it to reflect the needs of the ACT population. It is anticipated the Committee will make its decision on the register in the near future.

1 Section 727N(1) of the Act.
2 Section 727N(3) of the Act.

Activities of the Committee 2012–13

Retrospective report of child and young people deaths

The Committee must use its best endeavours to report about the following information set out under section 727U of the Act in relation to the deaths of children and young people included on the register for the period 1 January 2004 to 17 September 2011 (the retrospective report):

- the number of deaths of children and young people
- the age of each child or young person
- the sex of each child or young person
- whether, within three years before his or her death, the child or young person, or a sibling of the child or young person, was the subject of a Child Protection Report.

The Committee may include in its retrospective report its recommendations about legislation, policies, practices and services for implementation by the ACT Government and non-government bodies to help prevent or reduce the likelihood of the death of children and young people and any other matter it considers relevant.

The process of obtaining information for the retrospective report has commenced; however, any other work for the retrospective report has been put on hold to allow the Committee to focus on the release of this report. Work on the report on the deaths of children and young people in the ACT for the period from 1 January 2004 will recommence in earnest in November 2013 and will include information from a 10-year period (1 January 2004 to 31 December 2013).

Individual reviews

During 2012–13 the Committee started to formalise its working arrangements for undertaking individual reviews, including its methodology and approach concerning these reviews.

There are two distinct parts to the individual reviews to be undertaken by the Committee:

1. A first level review and analysis undertaken by the Senior Research and Review Officer. The methodology and approach for this first level review is based on the Committee's needs in order to carry out its legislative functions under the Act. The Senior Research and Review Officer will have access to firsthand documents containing identifying information, as well as access to any people considered necessary.
2. A second level of analysis and high level multi-sectoral overview undertaken by the members of the Committee. Committee members do not have access to either firsthand documents containing identifying information or people considered necessary to talk to. The Committee members will be provided with a de-identified report from the Senior Research and Review Officer for each individual review completed.

Individual reviews will aim to provide an understanding of the child or young person's family and social context prior to his or her death and the facts to be outlined would include:

- a genogram of the family, including family, extended family and household
- an ecomap mapping the service and community involvement with the family
- a child-centred chronology, based on information sourced from those agencies involved with the family, detailing involvement with the child or young person and their family and looking at all relevant agencies/professionals/others, including when the child was seen and the views and wishes of the child sought/expressed
- investigations/clinical summaries of agencies involved
- an overview summarising relevant information known to each involved agency about the family, including the parents, perpetrator (if applicable) and home circumstances for all children in the family.

Not every death of a child or young person that occurs in the ACT will be the subject of an individual review. This is because the time taken to conduct a high level review for every single death of a child or young person would be prohibitive.

To assist the Committee in determining those deaths that will be subject to an individual review, the Committee has begun developing review criteria. The purpose of these review criteria is to highlight to the Committee those deaths that are likely to provide significant insights or knowledge. It is not to suggest that the death of one child or young person is more important than the death of another child or young person.

It is envisaged the Committee will include what is learnt from these individual reviews in future reports, information sheets and occasional papers. The nature of what and how such matters are reported and used in a non-identifiable and yet informative way will require careful consideration by the Committee.

Appointment of a member from the education sector

In accordance with section 727D(2)(a)(vi) of the Act, a member from the education sector was appointed to the Committee in April 2013.[3]

Senior reviewer

In 2012 the Community Services Directorate (CSD) accepted the Committee's request to appoint a senior reviewer to ensure the Committee could operate effectively and carry out its legislative functions. A full-time Senior Research and Review Officer was appointed and commenced in the role in January 2013. The duties of the Senior Research and Review Officer include:

- coordinating, gathering and collating information relating to the deaths of children and young people; this may include analysis of the information held on the register and information gathered from other sources
- documenting information in relation to the deaths of children and young people and preparing reports for consideration and review by the Committee
- undertaking sensitive interviews with stakeholders to develop a thorough understanding in relation to the circumstances of death of a child or young person
- contributing to Committee meetings
- contributing to the preparation of the Committee's annual report and to the report on retrospective data
- liaising with external agencies.

The Senior Research and Review Officer is located in the Consumer Advocacy and Quality Service (CAQS), a section of the Policy and Organisational Services within the CSD, which is organisationally separate from the OCYFS. CAQS provides an independent complaints resolution service or 'internal review' function for the Director-General of the CSD.

Ensuring privacy and confidentiality

The ACT is fortunate that a relatively small number of deaths of children and young people occur each year. However, this small number, together with the size of the ACT, both geographically and in population, means the Committee must pay particular attention to the way it reports its information. The Committee must ensure it complies with sections 727T(2) and 727U(3) of the Act, which do not allow for the disclosure of the identity of a child or young person who has died or allow the identity of a child or young person who has died to be worked out.

The Committee continues to prioritise the ongoing challenge of honouring the right to privacy of all children, young people and their family members cited in this report while ensuring the community is able to benefit from examination of the circumstances that led to the death. The Committee continues to adhere to the information-sharing provisions of Chapter 25 of the Act

3 Page 50 provides information about the education member appointed to the Committee.

in that information obtained under the Act is only to be used for a function of the Committee. The Committee also adheres to Article 16 of the United Nations Convention on the Rights of the Child, which states: *'Every child has the right to privacy. The law should protect the child's private, family and home life.'*

To meet these obligations the Committee has undertaken a range of measures, including:

- aggregation of five years of information for this annual report to limit the likelihood of the identity of a child or young person being disclosed
- the use of a secure register that can only be accessed by authorised staff
- password protection of documents when sharing any identifiable data during the obtaining of information
- assignment of an identification number to each child, young person, family member or relevant person
- provision to Committee members of de-identified information only about a child, young person, family member or relevant person.

Communication strategy

The Committee considers it important for members of the community and for relevant government and non-government organisations to learn more about its work. This will ensure that any recommendations made by the Committee are communicated effectively in the hope of preventing or reducing the likelihood of the death of children and young people.

A sub-committee has been formed to consider the most effective ways of communicating key messages to the community.

The Committee's website has now been established at www.childdeathcommittee.act.gov.au and contains information about the Committee's functions, membership and publications, along with links to interstate child death review bodies and relevant ACT agencies and support services. The website will be updated regularly as the Committee's work progresses.

Media coverage related to the Committee in the past year occurred following the tabling of the Committee's first annual report in 2012 and the appointment of a new Chair in 2013.

National and international links

The Committee continues to be a member of the ANZCDR&PG and was represented at its annual meeting held in Melbourne in February 2013. Membership of this group has provided the Committee with the opportunity to form working relationships with similar child death review bodies across Australia and New Zealand and has allowed the Committee to take advantage of the breadth of knowledge and expertise members of the ANZCDR&PG have to offer.

The Committee was represented at the Third Australasian Conference on Child Death Inquiries and Reviews held in Sydney in November 2012. This conference involved keynote speakers, master classes and interactive workshops on a variety of topics ranging from using child death reviews to change practices to linking stories to preventative actions.

The Committee will endeavour to provide relevant information to other jurisdictions as requested and when this sharing of data will not impact on the Committee's requirements set out under sections 727T(2) and 727U(3) of the Act or on the child, young person or family's right to privacy.

CHAPTER 2 INFORMATION ON THE DEATHS OF ALL CHILDREN AND YOUNG PEOPLE IN THE ACT, 2008–2013

Reporting of deaths in the ACT

Data about deaths are largely based on the information from the register, which holds demographic, cause of death and other relevant information about ACT children and young people who have died. The Committee is able to provide in this report the demographic information required by legislation,[4] as well as additional information that may help to gain an understanding of broader contextual factors relevant to the deaths and a more holistic understanding of the children and young people who die.

As the Committee has not yet been able to consider any individual reviews of the death of a child or young person, it is limited in its ability to draw meaningful conclusions or make recommendations from the information provided in this report.

The Committee is dedicated to respecting the child, young person and their family's right to privacy. Under section 727S(3) of the Act, the Committee must not disclose the identity of a child or young person who has died or allow the identity of a child or young person to be worked out.

The Committee's previous annual report covered a three-year period from July 2009 to June 2012. The Committee has decided the most sensitive and useful way of proceeding this year is to report on a five-year period, including information for the period from July 2008 to June 2013. This will allow the Committee to further ensure it respects the child, young person and their family's right to privacy, as well as provide the reader with a level of understanding about the deaths of ACT children and young people over a five-year period.

It is important to sound a note of caution about the value of drawing conclusions from numerical data alone. Given the small number of deaths in the ACT, the data are susceptible to random variations in relation to the number of children and young people who die. Once the Committee is in a position to critically reflect on more qualitative and contextual data about individual deaths, it will be possible to consider what this might mean for the many services and interventions directed at this age group, including those provided by the health, education, welfare and youth justice sectors.

An overview of the ACT population

The ACT has a small population of 379,554.[5] The number of children and young people in the ACT aged less than 18 years was 81,468[6] in 2012, representing 21.5 per cent of the total ACT population. The total numbers of children and young people in the ACT and Australia by age and gender are presented in Table 1.

Table 1: Population of children and young people in the ACT and Australia, by age and sex, 2012

AGE (yrs)	MALES		FEMALES		TOTAL		% of Australian population
	ACT	Australia	ACT	Australia	ACT	Australia	
<1	2,669	152,661	2,458	144,636	5,127	297,297	1.7
1–4	10,268	607,610	9,608	576,862	19,876	1,184,472	1.7
5–9	11,424	721,135	10,770	682,656	22,194	1,403,791	1.6
10–14	10,638	708,804	10,342	673,832	20,980	1,382,636	1.5
15–17	6,844	442,839	6,447	420,429	13,291	863,268	1.5
Total	**41,843**	**2,633,049**	**39,625**	**2,498,415**	**81,468**	**5,131,464**	**1.6**

Source: Australian Bureau of Statistics (ABS) Estimate Resident Population by single year of age, Australian Capital Territory (Cat. No. 3101.0, Table 58) and ABS Estimate Resident Population by single year of age, Australia (Cat. No. 3101.0, Table 59)

4 Section 727S(1) of the Act.

5 ABS Estimate Resident Population, States and Territories, Australian Capital Territory (Cat No. 3101.0, Table 4).

6 ABS Estimate Resident Population by single year of age, Australian Capital Territory (Cat. No. 3101.0, Table 58) and ABS Estimate Resident Population by single year of age, Australia (Cat. No. 3101.0, Table 59).

In 2011, 5,184 ACT residents identified as being Aboriginal or Torres Strait Islander.[7] Of these residents, 2,149 (41.5%) were less than 18 years of age and this represents 2.64 per cent of the total ACT child and young person population.

Summary of key findings

Between July 2008 and June 2013 there were 105 deaths registered of children and young people who normally live in the ACT.

Table 2: Deaths of ACT children and young people (excludes those deaths still subject to a coronial inquiry) **Key demographic and individual characteristics, July 2008–June 2013**

			Number	%	% of ACT child and young person population*
All deaths			105	100.0	0.13
Gender	Female		43	41.0	0.05
	Male		62	59.0	0.08
Age	<1 year		63	60.0	0.08
	1–4 years		13	12.4	0.02
	5–9 years		6	5.7	0.01
	10–14 years		8	7.6	0.01
	15–17 years		15	14.3	0.02
Cause of death	Extreme prematurity		29	27.6	0.04
	Medical causes		64	61.0	0.08
	External causes		12	11.4	0.01
Place of death	Hospital		81	77.1	0.10
	House		12	11.4	0.01
	Hospice		5	4.8	0.01
	Other		7	6.7	0.01
Aboriginal and Torres Strait Islander status	Aboriginal		6	5.7	0.01
	Torres Strait Islander		0	0.0	0.00
	Both Aboriginal and Torres Strait Islander		0	0.0	0.00
	Not Aboriginal or Torres Strait Islander		99	94.3	0.12
Socioeconomic status**	Most disadvantaged	2006	0	0.0	0.00
		2011	0	0.0	0.00
	Least disadvantaged	2006	77	73.3	0.09
		2011	82	78.1	0.10
Coronial inquiry undertaken	No		76	72.4	0.09
	Yes		29	27.6	0.04
Known to Care and Protection Services***	No		83	79.0	0.10
	Yes: either child or young person or sibling known		10	9.5	0.01
	Yes: both child or young person and sibling known		12	11.4	0.01
Known to Youth Justice Services****	No		23	100.0	0.03
	Yes		0	0.0	0.00
Known to ACT Policing	No		82	78.1	0.10
	Yes: death incident only		15	14.3	0.02
	Yes: young person only		<5		
	Yes: parent only		<5		
	Yes: young person and parent		<5		

* *Population refers to the total number of children and young people aged up to 18 years in the ACT as presented in Table 1.*

** *To ensure the identity of any child or young person is not able to be determined, two groups, namely the second most disadvantaged and second least disadvantaged groups, have not been included in this table. For 2006, 9 (8.6%) children and young people have not been included due to their address being unknown or the suburb they resided in not being included in the census. For 2011 the number of children and young people is 8 (7.6%).*

*** *Known to refers to the child, young person or sibling being known to Care and Protection Services in the three years before the child or young person's death.*

**** *Applicable only to those children and young people over 10 years of age at the time of death.*

Source: ACT BDM, NSW BDM, NCIS, CPS, Youth Justice Services (YJS), ACT Policing and ABS Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia 2006 and 2011 (Cat. No. 2033.0.55.001, Table 3)

7 ABS 2011 Census of Population and Housing, Aboriginal and Torres Strait Islander Peoples (Indigenous) Profiles, Australian Capital Territory (Cat. No. 2001.0, Tables I01 and I06).

Deaths of ACT children and young people, July 2008–June 2013

When comparing these data to the data provided in the Committee's 2011–12 annual report, significant differences may be observed. This is because this report:

- excludes those children and young people who normally lived in other jurisdictions but died in the ACT
- includes those children and young people who normally lived in the ACT but died in NSW
- includes data over a five-year period from July 2008 to June 2013.

From July 2008 to June 2013, the total[8] number of deaths of children and young people recorded on the register was 155.[9] Of these children and young people, 115[10] (74.2%) were recorded as normally living in the ACT and this represents 0.14 per cent of the total ACT child and young person population. The number of ACT children and young people who died each year ranged from 21 (18.3%) to 26 (22.6%) (Table 3), representing 0.03 per cent of the total ACT child and young person population each year. Of the 115 ACT deaths registered during this period, 39 (33.9%) were subject to a coronial inquiry and, of these, 10 (25.6%) are still awaiting findings by the coroner.

Table 3: Deaths of ACT children and young people, July 2008–June 2013

Year	Total number of deaths of children and young people (n)*	%	% of ACT child and young person population**
2008–2009	26 (0)	22.6	0.03
2009–2010	26 (1)	22.6	0.03
2010–2011	21 (0)	18.3	0.03
2011–2012	21 (2)	18.3	0.03
2012–2013	21 (7)	18.3	0.03
Total	**115 (10)***	**100.0*****	**0.14**

* *( ) indicates number awaiting coroner findings.*

** *Population refers to the total number of children and young people aged up to 18 years in the ACT as presented in Table 1.*

*** *Percentages in this report have been rounded up to either one or two decimal places so percentage totals in tables may not equal 100.0.*

Source: ACT BDM, NSW BDM and NCIS

The majority (63 [60.0%]) of deaths of ACT children and young people were infant deaths (occurring at less than one year of age) and this represents 0.08 per cent of the total ACT child and young person population (Table 2). Between 10 and 15 per cent of deaths were of children aged either 1–4 years (13 [12.4%]) or young people aged 15–17 years (15 [14.3%]) Each of these two age groups represents 0.02 per cent of the total ACT child and young person population. A small number of deaths occurred in the 5–9 (6 [5.7%]) and 10–14 (8 [7.6%]) year age groups.

ACT age-specific mortality rates per 1,000 people are presented in Table 4. The mortality rates of children and young people who have died in the ACT are highest for children under 1 year (infant mortality rate) at 2.51 deaths per 1,000 infants; this rate is almost 12 times that of the next highest rate, among 15–17 year olds, at 0.22 deaths per 1,000 young people.

8 This total includes every child or young person who died in the ACT as reported by the ACT BDM, regardless of where the child or young person normally lives, and every child or young person who died in NSW but normally lives in the ACT as reported by the NSW BDM.

9 Appendix 3 provides an overview of the deaths of children and young people who normally lived in another jurisdiction but died in the ACT.

10 This includes 20 deaths that occurred in NSW of children and young people who normally lived in the ACT.

Table 4: Age-specific mortality rates for children and young people by age: ACT and Australia

Age	Number of deaths	Mortality rate per 1,000 population
<1 year	63	2.51
1–4 years	13	0.14
5–9 years	6	0.06
10–14 years	8	0.08
15–17 years	15	0.22
Total	**105**	

Sources: ACT BDM, NSW BDM, ABS Estimate Resident Population by single year of age, Australian Capital Territory (Cat. No. 3101.0, Table 58), ABS Population Projections by age and sex, Australian Capital Territory (Cat. No. 3222.0, Table A8)

Over half (62 [59.0]) of the ACT children and young people who died were male (Table 2) and this represents 0.08 per cent of the total ACT child and young person population. Of these male deaths, 67.7 per cent (42) occurred in infant males, representing 0.05 per cent of the total ACT child and young person population, with 9.7 per cent (6) of male deaths occurring in both the 1–4 and 15–17 years age categories (Table 5). Each of these two age groups represents 0.01 per cent of the total ACT child and young person population.

Almost half of the deaths (21 [48.8%]) of ACT female children were infant deaths and this represents 0.03 per cent of the total ACT child and young person population. Of these female deaths, 16.3 per cent (7) occurred in the 1–4 years age group and 20.9 per cent (9) occurred in the 15–17 years age group (Table 5). Each of these two age groups represents 0.01 per cent of the total ACT child and young person population.

Due to the small number of deaths recorded in the 5–9 and 10–14 years age groups for both females and males, these two age groups have been combined for the purpose of this analysis.

Table 5: Deaths of ACT children and young people by age and gender, July 2008–June 2013

Age	Female	%	% of ACT child and young person population*	Male	%	% of ACT child and young person population*
<1 year	21	48.8	0.03	42	67.7	0.05
1–4 years	7	16.3	0.01	6	9.7	0.01
5–14 years	6	14.0	0.01	8	12.9	0.01
15–17 years	9	20.9	0.01	6	9.7	0.01
Total	**43**	**100.0**	**0.05**	**62**	**100.0**	**0.08**

** Population refers to the total number of children and young people aged up to 18 years in the ACT as presented in Table 1.*

Source: ACT BDM and NSW BDM

The majority (81 [77.1%]) of deaths of ACT children and young people occurred at hospital, representing 0.10 per cent of the total ACT child and young person population. Just over 10 per cent (12 [11.4%]) of deaths occurred at a house and a small number of deaths occurred at a hospice (5 [4.8%]) or other location (7 [6.7%]). Each of these three places of death represents 0.01 per cent of the total ACT child and young person population (Table 2).

Overview of leading causes of death

For the purposes of this report, the causes of death indicated in the data have been more broadly categorised than the more detailed ICD-10 categorisations. Analysis that is more detailed has not occurred and caution must be applied in interpreting the data. The aim of presenting this information is to continue to provide an overview picture of children and young people who have died in the ACT.

Almost two-thirds (64 [61.0%]) of deaths of ACT children and young people are due to medical causes and this represents 0.08 per cent of the total ACT child and young person population. Over a quarter (29 [27.6%]) of deaths are due to extreme prematurity, representing 0.04 per cent of

the total ACT child and young person population (Table 2). A small number of deaths (12 [11.4%]) are due to external causes such as drowning, suicide and transport accidents. This represents 0.01 per cent of the total ACT child and young person population.

The majority of child deaths in the ACT involve children aged less than one year and the causes are extreme prematurity (29 [100.0%]) and medical causes (34 [53.1%]) (Table 6). Each of these two causes of death represents 0.04 per cent of the total ACT child and young person population. Medical causes are the most common cause of death for children and young people in all age groups, except young people aged 15 to 17 years, where external causes are the most common cause of death.[11] Deaths from medical causes represent 0.04 per cent of the total ACT child and young person population for the less than one year age group and 0.01 per cent of the total ACT child and young person population for all other age groups.

Due to the small number of deaths recorded in the 5–9 and 10–14 years age groups in each cause of death category, these two age groups have been combined for the purpose of this analysis. Due to the small number of deaths arising from external causes occurring in some age groups, this cause of death category has not been included in this analysis. However, external causes are responsible for a small number of deaths in the 1–4 years and 5–14 years age groups and are responsible for no deaths in the under 1 year age group.[12]

Table 6: Deaths of ACT children and young people by age and cause of death, July 2008 to June 2013

Age	Extreme prematurity	%	% of ACT child and young person population*	Medical causes	%	% of ACT child and young person population*
<1 year	29	100.0	0.04	34	53.1	0.04
1–4 years	n/a	n/a	n/a	12	18.8	0.01
5–14 years	n/a	n/a	n/a	12	18.8	0.01
15–17 years	n/a	n/a	n/a	6	9.4	0.01
Total	**29**	**100.0**	**0.04**	**64**	**100.0**	**0.08**

** Population refers to the total number of children and young people aged up to 18 years in the ACT as presented in Table 1.*

Source: ACT BDM and NSW BDM

The majority (32 [74.4%]) of ACT female child and young person deaths are due to medical causes and this represents 0.04 per cent of the total ACT child and young person population. A small number of female deaths resulted from extreme prematurity (5 [11.6%]) and external causes (6 [14.0%]) (Table 7). Each of these two causes of death represents 0.01 per cent of the total ACT child and young person population.

Over half (32 [51.6%]) of the deaths of ACT male children and young people are due to medical causes, followed by extreme prematurity (24 [38.7%]), representing 0.04 and 0.03 per cent of the total ACT child and young person population, respectively. A small number of male deaths are a result of external causes (6 [9.7%]), and this represents 0.01 per cent of the total ACT child and young person population.

Table 7: Deaths of ACT children and young people by gender and cause of death, July 2008 to June 2013

Cause of death	Female	%	% of ACT child and young person population*	Male	%	% of ACT child and young person population*
Extreme prematurity	5	11.6	0.01	24	38.7	0.03
Medical causes	32	74.4	0.04	32	51.6	0.04
External causes	6	14.0	0.01	6	9.7	0.01
Total	**43**	**100.0**	**0.05**	**62**	**100.0**	**0.08**

* *Population refers to the total number of children and young people aged up to 18 years in the ACT as presented in Table 1.*

Source: ACT BDM and NSW BDM

11 ACT BDM 2013 and NSW BDM 2013. Unpublished data.
12 ACT BDM 2013 and NSW BDM 2013. Unpublished data.

CHAPTER 3 NEONATAL DEATHS, 2008–2013

Summary of key findings

Between July 2008 and June 2013 the deaths of 47 ACT children were recognised as neonatal deaths. Neonatal deaths involve live born infants aged under 28 days.

Table 8: Neonatal deaths of ACT children: Key demographic and individual characteristics, July 2008–June 2013

			Number	%	% of ACT child and young person population*
All deaths			47	100.0	0.06
Gender	Female		14	29.8	0.02
	Male		33	70.2	0.04
Socioeconomic status**	Most disadvantaged	2006	0	0.0	0.00
		2011	0	0.0	0.00
	Least disadvantaged	2006	30	63.8	0.04
		2011	33	70.2	0.04
Cause of death	Extreme prematurity		26	55.3	0.03
	Medical causes		21	44.7	0.03
	External causes		0	0.0	0.00

* *Population refers to the total number of children and young people aged up to 18 years in the ACT as presented in Table 1.*

** *To ensure the identity of any child or young person is not able to be identified, two groups, namely the second most disadvantaged and second least disadvantaged groups, have not been included in this table. For 2006, 9 (19.1%) children and young people have not been included due to their address being unknown or the suburb they resided in not being included in the census. For 2011 the number of children and young people is 8 (17.0%).*

Source: ACT BDM, NSW BDM and ABS Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia 2006 and 2011 (Cat. No. 2033.0.55.001, Table 3)

Neonatal deaths, July 2008–June 2013

Almost half of the total deaths of ACT children and young people were neonatal deaths. During the five-year period from July 2008 to June 2013, there were 47 (44.8%) neonatal deaths. This represents 0.06 per cent of the total ACT child and young person population. Of the neonatal children who died, 70.2 per cent (33) were male, representing 0.04 per cent of the total ACT child and young person population (Table 8).

When analysing disadvantage in the ACT at the suburb level for neonatal deaths, the SEIFA Index of Relative Social Disadvantage (IRSD) identified that none of the ACT children fell into the most disadvantaged 20 per cent of Australians. It identified 0.04 per cent (30 [63.8%] in 2006 and 33 [70.2%] in 2011) as falling into the least disadvantaged 30 per cent of all Australians (Table 8). By contrast, the Socio-economic Indexes for Individuals (SEIFI) indicates that 16 of the suburbs where deaths occurred and that were considered by SEIFA as falling into the least disadvantaged 30 per cent of all Australians had over 10 per cent of their population among the most disadvantaged 20 per cent of Australians. This shows not only the high diversity of levels of disadvantage within ACT suburbs but also how difficult it is to ascertain the socioeconomic

status of children and young people for the purposes of this review. To identify whether any of the children and young people who died were part of each suburb's population considered as among the most disadvantaged 20 per cent of Australians requires data matching at an address level, which is currently not available.

Leading causes of neonatal death

Table 8 indicates that, for 26 (55.3%) neonatal deaths, cause of death could be categorised broadly as 'extreme prematurity', representing 0.03 per cent of the total ACT child and young person population. The remaining 21 (44.7%) deaths were identified as being attributable to medical causes, representing 0.03 per cent of the total ACT child and young person population. No neonatal deaths were recorded with an external cause of death.

CHAPTER 4 INFANT DEATHS, 2008–2013

Summary of key findings

Between July 2008 and June 2013, the deaths of 63 ACT children were recognised as infant deaths (including 47 neonatal deaths). Infant deaths involve children less than one year of age.

Table 9: Infant deaths of ACT children
Key demographic and individual characteristics, July 2008–June 2013

			Number	%	% of ACT child and young person population*
All deaths			63	100.0	0.08
Gender	Female		21	33.4	0.03
	Male		42	66.7	0.05
Socioeconomic status**	Most disadvantaged	2006	0	0.0	0.00
		2011	0	0.0	0.00
	Least disadvantaged	2006	42	66.7	0.05
		2011	45	71.4	0.06
Cause of death	Extreme prematurity		29	46.0	0.04
	Medical causes		34	54.0	0.04
	External causes		0	0.0	0.00

* *Population refers to the total number of children and young people aged up to 18 years in the ACT as presented in Table 1.*

** *To ensure the identity of any child or young person is not able to be identified, two groups, namely the second most disadvantaged and second least disadvantaged groups, have not been included in this table. For 2006, 9 (14.3%) children and young people have not been included due to their address being unknown or the suburb they resided in not being included in the census. For 2011 the number of children and young people is 8 (12.7%).*

Source: ACT BDM, NSW BDM and ABS Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia 2006 and 2011 (Cat. No. 2033.0.55.001, Table 3)

Infant deaths, July 2008–June 2013

Almost two-thirds of deaths of ACT children and young people were infant deaths (occurring at less than one year of age) (Table 2). During the five-year period from July 2008 to June 2013, there were 63 (60.0%) infant deaths. This represents 0.08 per cent of the total ACT child and young person population. Two-thirds (42 [66.7%]) of the infant children who died were male (Table 9), representing 0.05 per cent of the total ACT child and young person population.

When analysing disadvantage in the ACT at the suburb level for infant deaths, the SEIFA IRSD identified that none of the ACT children and young people fell into the most disadvantaged 20 per cent of Australians. It identified 0.05 per cent in 2006 (42 [66.7%]) and 0.06 per cent in 2011 (45 [71.4%]) as falling into the least disadvantaged 30 per cent of all Australians (Table 9). By contrast, the SEIFI indicates that 17 of the suburbs where deaths occurred and that were considered by SEIFA as falling into the least disadvantaged 30 per cent of all Australians had over 10 per cent of their population among the most disadvantaged 20 per cent of Australians. This shows not only the high diversity of levels of disadvantage within ACT suburbs, but also how difficult it is to ascertain the socioeconomic status of the children and young people for the purposes of this review. To identify whether any of the children and young people who died were part of each suburb's population considered as among the most disadvantaged 20 per cent of Australians requires data matching at an address level, which is currently not available.

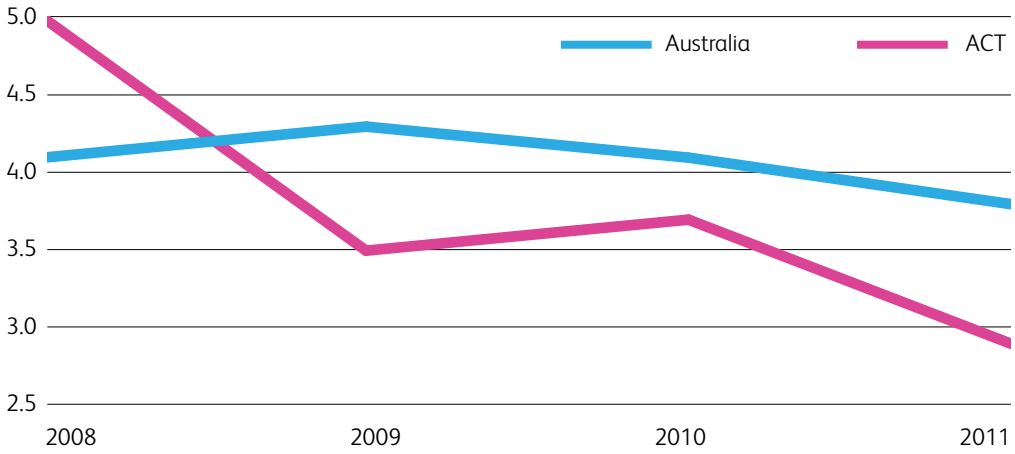
Leading causes of infant deaths

Table 9 indicates that all infant deaths were caused by either extreme prematurity (29 [46.0 %]) or medical causes (34 [54.0 %]). Each of these two age groups represents 0.04 per cent of the total ACT child and young person population. No infant deaths were recorded with an external cause of death.

Trends in infant mortality rates

Infant mortality rates for the ACT and Australia for the years 2008 to 2011 are presented in Figure 1. Over this period, the Australian rates remained stable at around 4.0 infant deaths per 1,000 live births. The ACT infant mortality rates are generally similar to the Australian rates; however, they fluctuate from 2.9 to 5.0 infant deaths per 1,000 live births. This is most likely to be due to the small number of births and infant deaths in the ACT each year.

Figure 1: Infant mortality rates, ACT and Australia, 2008–2011. Rates per 1000 live births



Source: ABS Deaths, Australia, 2011 (Cat. No. 3303.0, Table 2.8 – ACT and Table 2.9 – Australia)

CHAPTER 5 VULNERABLE AND AT RISK CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES, 2008–2013

The Committee has a wide remit to report on all deaths of children and young people in the ACT. However, as an independent and multidisciplinary committee, it is well positioned to take a particular interest in the deaths of vulnerable children and their families.

Aboriginal and Torres Strait Islander children and young people

According to the Australian Institute of Health and Welfare publication *The health and welfare of Australia's Aboriginal and Torres Strait Islander People, an overview 2011*, the Australian mortality rate for Aboriginal and Torres Strait Islander children aged 0–14 years was twice the rate of non-Aboriginal and Torres Strait Islander children between 2003 and 2007. For Aboriginal and Torres Strait Islander children aged 5–14 years, external causes were the leading cause of death between 2003 and 2007; this was three times the rate for non-Aboriginal and Torres Strait Islander children.

Six (5.7 %) ACT children and young people who died in the five-year period July 2008–June 2013 identified as Aboriginal and this represents 0.01 per cent of the total ACT child and young person population (Table 2). These children were either aged under one year or between 5 and 9 years of age and all died as a result of internal causes of death.[13]

These figures are reliant on accurate reporting of Aboriginal and Torres Strait Islander status at time of death.

Socioeconomic status

When analysing disadvantage in the ACT at the suburb level for all deaths, the SEIFA IRSD identified that none of the ACT children and young people fell into the most disadvantaged 20 per cent of Australians. It identified 0.09 per cent in 2006 (77 [73.3 %]) and 0.10 per cent in 2011 (82 [78.1 %]) as falling into the least disadvantaged 30 per cent of all Australians (Table 2). By contrast, the SEIFI indicates that 28 of the suburbs where deaths occurred and that were considered by SEIFA as falling into the least disadvantaged 30 per cent of all Australians had over 10 per cent of their population among the most disadvantaged 20 per cent of Australians. This shows not only the high diversity of levels of disadvantage within ACT suburbs but also how difficult it is to ascertain the socioeconomic status of the children and young people for the purposes of this review. To identify whether any of the children and young people who died were part of each suburb's population considered as among the most disadvantaged 20 per cent of Australians requires data matching at an address level, which is currently not available.

An analysis of disadvantage was conducted in the ACT at the suburb level by cause of death. For extreme prematurity, the SEIFA IRSD identified that none of the ACT children and young people fell into the most disadvantaged 20 per cent of Australians. It identified 0.02 per cent (16 [55.2 %] in 2006 and 18 [62.1 %] in 2011) as falling into the least disadvantaged 30 per cent of all Australians (Table 10). For medical causes, the SEIFA IRSD identified that none of the ACT children and young people fell into the most disadvantaged 20 per cent of Australians. It identified 0.06 per cent in 2006 (51 [79.7 %]) and 0.07 per cent in 2011 (54 [84.4 %]) as falling into the least disadvantaged 30 per cent of all Australians (Table 10). Due to the small number of deaths arising from external causes occurring in some SEIFA deciles, this cause of death category has not been included in this analysis.

13 ACT BDM 2013 and NSW BDM 2013. Unpublished data.

By contrast, the SEIFI indicates that for both cause of death categories, 28 of the suburbs where deaths occurred and that were considered by SEIFA as falling into the least disadvantaged 30 per cent of all Australians had over 10 per cent of their population among the most disadvantaged 20 per cent of Australians. This shows not only the high diversity of levels of disadvantage within ACT suburbs but also how difficult it is to ascertain the socioeconomic status of the children and young people for the purposes of this review. To identify whether any of the children and young people who died were part of each suburb's population considered as among the most disadvantaged 20 per cent of Australians requires data matching at an address level, which is currently not available.

Table 10: Deaths of ACT children and young people by cause of death and socioeconomic status, July 2008–June 2013

Socioeconomic status*	Extreme prematurity**		%	% of ACT child and young person population***	Medical causes	%	% of ACT child and young person population***
Most disadvantaged	2006	0	0.0	0.00	0	0.0	0.00
	2011	0	0.0	0.00	0	0.0	0.00
Least disadvantaged	2006	16	55.2	0.02	51	79.7	0.06
	2011	18	62.1	0.02	54	84.4	0.07
Total		**29**	**100.0**	**0.04**	**64**	**100.0**	**0.08**

* *To ensure the identity of any child or young person is not able to be identified, two groups, namely the second most disadvantaged and second least disadvantaged groups, have not been included in this table.*

** *For 2006 and 2011, 6 children and young people who died as a result of extreme prematurity have not been included due to their address being unknown or the suburb they resided in not being included in the census.*

*** *Population refers to the total number of children and young people aged up to 18 years in the ACT as presented in Table 1.*

Source: ACT BDM, NSW BDM and ABS Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia2006 and 2011 (Cat. No. 2033.0.55.001, Table 3)

Children and young people known to Care and Protection Services

Section 727S(1) of the Act requires the Committee to report whether, within three years before his or her death, the child or young person, or a sibling of the child or young person, was the subject of a child protection report.[14]

In the period from July 2008 to June 2013, just over one-fifth (22 [20.9%]) of the children and young people who died were known to CPS or had a sibling who was known to CPS, and this represents 0.03 per cent of the total ACT child and young person population. Of these 22 children and young people, 12 (54.5%) were known together with a sibling and less than five were known only because their sibling was known to CPS (Table 2). Each of these groups represents 0.01 per cent of the total ACT child and young person population.

For all ACT children and young people who died, seven (6.7%) were the subject of intervention by CPS at the time of their death and this represents 0.01 per cent of the total ACT child and young person population. This type of intervention was in the form of one of the following:

- voluntary casework
- a residence order
- a voluntary care agreement
- an appraisal.

14 Appendix 1 provides information about what constitutes a child protection report for the purpose of this report.

Children and young people known to Youth Justice Services

A review of the YJS records in relation to the children and young people over 10 who died in the ACT between July 2008 and June 2013 indicates that none of them were known to YJS as part of statutory intervention.

Children, young people and their families known to ACT Policing

A review of the ACT Policing records in relation to the children and young people who died in the ACT between July 2008 and June 2013 indicates 78.1 per cent (82) of the children, young people and their families were not known to ACT Policing prior to the date of death (Table 2). This represents 0.10 per cent of the total ACT child and young person population. ACT Policing were involved with 14.3 per cent (15) of the children, young people and their families at the time of the death incident only, with no previous contact with ACT Policing prior to this time. This represents 0.02 per cent of the total ACT child and young person population. A small number of young people and/or their parents were known to ACT Policing prior to the time of the death incident.

CHAPTER 6 FUTURE DIRECTIONS OF THE COMMITTEE

The Committee's priority over the next 12 months is to continue to work towards being one of the leading bodies in the ACT in helping to prevent or reduce the likelihood of the preventable death of children and young people. To do this, the Committee has identified a number of goals it would like to achieve.

Individual reviews

It is a priority for the Committee that it is presented with information about the circumstances of individual children and young people who died in a form that enables members to critically review, analyse and draw conclusions from the information.

During 2012–13 the Committee made significant progress in its working arrangements for undertaking individual reviews, including developing its methodology and approach concerning these reviews. The Committee has included in its protocols with the Office of the Coroner and the OCYFS the ability to access comprehensive case files as considered necessary by the Committee.

The Committee would like to commence reviewing certain individual deaths of children and young people over the next 12 months and will strive to draw evidence-based conclusions founded on a holistic picture of the circumstances surrounding the children and young people at the time they died.

The Committee will endeavour to work with the other Australian states and the Northern Territory on a collaborative approach to the individual review of deaths of children and young people.

Communication strategy

Communicating the lessons learnt from its work is a key priority for the Committee. In this way, it can ensure that the community gains maximum benefit from its work. To achieve this, the Committee has agreed to form a communications sub-group to examine how it can best reach out to the ACT community in the future.

Retrospective report

In accordance with the Act,[15] the Committee will provide a report on the deaths of children and young people in the ACT from 1 January 2004 to 17 September 2011 within the required timeframe of six years from commencement of the legislation. The Committee is aiming to recommence its work on this retrospective report in November 2013. It is expected that this report will include data for the 10-year period from 1 January 2004 to 31 December 2013.

Establishment of the new register

As outlined in Chapter 1, the Committee has finalised its business requirements for any future register and is close to finalising the information fields it would like included. The Committee anticipates being in a position to make an informed decision about whether to develop its own register or purchase another child death review body's register in the next 12 months.

15 Section 727U of the Act.

Coding cause of death

This year cause of death has been reported in the three broad mortality categories of extreme prematurity, medical causes and external causes. In the future, the Committee will also describe deaths according to the ICD-10 code for underlying and multiple causes of death. As outlined in Chapter 2, the Committee anticipates finalising these arrangements in the next 12 months.

Obtaining information—within the ACT

The Committee will continue to obtain information from those agencies within the ACT as discussed in Appendix 1 of this report. As the Committee develops and a new register is implemented, additional information may need to be obtained. The Committee will arrange to obtain this additional information from the relevant identified agencies.

The Committee will continue its discussions with ACT Health about how to obtain the information the Committee considers necessary to fulfil its functions.[16]

Obtaining information—outside of the ACT

The Committee plans to commence discussions with other Australian states and the Northern Territory about the possibility of obtaining information about the deaths that occur outside of the ACT of children and young people that normally live in the ACT. Given that this is likely to be a small number of deaths, the Committee is considering developing ad hoc arrangements with these jurisdictions as opposed to regular reporting arrangements.

Obtaining information about those children and young people who normally live in the ACT but die overseas may present some additional challenges and the Committee will begin to explore the best way to address these challenges over the next 12 months.

Ensuring privacy and confidentiality for families

Over the next 12 months the Committee will continue to consider how best to communicate what it is learning and the implications for government policy and service provision in a sensitive way that honours the right to privacy of all children, young people and their families.

National and international links

The Committee will continue to be a member of the ANZCDR&PG and attend any relevant meetings and conferences. The Committee will endeavour to provide relevant information to other jurisdictions as requested and when this sharing of data will not impact on the Committee's requirements set out under sections 727T(2) and 727U(3) of the Act or on the child, young person or family's right to privacy.

Legislative amendments

As the Committee continues to refine its operations and reporting, it intends to keep a watching brief on the need for any legislative amendments that would improve its ability to carry out its role.

16 Section 727B of the Act.

REFERENCES

ACT Office of Regulatory Services, Births, Deaths and Marriages and Background Screening. (2012–13). Unpublished data.

Australian Bureau of Statistics. (2012). *2011 Census of Population and Housing, Aboriginal and Torres Strait Islander Peoples (Indigenous) Profiles, Australian Capital Territory* (Cat. No. 2001.0, Tables I01 and I06). Australian Bureau of Statistics, Canberra, ACT.

Australian Bureau of Statistics. (2007). *Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia, 2006* (Cat. No. 2033.0.55.001). Australian Bureau of Statistics, Canberra, ACT.

Australian Bureau of Statistics. (2012). *Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia, 2011* (Cat. No. 2033.0.55.001). Australian Bureau of Statistics, Canberra, ACT.

Australian Bureau of Statistics. (2013). *Deaths, Australia, 2011* (Cat. No. 3303.0, Tables 2.1 to 2.9), Australian Bureau of Statistics, Canberra, ACT.

Australian Bureau of Statistics. (2013). *Estimate Resident Population by Single Year of Age, Australian Capital Territory* (Cat. No. 3101.0, Table 58). Australian Bureau of Statistics, Canberra, ACT.

Australian Bureau of Statistics. (2013). *Estimate Resident Population by Single Year of Age, Australia* (Cat. No. 3101.0, Table 59). Australian Bureau of Statistics, Canberra, ACT.

Australian Bureau of Statistics. (2013). *Estimate Resident Population, States and Territories, Australian Capital Territory* (Cat No. 3101.0, Table 4). Australian Bureau of Statistics, Canberra, ACT.

Australian Bureau of Statistics. (Accessed 13 August 2013). *Population FAQs.* Available: http://www.abs.gov.au/websitedbs/webfaq.nsf/home/Population.

Australian Bureau of Statistics. (2012). *Population Projections by Age and Sex, Australian Capital Territory* (Cat. No. 3222.0, Table A8). Australian Bureau of Statistics, Canberra, ACT.

Australian Institute of Health and Welfare. (2011). *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People, an Overview 2011* (Cat. No. IHW 42). Australian Institute of Health and Welfare, Canberra, ACT.

Chief Minister and Treasury Directorate. (2012). *Detecting Disadvantage in the ACT — Report on the Comparative Analysis of the SEIFI and SEIFA Indexes of Relative Socio-Economic Disadvantage in the Australian Capital Territory.* ACT Government, Canberra, ACT.

Community Services Directorate. (2008). *Policy and Procedure – Intake.* Community Services Directorate, Canberra, ACT.

Gallagher, K. (MLA). (2006). *Recommendations from the Murray-Mackie Study into the Deaths and Near Deaths of Children Known to Care and Protection and the Government Response.* ACT Government, Canberra, ACT. Available: www.hansard.act.gov.au/hansard/2006/week09/3027.htm.

National Coronial Information System. (Accessed 7 June 2013). About the NCIS. Available: http://www.ncis.org.au/.

New South Wales Department of Attorney General and Justice, Registry of Births, Deaths and Marriages (2013). Unpublished data.

Perinatal Society of Australia and New Zealand. (Accessed 7 June 2013). *Perinatal Society of Australia and New Zealand.* Available: http://www.psanz.com.au/.

Population Health Research Centre. (2006). *Review of ACT Child Deaths 1992–2003*. ACT Health, Canberra, ACT.

UNICEF. (Accessed 18 June 2013). *Convention on the Rights of the Child*. Available: http://www.unicef.org/crc/files/Rights_overview.pdf.

Vardon, C. (2004). *The Territory as Parent: Review of the Safety of Children in Care in the ACT and of ACT Child Protection Management*. ACT Government, Canberra, ACT.

World Health Organization. (Accessed 31 May 2013). *International Classification of Diseases*. Available: http://www.who.int/classifications/icd/en/.

Legislation

Australian Federal Police Act 1979.

Children and Young People Act 2008. Available: http://www.legislation.act.gov.au/a/2008–19/current/pdf/2008–19.pdf.

Health Act 1993.

Privacy Act 1988 (Commonwealth).

Public Health Act 1997

APPENDIX 1 METHODOLOGY

The information contained on the register is based on information provided by other agencies and the accuracy of this information is reliant on individual information gathering, record keeping and data provision. Accordingly, a small margin of error may occur. Where possible, information has been crosschecked against a variety of sources to ensure reliability.

Percentages in this report have been rounded up to either one or two decimal places so percentage totals may not equal 100.0. However, the total is still displayed in the table as 100.0.

Requirements

The Committee is required to provide to the Minister, within four months of the end of each financial year, a report that includes certain information in relation to the deaths of children and young people included on the register during the preceding year. The report must include the information provided under section 727S(1) of the Act, namely:

- the number of deaths of children and young people
- the age of each child or young person who died
- the sex of each child or young person who died
- whether, within three years before his or her death, the child or young person, or a sibling of the child or young person, was the subject of a Child Protection Report
- the patterns or trends (if any) identified in relation to the deaths of children and young people both:
  - generally, and
  - whether, within three years before his or her death, the child or young person, or a sibling of the child or young person, was the subject of a Child Protection Report.

The report may include:[17]

- the Committee's recommendations (if any) about legislation, policies, practices and services for implementation by the ACT Government and non-government bodies to help prevent or reduce the likelihood of the death of children and young people
- information about the implementation of any previous recommendations of the Committee
- any other matters it considers relevant.

The Committee must ensure it does not include in its report any information that would disclose the identity of a child or young person who has died or allow the identity of a child or young person who has died to be worked out.[18]

As set out in section 727B(2) of the Act, the Committee's report will not review the cause of death of a particular child or young person or seek to identify underperformance or to allocate blame. The Committee's aim is to identify what may be learnt from the circumstances of the death of the child or young person.

The Minister is responsible for presenting the report in the Legislative Assembly within six sitting days after the day the report is given to the Minister.[19]

17 Section 727S(2) of the Act.
18 Section 727S(3) of the Act.
19 Section 727S(5) of the Act.

Usual residents of the ACT who die in other jurisdictions

The Committee is required to include on its register the deaths that occur outside the ACT of children and young people who normally live in the ACT.[20] In 2013 the Committee commenced the process of obtaining information from other jurisdictions and made the decision to initially focus on obtaining information from NSW. This decision was based on the assumption that the majority of deaths that occurred outside the ACT of children and young people who normally live in the ACT were likely to have occurred in NSW given the ACT's close proximity to NSW and the regular use by a substantial segment of the ACT population of NSW health services and holiday destinations.

Information about the deaths that occurred in NSW of children and young people who normally lived in the ACT was obtained from the NSW BDM. The Committee recorded this information in its register and has included it in this report. The Committee was able to obtain additional information from the NCIS about those deaths that occurred in NSW of children and young people who normally lived in the ACT and whose deaths were subject to a coronial inquiry that had ended.

It is important to note that the number recorded in this report for the deaths that occurred outside the ACT of children and young people who normally lived in the ACT may not be a true indication of the total number of children or young people who normally lived in the ACT but who died in other jurisdictions.

One of the Committee's aims for 2013–14 is to develop arrangements with other Australian jurisdictions to obtain information for inclusion on the register and in any future reports. Obtaining information about those children and young people who normally lived in the ACT but died overseas may present some additional challenges and the Committee will begin to explore the best way to address these challenges.

Usual residents of other jurisdictions who die in the ACT

The information the Committee receives in its monthly spreadsheet from the ACT BDM includes information about the deaths of all children and young people that occur in the ACT, regardless of the child or young person's normal place of residence. The Committee records these deaths in its register, but excludes them from the data provided in this report to allow for accurate population-based analysis.

Furthermore, the amount of information the Committee is currently able to obtain about those children and young people who died in the ACT, but lived in another jurisdiction, is limited and this impacts on the ability of the Committee to explore in detail the circumstances and risk factors surrounding these deaths. This is concerning as those deaths, which may provide significant insight and knowledge for preventing or reducing the likelihood of future preventable deaths, may not be subject to adequate review by either jurisdiction.

A second concern relates to which jurisdiction would be the most appropriate to undertake a detailed review in these instances. Depending on the circumstances of the death, it may be that the jurisdiction where the child or young person normally lived would be better placed to undertake the review given its access to certain critical information.

The Committee will endeavour to work with the other states and the Northern Territory in an effort to ensure a collaborative approach to the review of deaths of children and young people.

Date of death reporting for the register

The Committee has established that occasionally there is a time lag between the date of death and the registered date of the death. This occurs when there are coronial inquiries pending and towards the end of the calendar year when there may be a backlog of registrations to be processed in the new year.

For the purpose of this report, the Committee has determined it will recognise the actual date of death of each child or young person in the ACT, rather than the registered date of death. This

20 Section 727N(1)(b) of the Act.

will provide an actual number of child and young person deaths for the reported five-year period and allow for a more accurate reflection of what was occurring at the time of the child or young person's death, namely the circumstances, risk factors, relevant agencies' policies and practices and the political environment at that time. The time between the actual date of death and the registered date of death may be significant and, in that time, there may have been changes in the aforementioned circumstances. However, there may need to be adjustments if additional deaths of children and young people are registered at a later time.

As the Committee is using the actual date of death rather than the registered date of death, there may be discrepancies between the information in this report and the information reported by the ACT BDM and the NSW BDM, which both use the registered date of death.

Deaths subject to a current coronial inquiry or review by the ACT

Section 727N(4) of the Act provides that if the death of a child or young person is subject to a coronial inquest or review by the ACT, the Committee must not include any information on the register about the cause or circumstances of the death until the coronial inquest or review has been finalised. Therefore, the deaths of those children and young people currently subject to a coronial inquiry or review by the ACT have not been included in this report. Future reports that provide data for the timeframe covered by this report may vary as coronial inquiries and reviews by the ACT are finished and information about the deaths are able to be included on the register.

Adjustments have been made in this report to the data provided in the Committee's previous annual report to now include those deaths where a coronial inquiry or review by the ACT has since ended.

Less than five total deaths

When a particular cohort of children and young people has less than five total deaths, the exact number of deaths will not be reported. This will ensure the Committee complies with section 727S(3) of the Act and does not disclose the identity of a child or young person who has died or allow the identity of a child or young person who has died to be worked out. The number of deaths will be reported as <5, which means the number of children and young people who died is less than five but greater than zero.

When a cause of death has less than five deaths, this report will not provide more detailed information about this cohort. This is not only to ensure the Committee's compliance with section 727S(3) of the Act, but to ensure the child, young person and family's right to privacy is maintained.

Population estimates and rates

The population estimates of both the ACT and Australia are taken from the latest ABS release of estimated resident populations, which provides the estimated resident population as of June 2012. The population estimates for Aboriginal and Torres Strait Islander children and young people are calculated using data from the 2011 census as the ABS does not provide estimated resident populations for Aboriginal and Torres Strait Islander people by year of age.

Rates are calculated using child death data contained in the register and both ABS estimated (2008 to 2012) and projected (2013) statistics of the ACT population. These rates are calculated per 1,000 children and young people by dividing the total number of deaths by the total population in each age group.

Infant mortality rates are provided for the calendar years from 2008 to 2011. The ABS is yet to release the data in relation to 2012. ACT and Australian age-specific mortality rates for children aged from 1 to 14 years have not been presented in this report. The ABS provides these rates for age groups 1–4, 5–9 and 10–14 years, but they are not published for the ACT due to the small numbers.

Rates for numbers less than five will not be calculated as the Committee does not report on numbers less than five to ensure the child or young person and their family's right to privacy is maintained.

Coding causes of death

The Committee's 2011–12 annual report included four broad mortality categories. For this report, the categories of congenital/genetic causes and disease have been combined into the one category of medical causes as it was found that some deaths could be categorised in either of these two categories. Therefore, for this report cause of death has been reported in the following three broad mortality categories:

- extreme prematurity
- medical causes
- external causes

Due to the small number of deaths of children categorised as SIDS or undetermined or unascertained, these deaths have been included in the numbers reported for the medical causes category.

Due to the small number of deaths of children and young people categorised as either drowning, transport or suicide, these deaths have been combined and reported in the external causes category.

Cause of death is based on the cause provided on the child or young person's death certificate and caution therefore needs to be applied to interpretation. The cause of death on the death certificate provides limited information on which to categorise the cause of death, but for this report, it has been used to allow some level of categorisation.

The Committee had hoped to include in this report the use of the ICD-10, to code cause of death. However, this was not possible as arrangements are still being finalised

It is the Committee's intention for all deaths in future reports to be described according to ICD-10 cause of death coding. Neonatal deaths will also be described according to the PSANZ Perinatal Death Classification System, a nationally accepted method of reporting neonatal deaths developed by the PSANZ.

Place of death

In this report place of death is divided into four categories:

- hospital
- house
- hospice
- other.

The term 'house' has been used rather than the term 'home' because when a house address has been recorded as a child or young person's place of death, further information has not always been provided to allow identification of whether the house is where the child or young person normally lived.

A place of death recorded as 'other' means that the location of death is known but that it does not fit into one of the other three categories for place of death. It includes areas such as a road, public area or overseas location.

Aboriginal and Torres Strait Islander identification

A child or young person has been identified as Aboriginal and/or Torres Strait Islander if:

- the child or young person has been identified as Aboriginal and/or Torres Strait Islander in the information provided by either the ACT BDM or NSW BDM or in information provided by another government department where this information has been corroborated and is considered reliable, as determined by the Committee, or
- one or both of the child or young person's parents has been identified as Aboriginal and/or Torres Strait Islander in the information provided by either the ACT BDM or NSW BDM or in information provided by another government department where this information has been corroborated and is considered reliable, as determined by the Committee.

Socioeconomic status

In this report, socioeconomic status is defined using both the SEIFA and the SEIFI developed by the ABS.

According to the ABS website, *'SEIFA uses a broad definition of relative socio-economic disadvantage in terms of people's access to material and social resources, and their ability to participate in society.'*

The SEIFA index used in this report is the IRSD from both the 2006 and 2011 censuses. This index ranks geographical areas against the Australian average to reflect disadvantage. IRSD scores are divided into ten deciles – decile one represents the most disadvantaged areas and decile ten represents the least disadvantaged areas. To coincide with SEIFI, the SEIFA-IRSD will be reported as four socioeconomic status groups:

- Group 1 – anyone in the most disadvantaged 20% of Australians (first and second deciles)
- Group 2 – anyone in the second most disadvantaged 20% of Australians (third and fourth deciles)
- Group 3 – anyone in the second least disadvantaged 30% of Australians (fifth, sixth and seventh deciles)
- Group 4 – anyone in the least disadvantaged 30% of Australians (eighth, ninth and tenth deciles).

According to the Chief Minister and Treasury Directorate (CMTD) of the ACT Government

> *SEIFI is a new set of multi-dimensional measures of relative social-economic disadvantage that captures and scores an individual's relative access to material and social resources being produced by the ABS. ...SEIFI is a location-based measure using variables on income, employment, occupation, education and housing from the 2006 census.*

The use of this measure is supported by the CMTD who state that SEIFI more accurately reflects individual circumstances in the ACT because *'the ACT has one of the highest proportions of "diverse" suburbs... where diverse suburbs... have high numbers of both the most and the least disadvantaged individuals living side by side. This is highly unique to the ACT and, as a result, the averaging effects of SEIFA chronically under-reports disadvantage.'*

The child or young person's usual place of residence was used to determine geographical area. Therefore, the relative disadvantage of where the child or young person resided at the time of their death is measured, not the relative disadvantage of the individual child or young person and their family.

Known to Care and Protection Services

A child or young person or their sibling(s) is identified as known to CPS if, within the three years before the child or young person died, the child or young person or their sibling(s) was the subject of one of the following types of reports received by CPS:

- an inquiry
- a child concern report
- a child protection report
- the equivalent type of report for those contacts with CPS prior to the commencement of the Act.

Known to Youth Justice Services

A search of a child or young person's youth justice records is conducted for all children and young people aged 10 years and over at the time of their death. The information provided by this search includes information about the child or young person's statutory involvement with YJS, namely his or her involvement in:

- youth justice custody
- community-based supervision by YJS
- court-ordered reports prepared or arranged by YJS.

The information provided does not include information about a child or young person's involvement with YJS when it is not statutory involvement.

Obtaining information

Information is obtained within the powers provided by legislation[21] and through collaborative, respectful and confidential processes. Section 7270(6) of the Act provides the Committee with the power to obtain information from other sources, including the ACT Chief Police Officer, the Office of the Coroner, the Community Services Directorate, the Education and Training Directorate, ACT Health and a licensed proprietor of a childcare service. It may receive information from other entities as prescribed by regulation.

The information the Committee is able to obtain is set out in section 7270(1) of the Act, which requires a relevant entity to provide the following information in relation to the death of a child or young person:

- information required under section 727N(2) of the Act to be included on the register[22]
- other information requested in writing by the Committee that the Committee considers necessary to exercise its functions.

A major part of the Committee's work this year has been to finalise arrangements with other agencies to obtain necessary information. In doing this, the Committee remained aware of the importance of the legislative requirements under which a number of government departments operate.

The information obtained as a result of these finalised arrangements has been included in this report where relevant.

ACT Registry of Births, Deaths and Marriages

The Committee formalised its memorandum of understanding with the ACT BDM in 2012 and has continued to receive a monthly spreadsheet providing all the agreed information (if known) about the death of a child or young person, namely:

- death registration number
- date the death was registered
- name, including any aliases
- date of birth
- date of death
- age
- gender
- Aboriginal and Torres Strait Islander status
- place of birth
- place of death
- address
- mother's name, date of birth, address, occupation and Aboriginal and Torres Strait Islander status
- father's name, date of birth, address, occupation and Aboriginal and Torres Strait Islander status
- cause of death information
- coroner/medical practitioner information
- birth information, including hospital, birth weight, gestation, plurality and whether stillborn or living
- relationship details of the parents, including partnership type and date and place of marriage
- number of other children from the parents' relationship and their dates of birth.

The ACT BDM has also provided the above information about those children and young people who died in the ACT from 1 July 2004 to 30 June 2008.

21 Section 7270 and 727Q of the Act.
22 Chapter 1 of this report provides the information to be included on the register as required by section 727N(2) of the Act.

ACT Policing

ACT Policing did not require a memorandum of understanding or protocol to allow the Committee to obtain information.[23] However, they did request terms of reference be drafted to guide the exchange of information. The development of these terms of reference was a collaborative process between ACT Policing and the Committee and allowed for the collection of relevant information used in this report.

ACT Education and Training Directorate

The Committee does not currently obtain information from the ACT Education and Training Directorate on a regular basis. Once the Committee starts conducting reviews into the deaths of individual children and young people, information may be obtained on an ad hoc basis by way of letter from the Committee. Information that the Committee may consider requesting includes:

- discipline history, including suspensions
- attendance records
- any other information considered relevant.

ACT Health

The obtaining of information from ACT Health is challenged by the provisions of the *Health Act 1993*. This means the Committee is not able to get any sensitive information from ACT Health that identifies a person, or allows the identity of a person to be worked out, who:

- has received a health service
- is a health service provider
- has provided information to a Quality Assurance Committee in the course of that committee carrying out its function, or
- has provided information to a Scope of Clinical Practice Committee in the course of that committee carrying out its functions.[24]

There are currently no formal arrangements in place for the Committee to obtain information from ACT Health on a regular basis. An ad hoc request for information was made to ACT Health in April 2013 and this request asked for the Committee to be provided with the following information:

- any broad systems issues identified in the clinical reviews conducted for all those children and young people who were usual residents of the ACT and died in the ACT
- information about what has been put in place to remedy the identified broad systems issues.

The Committee received this information from ACT Health in June 2013.

A second request was made to ACT Health in May 2013 seeking data from the ACT Perinatal Mortality Committee for those children who have died since 1 January 2004. The Committee received this information from ACT Health in June 2013.

The interaction of various pieces of legislation relating to sharing other information will require further consideration by the relevant parties and it is anticipated the Committee will meet with the appropriate officers of ACT Health to discuss the future exchange of information.

23 ACT Policing lawfully provided information to the Committee under the provisions of the Act and under section 60A of the *Australian Federal Police Act 1979*.

24 Section 124 of the *Health Act 1993*.

Office for Children, Youth and Family Support

The Committee has finalised its protocol with the OCYFS. This protocol allows the Committee to access information from both the CPS and YJS, which are part of the OCYFS, and covers the retrospective collection of information, as well as the future collection of information on a monthly basis. The information obtained as part of this protocol includes:

Care and Protection Services

- known to CPS by way of an Inquiry, Child Concern Report or Child Protection Report (or the equivalent for those contacts with the OCYFS prior to the Act) within the three years before the child or young person's death
- types of reports (includes an Inquiry, Child Concern Report or Child Protection Report or the equivalent for those contacts prior to the current Act) received for the life of the child or young person who died and their siblings
- dates all reports identified were received
- type of report (either mandatory or voluntary) for all reports identified
- all harm indicators present for all reports identified; for example, physical abuse, sexual abuse, emotional abuse, neglect, domestic and family violence, drug and alcohol abuse and mental health
- the outcome of any appraisal (or the equivalent) completed – either substantiated, including primary harm substantiated, or unsubstantiated
- the type of intervention the child or young person, or a sibling, was subject to at the time of the death (includes voluntary work with the family, a voluntary care agreement, an appraisal order where the Director-General has parental responsibility, parental responsibility that is either Director-General sole or Director-General shared, or the equivalent for intervention prior to the current Act and for court ordered interventions, whether interim or final orders)
- the type and dates of intervention the child or young person, or a sibling, was subject to for the life of the child, young person or sibling (includes voluntary work with the family, a voluntary care agreement, an appraisal order where the Director-General has parental responsibility and parental responsibility, either Director-General sole or Director-General shared, or the equivalent for intervention prior to the current Act and for court ordered interventions, whether interim or final orders)
- whether the child or young person's parent(s) was known to CPS, Family Services, Welfare Branch or the equivalent agency, as a child by the way of an Inquiry, Child Concern Report or Child Protection Report (or the equivalent for those contacts prior to the current Act).

Youth Justice Services

- whether the young person had ever been in Youth Justice custody, or under community based supervision by YJS, or the subject of a court ordered report prepared, or arranged, by YJS
- whether the young person was subject to any conditions as part of a Youth Justice Order at the time of the death and the details of those conditions
- whether the young person had spent any time at either the Bimberi Youth Justice Centre or the Quamby Youth Detention Centre
- details about any periods of time the young person spent in either the Bimberi Youth Justice Centre or the Quamby Youth Detention Centre or on a community based order supervised by YJS
- whether the young person was involved with any services, programs or other interventions during a period of custody or while on a community based order supervised by YJS
- details about what services, programs or other interventions the young person was involved in during a period of custody or while on a community based order supervised by YJS.

ACT Office of the Coroner

It is anticipated the Committee will soon finalise its protocol with the ACT Office of the Coroner. This protocol will allow the Committee access to information about the children and young people who died in the ACT whose deaths were subject to a coronial inquiry that has ended. The protocol covers both the retrospective and future collection of information. The information to be obtained as part of this protocol includes:

- cause of death
- brief of evidence
- coronial inquiry report
- ACT Policing reports.

NSW Registry of Births, Deaths and Marriages

The Committee obtained information from the NSW BDM about those children and young people who normally lived in the ACT but died in NSW between 1 July 2008 and 30 June 2013. The information obtained (where known) included:

- death registration number
- date death registered
- name, including any aliases
- date of birth
- date of death
- age
- gender
- Aboriginal and Torres Strait Islander status
- place of birth
- place of death
- address
- cause of death information, including duration
- coroner/medical practitioner information.

The Committee will also seek the above information from the NSW BDM about those children and young people who normally lived in the ACT but died in NSW from 1 January 2004 to 30 June 2008.

National Coronial Information System – Department of Justice, Victoria

The Committee has finalised its Access Agreement with the NCIS run by the Department of Justice, Victoria. This agreement allows the Committee to access information held on the NCIS internet based system, including information about every death reported to an Australian coroner.[25]

The NCIS is a valuable tool to access information about those coronial inquiries undertaken by another state or the Northern Territory of a child or young person who normally lived in the ACT. The collection of the information housed within the NCIS database will assist the Committee to comply with section 727N(1) of the Act, which requires the Committee to keep a register of the deaths that occurred outside the ACT of children and young people who normally lived in the ACT.

25 The NCIS website states that this information provides a valuable hazard identification and prevention tool for coroners and research agencies.

APPENDIX 2 CHAPTER 19A OF *THE CHILDREN AND YOUNG PEOPLE ACT 2008*

Part 19A.1 Establishment and functions of committee

727A Establishment of committee

The Children and Young People Death Review Committee (the *CYP death review committee*) is established.

727B Functions of committee

1 The CYP death review committee has the following functions:

a to keep a register of deaths of children and young people under part 19A.3;

b to identify patterns and trends in relation to the deaths of children and young people;

c to undertake research that aims to help prevent or reduce the likelihood of the death of children and young people;

d to identify areas requiring further research, by the committee or another entity, that arise from the identified patterns and trends in relation to the deaths of children and young people;

e to make recommendations about legislation, policies, practices and services for implementation by the Territory and non-government bodies to help prevent or reduce the likelihood of the death of children and young people;

f to monitor the implementation of the committee's recommendations;

g to report to the Minister under part 19A.4;

h any other function given to the committee under this chapter.

2 The CYP death review committee has no function in relation to reviewing the cause of death of a particular child or young person.

727C Committee members

The CYP death review committee is made up of—

a the director-general; and

b the children and young people commissioner; and

c the members appointed by the Minister under section 727D; and

d the chair appointed under section 727E.

727D Appointment of committee members

1 The Minister must appoint at least 8, but not more than 10, members to the CYP death review committee.

Notes *(1) For the making of appointments (including acting appointments), see the Legislation Act, pt 19.3.; (2) In particular, a person may be appointed for a particular provision of a law (see Legislation Act, s 7 (3)) and an appointment may be made by naming a person or nominating the occupant of a position (see Legislation Act, s 207); and (3) Certain Ministerial appointments require consultation with an Assembly committee and are disallowable (see Legislation Act, div 19.3.3).*

2 The Minister must, unless it is not reasonably practicable, ensure that the committee includes—

a people with experience or expertise in the following:

i psychology;
ii paediatrics;
iii epidemiology;
iv child forensic medicine;
v public health administration;
vi education;
vii engineering and child safety products or systems;
viii working with Aboriginal and Torres Strait Islander children and young people; and

b a social worker with expertise or experience in working with children and young people and families; and

c a police officer with experience in working with children and young people and families.

3 The Minister must not appoint someone to the committee under this section unless satisfied that the person is suitable to be a member of the committee.

4 In considering whether someone is suitable to be a member of the committee, the Minister—

a must consider relevant information mentioned in section 65 (1), definition of suitability information, paragraphs (a), (b) and (c) about the person; and

b may consider other suitability information about the person.

5 The appointment of a member under this section is for not longer than 3 years.

6 The conditions of appointment of a member under this section are the conditions stated in the appointment, subject to any determination under the Remuneration Tribunal Act 1995.

727E Appointment of chair of committee

1 The Minister must appoint someone as the chair of the CYP death review committee.

2 However, the chair must not be someone who is otherwise a member of the CYP death review committee.

3 Also, the Minister must not appoint someone unless satisfied that the person—

a has the expertise or experience to be the chair of the CYP death review committee; and

b is otherwise suitable to be the chair.

4 In considering whether someone is suitable to be a chair of the CYP death review committee, the Minister—

a must consider relevant information mentioned in section 65 (1), definition of suitability information, paragraphs (a), (b) and (c) about the person; and

b may consider other suitability information about the person.

5 The appointment of the chair is for not longer than 3 years.

6 The conditions of appointment of the chair are the conditions stated in the appointment, subject to any determination under the *Remuneration Tribunal Act 1995*.

727F Conflict of interest

A member of the CYP death review committee must take all reasonable steps to avoid being placed in a position where a conflict of interest arises during the exercise of the committee's functions.

727G Appointment of advisers

1 The Minister may, on the request of the CYP death review committee, appoint a person as an adviser to the committee.

Note 1 For the making of appointments (including acting appointments), see the Legislation Act, pt 19.3.

Note 2 In particular, a person may be appointed for a particular provision of a law (see Legislation Act, s 7 (3)) and an appointment may be made by naming a person or nominating the occupant of a position (see Legislation Act, s 207).

Note 3 Certain Ministerial appointments require consultation with an Assembly committee and are disallowable (see Legislation Act, div 19.3.3).

2 However, the Minister must not appoint someone unless satisfied that the person has the experience or expertise to exercise the functions of an adviser.

3 An appointment may be subject to conditions stated in the appointment.

4 An adviser must, on request of the CYP death review committee, provide advice to the committee in relation to the committee's functions and otherwise in accordance with any conditions of appointment.

5 The Minister may end the appointment of an adviser if the adviser breaches a condition of appointment.

727H Ending member appointments

The Minister may end the appointment of a member of the CYP death review committee appointed under section 727D or the chair—

a for misbehaviour; or

b if the member is convicted, or found guilty, in Australia of an indictable offence; or

c if the member is convicted, or found guilty, outside Australia of an offence that, if it had been committed in the ACT, would be an indictable offence; or

d if the member is absent from 3 consecutive meetings of the committee, otherwise than on approved leave; or

e for physical or mental incapacity, if the incapacity substantially affects the exercise of the member's functions.

Note *A person's appointment also ends if the person resigns (see Legislation Act, s 210).*

727I Arrangements for staff

1 The director-general must, on request of the CYP death review committee, make arrangements with the committee to use public servants in the administrative unit under the director-general's control.

Note *The director-general means the director-general of the administrative unit responsible for this section (see Legislation Act, s 163 (References to a director-general or the director-general)). Administrative units are established under the administrative arrangements (see Public Sector Management Act 1994, s 13).*

2 The *Public Sector Management Act 1994* applies to the management by the committee of public servants who are the subject of an arrangement under subsection (1).

Part 19A.2 Meetings of committee

727J Meetings

1 The CYP death review committee must meet at least once each year.

2 The chair must give the committee at least 14 days written notice of a meeting.

727K Presiding member at meetings

The chair presides at all meetings of the CYP death review committee.

727L Quorum at meetings

1 Business may be carried on at a meeting of the CYP death review committee only if at least 2/3 of the members (other than the chair) are present.

2 A member must not be represented at a meeting by anyone else.

727M Voting at meetings

1 At a meeting of the CYP death review committee, each member, other than the chair, has a vote on each question to be decided.

2 A question is decided by a majority of the votes of the members present and voting.

3 Despite subsection (1), if the votes are equal, the chair has a deciding vote.

Part 19A.3 Register of deaths of children and young people

727N Children and young people deaths register

1 The CYP death review committee must keep a register (the children and young people deaths register) of—

a the deaths of children and young people that occur in the ACT; and

b the deaths that occur outside the ACT of children and young people who normally live in the ACT.

Note *Information in the register is protected information (see ch 25).*

2 The register must include the following information in relation to the death of a child or young person that is available to the CYP death review committee:

a the cause of the death of the child or young person;

b the age and sex of the child or young person;

c whether the child or young person is Aboriginal or a Torres Strait Islander;

d whether, within 3 years before his or her death, the child or young person, or a sibling of the child or young person, was the subject of a report the director-general decided, under section 360 (5), was a child protection report;

e anything else prescribed by regulation.

3 The register may contain—

a any other demographic data available to the CYP death review committee; and

b any information about a child or young person, or the circumstances of the child or young person's death, that the committee considers relevant to exercise its reporting functions under part 19A.4; and

c anything else the committee considers relevant.

4 If the death of a child or young person is subject to a coronial inquest or review by the Territory, the CYP death review committee must not include any information on the register about the cause or circumstances of the death until the coronial inquest or review has ended.

Examples—review by Territory

- an internal review by the Office for Children, Youth and Family Support
- a joint review by ACT Health and the Office for Children, Youth and Family Support

Note *An example is part of the Act, is not exhaustive and may extend, but does not limit, the meaning of the provision in which it appears (see Legislation Act, s 126 and s 132).*

5 The CYP death review committee—

a must index the deaths on the register according to cause of death and age and sex of the children and young people; and

b may also index the deaths in any other way the committee considers relevant.

6 The CYP death review committee—

a must use its best endeavours to include on the register information about the deaths of children and young people that occurred during the period starting on 1 January 2004 and ending the day before the commencement of this section; and

b may include on the register information about the deaths of children and young people that occurred before 1 January 2004.

7 This subsection and subsection (6) expire 6 years after the day this subsection commences.

727O Obtaining information from certain entities

1 A relevant entity must give the CYP death review committee the following information in relation to the death of a child or young person:

a information required under section 727N (2) to be included on the register;

b other information requested in writing by the committee that the committee considers is necessary to exercise its functions.

2 Information mentioned in subsection (1) (a) must be given within 3 months after the death of the child or young person.

3 Information mentioned in subsection (1) (b) must be given as soon as practicable after the request is made.

4 However, information mentioned in section 727N (4) must be given as soon as practicable after the end of the inquest or review.

5 A relevant entity is only required to give information under this section that is within the knowledge of the entity because of the exercise of its functions.

6 In this section:

relevant entity means each of the following:

a the chief police officer;

b the registrar-general;

c the Coroner's Court;

d the director-general responsible for administering this Act, chapter 10;

e the director-general responsible for administering the *Education Act 2004*, chapter 2;

f the director-general responsible for administering the *Health Act 1993*, part 3;

g a licensed proprietor of a childcare service;

h an entity prescribed by regulation.

727P Exchanging information with corresponding interstate entities

The CYP death review committee may enter into an agreement with an entity who exercises a function under a law of a State, that corresponds or substantially corresponds to a function of the committee, to exchange information relevant to the function.

727Q Power to ask for information, documents and other things

1 This section applies if the CYP death review committee believes on reasonable grounds that a person can give information or produce a document or something else that the committee considers necessary to allow it to exercise its functions.

2 The CYP death review committee may, by written notice given to the person, require the person to give the information in writing or produce the document or other thing.

Note *Information given or contained in a document or something else produced is protected information (see ch 25).*

3 However, the CYP death review committee must not require a family member of a child or young person who has died to give information or produce a document or something else in relation to the child or young person.

4 The notice must state how, and the time within which, the person must comply with the requirement.

5 A person commits an offence if—

a the person is required by a notice under this section to give information in writing or produce a document or other thing to the CYP death review committee; and

b the person fails to give the information or produce a document or other thing to the committee as required.

Maximum penalty: 50 penalty units.

Note 1 *The Legislation Act, s 170 and s 171 deal with the application of the privilege against self-incrimination and client legal privilege.*

Note 2 *Giving false information is an offence against the Criminal Code, s 338.*

6 Subsection (5) does not apply if the person has a reasonable excuse for failing to give the information or produce the document or other thing to the CYP death review committee as required.

727R Children and young people deaths register—who may have access?

1 The CYP death review committee must ensure that the register is accessed only by the following:

a committee members;

b staff mentioned in section 727I;

c advisers appointed under section 727G;

d someone authorised by the committee to have access to the register.

2 An authorisation is a notifiable instrument.

Note *A notifiable instrument must be notified under the Legislation Act.*

3 The committee must notify a person who can access the register of the person's obligations to deal with information on the register in accordance with the requirements under chapter 25 (Information secrecy and sharing).

Note *Information on the register is protected information (see ch 25).*

Part 19A.4 Annual reports about deaths of children and young people

727S Annual report

1 For each financial year, the CYP death review committee must report to the Minister about the following in relation to the deaths of children and young people included on the children and young people deaths register during the year:

a the number of deaths of children and young people;

b the age and sex of each child or young person who died and whether, within 3 years before his or her death, the child or young person, or a sibling of the child or young person, was the subject of a report the director-general decided, under section 360 (5), was a child protection report;

c the patterns or trends (if any) identified in relation to the deaths of children and young people—

i generally; and

ii who, within 3 years before their death were, or had a sibling who was, the subject of a report the director-general decided, under section 360 (5), was a child protection report.

Note *There are restrictions on recording and divulging protected and sensitive information (see ch 25).*

2 The CYP death review committee may include in the report—

a its recommendations (if any) about legislation, policies, practices and services for implementation by the Territory and non-government bodies to help prevent or reduce the likelihood of the death of children and young people; and

b information about the implementation of any previous recommendations of the committee; and

c any other matter it considers relevant.

3 However, the CYP death review committee must not include in the report any information that would—

a disclose the identity of a child or young person who has died; or

b allow the identity of a child or young person who has died to be worked out.

4 The CYP death review committee must give the Minister the report within 4 months after the end of the financial year.

5 The Minister must present the report in the Legislative Assembly within 6 sitting days after the day the report is given to the Minister.

727T Other reports

1 The CYP death review committee may at any time prepare a report for the Minister on any matter arising in connection with the exercise of the committee's functions.

2 The CYP death review committee must not include in the report any information that would—

a disclose the identity of a child or young person who has died; or

b allow the identity of a child or young person who has died to be worked out.

3 The Minister must present the report to the Legislative Assembly within 6 sitting days after the report is given to the Minister.

4 Within 3 months after receiving a report under subsection (1), the Minister must give information to the CYP death review committee about any action the Minister has taken, or will take, in relation to the matters raised in the report.

727U Reporting on deaths of children and young people before the commencement of ch 19A

1 For the period starting on 1 January 2004 and ending the day before the commencement of this chapter, the CYP death review committee must use its best endeavours to report about the following in relation to the deaths of children and young people included on the register for that period:

a the number of deaths of children and young people;

b the age and sex of each child or young person who died and whether, within 3 years before his or her death, the child or young person, or a sibling of the child or young person, was the subject of a report the director-general decided, under section 360 (5), was a child protection report;

c the patterns or trends (if any) identified in relation to the deaths of children and young people—

i generally; and

ii who, within 3 years before their death were, or had a sibling who was, the subject of a report the director-general decided, under section 360 (5), was a child protection report.

Note *There are restrictions on recording and divulging protected and sensitive information (see ch 25).*

2 The CYP death review committee may include in the report—

a its recommendations (if any) about legislation, policies, practices and services for implementation by the Territory and non-government bodies to help prevent or reduce the likelihood of the death of children and young people; and

b any other matter it considers relevant.

3 However, the CYP death review committee must not include in the report any information that would—

a disclose the identity of a child or young person who has died; or

b allow the identity of a child or young person who has died to be worked out.

4 The CYP death review committee must give the Minister the report within 6 years after the day this section commences.

5 The Minister must present the report in the Legislative Assembly within 6 sitting days after the day the report is given to the Minister.

6 This section expires 6 years after the day it commences.

APPENDIX 3 DATA ABOUT NORMAL RESIDENTS OF OTHER JURISDICTIONS WHO DIED IN THE ACT, JULY 2008 TO JUNE 2013

Number of deaths* of children and young people who were normal residents of other jurisdictions who died in the ACT, July 2008–June 2013**

Year	Total number of deaths of children and young people nsw	Total number of deaths of children and young people Victoria
2008–2009	10 (0)***	<5 (0)***
2009–2010	10 (0)***	
2010–2011	7 (0)***	
2011–2012	7 (0)***	<5 (0)***
2012–2013	<5 (0)***	
Total		

** <5 means the number of children is less than five but greater than zero.*

*** NSW and Victoria were the only other jurisdictions recorded by the ACT BDM.*

**** ( ) indicates number awaiting coroner findings.*

Source: ACT BDM

Deaths* of children and young people who were normal residents of other jurisdictions
Key demographic and individual characteristics, July 2008–June 2013**

		NSW	VICTORIA
Gender	Female	***	<5
	Male	***	<5
Age	< 1 year	34	<5
	1–4 years	<5	0
	5–9 years	<5	0
	10–14 years	0	0
	15–17 years	<5	0
Cause of death	Extreme prematurity	19	<5
	Medical causes	17	<5
	External causes	<5	0

** <5 means the number of children is less than five but greater than zero.*

*** NSW and Victoria were the only other jurisdictions recorded by the ACT BDM.*

**** The number of deaths by gender of NSW children and young people has not been provided as this may allow for the exact number in other '<5 (less than five total deaths) ' categories included in this appendix to be worked out.*

Source: ACT BDM

Number of deaths* of children and young people who were normal residents of NSW who died in the ACT by age and cause of death, July 2008–June 2013

Age	Extreme prematurity	Medical causes	External causes
< 1 year	19	15	0
1–4 years	n/a	<5	0
5–9 years	n/a	<5	<5
10–14 years	n/a	0	0
15–17 years	n/a	0	<5
Total	**19**		

** <5 means the number of children is less than five but greater than zero.*

Source: ACT BDM

Number of deaths* of children and young people who were normal residents of Victoria who died in the ACT by age and cause of death, July 2008–June 2013

Age	Extreme prematurity	Medical causes	External causes
< 1 year	<5	<5	0
1–4 years	n/a	0	0
5–9 years	n/a	0	0
10–14 years	n/a	0	0
15–17 years	n/a	0	0
Total	**<5**	**<5**	**0**

** <5 means the number of children is less than five but greater than zero.*

Source: ACT BDM

Number of deaths* of children and young people who were normal residents of NSW who died in the ACT by gender and cause of death, July 2008–June 2013

Gender	Extreme prematurity	Medical causes	External causes
Female	9	9	<5
Male	10	8	0
Total	**19**	**17**	**<5**

** <5 means the number of children is less than five but greater than zero.*

Source: ACT BDM

Number of deaths* of children and young people who were normal residents of Victoria who died in the ACT by gender and cause of death, July 2008–June 2013

Gender	Extreme prematurity	Medical causes	External causes
Female	0	<5	0
Male	<5	0	0
Total	**<5**	**<5**	**0**

** <5 means the number of children is less than five but greater than zero.*

Source: ACT BDM

ACT CHILDREN AND YOUNG PEOPLE DEATH REVIEW COMMITTEE

In accordance with section 727D(2) of the *Children and Young People Act 2008*, membership of the ACT Children and Young People Death Review Committee reflects a multidisciplinary approach to undertaking reviews of the deaths of children and young people resident in the ACT. The Committee includes the Director-General of the Community Services Directorate as a standing member, as well as the Children and Young People Commissioner, who is an independent statutory officer based within the ACT Human Rights Commission. In addition, the Minister appointed ten members from government, private sector and independent agencies. Collectively, current members offer expertise in the areas of psychology, paediatrics, epidemiology, child forensic medicine, public health administration, engineering and child safety products, working with Aboriginal and Torres Strait Islander children and young people, social work and policing.

Members

Dr Penny Gregory Chair, ACT Children and Young People Death Review Committee

Dr Gregory was appointed as the new Chair in June 2013 for a three-year term. Dr Gregory is a Principal at the Nous Group with more than 30 years experience in the health and community sector, including as Director of the Australian Institute of Health and Welfare and the Chief Executive of the then ACT Department of Health and Community Care. Dr Gregory has also held various senior positions with ACT Treasury. She has a strong appreciation of the complex relationships that underlie the health system in Australia and an excellent understanding of organisations and change. Dr Gregory has experience on a number of boards and committees across the government and community sectors including as a current Director on the Northside Community Services Board.

Mr Eric Chalmers Chief Executive Officer, Kidsafe ACT Inc

Mr Chalmers has been the Chief Executive Officer of Kidsafe (ACT), the Child Accident Prevention Foundation of Australia, for more than a decade. He has a strong background in management consulting, industry regulation at commonwealth and state levels, and experience in the financial and banking sectors. Mr Chalmers is linked internationally as Chair of the Network Advisory Council for the Safe Kids Worldwide network of 22 injury prevention organisations. He also has a role in a number of community organisations, including being the Chair of ACT Playgroups, the Chief Executive of the ACT School Sports Council and President of the ACT Chapter, and a member of the National Executive of the Australasian College of Road Safety.

Ms Louise Freebairn Epidemiology Branch, ACT Health

Ms Freebairn holds the position of Manager, Epidemiology Section, Health Improvement Branch, Population Health Division at ACT Health. She has expertise in population health informatics, epidemiological analysis and reporting, with a focus on maternal and perinatal health, children's health and the health of Aboriginal and Torres Strait Islander people. Ms Freebairn is a member of the ACT Perinatal Mortality Committee. She has worked with health services in both the ACT and NSW since 1997 in a number of roles, including clinical psychology, health services planning and epidemiology.

Ms Natalie Howson Director-General, Community Services Directorate

Ms Howson has been an officer in the Senior Executive Service (SES) of the Australian and ACT governments since 1995. Her public sector experience spans senior positions in government policy and service delivery agencies, including Human Services, Climate Change, Defence, and most recently as the Director-General of the Community Services Directorate in the ACT. In each of these roles, as diverse as they seem, Ms Howson has had the opportunity to work with the community and business sectors on significant reform programs, as well as develop her

understanding of contemporary human service delivery challenges. Ms Howson was responsible for teacher training in drug and alcohol issues as an officer in the Queensland Department of Education. Her first career was as a secondary school teacher, and she was heading back into the school setting when, in 1989, she moved to Canberra. She was attracted to the reputation of the Australian Institute of Sport and the opportunity to work in the city that is the seat of the Australian Government. Ms Howson joined a small team to establish the Australian Sports Drug Agency, and in 1995 became the CEO – a role she played up to the Sydney 2000 Olympic Games. Ms Howson has worked with a range of key stakeholders in the government, international and national NGOs, community, medical, scientific research and business sectors. In 2000, Ms Howson was named the ACT Telstra Business Woman of the Year.

Associate Professor Alison Kent Department of Neonatology, The Canberra Hospital

Associate Professor Alison Kent is a Consultant Neonatologist who has worked at The Canberra Hospital for 13 years in the Neonatal Intensive Care Unit. Associate Professor Kent established and has chaired the ACT Perinatal Mortality Committee since 2001, is a member of the Perinatal Society of Australia and New Zealand (PSANZ) Special Interest Mortality Group and has been an active participant in the development and maintenance of the PSANZ Perinatal Mortality Guideline aimed at improving the classification, reporting and research of perinatal deaths. She is currently the Chair of the Australian and New Zealand Stillbirth Association Clinical Practice and Education Committee and is a former Board Member of SIDS and Kids ACT.

Ms Beth Mitchell Education and Training Directorate

Ms Mitchell holds the position of Director, Aboriginal and Torres Strait Islander Education and Student Engagement in the Education and Training Directorate. She has extensive experience and expertise in the education sector and working with young people. She has previously held positions including Principal at Dickson College, Faculty Head of Special Education and Alternative Education at Dickson College, Manager of Student Services English and LOTE at Ginninderra High School, Manager of Athlete Career and Education, Australian Institute of Sport, and was a classroom teacher for 14 years.

Dr Sue Packer AM Paediatrician, The Canberra Hospital

Dr Packer has worked as a paediatrician since 1972 and as a community paediatrician with a special interest in child abuse and abuse prevention since 1990. She undertakes a range of work, including working in a health-funded child abuse assessment unit in the ACT that also serves adjacent NSW, teaching and consulting, and currently is serving on the NAPCAN (National Association for Prevention of Child Abuse and Neglect) National Board. In 1999, Dr Packer was awarded an Order of Australia for services to paediatrics, child protection and the community. In 2013 she was named Canberra Citizen of the Year.

Ms Samantha Page Chief Executive Officer, Early Childhood Australia

Ms Page is the Chief Executive Officer of Early Childhood Australia, the peak national early childhood advocacy organisation, which acts in the interests of children from birth to eight years old. Ms Page has been an advocate for children, young people and parents for many years through her work in the not-for-profit, public and private sectors. Her previous role with Family Relationship Services Australia involved working with both the family services sector and the family law system. She has also served on governance boards and advisory groups reporting to Territory and Commonwealth Government ministers. She is currently a Board Director at the Australian Council of Social Service and the Australian Institute of Health and Welfare.

Dr Michael Rosier Paediatrician

Dr Rosier is a consultant paediatrician who has worked in private practice in the ACT since January 1990. He is a Visiting Medical Officer at The Canberra Hospital, Calvary Bruce and Calvary John James Hospitals. Dr Rosier has extensive experience in all fields of paediatric medical practice, including neonatology and children through to 18 years of age. He has a special interest in paediatric epilepsy and neurological conditions.

Mr Alasdair Roy ACT Children and Young People Commissioner

Mr Roy, who holds a Masters in Counselling Psychology, is the ACT Children and Young People Commissioner with the ACT Human Rights Commission, a position he has held since 2008. He has lived and worked in Canberra for most of his life and has always worked with and for children and young people. Prior to becoming the Children and Young People Commissioner, he was Deputy Public Advocate in the Public Advocate of the ACT. Mr Roy has also worked for Care and Protection Services, Youthline and the Streetlink Youth Support Program, as well as in children and young people policy areas, adolescent mental health and services for children with sexually harmful behaviour. He is committed to the rights of children and young people and making Canberra a friendlier and safer place for them.

Dr Catherine Sansum Forensic Medicine, Child at Risk Health Unit, The Canberra Hospital

Dr Sansum holds the position of Staff Specialist at The Canberra Hospital in the area of clinical forensic medicine (adult) and in paediatric forensic medicine at the Child at Risk Health Unit. She has worked as a doctor in the ACT for the past 26 years, initially in paediatrics and obstetrics and gynaecology, general practice and then specialising in forensic medicine. Dr Sansum is a Clinical Lecturer at the Australian National University Medical School and is a member of the Australian Academy of Forensic Sciences, the Australian and New Zealand Forensic Science Society and the Sydney Forensic Medicine and Science Network. She is the treasurer of FAMSACA (Forensic and Medical Sexual Assault Clinicians Australia).

Sergeant Sue Smith Acting Officer in Charge, ACT Policing

Sergeant Smith joined the Australian Federal Police (AFP) in 1989 after five years with the NSW Police Service. Since joining the AFP, she has performed community and national policing roles. In 1992, Sergeant Smith took up a position within the ACT Police Juvenile Aid Bureau, the unit responsible for managing young offenders, young people who were victims of crime, and young people who were engaging in 'at risk' behaviour. She is involved in committees, including ACT Violence Against Women and Children and the Domestic Violence Prevention Council.

Ms Julie Tongs OAM Chief Executive Officer, Winnunga Nimmityjah Aboriginal Health Service

Ms Tongs has 20 years experience working in Aboriginal and Torres Strait Islander affairs. Ms Tongs has extensive experience in advising, formulating, implementing and evaluating public health initiatives, programs and policies at local, regional and national levels. She has been a national leader and strong advocate of quality improvement initiatives within the Aboriginal Community Controlled Sector. Ms Tongs was a recipient of the 2012 ACT Local Hero Award and was recognised in the 2012 Australia Day Honours List.

Previous chair

Dr Judith Gibbs

Dr Judith Gibbs resigned as the Committee Chair for personal reasons and chaired her last meeting in April 2013. The Committee thanks Dr Gibbs for her hard work and the significant contribution she made in establishing the Committee, particularly in its first year of operation.

Secretariat and support

The Community Services Directorate arranged for the Committee's secretariat and support to be provided in accordance with Section 727I (1) of the *Children and Young People Act 2008*. The Committee's secretariat and support services are provided by:

Ms Christina Myers Secretariat

Ms Lizzie Spulak Senior Research and Review Officer

ACKNOWLEDGEMENTS

The ACT Children and Young People Death Review Committee would like to take this opportunity to acknowledge the ACT and state governments that provided data and information for this report. In particular, the Committee would like to acknowledge the officers from:

- ACT Policing
- ACT Health
- ACT Community Services Directorate, in particular the Office for Children, Youth and Family Support and the Data and Research Branch of the Policy and Organisational Services Unit
- ACT Office of the Coroner
- ACT Office of Regulatory Services, in particular Births, Deaths and Marriages and Background Screening
- NSW Department of Attorney General and Justice, in particular the Registry of Births, Deaths and Marriages
- Queensland Commission for Children and Young People and Child Guardian, in particular the Child Death Review Team
- Victorian Department of Justice, in particular the National Coronial Information System.

The Committee would also like to acknowledge the ongoing assistance given to us by a number of people from other jurisdictions who are willing to share their experiences and advice, namely the members of the Australian and New Zealand Child Death Review and Prevention Group.

DEFINITIONS OF TERMS

Aboriginal In the *Children and Young People Act 2008*: ***Aboriginal*** means a person who—

a is a descendant of the Indigenous inhabitants of Australia; and

b either—

i for any person—regards himself or herself as an Aboriginal; or

ii if the person is a child—is regarded as an Aboriginal by a parent or family member; and

c is accepted as an Aboriginal by an Aboriginal community.

Australian and New Zealand Child Death Review and Prevention Group Refers to the collective group made up of a number of child death review agencies across the states and territories of Australia and New Zealand who review the population of children and young people who die in their jurisdictions. The aim of this group is to identify, address and potentially decrease the number of child and young people deaths and to work collaboratively towards national and international reporting.

Business requirements Refers to the document developed by the Committee to describe the information requirements and data management activities associated with the responsibilities of the Committee under the *Children and Young People Act 2008*.

Child In the *Children and Young People Act 2008*:
child means a person who is under 12 years old.
The *Children and Young People Act 2008* does not provide guidance on when an individual becomes a 'child'. In accordance with common law, a child is a person who has been born alive, which means the child must be living outside its mother's body by virtue of the functioning of its own organs and indicated by breathing, beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles. The term 'a child born alive' does not include stillbirths or other fetal deaths.

Child Concern Report A Child Concern Report is a report made to Care and Protection Services in accordance with section 359 of the *Children and Young People Act 2008* and can be made by either a voluntary or a mandated reporter. A Child Concern Report is a record of information regarding the needs of a child or young person or is about a child or young person's safety or wellbeing (CSD definition).

Child Protection Report Care and Protection Services undertakes an initial assessment of matters raised in all Child Concern Reports to determine if the information received meets the threshold of a Child Protection Report. Only Care and Protection staff can decide if a Child Concern Report becomes a Child Protection Report. This decision is made when Care and Protection staff form a reasonable belief that information received in a Child Concern Report indicates that the child or young person is in need of care and protection. Section 344 of the *Children and Young People Act 2008* defines that a child is in need of care and protection if the child has been, is being, or is likely to be abused or neglected AND there is no one with parental responsibility willing and able to protect the child or young person from the abuse or neglect (CSD definition).

Coroner Refers to a coroner for the ACT appointed under the *Coroners Act 1997*.

Entity Refers to the ACT Chief Police Officer, the Registrar-General of the Office of the Coroner, the Director-General of the Community Services Directorate, the Director-General of the Education and Training Directorate, the Director-General of ACT Health, a licensed proprietor of a childcare service and another agency prescribed by regulation.

Fetal death Refers to death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400 grams or more of birth weight. The death is indicated by the fact that after separation the fetus does not breathe or show any other evidence of life, such as the beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles (WHO definition).

Infancy Refers to the period from birth to one year of age.

Interim register Refers to the current register, used by the ACT Children and Young People Death Review Committee, that holds information about the deaths of children and young people that occur in the ACT and of children and young people who normally live in the ACT but die outside of the ACT.

ICD-10 Refers to the World Health Organization's (WHO) International Statistical Classification of Diseases and Related Health Problems – Version 10 (ICD-10). ICD-10 is the standard diagnostic tool for epidemiology, health management and clinical purposes and is used to monitor the incidence and prevalence of diseases and other health problems (WHO definition).

Mortality Refers to a fatal outcome.

National Coronial Information System Refers to the initiative of the Australasian Coroners Society that is managed by the Victorian Department of Justice on behalf of the federal government and the states and territories. Information about every death subject to a coronial inquiry in Australia is stored within the system, providing a valuable hazard identification and death prevention tool for researchers, including state and territory Death Review Committees (NCIS definition).

Neonatal Refers to the period from birth to 28 days of age.

Parent Refers to a birth, step, de facto or adoptive parent of a child or young person as identified by the Committee from information obtained as part of its functions.

Perinatal Refers to the period from 20 weeks gestation to 28 days of age.

Perinatal Society of Australia and New Zealand Refers to the multidisciplinary society dedicated to improving the long-term outcomes for mothers and their babies (PSANZ definition).

Register Refers to the register of all deaths of children and young people in the ACT that is used by the Committee.

Report Refers to this annual report of the Committee. The Report covers information for five financial years: 2008–09, 2009–10, 2010–11, 2011–12 and 2012–13, which is denoted throughout the report as July 2008–June 2013.

Review by the ACT These reviews are undertaken in the ACT and may include: a coronial inquest into the manner and cause of death of a person who dies in circumstances set out in the *Coroners Act 1997;* a Clinical Health Review Committee; an internal review by the Office for Children, Youth and Family Support; or a joint ACT Health and Office for Children, Youth and Family Support review.

Sibling Refers to all biological, half, step and adoptive siblings as identified by the Committee from information obtained as part of its functions.

Torres Strait Islander In the *Children and Young People Act 2008*: ***Torres Strait Islander*** means a person who –

a is a descendant of the Indigenous inhabitants of the Torres Strait Islands; and
b either—
  i for any person – regards himself or herself as a Torres Strait Islander; or
  ii if the person is a child—is regarded as a Torres Strait Islander by a parent or family member; and
c is accepted as a Torres Strait Islander by a Torres Strait Islander community.

Young people In the *Children and Young People Act 2008*: ***Young people*** means a person over the age of 12 years and not yet 18 years.

GLOSSARY

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
Act	*Children and Young People Act 2008*
ACT BDM	ACT Registry of Births, Deaths and Marriages, Office of Regulatory Services
ANZCDR&PG	Australian and New Zealand Child Death Review and Prevention Group
CAQS	Consumer Advocacy and Quality Services
CHYPS	Children and Young People System
CPS	Care and Protection Services
CSD	ACT Community Services Directorate
Committee	ACT Children and Young People Death Review Committee
ICD-10	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision
MLA	Member of the ACT Legislative Assembly
NCIS	National Coronial Information System
NSW BDM	NSW Registry of Births, Deaths and Marriages, NSW Department of Attorney General and Justice
OCYFS	Office for Children, Youth and Family Services
POS	Policy and Organisational Services
PSANZ	Perinatal Society of Australia and New Zealand
YJS	Youth Justice Services

ACT Children & Young People
Death Review Committee