

CHILD DEATH & SERIOUS INJURY  
REVIEW COMMITTEE  
**ANNUAL REPORT 2013–14**



Government  
of South Australia



# LETTER OF TRANSMISSION

Hon Jennifer Rankine MP  
Minister for Education and Child Development

Dear Minister

I submit to you for presentation to Parliament the 2013–14 Annual Report of the South Australian Child Death and Serious Injury Review Committee which has been prepared pursuant to Part 7C of the *Children's Protection Act 1993*.

This report highlights the Committee's activities in fulfilling its statutory obligations.

In compliance with the *Public Sector Act 2009* and the *Public Finance and Audit Act 1987* a further report concerning the management of human resources and financial issues of the Committee has been submitted as part of the Annual Report of the Department for Education and Child Development 2013–14.

Yours faithfully



**Dymphna Eszenyi**

Chair  
Child Death and Serious Injury Review Committee

31 October 2014

## CHAIR'S FOREWORD

I am pleased to present the Committee's ninth Annual Report to Parliament under Part 7C of the *Children's Protection Act 1993*.

The Committee continues its work of reviewing the circumstances and causes of child deaths in South Australia. The knowledge gained from these reviews over nine years informs the contribution it makes to the safety and wellbeing of children. In 2013–14 the Committee has paid particular attention to following-up on the ways that services are provided to vulnerable infants, children with disabilities and at risk young people through recommendations about systemic change it has made about health, housing child protection and education systems.

The Committee has continued to be conscious of how much can be learned from our reviews of deaths and serious injuries to children. Each child's story helps to build not only our knowledge but also that of all of those who strive to serve and care for children.

On behalf of the Committee I extend my condolences to the families and friends who have experienced the death of a child and to the communities and professionals who cared for them.

The Committee thanks each member of the Secretariat for their advice and support and for the care and respect for each child that they have brought to the Committee's deliberations.

I thank my colleagues on the Committee. One of the Committee's great strengths is its multidisciplinary membership which lends tremendous knowledge and experience to its work. I would like to acknowledge the contributions of two members whose service on the Committee was completed this year: Dr Diana Hetzel, one of the Committee's founding members, contributed her knowledge and understanding of children both as a medical practitioner and as a public health expert. Over several years, Ms Dana Shen contributed her in-depth understanding of operational matters in the health and child welfare systems. The expertise of both will be missed.

As a community we seek to care for all our children and to keep them safe. I share the Committee's hope that this Report will assist those who work with and for children in their efforts to keep them safe from harm.

### **Dymphna Eszenyi**

Chair

Child Death and Serious Injury Review Committee

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# GLOSSARY

ABS	Australian Bureau of Statistics
Act	<i>Children's Protection Act 1993</i>
AIHW	Australian Institute of Health and Welfare
ARIA+	Index of Remoteness and Accessibility, Australia
ATSI	Aboriginal and Torres Strait islander
CDSIRC	Child Death and Serious Injury Review Committee
Children	In this report 'children' includes infants, children and young people from birth up to 18 years
Coroner	State Coroner SA
DCSI	Department of Communities and Social Inclusion
DECD	Department of Education and Child Development
ICD-10	International Classification of Disease (Version 10)
IMR	Infant Mortality Rate
Infant	A child less than one year of age
IRSD	Index of Relative Socio-economic Disadvantage
MAC	Motor Accident Commission
MAPS	Multi-agency Protection Service
MOU	Memorandum of Understanding
NDIS	National Disability Insurance Scheme
SAPOL	SA Police
SEIFA IRSD	Socio-Economic Indexes for Areas, Index of Relative Socio-economic Disadvantage (IRSD)
SIDS	Sudden Infant Death Syndrome
SUDI	Sudden Unexpected Death in Infancy
TAC	Team Around the Child
UCV	Universal Contact Visit
VP shunts	Ventriculoperitoneal shunts
WCH	Women's and Children's Hospital
WCHN	Women's and Children's Health Network
WHO	World Health Organization

## ACKNOWLEDGEMENTS

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- Australian and New Zealand Child Death Review and Prevention Group (ANZCDR&PG), representatives attending ANZCDR&PG meetings who share insights gained from their own jurisdictions and especially the Victorian Council on Obstetric and Paediatric Mortality and Morbidity which currently chairs ANZCDR&PG meetings
- Department for Communities and Social Inclusion which continues to provide technical advice and support for the Committee's database, and assistance with records management
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- Women's and Children's Health Network Records Management team
- Chief Executives and Senior Officers from the Department of Education and Child Development, the Department for Communities and Social Inclusion, SA Health and SA Police for contributing to the Committee's understanding of service delivery in their departments

# COMMITTEE MEMBERS 2013–14

## Chair

Ms Dymphna (Deej) Eszenyi

## Members

Professor Roger Byard AO

Mr Alwin Chong

*from 26 June 2014*

Ms Lynne Cowan

*from 26 June 2014*

Ms Angela Davis

Ms Dianne Gursansky

Ms Michelle Hasani

Dr Diana Hetzel

*until 31 May 2014*

Mr Barry Jennings QC

Dr Margaret Kyrkou OAM

Mr Tom Osborn APM

Ms Dana Shen

*until 16 August 2013*

Ms Nicole Stasiak

*from 26 June 2014*

Dr Nigel Stewart

Ms Trish Strachan

Ms Barbara Tiffin

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*Senior Project Officer*

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# EXECUTIVE SUMMARY

This is the ninth Annual Report of the Child Death and Serious Injury Review Committee.

## Purpose and establishment

The Committee contributes to efforts to prevent death or serious injury to children in South Australia. It was established by the *Children's Protection Act 1993* (the *Act*) in February 2006.

The Committee reviews the circumstances and causes of death and serious injury to children. It makes recommendations to Government for changes to legislation, policies and procedures that may help prevent similar deaths or serious injuries.

## Improving services for vulnerable children and young people

This report summarises the Committee's efforts to guide Government and non-government agencies who provide services to children to develop and implement strategies that will improve the safety and wellbeing of children. Issues considered in this Annual Report include:

- Assessment of antenatal risks. Timely and appropriate assessment of infants after birth and prior to discharge from hospital so that plans can be made to make sure that the infants are safe and well.
- Responses by child protection and education systems to signs of neglect such as repeated 'low level' child protection notifications and chronic non-attendance at school.
- The need for a child protection system that is capable of thorough and timely assessment of risk, that adequately trains and supervises its practitioners and provides case management that responds to and reflects the complex nature of cases.

- Government and non-government agencies' ability to exchange and act on information they receive about certain cases and their efforts to identify opportunities for such information exchange.
- The need for a joint response from Government and non-government agencies responsible for providing services to young people who are homeless or at risk of homelessness.
- Particular challenges to service delivery for agencies providing services to Aboriginal children or children with disabilities. These challenges should be in the forefront of an agency's mind not only when planning services but also in service delivery.
- Analysis of the lives of young people who have suicided and the identification of opportunities for prevention and intervention.

## Keeping children safe

The Committee has also turned its time and attention to safety issues for children across a number of different areas including:

- The ways in which the health system recognises signs of ventriculoperitoneal (VP) shunt malfunction and the processes in place to respond to such malfunction.
- The ways in which the health system recognises signs of neonatal sepsis and the processes in place to respond to these signs.
- Legislation about homebirthing.
- Arguing that policies and actions taken to address severe domestic squalor recognises that children may be in such situations and may need protection.
- The safety of young pedestrians and of children using quad bikes.

- Supporting prevention efforts that make sure infants are sleeping safely.
- Supporting legislative changes to improve the safety of domestic swimming pools so that young children are less likely to drown.

### Reviews into the deaths of children

The Committee's efforts are underpinned by all of the reviews it has undertaken in the previous nine year period. In 2013–14, these reviews included the deaths of children with disability, deaths of children who had VP shunts, deaths of children as pedestrians and on quad bikes, and the suicide deaths of young people.

### Analysis of information about the deaths of children in South Australia between 2005 and 2013

The report contains analysis of information about all deaths of children in South Australia between 2005 and 2013. In 2013 the Committee decided that it would exclude from the analysis the deaths of infants who were born spontaneously before 20 weeks and the deaths of infants resulting from the genetic termination of pregnancy. The Committee's data from 2005 to 2013 was re-analysed after these exclusions were made.

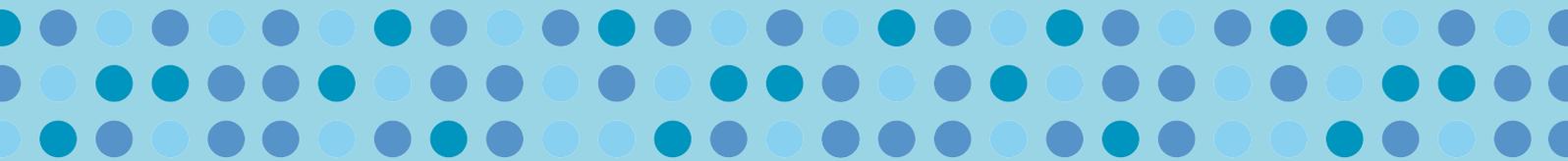
Findings of note arising from the analysis of all deaths in this nine year period are:

- 1031 children died in South Australia between 2005 and 2013, 967 of these children were South Australian residents
- The death rate for all children who died in South Australia between 2005 and 2013 shows a 2% decrease on average, per year
- Aboriginal children were three times more likely to die than non-Aboriginal children
- Of the 1031 children who died, 230 (23%) were identified as children with a disability.

### Future plans

In the next twelve month period, the Committee will make its contribution to the safety and wellbeing of children in South Australia by:

- Continuing its work monitoring issues highlighted in previous recommendations.
- Reviewing particular cases of death and serious injury; one of these reviews will be about the deaths of infants whose parents were under Guardianship of the Minister.
- Analysing information about all deaths of children in South Australia.



## SECTION ONE

# IMPROVING THE SAFETY AND WELLBEING OF SOUTH AUSTRALIAN CHILDREN

### ***S52S – Functions of the Committee***

*b) to make, and monitor the implementation of, recommendations for avoiding preventable child death or serious injury.*

*Children's Protection Act, 1993*

## SECTION ONE: IMPROVING THE SAFETY AND WELLBEING OF SOUTH AUSTRALIAN CHILDREN

Throughout 2013–14 the Committee contributed to better outcomes for children and young people by monitoring, promoting and supporting change to legislation, policy and practice across a number of different areas. Primarily through the exchange of information, it has continued to follow-up on service provision issues in the child protection, health, education, housing and disability sectors. It has worked on maintaining agency and community awareness about safety issues for children and young people including safe sleeping for infants, transport safety and changes to legislation for domestic swimming pools and quad bikes.

### 1.1. Improving services for vulnerable children and young people

#### 1.1.1 Discharge of vulnerable infants from hospital

The Committee has continued to monitor progress with the implementation of recommendations made in its 2011–12 review of 14 sudden and unexpected infant deaths, pursuing service improvements that demonstrate strengthening engagement with vulnerable families antenatally and co-ordination of services after discharge.

In May 2014, updates on the implementation of the 'Common discharge protocol for vulnerable infants' were provided by both SA Health and Families SA. The protocol stated it would assist with the identification and assessment of at risk infants, provide a process to follow if an infant was to be removed from the care of the birth parents, and a process for both agencies with respect to the discharge and follow-up of high risk infants.

Both agencies agreed that the protocol was an important way of guiding their service delivery and they were committed to its implementation. In the 12 months since last reporting on progress with this Protocol the *in principle* agreement of both agencies has been achieved. However, as of May 2014, final endorsement had not been received from either agency, nor had the Protocol been implemented.

This is an important Protocol. The Committee will continue to monitor its implementation closely. An update on its implementation will be requested from both agencies in six month's time.

#### 1.1.2 The universal contact visit (UCV)

A 'service snapshot' of seven cases of sudden unexpected infant death was provided to SA Health and the Department for Education and Children's Services (DECD) in 2013. It highlighted the difficulties involved in service provision to vulnerable infants and their families once these infants were discharged from hospital.

SA Health responded to the Committee's long-standing recommendation that it analyse the cases where infants failed to receive a UCV so that services to such infants and their families could be improved. In 2013 the Women's and Children's Health Network (WCHN) undertook a data audit of 20 mothers who gave birth at the Women's and Children's Hospital (WCH) and who did not consent to a UCV. This audit showed that the majority of the 20 women who gave birth at the WCH and declined a UCV were supported in some way when they returned home with their newborn.

***The universal contact visit connects infants and mothers to the Child and Family Health Service and to other support services such as Family Home Visiting. The analysis of mothers who have refused a universal contact visit by the Women’s and Children’s Health Network is a step forward in helping to determine the best ways to ensure that vulnerable infants and their families receive appropriate support after discharge from hospital.***

The Committee will recommend to SA Health that they broaden the scope of their audit and analysis to include ongoing state-wide monitoring of this issue and will enquire into the ways in which the results of this kind of monitoring will be used to change the WCHN’s practices with women who decline or do not receive the UCV.

DECD also responded to the Committee about progress made towards achieving better outcomes for vulnerable infants since the Committee’s review of the sudden and unexpected deaths of seven infants in 2010. However, because evaluation of the efficacy of these changes was ongoing, DECD did not comment on whether they had contributed to improved outcomes for infants.

The Committee has accepted DECD’s invitation to be involved in ongoing discussions about how services to vulnerable infants can be improved and evaluated.

### **1.1.3 The child protection system**

Over the nine year period since 2005, approximately one quarter of children who have died, or their families, had had contact with the child protection system in the three years before their death. The Committee’s past reviews have identified consistent themes

about the responses of the child protection system in the years before the child’s death. These themes commonly highlight the complexity of cases and the consequent need for careful consideration of all aspects of the history of contact between the child’s family and the child protection agency, for high quality case management practices, the need to seek out and share information from other agencies (information sharing) and for interagency collaboration.

In relation to progress with the various recommendations the Committee has made about these issues, the 2012–13 Annual Report noted the 2–3 year commitment Families SA has made to a ‘redesign’ program. In light of those recommendations, Families SA were requested to ensure the following issues were addressed in the course of that redesign:

- Staff training, support and supervision, especially in relation to understanding, identifying and responding to cumulative harm
- An appropriate system of case management
- Services of equal quality and availability for families living in regional and remote areas
- Continuation of services for children during the ‘transition’ period of the redesign

## SECTION ONE: IMPROVING THE SAFETY AND WELLBEING OF SOUTH AUSTRALIAN CHILDREN

The issues of neglect, cumulative harm and improved case management were pursued again by the Committee as part of its 2012 review of six seriously injured children.<sup>1</sup> The Committee recommended that Families SA review the priority and resources assigned to notifications of neglect.

It made this recommendation because the Committee considered it imperative that an effective child protection system have the will, the capacity and the resources to carry out an investigation into cases which present with indicators of neglect.

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***The Committee's view is that there is a real risk that children who are neglected or living in situations where harm is cumulative will suffer significant emotional, developmental and social harm; such harm can be pervasive and long-term and in some cases will lead to a child's serious injury or death.***

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In the same 2012 review, the Committee made recommendations about strengthening case management. Families SA indicated that it would be reviewing the manuals that guide the work of its practitioners (the Manuals of Practice) and that it would be making changes to its online case-management system (C3MS) that would better inform practitioners about how to manage cases in this online environment.

Families SA have indicated to the Committee that the issues about recognition of neglect, cumulative harm and case management have been considered and form part of its program of redesign. The agency has said that the adoption of the solution-based casework model<sup>2</sup> will strengthen practice, build workforce skills and enhance the ways in which it works with children and their families.

The Committee has monitored Families SA's progress with its redesign through correspondence, meetings with senior executives and attendance at briefings about the redesign. It has also requested to be updated on progress with the recommendations arising out of the review of the six seriously injured children. The Committee will ask that those updates include evidence of implementation of redesigned practice and how Families SA now investigates cases which present with indicators of neglect.

With system reform on such a broad scale the Committee anticipates that it may be several years before its reviews identify any real changes to, for example, case management practices, or better service provision in rural and remote areas.

1 South Australian Government Response to Recommendations Regarding the Case of Six Children with Serious Injuries referred by former Minister for Families and Communities under Section 52N(2) of the Children's Protection Act 1993. <http://www.decd.sa.gov.au/aboutdept/files/links/GovernmentCDSIRCResponse.pdf>

2 DECD newslink 17/7/2013 Solution Based Casework [http://www.decd.sa.gov.au/mediacentre/a8\\_publish/modules/news\\_64\\_new/details.asp?ID=1496&](http://www.decd.sa.gov.au/mediacentre/a8_publish/modules/news_64_new/details.asp?ID=1496&) Accessed September 2014.

### 1.1.4 Child protection and the health system

As part of the 2012 review of six seriously injured children, the Committee made recommendations about General Practitioners and their responsibilities as mandated notifiers and about the importance of health staff in hospitals and community health services receiving training that would enhance their awareness and understanding of the risk factors associated with neglect.

The Committee has requested that SA Health provide it with information about what has been done to promote knowledge and training programs for General Practitioners that address their mandated responsibilities. SA Health said it would work closely with Medicare Locals to achieve these goals. The Committee will seek a progress report in 2014–15.

SA Health was also asked to confirm that all new and existing staff and volunteers in hospitals and community health services have completed Child Safe Environment training.

### 1.1.5 Interagency communication

The review of six seriously injured children raised the issue of effective inter-agency communication, an issue that the Committee has pursued with all agencies, through its recommendations, over a number of years. With regard to the six seriously injured children and the other children in that household, it was the Committee's view that had all agencies gotten together and asked the right questions, early investigation of the children's circumstances would have been seen as imperative. A recommendation about the exchange of information between Families SA, SA Police (SAPOL) and other agencies was made. The Committee has asked Families SA for information about its involvement with the newly formed Multi-agency Protection Service (MAPS). MAPS is an integrated, early intervention gateway for sharing information about child protection and domestic violence issues and jointly identifying and directing appropriate agency responses.

### 1.1.6 Housing and homelessness

Monitoring progress with improvements to service provision around housing and homelessness is associated with two reviews submitted in 2012. One was in relation to a young person whose death occurred against a background of disengagement from school, high risk behaviours and homelessness, and the other was the Committee's review into six seriously injured children.

Although the issues were quite different in those two cases, responding to them requires a cooperative endeavour between Housing SA, located in the Department for Communities and Social Inclusion (DCSI) and the Department for Education and Child Development (DECD). Access to education is a key factor in the lives of children and young people, and disengagement from this system is disadvantageous to the health and wellbeing of children and young people and places them at greater risk of harm.

#### *Housing*

The Committee has had an active and productive exchange of information with DCSI about the recommendations arising from the review of six seriously injured children that was submitted to the Minister for Education and Child Development in 2012.

One of the main concerns arising from that review was the importance of knowing something about the safety of children in overcrowded households and about Housing SA's role in the recognition of that, and response to it. The Committee was in no doubt that overcrowding placed children at risk. It was especially concerned about those cases where tenants might be actively avoiding scrutiny of Housing SA or other Government agencies.

## SECTION ONE: IMPROVING THE SAFETY AND WELLBEING OF SOUTH AUSTRALIAN CHILDREN

Housing SA reported that it has made progress with work that seeks to identify and support 'high risk tenancies' including:

- A case work support program created to assist tenants with high or complex needs who are at risk of tenancy failure
- A new practice framework for the delivery of specialist services. For example, from early 2014 Housing SA will begin a program where the frequency of home visits will be based on an assessment of a tenant's needs.

The review of six seriously injured children highlighted the importance of opportunities for agencies to share information about high risk cases and the Committee sought information about Housing SA's involvement in such forums. Housing SA indicated that it was involved in and contributed to information sharing including Memoranda of Understanding (MOUs) with several agencies such as SAPOL, and that it was involved in MAPS.

It was stated that both DCSI and DECD were committed to working together to provide a better response to vulnerable children who live in Government-owned housing and are at high risk, and that an MOU was being developed between these agencies to further this commitment.

The Committee intends to continue this active and productive exchange of information with DCSI. It is currently awaiting answers to questions about:

- Whether the risk assessment tool associated with the new practice framework for the delivery of specialist services is structured to ensure that the presence of children in the household is carefully investigated and that their vulnerability and the risks associated with their presence in that household are adequately assessed

- The time-frame for the delivery of this service
- The time-frame for the completion of the MOU between DCSI and DECD.

The Committee also commented on the forums available to Housing SA for information sharing about clients in common; it reminded this agency that the harm and trauma to children arising from chronic neglect may not necessarily involve family violence, parental mental health problems or drug use.

### *Homelessness*

At the Committee's request, both DCSI and DECD have continued to provide information about progress being made to improve service provision to homeless children and young people, and about the collaborative efforts between these two agencies. In October 2013, the Minister for Education and Child Development provided a response on behalf of these two agencies stating that:

*...in late 2012 DECD and DCSI agreed that the most effective strategy to support the CDSIRC recommendations around Case 498 would be the establishment of a Protocol between both agencies to develop a streamlined process between schools and homelessness service providers to ensure that young people who are experiencing homelessness and disengagement from education are linked into appropriate services and collaboratively case managed and supported.*

Progress has been made with this protocol. In December 2013, both agencies gave *in principle* agreement to develop a strategic and governance framework for all agreements between DCSI and DECD that emphasises a collaborative approach in keeping with children's and young people's needs.

Further to this, DCSI had consulted with DECD and Specialist Homelessness Services (SHS) in the development of guidelines for collaborative practice between these services to ensure that homeless young people or those at risk of homelessness, remain connected to school and education. DCSI said that it was progressing with training within SHS about the Homelessness Case Management Framework which began in January 2014 and was expected to conclude in October 2014.

DECD provided further information about the ways in which its local and regional partnerships are used to provide services that enable homeless young people to remain linked to education. The Committee will seek an update in six months about particular aspects of these programs.

### 1.1.7 Chronic school non-attendance

It is the Committee's view that all children have a fundamental right to access to education and that to deprive a child of education is to hamper that child's overall development including their social development. School attendance acts as a powerful protective factor in the lives of children. Information about rates of child death show that there are far fewer deaths, from any cause, when children are of an age to attend school.

As part of the review of six seriously injured children, recommendations were made about the identification of children who were not attending school. One of the issues identified was the possibility that children transferring between states could remain unknown to the education system if parents chose not to enrol them. The response provided by DECD in May 2013 about current interstate student transfer protocols did not address this issue. DECD said that this was an issue requiring cooperation

between all states and territories and it would be raised at the Australian Education, Early Childhood Development and Youth Affairs Senior Officials' Committee (AEEYSOC). DECD was encouraged to provide AEEYSOC with the Committee's recommendations.

Families SA identified opportunities through the *National Framework for Protecting Australia's Children 2009–20*<sup>3</sup> that would drive improvements across all systems and jurisdictions to improve information sharing about children at risk. It also identified the *Information Sharing Protocol* between the Commonwealth and Child Protection Agencies as one that would allow the disclosure of necessary information to assist statutory authorities to locate and assess children at risk.

The Committee has requested that Families SA provide information about the numbers of children at risk who have been successfully located using this protocol and about improvements under the *National Framework* that have contributed to the identification of children moving between jurisdictions.

DECD stated that it was awaiting the outcome of a '90 day change project' designed to identify ways to address issues for students who are chronic non-attenders. The potential for legislative change and for the involvement of other agencies who provide services to children and families would be examined as part of this project. In its last correspondence with DECD the Committee queried whether DECD had any plans for other, more immediate means to address chronic school non-attendance.

<sup>3</sup> *Protecting children is everyone's business: the national framework for protecting Australia's children 2009-20*. <http://www.dss.gov.au/our-responsibilities/families-and-children/publications-articles/protecting-children-is-everyones-business> Accessed September 2014.

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DECD also outlined its 'High Risk Chronic Non-attenders' protocol which, it was stated, covered situations where a child may be at high risk of harm and there was no current knowledge of their wellbeing. Given the importance that the Committee places on improvements to policies and practices about chronic non-attendance, the following information has been requested:

- Clarification about the length of time that must elapse before action under DECD's non-attenders protocol is taken
- Information that shows whether action under this protocol has resulted in improved outcomes for 'high risk chronic non-attenders'
- A progress report from Families SA about a review of an administrative arrangement that was said to be able to guide Families SA and school staff about when and how to jointly respond to non-attendance
- Details about the DECD 'Whereabouts unknown' process and the agency's intention to cross-match DECD with Australian Government data to ensure that children at risk are found.

Through the exchange of information about these issues between the Committee, DCSI and DECD, the Committee will continue to advocate for effective strategies to address chronic school non-attendance.

### **1.1.8 The management of child protection emergencies and the support of children who have experienced trauma**

In the 2012 review of six seriously injured children, the Committee recommended that an over-arching emergency response plan should be developed and adequately resourced to respond to service and resource requirements where a large number of children are in need of urgent and intensive care.

Families SA was identified as the appropriate agency to develop and manage the implementation of such a plan. It indicated that a plan was 'currently engaged,' had multiple layers of governance and, in response to the Committee's recommendations, had a strong focus on responding to each child's therapeutic needs, protecting children's privacy and ensuring a smooth transition from an emergency response phase to longer-term strategies for each child. When complete, Families SA said there would be emergency management and response training exercises.

In addition to the emergency plan, Families SA said that there would be a Child Protection Emergency Response Case Coordination Plan that would be implemented alongside a Complexity Assessment Tool for each child.

It is 12 months since Families SA outlined its response to these recommendations and the Committee has asked for a copy of the plan.

### **1.1.9 Residential care service agreements**

Families SA indicated that a major revision of its residential care service agreements occurred in 2012 and it was committed to ensuring that service agreements with non-government organisations and agency partners would clearly articulate responsibilities that ensure all children's needs were met and sufficient monitoring of performance was undertaken. Improvements included 'complexity ratings' for each child.

***The Committee has asked Families SA for information about how changes to service agreements have impacted on the quality of residential care provided to children, in particular how these changes have improved the selection and training of new and specialist foster care and residential care service staff and how they have influenced decisions about the necessary qualifications and experience of staff and the training, support and supervision they receive.***

### **1.1.10 Children with disability**

With the development of the Disability Register in 2012–13, the Committee reported that since 2005, about one third of the children aged 1–17 years who died had some kind of disability or disabling medical condition. In-depth reviews of two deaths of children with disability were undertaken in 2013–14. These reviews highlighted some issues faced by children with a disability and their families.

Every child should receive the services they require to live a fulfilling life. The families of children with significant disability should themselves receive services that will support them in their role as carers. It should not be necessary for a family to have to make a decision about relinquishment just to ensure that their child receives the services they need. It should certainly not be the case that the mental health of a carer becomes so compromised that, through neglect or other means, the child or young person dies or is seriously injured.

The Committee has made recommendations that seek to address these issues including:

- The adoption of processes to ensure the health and wellbeing of siblings and parents are assessed and appropriate supports provided
  - Provision of expert services to help carers and teaching staff work with children with disabilities who have challenging behaviours
  - The adoption of processes to assess and implement long-term care plans which take into account the parents' future capacity to care for their disabled child
  - The provision of integrated and comprehensive services in rural areas.
- The Committee remains deeply concerned about the issues that were raised in the two reviews it undertook during 2013–14. With the launch of the National Disability Insurance Scheme (NDIS) in South Australia, it was anticipated that there would be significant improvements in service delivery so that those who are most vulnerable would not continue to experience the worst outcomes. However, in light of the February 2014 review of the capabilities of the NDIS<sup>4</sup> the Committee continues to have these concerns for these most vulnerable children.
- Models of care provision that have been integrated and coordinated both within and between agencies

4 A review of the capabilities of the National Disability Insurance Agency January 2014 p 7  
[http://www.ndis.gov.au/sites/default/files/documents/capability\\_review\\_2014\\_3.pdf](http://www.ndis.gov.au/sites/default/files/documents/capability_review_2014_3.pdf)  
 Accessed September 2014.

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A letter was received from the Minister for Disability, supporting the development of the Disability Register. With reference to the NDIS, the Minister noted it 'will change the way disability services are assessed and delivered'. The Minister also acknowledged that Disability SA and Disability Services played an important role in overseeing the delivery of services to children with disability, especially vulnerable children, and that this role was not likely to continue under the NDIS.

This response confirmed the Committee's concerns about service delivery to vulnerable children with disability under the NDIS. However, as an entity established under South Australian legislation, the Committee is not able to request information from, or make recommendations that will affect the NDIS. The Committee will seek the support of the Minister for Education and Child Development and the Minister for Disability to bring issues about service delivery to vulnerable children and their families to the attention of the NDIS.

The Committee's reviews highlighted the complex needs of children with severe disabilities and the potential for families to be overwhelmed as they face the challenges of trying to meet those complex needs.

Under a National Partnerships Agreement, DECD and DCSI are currently trialling a service provision model for children with complex needs based on the Team Around the Child (TAC) model of care. The 2013 report about this project indicated that there were consistently positive responses from parents and carers who trialled this approach. They valued their inclusion in the process of planning and goal-setting for their child. Schools confirmed that the model promoted better communication between the family and service providers which ultimately contributed to achievement of the child's goals.

The Committee views the TAC model as a promising approach to meeting the high and complex needs of vulnerable children with disability. It addresses the challenges of collaboration and integration of service response and recognises the need for case management to be led by one agency. However, the Committee anticipates that the NDIS model of service delivery may make such integration more difficult to achieve.

### 1.1.11 Aboriginal children

It is the Committee's view that service providers must demonstrate appropriate cultural sensitivity and competence in their work with Aboriginal children and their families. The vulnerability of Aboriginal children is well demonstrated by the difference in the deaths rates between Aboriginal and non-Aboriginal children – Aboriginal children are three times more likely to die than non-Aboriginal children.

The review of six seriously injured children highlighted the risks to children of neglect or other harm by virtue of overcrowding, poor living conditions or chronic truancy. These issues must be addressed by adopting the same standards of service for all children irrespective of their cultural background.

In relation to the recommendations that the Committee made in that review the Minister sought responses from four agencies: SAPOL, SA Health, DECD (Families SA) and DCSI. Each agency outlined cultural inclusion, respect or reconciliation frameworks and plans designed to guide policies, programs and service delivery to Aboriginal people. For example SA Health requires Aboriginal Health Impact Statements for all policies and programs to ensure they meet the health needs of Aboriginal people. In addition it has an Aboriginal Health Care Plan.

Families SA expressed confidence that the solution-based casework approach it is currently adopting as part of its program of redesign has *'underlying principles (that) have strong synergies with the values and ideals of Aboriginal families and communities and can be adapted to meet the needs of local communities.'*

In terms of workforce capacity and competence it was evident that all four agencies had in place (DCSI, SA Health, SAPOL) or were planning (Families SA) specifically tailored Aboriginal employment strategies designed to improve recruitment, retention, competence and capacity of Aboriginal employees.

The Committee also enquired about the ways in which each agency would know if it was meeting its goals in terms of service delivery to Aboriginal people. DCSI had monitoring and reporting processes in place for each of its strategies and SA Health also had processes in place to monitor implementation of its Aboriginal Health Care Plan.

Families SA had reviewed its capacity to provide culturally appropriate services and found that it needed to address issues of cultural competence and confidence. It now has an Aboriginal Programs and Services Development Unit and is developing an Aboriginal Reporting Framework which, it said, would help to assess the impact of its initiatives on its capacity to provide appropriate services to Aboriginal families.

The Committee draws confidence from these agency reports. Each has a recognisable intent to provide culturally appropriate services to Aboriginal people – whether it be health, child protection or policing services – and each monitors implementation of its overarching policies.

In this regard, the Committee's reviews provide invaluable and objective feedback to agencies in terms of how their policies are impacting on outcomes for individual children and their families. Also, through its yearly statistical analysis of child deaths the Committee can monitor any improvements in the gap between the death rates of Aboriginal and non-Aboriginal children. This gap has not yet shown significant improvement over the nine year reporting period.

The Committee will always have, as a priority, consideration of the ways in which Government agencies are providing services to Aboriginal children and their families and through its reviews will continue to make recommendations designed to improve such service provision. The Committee will publish a Special Report in its 2014–15 Annual Report about the deaths of Aboriginal children.

### **1.1.12 Young people and suicide prevention**

Work to address the issue of suicide and young people has sought to reconstruct key events in the lives of young people as a means of identifying opportunities for intervention and prevention across the life span rather than just at the point of 'imminent risk'. This analysis suggested that young people who suicide fall into one of three distinct groups (see Section 2.2). The work has highlighted the importance of considering different avenues of intervention, many of which are not aimed specifically at young people at risk of suicide.

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The Committee has considered the following intervention and prevention issues in relation to each of three groups:

### Group 1

Intervention and prevention efforts should be focused on:

- Infancy – strengthening parenting capacity within families
- Early childhood – when learning problems are identified
- Transition to high school – assistance with ‘learning challenges’
- Youth specific programs to promote/create engagement
- Integrated service delivery

This group can often be missed by suicide prevention strategies focused on risk factors, tipping points and imminent harm. The analysis noted that young people who have died in high risk circumstances (e.g. transport crashes, falls from a high place) often have life histories similar to those apparent in this group of young people who died by suicide.

### Group 2

Intervention and prevention efforts should build on existing engagement and include:

- Adult and youth mental health services providing support for families
- Assertive outreach
- Support for schools
- Coordination between school and mental health service support
- Exploring the role of work place
- Youth specific services to address romantic relationship challenges and to provide support for sexually active young people.

### Group 3

There were few if any indicators of potential challenges in the life charts of this group of young people and intervention and prevention might need to encompass:

- Population based prevention programs
- Providing information about ‘crisis’ support
- Access to help for young people during the critical hours when they appear to decide to suicide
- Consideration of the role of social media and suicide publicity
- Providing support for parents and friends and advice about suicide to the community.

Presentation of the key considerations arising from this work have been made at meetings with the South Australian Inter-Ministerial Advisory Committee on Suicide Prevention, the State Coroner, and paediatric grand rounds at Flinders Medical Centre and the Women’s and Children’s Hospital. The Committee will continue to seek opportunities to present its findings to policy-makers, researchers and practitioners.

## 1.2 Keeping children safe

The Committee has made comment on, and monitored changes across, a broad range of issues related to the safety of children.

### 1.2.1 Ventriculoperitoneal (VP) shunt malfunction

Following its 2013 review of issues about recognition and response to VP shunt malfunction, the Committee wrote to the Chief Executive of SA Health seeking information about the management of children with blocked VP shunts.

In particular the Committee asked whether current clinical guidelines about management of VP shunts was available in all emergency departments across South Australia where a child might present with signs of raised intra-cranial pressure. It also inquired whether the WCH radiological imagery system was accessible across all South Australian hospitals.

SA Health advised that the management of children with VP shunts was only undertaken by three local, metropolitan Health Networks, who all had access to information about the management of raised intra-cranial pressure on the WCHN intranet.

The Committee sought to clarify how this standard of care extended to children who presented to rural or remote hospitals. SA Health has responded to these queries indicating that parents of children in rural and remote locations are responsible, on presentation at a local hospital with concerns about their child's VP shunt, for requesting that the hospital staff contact WCH for management guidance.

The Committee also inquired about access to real time imaging and SA Health indicated that WCHN was intending to make computerised radiological imagery available in real time to treating physicians managing children with VP shunts in non-WCHN locations.

The Committee's review of the management of VP shunt malfunction in children showed that over time, SA Health has made significant improvements to its standards of care for these children. Any further deaths involving VP shunt malfunction will be carefully considered in light of these changes to practice and policy.

### 1.2.2 Homebirthing

In 2012–13 the Committee wrote to the Minister for Health supporting the introduction of legislation that would ensure women received antenatal, intrapartum and postnatal care from an appropriately qualified health or medical practitioner.

In October 2013 the Health Practitioner Regulation National Law (South Australia) (Restricted Birthing Practices) Amendment Bill was passed in both Houses of Parliament and is awaiting assent. The Submission from the Committee was noted in the second reading speech as one of 25 submissions that assisted with the drafting of the Bill.

The Committee remains of the view that legislative measures should be used to ensure infants are born as safely as possible in the home setting.

### 1.2.3 Neonatal sepsis

In 2012 the Coroner released recommendations concerning an inquest into the death of an infant less than one day old.<sup>5</sup> The cause of death was associated with neonatal sepsis which the Coroner found could have been prevented had the infant received antibiotics immediately after birth.

Both the Coroner and SA Health made recommendations about the care of infants that could prevent neonatal sepsis. As at the end of June 2014, the Committee was awaiting a response from SA Health about the implementation of both its own recommendations and those of the Coroner.

<sup>5</sup> *Inquest into the death of Trinity Kison* <http://www.courts.sa.gov.au/CoronersFindings/Lists/Coroners%20Findings/Attachments/469/KISON%20Trinity%20Isabel.pdf>  
Accessed September 2014.

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### 1.2.4 Children and pregnant women living in rural and remote areas – the Patient Assistance Transport Scheme (PATS)

Death rates for children living in regional rural and remote locations in South Australia are markedly higher than that of children living in major city areas. The Committee has undertaken several reviews where isolation and distance made it difficult for families to access the best care for their child.

In October 2013 the Committee provided feedback to SA Health's consultation about the Patient Assistance Transport Scheme (PATS). It noted that PATS had provided important assistance for families to overcome isolation and distance barriers. It was concerned that the consultation paper did not mention children or address issues related to the needs of children and their families or women with a high risk pregnancy living in rural and remote areas. It also raised the concern that remuneration for transport to a metropolitan centre for medical care provided to a sick or disabled child should reflect the real cost of that transport. The Committee considered that Aboriginal families, vulnerable families in rural and remote areas and those living the furthest away should be assisted to equitably access specialist medical services. The Committee awaits the final report arising from SA Health's review at the end of 2014.

### 1.2.5 Health information for families

The Committee undertook a brief review into the circumstances leading up to the death of a child whose parents, in the hours before the death, had sought advice from a medical help line. The Committee noted that the parents were referred to a hospital where there was no emergency or paediatric service and no doctor on site. A letter was sent to the Australian

Government Health Minister seeking to ensure that the lists kept by Government-run health lines were up-to-date. The advice received from the Minister stated that service directories were 'maintained by a team dedicated to ensuring the service provider information is current and correct' and a list was provided for the Committee's scrutiny.

### 1.2.6 Severe Domestic Squalor

Since November 2013 the Committee has attended meetings of the Severe Domestic Squalor Interagency Working Group. The Committee considers its role on the Interagency Group as one of advocating for the recognition of the importance of securing the safety and wellbeing of children in situations of severe domestic squalor. The group is hosted by SA Health and has representatives from a broad range of State, local and non-government agencies including Mental Health and Substance Abuse, SA Health, Local Government, Disability SA, Housing SA, RSPCA, SA Ambulance Service, Uniting Communities and Red Cross.

The Committee has reviewed cases where the conditions that children were found to be living in would be assessed as 'severe domestic squalor.' The reasons for these conditions were complex and not always related to the mental health of any one individual but seemed more about a history of poverty, deprivation and chaotic lifestyles that ultimately contributed to the fatal, or near fatal, neglect of a child or children. Had the plight of the child or children become known to an authority earlier the outcome for the child or children may have been different.

In addition, the Committee has reviewed many deaths where well coordinated interagency collaboration was lacking, despite interagency protocols, policies and guidelines.

In most cases, what seemed to be needed was the appointment of a person who was responsible for managing the case and making sure that each agency understood its responsibilities, followed through on its agreed actions, and evaluated the impact of the actions that were taken. It is the Committee's view that one agency must take a case management role especially where more than one agency is working with the individual or family. It must be clear that this agency accepts the responsibilities that go along with this role.

The recommendations the Committee has made in its reviews and annual reports about issues such as housing, truancy and the needs of large families, reflect the relationship between a child's housing conditions and neglect and trauma.

SA Health has produced a set of guidelines to support local government environmental housing officers to understand, assess and manage cases of severe domestic squalor in South Australia.<sup>6</sup> SA Health followed advice provided by the Committee that much higher priority be given to ascertain whether children are living in a household and ensuring their safety if they are. The Committee liaised with Families SA and information was added to the Guidelines about key indicators of child abuse and neglect and guidance about the actions that should be taken if these indicators were apparent.

In 2015 the Committee will seek further changes to the Guidelines that ensure attention is appropriately drawn to securing the safety and wellbeing of children in situations of severe domestic squalor.

### 1.2.7 Young children and transport safety

The Motor Accident Commission (MAC) has carriage of South Australia's major transport safety campaigns. Following its review of transport deaths in children under five years of age, the Committee sought confirmation from MAC about the key safety issues for young children and about the ways in which MAC sought to address these issues.

MAC confirmed the findings from the Committee's review of these deaths. In comparison to the death rate for other age groups like 15–19 year olds, MAC considered that deaths of children under five years were relatively low and that these deaths were not associated with 'extreme behaviours' such as drink driving or speeding but were associated with 'errors of judgement that have led to tragic consequences'.

It was MAC's view that its actions and strategies aimed at improving overall road safety also have the potential to improve road safety for young children and include:

- Advocacy for lower speed limits
- Campaigns addressing driver inattention
- Advocacy for purchase of newer cars with improved safety features
- Working with industry on pedestrian protection in car design
- Encouraging fitting and use of appropriate child restraints.

MAC said that its planning for future road safety campaigns would consider the safety of young children and identify further opportunities to engage with the community about these issues.

<sup>6</sup> *A foot in the door: stepping towards solutions to resolve incidents of severe domestic squalor in South Australia* [http://www.sahealth.sa.gov.au/wps/wcm/connect/f8561b804fbc211e98559a5cbc1ea1e9/Hoarding+Guideline\\_FINAL\\_23\\_Aug\\_13.pdf?MOD=AJPERES&CACHEID=f8561b804fbc211e98559a5cbc1ea1e9](http://www.sahealth.sa.gov.au/wps/wcm/connect/f8561b804fbc211e98559a5cbc1ea1e9/Hoarding+Guideline_FINAL_23_Aug_13.pdf?MOD=AJPERES&CACHEID=f8561b804fbc211e98559a5cbc1ea1e9) Accessed September 2014.

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### 1.2.8 Quad bikes

Two children, both passengers, have died in quad bike crashes since 2005. The Attorney General's attention was called to the Committee's view that children under 16 years be prohibited from using quad bikes, either as drivers or passengers, and that laws about safety measures such as compulsory helmet use and crush protection devices be considered. Information about efforts by child death review committees in other states, especially NSW, was also brought to the Attorney General's attention as a means of highlighting the importance of this issue nationally.

The Attorney General indicated that the Committee's findings were being considered by his department and that:

*He would be inclined to support a national approach to preventing deaths from quad bike accidents including raising public awareness about the risks of quad bike use by children and the introduction of engineering controls as suggested in the NSW Child Death Review Team's Annual report 2012.*

In August 2014 the Centre for Automotive Safety Research in South Australia, announced that it was undertaking an 18 month research project investigating the circumstances and causes of quad bike crashes on farms. This research has the potential to address issues of quad bike design and engineering that may reduce deaths and serious injuries for quad bike users.

### 1.2.9 Infants and safe sleeping

Trends in the incidence of sudden unexpected deaths of infants and the relationship to unsafe sleeping environments continue to be monitored. In the nine year period between 2005 and 2013, 69 infants have died whose sleeping environment was unsafe in one or more ways. It is crucial that the South Australian Safe Infant Sleeping Standards<sup>7</sup> continue to be updated and that practitioners in all agencies are trained so that they can identify and discuss with parents and carers the best possible ways to provide a safe sleeping place for their infant.

The Committee has supported the introduction of 'safe mattress' testing into sudden unexplained death scene investigations. This project is being led by SA Health's Systems Performance Division and implemented by SAPOL.

#### 1.2.10 Swimming pool legislation

In the nine year period 2005–13, 25 children have drowned; ten of these deaths were in domestic swimming pools. The Committee noted last year that lapses in safety precautions and non-compliance with legislative requirements about swimming pool safety are major contributors to the deaths of children in domestic swimming pools.

Following the Attorney-General's public consultation about monitoring compliance for swimming pool safety, swimming pool owners must now provide details about safety barriers when they lodge their application to construct a pool with their local council. Council inspections are required when these safety features have been completed.<sup>8</sup>

<sup>7</sup> South Australian Safe Infant Sleeping Standards <http://www.sahealth.sa.gov.au/wps/wcm/connect/a965e20048a319a3bafcf7675638bd8/4858-Safe+Sleeping+Standards.V9.2.PROOF.PDF?MOD=AJPERES&CACHEID=a965e20048a319a3bafcf7675638bd8> Accessed September 2014

<sup>8</sup> Advisory notice 07/13 Swimming pool safety – Council inspections of new swimming pools. [http://www.sa.gov.au/\\_data/assets/pdf\\_file/0016/44116/Advisory\\_Notice\\_Building\\_Council\\_inspections\\_of\\_new\\_swimming\\_pools.pdf](http://www.sa.gov.au/_data/assets/pdf_file/0016/44116/Advisory_Notice_Building_Council_inspections_of_new_swimming_pools.pdf)

The Committee supports ongoing efforts within the South Australian Government to promote, enforce and monitor isolation pool fencing including regular inspection for maintenance of safety features.

### **1.3 The voice and view of children – a Children’s Commissioner in South Australia**

The Committee continued to provide feedback to the Minister for Education and Child Development about legislation to establish a Children’s Commissioner. Throughout this process the Committee remains of the view that such legislation should:

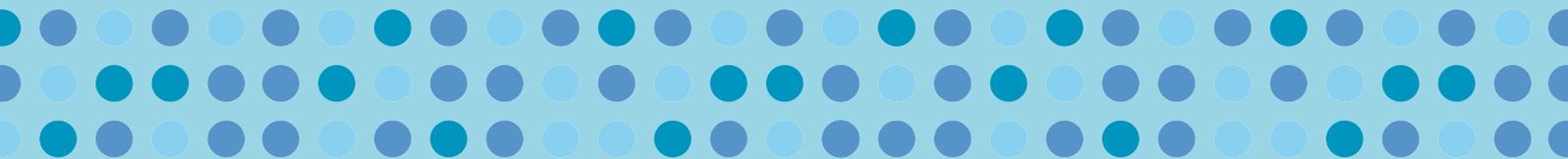
- Take as its foundation the rights of children and young people and that the Objects, Principles and Statutory Duties should reflect this foundation
- Ensure that the voice of children and young people is fostered and heard
- Make the Commissioner, first and foremost, an advocate for these rights
- Clearly articulate the relationship between the Commissioner, and other bodies established under this legislation, and with the Guardian for Children and Young People, and the State Ombudsman.

The final draft of the legislation was not available at the time of writing.

### **1.4 Continuing the Contribution to Systemic Change**

The ways in which child protection, education, health and housing services are delivered have a significant impact on the safety and wellbeing of children, particularly vulnerable children. This impact is felt in the provision of timely antenatal services through to intervention for young people at risk of homelessness. Through its monitoring and review processes, the Committee will continue to contribute to systemic change that will improve the provision of such services.

Through these same processes, it will also continue to seek to influence change to legislation, policies and practices that impact on children’s safety – in such diverse areas as medical practices, transport policy and swimming pool legislation.



## SECTION TWO

### CHILD DEATH REVIEWS 2013–14

#### ***S52S – Functions of the Committee***

*a) to review cases in which children die or suffer serious injury with a view to identifying legislative or administrative means of preventing similar cases of death or serious injury in the future.*

*Children's Protection Act, 1993*

## SECTION TWO: CHILD DEATH REVIEWS 2013–14

Part 7C of the *Act* gives the Committee authority to undertake the in-depth review of cases of child death and serious injury. The objective of such reviews is the identification of systemic issues which might give rise to changes in legislation, policies, practices or procedures that will reduce the likelihood of deaths or serious injuries in similar circumstances. The Committee has adopted a process for the identification of cases for review and for the conduct of reviews (see Section 5.2).

In 2013–14 two in-depth reviews, both about children with disabilities, were completed in addition to the ongoing analysis of cases of youth suicide and reviews about particular service improvement issues.

### **2.1 In-depth reviews about the deaths of two children with disability**

Two reviews were submitted in 2013–14. One considered the circumstances of death of a child with severe physical and intellectual disabilities and the other was about a young person with significant intellectual disabilities and very challenging behaviours.

One of these reviewed cases illustrated how timely, high quality services when made available to a family, can result in extension of life expectancy and a better quality of life for the child. Again however, there were challenges for the child's parents and care providers. The child who was the subject of this review had severe cerebral palsy.

Since 2005, the Committee has submitted several reviews to the Minister that have considered the death of a child or young person with severe, chronic disabilities affecting all aspects of their life including their physical and intellectual capacities and involving very challenging behaviours. In these cases the Committee has noted the potential for obvious and significant damage to adult and child members of the families of origin of children with disability. Parents and siblings are reported to have suffered significant mental health problems. The stress in the lives of some carers appears to have resulted in a process of disengagement and depression. In some cases, despite being devoted to their children, carers took steps that resulted in the untimely death of their child. In another case a parent relinquished the care of their disabled child to the State, in order that this child received the care they required. The recommendations arising from these reviews are provided on the next page.

## In-depth review: A young person with disability

*Submission date: May 2014*

### Issues Arising from the Reviews

All agencies expected this family to provide a high level of care for the young person. There was no assessment of:

- The family's ability or capacity to provide this care
- The impact of the carer role on their mental health and wellbeing
- The need for higher levels of support.

The family expressed concerns about the future, but an assessment of 'unmet need' seemed to have no impact on service provision. The family had difficulty finding suitable respite carers.

The school also needed a higher level of guidance and support to manage the young person's challenging behaviours.

### Recommendations – Review 1

#### *Recommendation 1*

Disability SA consider the mental and physical health of carers and siblings as part of its assessment process when prioritising needs, and advocate for any necessary supports.

#### *Recommendation 2*

Disability SA demonstrate how it intervenes early in a child's life such that the unique needs of each child are assessed and met.

#### *Recommendation 3*

Disability SA demonstrate that completion of any unmet needs assessment or any other form of assessment will:

- 3.1 Result in the prompt provision of the resources necessary to accommodate for a child's individual needs at the appropriate time and that the results of the assessment be provided to parents and updated if the child's needs change.
- 3.2 Directly affect the timely provision of services to the family.

## SECTION TWO: CHILD DEATH REVIEWS 2013–14

### *Recommendation 4*

Disability SA outline the escalation process for assisting families who are having difficulties contracting respite care staff because of the challenges posed by their child's behaviour.

### *Recommendation 5*

DECD and Disability SA demonstrate how it supports school staff to develop, implement and monitor behaviour change programs for children and young people with disabilities, especially intellectual disabilities, who have challenging behaviour and who are not able to communicate their needs.

### *Recommendation 6*

Disability SA demonstrate how it provides assessment, including medical or psychiatric assessment, that addresses the reasons for change in the behaviour of children and young people with disability who are not able to communicate their needs.

### *Recommendation 7*

DECD demonstrate how it undertakes holistic assessments that precede DECD placement decisions for the transition from kindergarten to primary school and from primary to secondary school services. This assessment, amongst other things, must:

- 7.1 Give careful consideration to the training and skills of DECD staff to ensure they are able to meet the developmental needs of each student.
- 7.2 Incorporate working with the child's family to support them to consider the available options and make decisions that are in the best interests of their child.
- 7.3 Take into account the impact of long travel times and if necessary provide guidelines for coping with long travel times.

### *Recommendation 8*

Disability SA develop guidelines for the closure of files when a child has died, to ensure that case notes cannot be updated after the death; but allow for supplementary information to be submitted.

## In-depth review: A child with profound physical disability

*Submission date: May 2014*

### Recommendations – Review 2

#### *Recommendation 1: Co-ordinated care*

A co-ordinated model of care such as The Team around the Child approach should be adopted in the care of any child with profound disabilities. Agencies adopting this approach should be able to provide evidence of:

- 1.1 How children with a profound disability are identified,
- 1.2 The ways in which the Team around the Child approach is implemented for each child,
- 1.3 How the progress and outcomes for such children with profound disabilities are reviewed and monitored and services escalated when needed,
- 1.4 Assessment and regular review of parents' or caregivers' ability to provide for the needs of such children.

#### *Recommendations 2 and 3: Rural services*

- 2.0 Relevant service providers should ensure there is local case management for children with disabilities living in rural areas and should be able to demonstrate that:
  - 2.1 Every child with a profound disability living in a rural area has a case management plan in place
  - 2.2 Case management decisions are made locally for these children in partnership with the family.
- 3.0 When necessary, additional resources should be allocated to provide comprehensive case management services at a local level.

#### *Recommendations 4 and 5: Interagency collaboration*

- 4.0 Timely and responsive service delivery to children with profound disabilities and their carers relies on effective interagency collaboration. Each agency providing services to any child with profound disability must be able to provide evidence of:
  - 4.1 How it works with the other agencies providing services to the child and their family,
  - 4.2 Engagement with the requirements of the case plan,
  - 4.3 Participation in case reviews,
  - 4.4 How each agency monitors the quality of the management of each case,
  - 4.5 The ways in which each agency responds to changes in the child's and family's needs,
  - 4.6 How each agency communicates with the family.
- 5.0 Current treating service providers should have regular meetings at a frequency that reflects the needs of children with profound disabilities and their families.

#### *Recommendation 6: Special food and equipment*

The case manager must designate a clinician who is responsible for:

- 6.1 Organising the provision of special food and other necessary equipment to families caring for a child with a disability.
- 6.2 Assisting families experiencing economic hardship who are caring for a child with a disability to apply for financial assistance towards the cost of specialised food and other necessary equipment.

## SECTION TWO: CHILD DEATH REVIEWS 2013–14

### 2.2 Continuing analysis about suicide and young people

Suicide deaths are the rare end point of self-injurious behaviour. There are many forms of this behaviour. Self-harm is 40–100 times more prevalent than suicide in young people who may use it as a coping strategy that allows them to continue to live.<sup>10 11</sup>

Analysis of the reasons for suicide in young people is often based on knowledge of the risk and protective factors operating in their lives. Models that consider risk factors, warning signs, tipping points and imminent risk are often used as the basis for suicide prevention strategies, and models for intervention e.g. the SA Suicide Prevention Strategy.

In its current review of the suicide deaths of young people, all available records for the suicide deaths of 21 young people were considered. The aim of the review was to identify intervention and prevention points in the life of a young person that would lead to a better understanding of the best ways in which to provide services to young people who might be at risk of suicide.

'Life chart analysis' was used as a way of maximising the rich source of information held about each of these young people and as a means of identifying opportunities for intervention and prevention. This methodology was outlined in a paper by Fortune, Stewart, Yadav and Hawton (2007).<sup>11</sup> The Committee is committed to ongoing refinement of its methodology and analysis, however it has already provided a unique perspective about intervention and prevention for young people at risk of suicide.

This life chart analysis found that there were three distinct groups of life histories within the cohort of 21 young people:

#### Group 1

This group was characterised by multiple and complex problems occurring since birth or early childhood. Some of the significant factors in the life charts of these eight young people, all males, were:

- Limited parenting capacity at home, and little or no support available from home for the child/young person
- Significant upheaval in the family and lack of attachment and, later, engagement with family
- From early school years – multiple assessments, learning problems, multiple changes of school
- Challenging relationships – family, peers, romantic
- Poor transition to high school followed by increasing frequency and severity of school-based problems – truancy, suspensions, expulsion
- Housing insecurity, transience, homelessness
- Disengagement from home, school and family
- Alcohol and other drug use
- Often juvenile justice system involvement
- Multiple services involved including housing, welfare, child protection and mental health.

It was noted that in 'risk-taking' (non-suicide) deaths within the same age group (e.g. transport crashes or a fall from a high place) a similar pattern of multiple and complex problems, often occurring since birth or early childhood was evident.

9 Fox, C. & Hawton, K. (2004) *Deliberate self-harm in adolescence*. Jessica Kingsley Publishers: London

10 Nock, M.K., Prinstein, M.J. et al. (2009) *Revealing the form and function of self-injurious thoughts and behaviours: A real-time ecological assessment study among adolescents and young adults*. *J Abnormal Psychol.* 118(4): 816-827

11 Fortune, S. Stewart, A. Yadav, K. and Hawton, K (2007) *Suicide in adolescents: using life charts to understand the suicidal process*. *J Affect Disorders*, 100, 199-210

### **Group 2**

This group was characterised by emerging mental health issues such as depression and anxiety, which appeared to start in the teenage years. There were six young people in this group, three males and three females. Some of the significant factors in their life charts were:

- Some instability in family circumstances but one parent perceived as engaged and supportive
- Parental capacity limited (mental health, alcohol and other drug use, attempted suicide)
- Positive primary school years – actively engaged, good learner
- Issues emerging after transition to high school
- Challenges in peer relationships
- Emergence of mental health problems in early adolescence
- Deliberate self-harm and/or suicide attempt(s)
- Involvement with school counsellors/mental health services
- Changes of schools
- Suicide notes

### **Group 3**

This group had no recorded problems at home or at school and had no previous contact with services about mental health issues. There were five young people in this group, two males and three females. The life charts of these young people included:

- Unremarkable early years
- Stability at home, in friendships, at school
- Non-problematic transition to high school
- Friends described them as having a 'positive' approach to life
- No contact with services
- May have been exposed to suicide in their school communities

### **'No group'**

This group was formed because it was recognised that the Committee did not have sufficient information to be able to construct a life chart for these young people both of whom lived in remote or very remote locations. The Committee also recognised that it did not have a sufficient understanding of cultural issues and influences to decide how to interpret the limited life history of these young people.

The ways in which the Committee has utilised this information to address intervention and prevention issues are summarised in Section 1.

## SECTION TWO: CHILD DEATH REVIEWS 2013–14

### 2.3 Young children and transport safety

The Committee noted a significant decrease in the number of deaths resulting from transport incidents over the nine year period since 2005. This has contributed to an overall decrease in the number of deaths, on average per year, from 'external causes'.

Between one and three children under five years of age have died in transport crashes in each year since 2005, 17 children in total. Eleven were passengers in cars and six were pedestrians hit by a car, including toddlers in driveways, or were hit by other vehicles like a train. The circumstances of these deaths raised the following safety issues for children under five:

- The importance of using appropriate child restraints when children are passengers in cars
- Safe driving issues on rural roads
- Child safety and supervision at home and near roadways

The Committee wrote to the Motor Accident Commission about these issues and its response is detailed in Section 1.

### 2.4 Ventriculoperitoneal (VP) shunt malfunction

The Committee has considered the deaths of children between 2005 and 2013 where a VP shunt malfunction played a significant part in the circumstances leading to the child's death.

The Committee was aware that both the State Coroner and SA Health had undertaken investigation into the circumstances of these deaths and both agencies had made recommendations about improving SA Health staff's awareness about the identification and management of children presenting with signs of VP shunt malfunction.

The Committee reviewed the circumstances of the deaths known to them and also the range of recommendations that had been made by both the Coroner and SA Health since 2005 about the management of VP shunt malfunction.

It noted that the Coroner had made recommendations arising out of an inquest in 2004 about adequate training for clinicians in the recognition and management of VP shunt malfunction. SA Health made recommendations in 2005 and 2007 about the development of systems that would support recognition and management of altered states of consciousness in children across South Australia, and about the review of morbidity and mortality data relating to VP shunt malfunction.

The Committee requested information from SA Health about its responses to these recommendations. In 2011 SA Health had undertaken significant work to improve reporting systems, imaging systems, nursing processes, clinical standards, a competency framework for responding to raised intra-cranial pressure in children and ongoing learning opportunities for medical staff who respond to VP shunt malfunctions.

In 2012 the Committee reviewed the recommendations arising from a second coronial investigation into the medical system's response to the death of a child involving VP shunt malfunction. These recommendations again called for more comprehensive education of medical staff across the State and faster whole-of-state access to radiological imaging that would assist in the diagnosis of VP shunt malfunction.

As part of its review the Committee collated all of this information and wrote to SA Health's Chief Executive requesting an update on progress with implementation of the Coroner's recommendations. See Section 1 for progress monitoring these issues.

## 2.5 Non-attendance at medical appointments

The Committee reviewed the death, in 2009, of a child with Goldenhaar Syndrome. This child's medical condition necessitated frequent presentation at outpatient clinics. In the year prior to death, records showed that many medical appointments were missed. It was clear that the family found it difficult to prioritise these appointments.

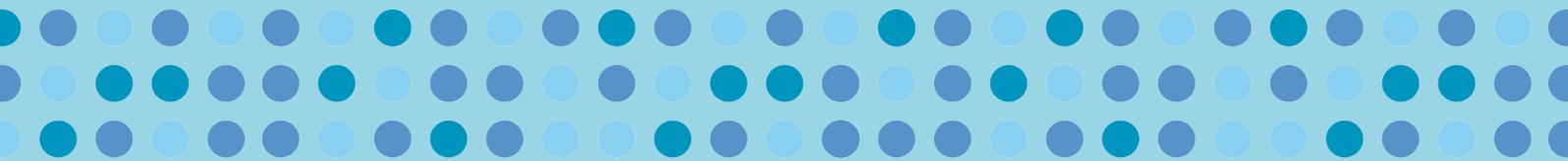
As part of this review it was noted that the Women's and Children's Health Network Mortality Committee had also identified the issues of frequent non-attendance at outpatient appointments as an indication of vulnerability for a child and had made recommendations about the implementation and monitoring of procedures aimed at following up patients with such records.

The WCHN Mortality Committee's recommendations represented an appropriate first step towards recognising and addressing this issue, especially for children with complex medical conditions. The Committee has written to the WCHN asking for information about the actions that have been taken to implement its Mortality Committee's recommendations.

## 2.6 In-depth Reviews in progress and planned

The Committee has a number of reviews in progress including reviews relating to:

- The deaths of very young infants whose parents have been under the Guardianship of the Minister.
- Ongoing analysis of deaths attributed to suicide since 2007.
- The deaths of children with disability including deaths from drowning and those with high care needs.
- Several cases of serious injury to young children that have occurred against backgrounds of neglect and domestic violence.
- The Minister for Education and Child Development has requested the Committee to review the circumstances relating to the death of Chloe Valentine, a young child who died in tragic circumstances in 2013. This review cannot commence until the present coronial inquest has concluded.



# SECTION THREE

## CHILD DEATHS SOUTH AUSTRALIA 2005–13

### **S52T – Database**

*The Committee will maintain a database of child deaths and serious injury cases and their circumstances.*

*Children's Protection Act, 1993*



## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

Opportunities for prevention and intervention to improve the safety and wellbeing of children can be identified through the systematic collection and analysis of information about death and serious injury.

### 3.1 Rates of child death 2005–13

The Committee's analysis is based on the deaths of children up to 18 years of age recorded by the Office of Births, Deaths and Marriages. Deaths after a spontaneous birth of an infant with a gestation of less than 20 weeks or a termination of pregnancy at any gestation are not included in this analysis regardless of whether the infant showed any sign of life after birth.

Table 1: Rates of child death, South Australia 2005–13

Year	All Children		Resident Children	
	Number	Rate <sup>1</sup> per 100 000	Number	Rate <sup>1</sup> per 100 000
2005	131	37.9	118	34.1
2006	118	34.1	109	31.5
2007	121	34.7	115	33.0
2008	111	31.7	102	29.2
2009	125	35.6	120	34.1
2010	116	32.9	114	32.3
2011	105	29.7	100	28.3
2012	98	27.6	93	26.2
2013	106	29.7	96	26.9
<b>2005–13</b>	<b>1031</b>	<b>32.6</b>	<b>967</b>	<b>30.6</b>

<sup>1</sup> Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15

Source: Child Death and Serious Injury Review Committee

- The death rate for all children who died in South Australia in the nine years between 2005 and 2013 was 32.6 deaths per 100 000 children.
- The death rate for resident children was 30.6 deaths per 100 000 children.

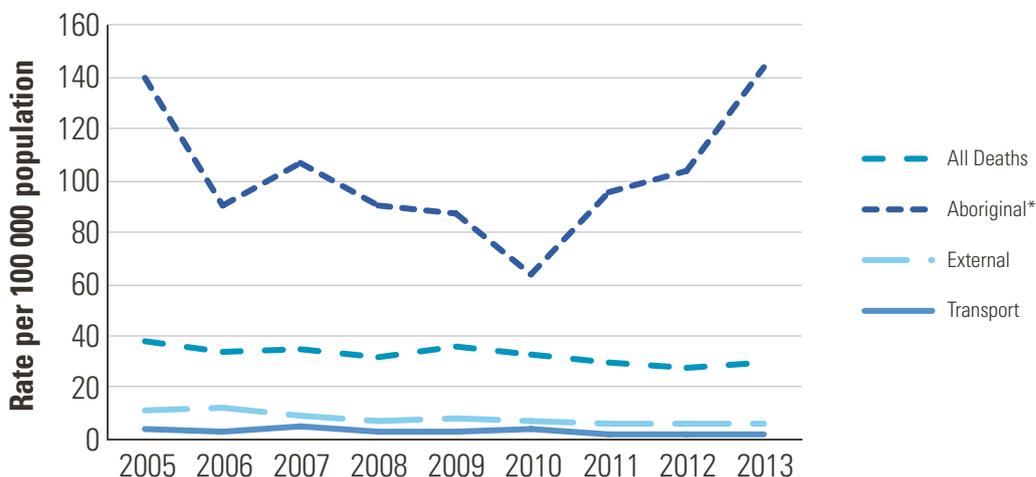
### 3.2 Trends in child death rates 2005–13

Table 2: Trends in child death rates<sup>1</sup>, South Australia 2005–13

Year	All <sup>2</sup>	Res <sup>3</sup>	IMR <sup>4</sup>	I&D <sup>5</sup>	Under <1 year <sup>6</sup>	Ext <sup>7</sup>	FSA <sup>8</sup>	ATSI <sup>9</sup>
<b>2005–2013</b>	<b>32.6</b>	<b>30.6</b>	<b>3.3</b>	<b>21.7</b>	<b>35.7</b>	<b>8.1</b>	<b>8.5</b>	<b>102.2</b>
2005	37.9	34.1	4.4	24.3	27.7	11.0	8.7	139.2
2006	34.1	31.5	3.3	19.4	37.5	11.8	9.0	90.1
2007	34.7	33.0	3.9	22.4	56.1	9.2	8.3	106.5
2008	31.7	29.2	3.1	22.0	30.3	7.4	7.4	90.1
2009	35.6	34.1	3.4	23.9	30.4	8.3	9.1	87.6
2010	32.9	32.3	3.5	21.8	65.4	7.1	8.8	63.7
2011	29.7	28.3	2.8	21.3	39.6	5.7	9.9	95.6
2012	27.6	26.2	2.7	19.7	14.6	5.9	7.6	103.6
2013	29.7	26.9	3.0	20.2	19.9	6.5	7.3	143.4
p value	0.02	0.05	0.04	0.5	0.5	0.001	0.8	0.9

1 Rates have been calculated per 100 000 children using ABS population estimates for children between 0–17 years with the exception of the Infant Mortality Rate which is calculated per 1000 live births. See Section 5.15  
 2 All children who died in South Australia  
 3 Only children resident in South Australia at the time of their death  
 4 Infant Mortality Rate – per 1000 live births  
 5 Death attributed to illness or disease  
 6 Death attributed to undetermined causes in infants aged less than one year per 100 000 live births  
 7 Death attributed to external causes including deliberate acts, neglect, suicide, transport incidents, drowning and various kinds of accidents such as falls, poisoning and suffocation  
 8 Children or their families who had contact with Families SA in the three years prior to their death  
 9 Aboriginal children  
 Source: Child Death and Serious Injury Review Committee database

Figure 1: Trends in child death rates from 2005–13, South Australia



\*The small numbers of deaths of Aboriginal children results in wider fluctuations in the rate of death shown.

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

### 3.3 Demographics of child death 2005–13

Table 3: Demographics of child death, South Australia 2005–13

	2005–07	2008–10	2011–13	2005–13	Rate <sup>1</sup> per 100 000 2005–2013
<b>Total</b>	<b>370</b>	<b>352</b>	<b>309</b>	<b>1031</b>	<b>32.6</b>
<b>Sex</b>					
Female	166	138	138	442	28.7
Male	204	214	171	589	36.4
<b>Age Group</b>					
Infants (<1 year) <sup>2</sup>	219	199	173	591	334.6
1–4 years	51	43	47	141	20.8
5–9 years	22	23	26	71	8.3
10–14 years	26	26	25	77	8.6
15–17 years	52	61	38	151	27.0
<b>Cultural Background</b>					
Aboriginal	41	30	43	114	102.1
<b>Contact with Families SA<sup>3</sup></b>					
Families SA	90	89	88	267	
<b>Usual Residence</b>					
Outside SA	28	16	20	64	
<b>Socioeconomic Background (SEIFA IRSD)<sup>4</sup></b>					
Most disadvantaged					
SEIFA 5	87	99	91	277	42.3
SEIFA 4	79	73	53	205	33.0
SEIFA 3	70	67	66	203	34.7
SEIFA 2	52	57	41	150	25.2
Least disadvantaged					
SEIFA 1	54	40	38	132	21.7
<b>Remoteness (ARIA)<sup>4</sup></b>					
Major City	212	222	187	621	28.6
Inner Regional	47	60	33	140	36.2
Outer Regional	48	40	58	146	37.8
Remote and Very Remote	35	14	11	60	48.5

<sup>1</sup> Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

<sup>2</sup> The infant mortality rate is calculated per 100 000 live births. See Section 5.15.

<sup>3</sup> Death rates for Families SA are not included. See Section 5.15.

<sup>4</sup> South Australian residents only included.

Source: Child Death and Serious Injury Review Committee database

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For the period between 2005 and 2013:

- The death rate for all children who died in South Australia showed a 2% decrease on average per year ( $p=0.02$ ).
  - Children younger than one year and young people 15–17 years had a higher rate of death than those children aged between 1–14 years.
  - Male children had a higher death rate than female children.
  - Aboriginal children were three times more likely to die than non-Aboriginal children.
  - Two hundred and sixty-seven children who died, or their families, had contact with Families SA (26%) in the three years before death.
  - Children who lived in areas of greatest disadvantage had a higher rate of death than those who lived in areas of least disadvantage.
  - Living in a remote area was associated with a higher child death rate in comparison to living in a major city area.
- 

### 3.3.1 Infant mortality rates

Over the nine year period from 2005 to 2013, the death rate for infants showed a 3% decrease on average per year ( $p=0.04$ ).

Information about infant mortality in South Australia is recorded in a number of different statistical collections including the Australian Bureau of Statistics, the South Australian Maternal, Perinatal and Infant Mortality Committee and this Committee. Each collection has different ways of registering and recording the deaths of infants, consequently the infant mortality rates differ slightly.

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

### 3.4 Causes of child death and age at death

Table 4: Causes of child death by age group, South Australia 2005–13

Causes of Death	< 28 days	28 days – 1 year	1–4 years	5–9 years	10–14 years	15–17 years	Total	Rate <sup>1</sup> per 100 000 2005–13
Certain infectious and parasitic diseases	2	11	3	0	1	1	18	0.6
Cancer	1	2	22	20	14	13	72	2.3
Endocrine, nutritional and metabolic diseases	4	4	6	3	3	5	25	0.8
Diseases of the nervous system	7	15	15	8	12	8	65	2.1
Diseases of the circulatory system	1	7	5	4	2	3	22	0.7
Diseases of the respiratory system	0	6	3	4	5	4	22	0.7
Certain conditions originating in the perinatal period	255	31	1	0	1	2	290	9.2
Congenital malformations, deformations and chromosomal abnormalities	92	35	13	8	7	5	160	5.1
<b>Illness or Disease<sup>2</sup></b>	<b>363</b>	<b>114</b>	<b>70</b>	<b>47</b>	<b>47</b>	<b>43</b>	<b>684</b>	<b>21.6</b>
<b>Undetermined Causes</b>	<b>11</b>	<b>52</b>	<b>10</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>76</b>	<b>2.4</b>
<b>SIDS<sup>3</sup></b>	<b>0</b>	<b>13</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>13</b>	<b>7.4<sup>3</sup></b>
Transport	2	3	16	10	13	56	100	3.2
Drowning	0	3	14	4	2	2	25	0.8
Accidents	2	13	7	4	4	9	39	1.2
Deliberate acts	0	6	12	1	2	6	27	0.9
Suicide	0	0	0	0	3	33	36	1.1
<b>External Causes<sup>4</sup></b>	<b>7</b>	<b>29</b>	<b>60</b>	<b>22</b>	<b>30</b>	<b>107</b>	<b>255</b>	<b>8.1</b>
Cause not yet known	0	2	1	0	0	0	3	
<b>Total</b>	<b>381</b>	<b>210</b>	<b>141</b>	<b>71</b>	<b>77</b>	<b>151</b>	<b>1031</b>	<b>32.6</b>

<sup>1</sup> Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

<sup>2</sup> Ten deaths were due to other causes of illness and disease

<sup>3</sup> Death rates for SIDS are calculated per 100 000 live births. See Section 5.8.7

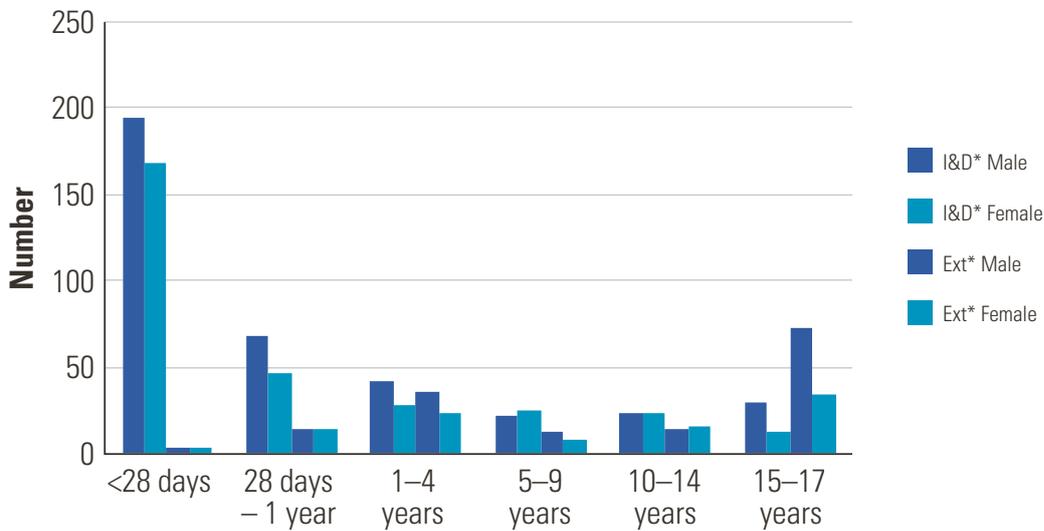
<sup>4</sup> Twenty-eight deaths were due to other external causes

Source: Child Death and Serious Injury Review Committee database

In the nine year period between 2005 and 2013:

- The majority of infant deaths were attributed to illness or disease (81%). Of these, most deaths were due to conditions originating in the perinatal period and deaths due to congenital malformation, deformations and chromosomal abnormalities.
- There were 381 deaths in the neonatal period (less than 28 days of life) and 210 deaths in the post-neonatal period (28 days to 1 year of life).
- Between 1–17 years, roughly equal numbers of children died from illness or disease as from external causes.

Figure 2: Death from illness and disease and external causes by age at death and sex, South Australia 2005–13



\*I&D' Deaths attributed to illness or disease, 'Ext' Deaths attributed to external causes

### 3.5 Child death attributed to illness or disease

Causes of child death attributed to illness or disease include infections, cancer, nervous system disease such as epilepsy, and diseases of the respiratory system such as asthma. Also included are deaths arising from conditions associated with pregnancy, labour and birth,

and from congenital conditions such as heart malformations or chromosomal abnormalities. Some of these conditions are associated with chronic ill health which increases vulnerability to infections such as pneumonia. Other conditions are associated with medical or surgical interventions that increase vulnerability to secondary illnesses such as sepsis.

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

Table 5: Demographics of child death attributed to illness or disease, South Australia 2005–13

	2013	2005–13	Rate <sup>1</sup> per 100 000 2005–13
<b>Total</b>	<b>72</b>	<b>684</b>	<b>21.7</b>
<b>Sex</b>			
Female	29	304	19.7
Male	43	380	23.5
<b>Age Group</b>			
Infants (<1 year)	50	477	270.0 <sup>2</sup>
1–4 years	10	70	12.5
5–9 years	4	47	4.1
10–14 years	6	47	6.2
15–17 years	2	43	3.3
<b>Cultural Background</b>			
Aboriginal	10	65	58.3
<b>Contact with Families SA<sup>3</sup></b>			
Families SA	11	130	
<b>Usual Residence</b>			
Outside SA	8	48	
<b>Socioeconomic Background (SEIFA IRSD)<sup>4</sup></b>			
Most disadvantaged			
SEIFA 5	18	174	26.6
SEIFA 4	13	141	22.7
SEIFA 3	16	132	22.6
SEIFA 2	5	98	16.4
Least disadvantaged SEIFA 1	12	91	14.9
<b>Remoteness (ARIA)<sup>4</sup></b>			
Major City	46	429	19.7
Inner Regional	4	89	23.0
Outer Regional	11	87	22.5
Remote and Very Remote	3	31	25.1

<sup>1</sup> Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

<sup>2</sup> The infant mortality rate is calculated per 100 000 live births. See Section 5.15.

<sup>3</sup> Death rates for Families SA are not included. See Section 5.15.

<sup>4</sup> South Australian residents only included.

Source: Child Death and Serious Injury Review Committee database

### 3.5.1 Causes of child death attributed to illness or disease

In the nine year period between 2005 and 2013:

- Although the death rate has fluctuated over the individual years recorded by the Committee, no trend was found ( $p=0.51$ ).
- Children younger than one year had a higher rate of death from illness and disease than older children. Male children had a higher death rate than female children.
- Aboriginal children were 2.9 times more likely to die from illness and disease than non-Aboriginal children.
- One hundred and thirty children who died from illness or disease, or their families, had contact with Families SA (19%) in the three years before death.
- Children who lived in areas of greatest disadvantage had a higher rate of death from illness and disease than those who lived in areas of least disadvantage.
- Living in a remote area was associated with a higher child death rate from illness and disease in comparison to living in a major city area.

In the nine year period between 2005 and 2013:

- The most frequent causes of death from illness and disease were attributed to conditions originating in the perinatal period and deaths due to congenital malformation, deformations and chromosomal abnormalities, seen predominantly in children aged younger than one year. (Table 4)<sup>12</sup>
- Prematurity and its complications were often involved in the deaths of children with conditions originating in the perinatal period and congenital malformations.
- Seventy-two deaths were attributed to cancer, 44 of these determined to be disabling because the child's daily activities were adversely affected for a period of six months or more. For further information about death from cancer, see the SA Cancer Registry Annual Report.<sup>13</sup>

### 3.5.2 Death attributed to illness or disease of infants younger than one year

Details were obtained from Perinatal Death Certificates for all infants who died before 28 days of age. Further information about causes of death before 28 days of life is available in the infant mortality publications produced by the Pregnancy Outcome Unit of SA Health.<sup>14</sup>

12 *The South Australian Birth Defects Register publishes a comprehensive annual report of the epidemiology of birth defects in South Australia.*

13 *Cancer in South Australia 2009* <http://www.sahealth.sa.gov.au/wps/wcm/connect/48188b804fc928a01cba5cbc1ea1e9/CancerInSA2009-Epidemiology-20130601.pdf?MOD=AJPERES&CACHEID=48188b804fc928a01cba5cbc1ea1e9> Accessed September 2014.

14 *Maternal, perinatal and infant mortality in South Australia 2011* <http://www.sahealth.sa.gov.au/wps/wcm/connect/6833fa0041fdd8495b6bdf8b1e08c6d/13103.2+Mortality+Report+A5-ONLINE.pdf?MOD=AJPERES&CACHEID=6833fa0041fdd8495b6bdf8b1e08c6d> Accessed September 2014.

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

Table 6: Causes of infant death attributed to illness or disease, South Australia 2005–13

	2013	2005–13
<b>Sex</b>		
Female	18	214
Male	32	263
<b>Age Group</b>		
Less than 1 day	22	208
1 day to less than 1 week	10	84
1 week to less than 28 days	7	71
28 days to less than 1 year	11	114
<b>Causes of Death</b>		
Certain conditions originating in the perinatal period	32	286
Congenital malformation, deformations and chromosomal abnormalities	13	127
All other causes of illness and disease	5	64
<b>Total</b>	<b>50</b>	<b>477</b>

Source: Child Death and Serious Injury Review Committee database

In the nine year period between 2005 and 2013:

- Two hundred and eight of the 477 (43.6%) deaths of infants from illness or disease were infants younger than twenty-four hours.
- The most common causes of death were associated with conditions originating in the perinatal period.

### 3.6 Child death attributed to undetermined causes

A child's death is attributed to an undetermined cause when, after consideration of all information, no one manner of death is more compelling than other possible causes.

Table 7: Demographics of child death attributed to undetermined causes, South Australia 2005–13

	2013	2005–13	Rate <sup>1</sup> per 100 000 2005–13
<b>Total</b>	<b>5</b>	<b>76</b>	<b>2.4</b>
<b>Sex</b>			
Female	2	29	1.9
Male	3	47	2.9
<b>Age Group</b>			
Infants (<1 year)	4	63	35.7 <sup>2</sup>
1–4 years	1	10	1.5
5–9 years	0	2	0.2
10–14 years	0	0	0
15–17 years	0	1	0.2
<b>Cultural Background</b>			
Aboriginal	2	14	12.5
<b>Contact with Families SA<sup>3</sup></b>			
Families SA	2	42	
<b>Usual Residence</b>			
Outside SA	0	0	
<b>Socioeconomic Background (SEIFA IRSD)<sup>4</sup></b>			
Most disadvantaged SEIFA 5	2	35	5.4
SEIFA 4	0	9	1.5
SEIFA 3	2	13	2.2
SEIFA 2	1	9	1.5
Least disadvantaged SEIFA 1	0	10	1.6
<b>Remoteness (ARIA)<sup>4</sup></b>			
Major City	4	48	2.2
Inner Regional	0	12	3.1
Outer Regional	1	12	3.1
Remote and Very Remote	0	4	3.2

1 Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

2 The infant mortality rate is calculated per 100 000 live births. See Section 5.15.

3 Death rates for Families SA are not included. See Section 5.15.

4 South Australian residents only included.

Source: Child Death and Serious Injury Review Committee database

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

In the period between 2005 and 2013, there were 76 deaths attributed to undetermined causes:

- Although the death rate has fluctuated over the individual years recorded by the Committee, no trend was found ( $p=0.5$ )
- More than half of these deaths were males
- Two major indicators of vulnerability were seen in these deaths – nearly half of these children or their families had had contact with the child protection system in the three years before their death and the majority of children came from the State's most disadvantaged areas
- Sixty-three were infants younger than one year. In 56 deaths (90%) one or more unsafe sleeping factors were present in the circumstances and nearly half of these 56 infants were co-sleeping. Two-thirds of these 56 infants lived in the State's most disadvantaged areas (SEIFA 4 and 5).

### 3.7 Sudden unexpected death in infancy (SIDS)

In the period between 2005 and 2013, 13 deaths have been attributed to Sudden Infant Death Syndrome (SIDS), three in 2013.<sup>15</sup> These infants died during sleep, however no anatomical, biochemical, microbiological, neuropathological or other indicators as to the cause of death could be found at post mortem. There was no evidence of unsafe sleeping conditions. These infants ranged in age from one to nine months. Seven were female. Three were Aboriginal. Eight of the 13 came from the State's most disadvantaged areas (SEIFA 4 and 5). Although the death rate has fluctuated over the individual years recorded by the Committee, no trend was found ( $p=0.7$ ).

### 3.8 Sudden unexpected death in infants (SUDI)

The use of the term 'sudden unexpected death in infants' allows the grouping of infant deaths from various causes in ways that help identify common risk factors for particular kinds of deaths. In the nine year period between 2005 and 2013, 140 infants younger than one year died suddenly and unexpectedly. This number includes five deaths in transport crashes, three drownings and seven deliberate acts causing death. Thirty-three infants died suddenly and unexpectedly, often during sleep but at post mortem it was found that the death was due to some kind of illness or disease. Thirteen had signs of overwhelming infections including meningococcal infection, cytomegalovirus and lept meningitis; other infants died suddenly of heart problems including cardiomyopathy and myocarditis and undetected congenital heart problems.

A cause of death for nearly half of these 140 infants (63 deaths) could not be determined. As mentioned previously, in 56 undetermined infant deaths, risk factors for unsafe sleeping were identified in the sleep environment. In addition, in 13 of the 15 sudden and unexpected 'accidental' deaths of infants, such risk factors were also identified. In total, across the nine year period, unsafe sleeping environments have been identified for 69 infants.

### 3.9 Child death attributed to external causes

External causes of death encompass deaths from deliberate acts, neglect, suicide, transport incidents, drowning and various kinds of accidents including falls, poisoning and suffocation. This category of death also includes health system-related adverse events. The criteria used to classify deaths into each of these categories are detailed in Section 5.8.

<sup>15</sup> Section 5.8.7 explains SUDI, SIDS and the differences between these two terms.

Table 8: Demographics of child death attributed to external causes, South Australia 2005–13

	2013	2005–13	Rate <sup>1</sup> per 100 000 2005–13
<b>Total</b>	<b>23</b>	<b>255</b>	<b>8.1</b>
<b>Sex</b>			
Female	10	101	6.6
Male	13	154	9.5
<b>Age Group</b>			
Infants (<1 year)	2	36	20.4 <sup>2</sup>
1–4 years	6	60	8.8
5–9 years	1	22	2.6
10–14 years	5	30	3.4
15–17 years	9	107	19.1
<b>Cultural Background</b>			
Aboriginal	4	32	28.7
<b>Contact with Families SA<sup>3</sup></b>			
Families SA	11	91	
<b>Usual Residence</b>			
Outside SA	2	16	
<b>Socioeconomic Background (SEIFA IRSD)<sup>4</sup></b>			
Most disadvantaged			
SEIFA 5	6	62	9.5
SEIFA 4	3	51	8.2
SEIFA 3	4	55	9.4
SEIFA 2	4	41	6.9
Least disadvantaged SEIFA 1	4	30	4.9
<b>Remoteness (ARIA)<sup>4</sup></b>			
Major City	12	133	6.1
Inner Regional	5	38	9.8
Outer Regional	4	44	11.4
Remote and Very Remote	0	24	19.4

1 Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

2 The infant mortality rate is calculated per 100 000 live births. See Section 5.15.

3 Death rates for Families SA are not included. See Section 5.15.

4 South Australian residents only included.

Source: Child Death and Serious Injury Review Committee database

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

Table 9: External causes of child death by year and cause of death, South Australia 2005–13

Causes of Death	2005–07	2008–10	2011–13	2005–13	Rate <sup>1</sup> per 100 000 2005–13
Transport	42	36	22	100	3.2
Accidents	19	10	10	39	1.2
Suicide	11	10	15	36	1.1
Deliberate acts	8	13	6	27	0.9
Drowning	11	7	7	25	0.8
Health system-related adverse events	11	2	1	14	0.4
Fire-related	5	1	2	8	0.3
Neglect	4	1	1	6	0.2
<b>Total</b>	111	80	64	255	8.1

<sup>1</sup> Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

Source: Child Death and Serious Injury Review Committee database

For the nine year period between 2005 and 2013:

- The death rate for all deaths attributed to external causes showed an 8% decrease on average per year ( $p=0.001$ ). Both deaths attributed to transport incidents and deaths attributed to accidents declined by 8% on average per year ( $p=0.03$  and  $p=0.2$  respectively).
- Thirty-nine percent of deaths attributed to external causes were due to transport incidents, 15% to accidents and 14% to suicide.
- Males have a higher rate of death than females.

Figure 3: Transport, suicide and accidental child death by sex, South Australia 2005–13

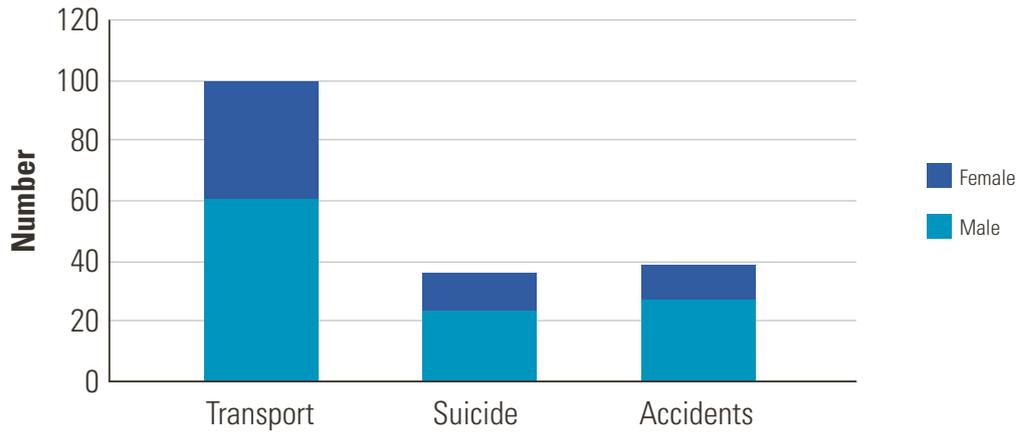
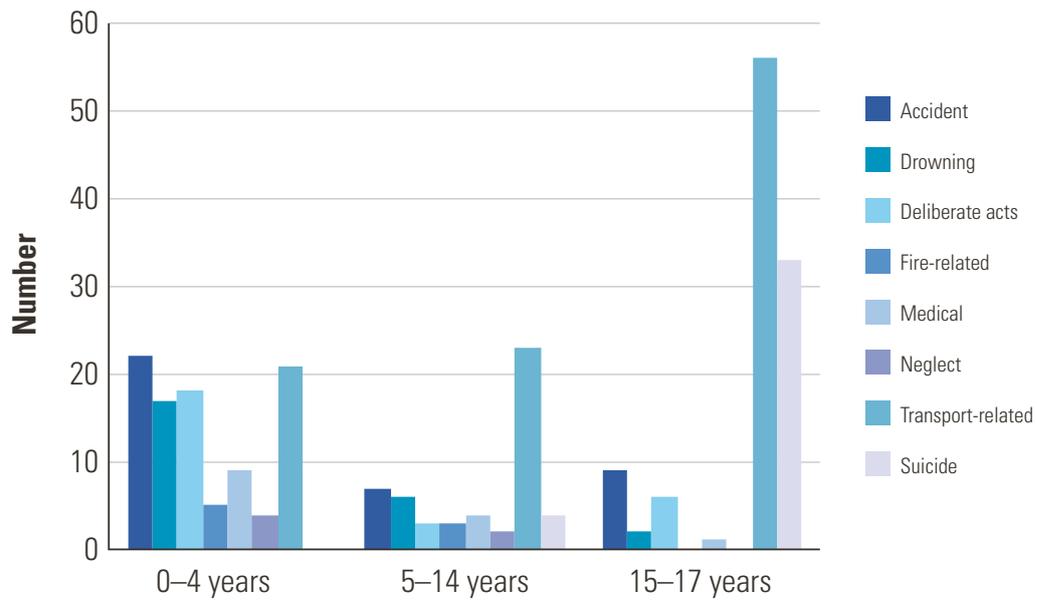


Figure 4: External causes of child death by age and cause of death, South Australia 2005–13



## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

### *Children 0–4 years old*

The most common causes of death for children 0–4 years included accidents, transport crashes, deliberate acts and drowning. In this age group, 15 of the 22 accidents were infants younger than one year, and 13 of these deaths were from suffocation or asphyxiation in unsafe sleeping environments. Two children over one year of age died in ‘blind cord’ accidents. The greatest number of deaths resulting from deliberate acts causing death (18 deaths) also occurred in this age group. Eight of these children were killed by their mother. In six other cases, although both parents or a parent and a de facto partner were present, the perpetrator remains unknown. Eight of these 18 children died from some form of blunt force trauma. Other deliberate acts causing death included poisoning, suffocation, incineration and drowning. Of the 21 transport incidents, in 12 deaths the children were passengers. There were three low speed driveway rollovers and three children were pedestrians. In previous Annual Reports, the Committee has identified children in this age group as being at higher risk of drowning, especially in domestic swimming pools.

### *Children 5–14 years old*

Twenty-three 5–14 year olds died in transport crashes. The majority were passengers in cars; two were passengers on quad bikes. Four of these children were pedestrians; two were of school age and died whilst crossing the road after alighting from a bus. Three deaths in this age group have been recorded as suicide. The Committee is still considering the circumstances of one of these deaths and it may re-assigned to another cause of death category.

### *Young people 15–17 years old*

Young people 15–17 years old are more likely to die in transport crashes and from suicide. In the 56 transport incidents, 23 young people were drivers, 24 were passengers, seven were pedestrians, one was a cyclist and one a motorbike rider. Thirty-nine of these 56 young people were male. Seven young people were Aboriginal, all of whom were male.

Thirty-three deaths in this age group have been attributed to suicide. Three young men died from gun-shot wounds, three young people died from an overdose of over-the-counter and/or prescription drugs or illicit drugs. Almost all other deaths resulted from hanging. Twenty-two of these 33 young people were males. Seven young people were Aboriginal; five of them were male. Seven deaths were attributed to suicide in 2013. The Committee continues to compile and analyse the life charts of young people who suicide. See Sections 1 and 2.

### **3.10 Vulnerable groups of children**

Children living with disability, Aboriginal children or those who have contact with the child protection system are more likely to be at risk of poorer health. The deaths of these children are considered in more detail in the following sections of the report.

#### **3.10.1 Contact with Families SA**

Children or their families may have been in contact with Families SA for reasons not directly related to child protection issues. For example they or their families may have sought and received financial assistance. Families SA receives notifications from various sources about children who may be at risk of harm.

Table 10: Demographics of child death and contact with Families SA, South Australia 2005–13

	2013	2005–13	Rate <sup>1</sup> per 100 000 2005–13
<b>Total</b>	<b>26</b>	<b>267</b>	<b>8.5</b>
<b>Rate per 100 000</b>	<b>7.3</b>		
<b>Sex</b>			
Female	9	104	6.7
Male	17	163	10.1
<b>Age Group</b>			
Infants (<1 year)	11	128	72.5 <sup>2</sup>
1–4 years	7	47	6.9
5–9 years	0	18	2.1
10–14 years	3	27	3.0
15–17 years	5	47	8.4
<b>Cultural Background</b>			
Aboriginal	10	70	62.7
<b>Usual Residence</b>			
Outside SA	1	6	
<b>Socioeconomic Background (SEIFA IRSD)<sup>3</sup></b>			
Most disadvantaged SEIFA 5	12	101	15.4
SEIFA 4	4	72	11.6
SEIFA 3	6	46	7.9
SEIFA 2	1	25	4.2
Least disadvantaged SEIFA 1	2	17	2.8
<b>Remoteness (ARIA)<sup>3</sup></b>			
Major City	11	146	6.7
Inner Regional	5	36	9.3
Outer Regional	8	57	14.8
Remote and Very Remote	1	22	17.8

<sup>1</sup> Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

<sup>2</sup> The infant mortality rate is calculated per 100 000 live births. See Section 5.15.

<sup>3</sup> South Australian residents only included.

Source: Child Death and Serious Injury Review Committee database

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

Table 11: Child death and contact with Families SA by age and cause of death, South Australia 2005–13

Causes of Death	Infants < 1 year	1–9 years	10–17 years	Total	Rate <sup>1</sup> per 100 000 2005–13
<b>2013</b>					
Illness or Disease	6	3	2	11	3.1
Undetermined Causes	2	0	0	2	0.6
SIDS <sup>2</sup>	2	0	0	2	9.9
External Causes	1	4	6	11	3.1
<b>Total</b>	<b>11</b>	<b>7</b>	<b>8</b>	<b>26</b>	<b>7.3</b>
<b>2005–2013</b>					
Conditions in the perinatal period	44	0	0	44	1.4
Congenital and chromosomal abnormalities	21	5	2	28	0.9
Cancers	0	10	5	15	0.5
All other illness or disease	13	14	16	43	1.4
<b>Illness or Disease</b>	<b>78</b>	<b>29</b>	<b>23</b>	<b>130</b>	<b>4.1</b>
<b>Undetermined Causes</b>	<b>35</b>	<b>6</b>	<b>1</b>	<b>42</b>	<b>1.3</b>
<b>SIDS<sup>2</sup></b>	<b>4</b>	<b>0</b>	<b>0</b>	<b>4</b>	<b>2.3<sup>2</sup></b>
Transport	1	6	20	27	0.9
Suicide	0	0	17	17	0.5
Accidents	7	4	7	18	0.6
Deliberate acts	2	7	2	11	0.3
Neglect	1	2	2	5	0.2
All other external causes	0	11	2	13	0.4
<b>External Causes</b>	<b>11</b>	<b>30</b>	<b>50</b>	<b>91</b>	<b>2.9</b>
<b>Total</b>	<b>128</b>	<b>65</b>	<b>74</b>	<b>267</b>	<b>8.4</b>

<sup>1</sup> Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

<sup>2</sup> Death rates for SIDS are calculated per 100 000 live births. See Section 5.8.7

Source: Child Death and Serious Injury Review Committee database

Death rates are calculated using the number of children in South Australia, rather than the number of children in contact with Families SA, which is not readily available. This rate only allows for comparison across years (see Section 5.15).

#### For children or their families who had had contact with Families SA between 2005 and 2013:

- **Illness or disease accounted for the greatest number of deaths. Over half of these deaths were infants younger than one year**
- **Aboriginal children had a higher rate of death than non-Aboriginal children**
- **The majority of children and their families lived in the State's most disadvantaged areas.**
- **Although the death rate has fluctuated over the individual years recorded by the Committee, no trend was found ( $p=0.8$ ).**
- **Thirty-five infant deaths were attributed to undetermined causes. In 29 of these deaths, unsafe sleeping environments were noted. In three-quarters of these 29 cases, more than one notification had been made to Families SA about the care of this infant and/or their siblings. The history available from Families SA records would suggest that many of these infants would have been discharged into households where the care of a newborn infant would have been challenging and difficult.**

#### **Contact with Families SA, the nature of vulnerability and causes of death in 2013**

In 2013, in 22 of the 26 cases, there had been more than one notification made to Families SA about the child and/or their siblings, in the three years before their death. As in previous years, domestic violence between carers, financial difficulties and lack of stable accommodation were the most common factors that prompted notifications about the neglect of these children or their siblings. Notifications concerning young people were about challenging behaviours and family issues, and truancy. Five young people were noted to have learning difficulties associated with physical disabilities, ADHD or Autism Spectrum Disorders.

In 2013, ten of the 26 children who died were Aboriginal – roughly the same proportion of these deaths throughout the 2005–13 period. Eight of these children were less than four years old. The majority (8 children) lived in the State's most disadvantaged areas (SEIFA 4 and 5). Six of these ten Aboriginal children died from natural causes. For the majority of these Aboriginal children the history of contact with the child protection system often started with notifications about their parents when they themselves were children.

#### **3.10.2 Aboriginal children**

The death rate for Aboriginal children continues to be much higher than the death rate for non-Aboriginal children.

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

Table 12: Demographics of Aboriginal child death, South Australia 2005–13

	2013	2005–13	Rate <sup>1</sup> per 100 000 2005–13
<b>Total</b>	<b>18</b>	<b>114</b>	<b>102.1</b>
<b>Rate<sup>1</sup> per 100 000</b>	<b>143.4</b>		
<b>Sex</b>			
Female	9	49	88.8
Male	9	65	112.5
<b>Age Group</b>			
Infants (<1 year)	10	65	11.7 <sup>2</sup>
1–4 years	4	11	42.0
5–9 years	0	6	19.4
10–14 years	3	11	35.3
15–17 years	1	21	117.0
<b>Contact with Families SA<sup>3</sup></b>			
Families SA	10	70	
<b>Usual Residence</b>			
Outside SA	5	23	
<b>Socioeconomic Background (SEIFA IRSD)<sup>4</sup></b>			
Most disadvantaged SEIFA 5	8	54	NA <sup>5</sup>
SEIFA 4	3	23	NA
SEIFA 3	2	7	NA
SEIFA 2	0	6	NA
Least disadvantaged SEIFA 1	0	1	NA
<b>Remoteness (ARIA)<sup>4</sup></b>			
Major City	3	34	NA
Inner Regional	1	3	NA
Outer Regional	8	31	NA
Remote and Very Remote	1	23	NA

<sup>1</sup> Rates for Aboriginal children have been calculated using the Estimated Resident population of Aboriginal children aged younger than 18 years. See Section 5.15.

<sup>2</sup> The infant mortality rate is calculated per 1000 live births. See Section 5.15.

<sup>3</sup> Death rates for Families SA are not included. See Section 5.15.

<sup>4</sup> South Australian residents only included.

<sup>5</sup> Not Available

Source: Child Death and Serious Injury Review Committee database

Table 13: Aboriginal child death by age and cause of death, South Australia 2005–13

Causes of Death	Infants < 1 year	1–9 years	10–17 years	Total	Rate <sup>1</sup> per 100 000 2005–13
<b>2013</b>					
Illness or Disease	6	3	1	10	79.7
Undetermined Causes	2	0	0	2	15.9
SIDS <sup>2</sup>	2	0	0	2	284.5 <sup>2</sup>
External Causes	0	1	3	4	31.9
<b>Total</b>	<b>10</b>	<b>4</b>	<b>4</b>	<b>18</b>	<b>143.4</b>
<b>2005–13</b>					
Illness or Disease	46	10	9	65	58.2
Undetermined Causes	13	1	0	14	12.5
SIDS <sup>2</sup>	3	0	0	3	54.2 <sup>2</sup>
External Causes	3	6	23	32	28.7
<b>Total</b>	<b>65</b>	<b>17</b>	<b>32</b>	<b>114</b>	<b>102.1</b>

<sup>1</sup> Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

<sup>2</sup> Death rates for SIDS are calculated per 100 000 Aboriginal live births. See Section 5.8.7

Source: Child Death and Serious Injury Review Committee database

#### In relation to the deaths of Aboriginal children between 2005 and 2013:

- Although the death rate has fluctuated over individual years, no trend was found ( $p=0.9$ )
- Aboriginal children were 3.3 times more likely to die than non-Aboriginal children
- The majority of deaths were infants younger than one year. In 2013 seven infants younger than one year died, all from conditions associated with their premature birth
- The second highest death rate was in the 15–17 year old age group and these young people were more likely to die from external causes including seven young people who died in transport crashes and seven who suicided.

In the nine year period between 2005 and 2013, 23 Aboriginal children died who were not normally resident in South Australia at the time of their death. Seventeen of these children were resident in the Northern Territory. The majority of these children died in South Australian hospitals from causes attributed to illness or disease. These deaths reflect cross-border medical care arrangements whereby seriously ill children are brought to South Australia for high level medical care.

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

### 3.10.3 Children with disability

Families caring for children with a disability face significant challenges in accessing services and support for their children. Information on all deaths of South Australian children is reviewed each year by the Committee to determine whether a child's daily activities had been significantly limited because of a disability, illness, disease or health problem. Section 5.9 provides further information about the classification of disability and its subtypes.

There are a unique set of challenges associated with identifying disability in infants younger than one year old. In 2013 a specifically tailored definition was developed. The number of infant deaths that fell within the scope of this definition are recorded in this section. The Committee is yet to determine types of disability in this age group.

**Figure 5: Disability type by age at death for 1–17 year olds, South Australia 2005–13**

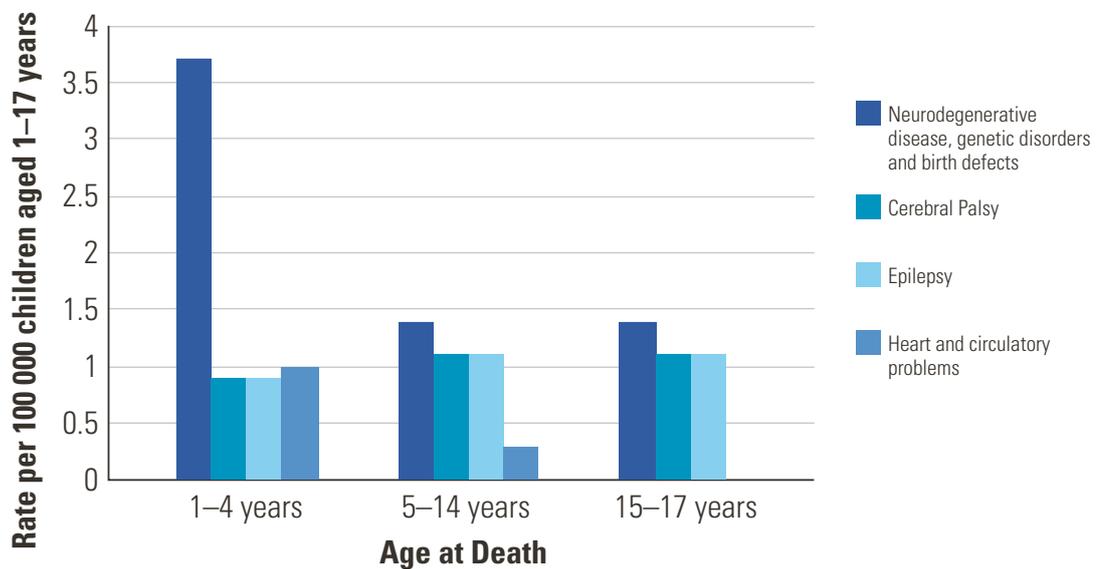


Table 14: Demographics of deaths of children with disability, South Australia 2005–13

	2013	2005–13	Rate <sup>1</sup> per 100 000 2005–13
<b>Total</b>	<b>29</b>	<b>230</b>	<b>7.3</b>
<b>Sex</b>			
Female	14	104	6.7
Male	15	126	7.7
<b>Age Group</b>			
Infants (<1 year)	15	117	66.2 <sup>2</sup>
1–4 years	4	38	5.6
5–9 years	2	25	2.9
10–14 years	4	28	3.1
15–17 years	4	22	3.9
<b>Cultural Background</b>			
Aboriginal	2	16	14.3
<b>Contact with Families SA<sup>3</sup></b>			
Families SA	7	54	
<b>Usual Residence</b>			
Outside SA	1	11	
<b>Socioeconomic Background (SEIFA IRSD)<sup>4</sup></b>			
Most disadvantaged			
SEIFA 5	6	62	9.5
SEIFA 4	6	51	8.2
SEIFA 3	8	48	8.2
SEIFA 2	3	29	4.9
Least disadvantaged SEIFA 1	5	29	4.8
<b>Remoteness (ARIA)<sup>4</sup></b>			
Major City	22	152	7.0
Inner Regional	2	23	5.9
Outer Regional	3	34	8.8
Remote and Very Remote	1	10	8.1

<sup>1</sup> Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

<sup>2</sup> The infant mortality rate is calculated per 100 000 live births. See Section 5.15.

<sup>3</sup> Death rates for Families SA are not included. See Section 5.15.

<sup>4</sup> South Australian residents only included.

Source: Child Death and Serious Injury Review Committee database

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

Table 15: Deaths of children with disability 1–17 years old, disability type and age at death, South Australia 2005–13

Disability type <sup>1</sup>	1–9 years	10–17 years	Total n=113	Rate <sup>2</sup> per 100 000 2005–13
Neurodegenerative disease, genetic disorder and birth defects	38	19	57	1.9
Cerebral palsy	12	19	31	1.0
Epilepsy	13	18	31	1.0
Heart and circulatory problems	10	2	12	0.4
Intellectual disability	2	5	7	0.2
Autism	2	2	4	0.1
Other disability types	6	4	10	0.3

<sup>1</sup> Children with multiple disabilities have been included in all relevant disability subtypes

<sup>2</sup> Rates have been calculated using ABS population estimates for children between 1–17 years. See Section 5.15.

Source: Child Death and Serious Injury Review Committee database

In the nine year period between 2005 and 2013:

- Two hundred and thirty of the 1031 children who died aged 0–17 years (22%) had a disability that impacted on their daily living. This percentage increased to 35% in 5–14 year old children.
- Aboriginal children with a disability were twice as likely to die than non-Aboriginal children with a disability.
- Male children with a disability had a higher rate of death than female children with disability.
- The death rate for children with disability was much higher in areas of socioeconomic disadvantage than in less disadvantaged areas.
- Extremely small numbers of children with disability died in remote and very remote areas of the State.
- The death rate for children with disability showed the following trends on average per year: all disability – no significant trend ( $p=0.3$ ), cerebral palsy – a 17% increase on average per year ( $p=0.02$ ), epilepsy – no significant trend ( $p=0.1$ ), neurodegenerative disease, genetic disorders and birth defects – no significant trend ( $p=0.4$ ).

**Table 16: Deaths of children with disability 1–17 years old and cause of death, South Australia 2005–13**

Disability type <sup>1</sup>	I&D <sup>2</sup>	Tr <sup>3</sup>	Delib <sup>4</sup>	Dro <sup>5</sup>	Sui <sup>6</sup>	Undet <sup>7</sup>	Acc <sup>8</sup>	Total <sup>9</sup> n=113
Neurodegenerative disease, genetic disorder and birth defects	51	0	0	1	2	1	0	57
Cerebral palsy	28	0	0	1	0	0	0	31
Epilepsy	27	0	0	2	0	0	0	31
Heart and circulatory problems	12	0	0	0	0	0	0	12
Intellectual disability	2	1	1	0	1	1	1	7
Autism	0	0	0	2	1	1	0	4
Other disability types	8	0	0	0	0	0	0	10

1 Children with multiple disabilities have been included in all relevant disability types

2 Deaths of children aged 1–17 with a disability attributed to illness and disease

3 Deaths of children aged 1–17 with a disability attributed to transport incidents

4 Deaths of children aged 1–17 with a disability attributed to deliberate acts

5 Deaths of children aged 1–17 with a disability attributed to drowning

6 Deaths of children aged 1–17 with a disability attributed to suicide

7 Deaths of children aged 1–17 with a disability attributed to undetermined causes

8 Deaths of children aged 1–17 with a disability attributed to accidents

9 Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15. Four deaths were attributed to health system events

Source: Child Death and Serious Injury Review Committee database

In the nine year period between 2005 and 2013:

- Most deaths of children with a disability were attributed to illness and disease
- Children with epilepsy or autism also died from drowning
- Children with intellectual disability died from various causes including drowning and suicide.

### 3.11 ICD-10 Coding for cause of death

Deaths have also been coded using the World Health Organization's (WHO) International Classification of Diseases (Version 10: ICD-10). Using this coding system, the underlying cause of death is considered the primary cause of death for classification.<sup>16 17</sup>

16 WHO ICD-10 Second Edition, 2005, 4. Rules and guidelines for mortality and morbidity coding. [http://www.who.int/classifications/icd/ICD-10\\_2nd\\_ed\\_volume2.pdf](http://www.who.int/classifications/icd/ICD-10_2nd_ed_volume2.pdf)

17 ICD-10 coding of deaths has been undertaken by the National Centre for Health Information Research and Training in Brisbane under a contractual arrangement.

## SECTION THREE: CHILD DEATHS SOUTH AUSTRALIA 2005–13

Table 17: Child death by ICD-10 chapter, South Australia 2005–13

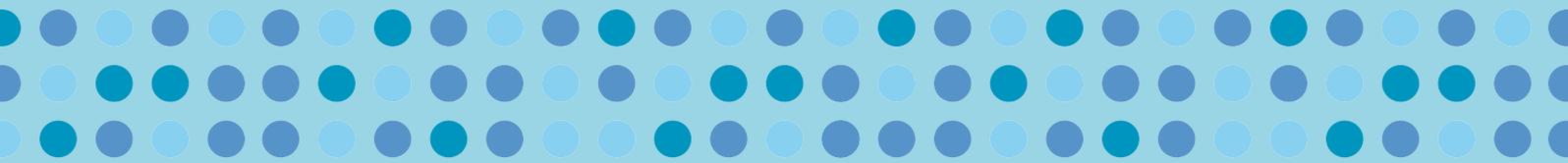
ICD-10 Chapter Description	Number of deaths per year			Total	Rate <sup>1</sup> per 100 000 2005–13
	2005–07	2008–10	2011–13		
<b>Illness or Disease (Natural Causes)</b>					
Certain infections and parasitic diseases (A00-B99)	5	9	4	18	0.6
Neoplasms (C00-D48)	25	22	25	72	2.3
Endocrine, nutritional and metabolic diseases (E00-E90)	8	9	10	27	0.9
Diseases of the nervous system (G00-G99)	24	27	16	67	2.1
Diseases of the eye and adnexa (H00-H59)	1	0	0	1	0.03
Diseases of the circulatory system (I00-I99)	7	7	9	23	0.7
Diseases of the respiratory system (J00-J99)	5	11	7	23	0.7
Diseases of the digestive system (K00-K93)	3	0	1	4	0.1
Diseases of the musculoskeletal system and connective tissue (M00-M99) or genitourinary system (N00-N99)	2	2	2	6	0.2
Certain conditions originating in the perinatal period (P00-P96)	103	97	95	295	9.3
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	60	56	47	163	5.2
<b>Illness or Disease – Total</b>	<b>243</b>	<b>240</b>	<b>216</b>	<b>699</b>	<b>22.1</b>

Table 17: Child death by ICD-10 chapter, South Australia 2005–13 *continued*

ICD-10 Chapter Description	Number of deaths per year			Total	Rate <sup>1</sup> per 100 000 2005–13
	2005–07	2008–10	2011–13		
<b>SIDS and Undetermined Causes</b>					
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	29	31	26	86	2.7
<b>External Causes</b>					
Transport-related (V01-V99)	46	35	23	104	3.3
Falls (W00-W19)	2	2	2	6	0.2
Exposure to inanimate mechanical forces (W20-W49)	5	2	2	9	0.3
Accidental drowning and submersion (W65-W74)	8	7	7	22	0.7
Other accidental threats to breathing (W75-W84)	13	8	7	28	0.9
Exposure to smoke fire and flames (X00-X09)	2	1	2	5	0.2
Accidental poisoning by exposure to noxious substance (X40-X49)	2	3	4	9	0.3
Accidental exposure to other unspecified factors (X58-X59)	0	2	0	2	0.1
Intentional self harm (X60-X84)	3	10	9	22	0.7
Assault (X85-Y09)	9	9	5	23	0.7
Event of undetermined intent (Y10-Y34)	7	2	0	9	0.3
Medical devices associated with adverse incidents (Y70-Y82)	1	0	3	4	0.1
<b>External Causes – Total</b>	<b>98</b>	<b>81</b>	<b>64</b>	<b>243</b>	<b>7.7</b>
Cause not yet known	0	0	3	3	
<b>All Deaths – Total</b>	<b>370</b>	<b>352</b>	<b>309</b>	<b>1031</b>	<b>32.6</b>

<sup>1</sup> Rates have been calculated using ABS population estimates for children between 0–17 years. See Section 5.15.

Source: Child Death and Serious Injury Review Committee database



## SECTION FOUR COMMITTEE MATTERS

### ***S52w – Committee’s reporting obligations***

- 2) The Committee must, on or before 31 October of each year, report to the Minister on the performance of its statutory functions during the preceding financial year.*

*Children’s Protection Act, 1993*

## SECTION FOUR: COMMITTEE MATTERS

### 4.1 Legislation and purpose

The Child Death and Serious Injury Review Committee was established by the Children's Protection Act, 1993 (the *Act*) in February 2006. It was an initiative arising out of recommendations made in *Our best investment: a State plan to protect the interests of children* (Layton, 2003).<sup>18</sup> An interim committee operated under directions issued by Cabinet from April 2005 until February 2006.

The role of the Committee is to contribute to the prevention of death or serious injury to children in South Australia.

The Committee reviews the circumstances and causes of death or serious injury to children and makes recommendations to Government that may help prevent similar deaths or serious injuries. Recommendations suggest changes in legislation, policies, procedures or practices.

### 4.2 Committee matters 2013–14

The Committee met ten times in 2013–14. Each member belongs to one of the four screening teams (see Figure 6) and each of these teams met as required.

The Committee continued to work across the following areas:

- The timely and accurate collection of information about the circumstances and causes of child deaths and serious injuries.
- Screening the circumstances and cause of each child death in South Australia and identifying systemic issues which should be addressed through the review process.

- Undertaking reviews of deaths and serious injuries to identify systemic issues and making recommendations to the Minister about systemic changes that will contribute to the prevention of similar deaths or serious injuries.
- Monitoring the progress of recommendations including supporting and contributing to prevention-based activities concerning child deaths and serious injuries.
- Contributing, through its Annual Report, to Government and community knowledge and understanding of the causes of child deaths and serious injuries and the efforts that should be made to prevent or reduce deaths or serious injuries.
- Reporting to the Minister on the performance of its statutory functions.
- Maintaining links with interstate and national bodies undertaking similar work.

### 4.3 Governance

The Committee reports to the Minister for Education and Child Development who has responsibility for the administration of the *Act*. The Committee's administrative, financial and human resource management is overseen by the Department for Education and Child Development.

<sup>18</sup> Our best investment: a State plan to protect the interests of children  
[http://www.decd.sa.gov.au/speced2/files/links/Child\\_Protection\\_Review\\_FU.pdf](http://www.decd.sa.gov.au/speced2/files/links/Child_Protection_Review_FU.pdf)

#### 4.4 Improving procedures, knowledge and skills

The Committee has continued to extend the range of its sources of information. Through an agreement with SA Health, electronic copies of autopsy reports for non-coronial deaths are provided to the Committee.

The Post-neonatal Mortality Sub-Committee of SA Health's Maternal, Perinatal and Infant Mortality Committee has ceased to conduct reviews of post-neonatal deaths (infants >28 days and <364 days old). That sub-committee has reviewed these deaths since 1986 and made recommendations for improved care in both hospitals and the community. Many of the recommendations made by the sub-committee have been similar to those made by this Committee and both Chairs have agreed that it is an appropriate course of action for this Committee to be the only body to review post-neonatal deaths. SA Health will provide expert medical advice about these deaths should the need arise.

#### 4.5 Supporting partnerships

The Chair met with the Minister for Education and Child Development as required, to discuss issues arising from the Committee's work. The Committee continues to hold regular and productive meetings with Families SA (Adverse Events Committee), the Coroner, Chief Executives and Ministers as required.

The Chair met with Shadow Ministers, the Honorable Stephen Wade and the Honorable Rachel Sanderson to discuss the work of the Committee.

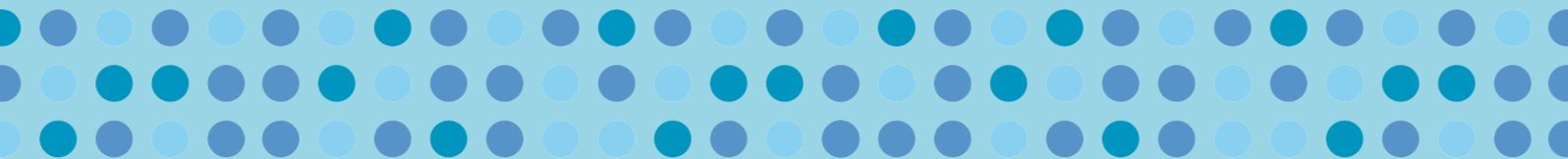
The Committee wrote to the State Coroner calling attention to the high quality of investigations undertaken by SA police in relation to several deaths in 2013.

The Committee has responded to requests for data about the deaths of non-resident children from its counterparts in Queensland, Northern Territory, NSW, ACT and Victoria. It has contributed to the reporting of national child death statistics that are collected and published in the Annual Report of Child Deaths by the Queensland Commission for Children and Young People.

#### 4.6 Confidentiality of Committee correspondence and reports

The status of the Committee's reports to and correspondence with the Minister for Education and Child Development under FOI legislation was considered in an action in the District Court.<sup>19</sup> The Court found that the *Act* provides an obligation to keep confidential all information about individual cases which is disclosed to the Committee to assist it in its work. The Court noted the seriousness of the issues dealt with by the Committee, the very high level of confidentiality with which the information obtained by the Committee must be treated and the sensitivity surrounding that information.

<sup>19</sup> *Minister for Education and Child Development v Chapman* [2013] SADC 130.



## SECTION FIVE METHODOLOGY

### ***S52w – Committee’s reporting obligations***

- 2) *The Committee must, on or before 31 October of each year, report to the Minister on the performance of its statutory functions during the preceding financial year.*

*Children’s Protection Act, 1993*

## SECTION FIVE: METHODOLOGY

### 5.1 Deaths included in the Annual Report

In Section 3 the numbers of deaths referred to are based on the calendar year: 1 January 2013 to 31 December 2013. Reporting by calendar year is also consistent with the practices of the Australian Bureau of Statistics (ABS) and child death review teams in other states and territories.

The date of death is used as the marker for its inclusion in the data set for that year.

The number of deaths the Committee reports on each year is based on information received from the Office of Births, Deaths and Marriages. In 2013 the Committee determined that there would be a number of deaths excluded from the annual report if:

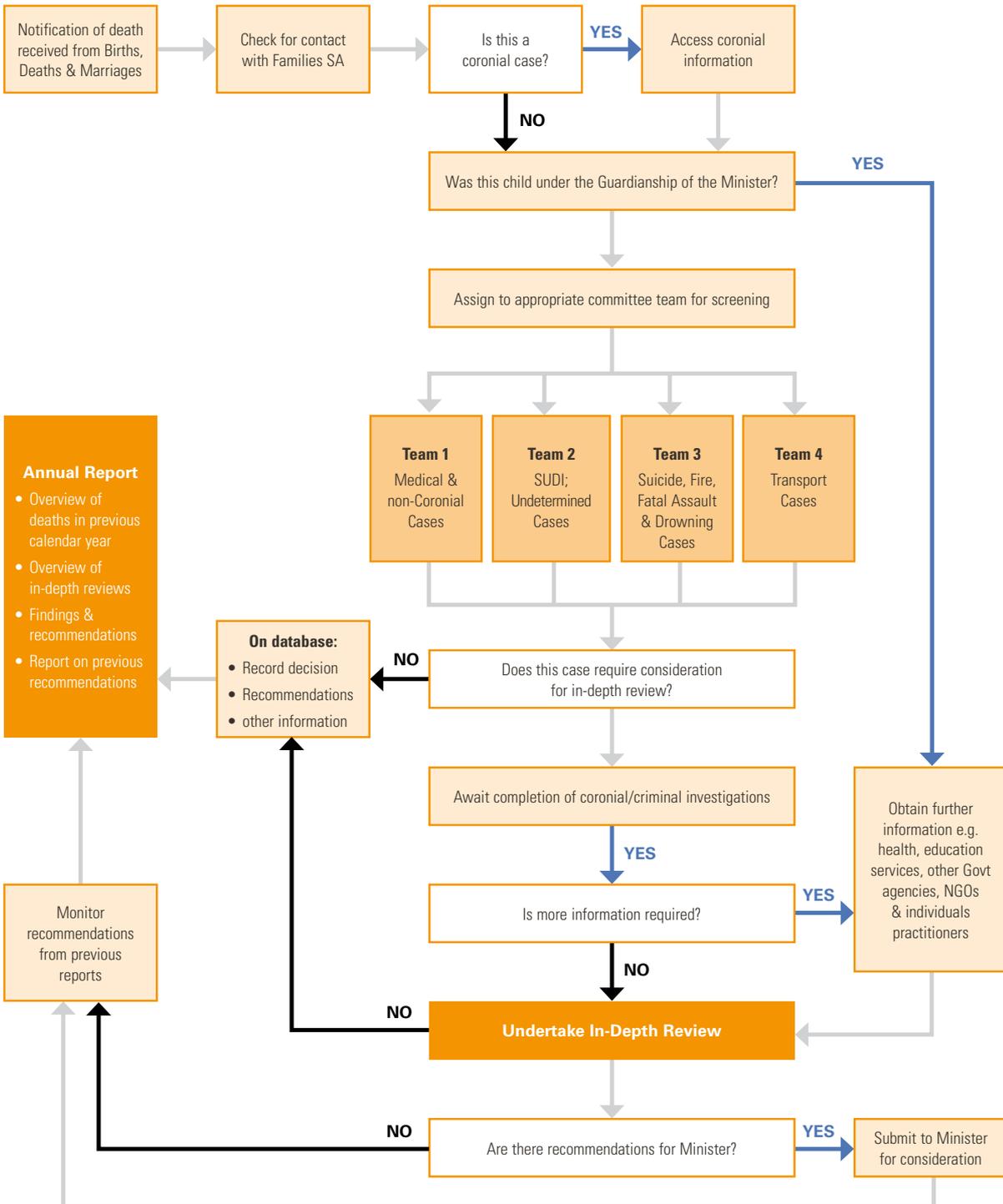
- The death of an infant occurred after a genetic termination of pregnancy as recorded in the Perinatal Death Certificate, or
- The death occurred after the spontaneous birth of an infant prior to 20 weeks gestation.

### 5.2 Access to information and the process for screening and review of deaths

This section provides details about the Committee's processes for obtaining, analysing and storing information; for screening deaths, and for classifying causes of death.

Figure 6 indicates the key sources of information available to the Committee about the deaths of children in South Australia and illustrates the processes the Committee uses to screen and review this information.

Figure 6: Committee’s Screening and Reviewing Process



## SECTION FIVE: METHODOLOGY

### 5.3 The Office of Births, Deaths and Marriages

The Committee currently has a protocol with the Office of Births, Deaths and Marriages for the release of information about the deaths of children and young people in South Australia. This information is provided to the Committee on a monthly basis.

### 5.4 The Office of the State Coroner

Under an arrangement with the Coroner, information is released to the Committee for each reportable death of a child aged under 18 years of age.

A further protocol outlines the exchange of information between the Committee and the Domestic Violence Research Officer, attached to the Coroner's Office.

### 5.5 Release of information from Government agencies

The Committee has protocols with the Department for Education and Child Development, which includes Families SA, and SA Health regarding release of information.

A further protocol outlines the exchange of information between the Committee and the SA Health Maternal, Perinatal and Infant Mortality Committee.

### 5.6 In-depth review process

Deaths screened by the Committee are assigned one of the following criteria:

- **Not eligible for review** – a case will be considered ineligible for review under s52S (2) of the *Act* – if the child was not normally resident in the State at the time of death or serious injury or the incident resulting in death or serious injury did not occur in the State; or
- **Not for review** – a case may not require in-depth review if the screening of information available at the time indicates that there are no systemic issues arising from the death. These cases are assigned a category of death eg illness or disease, SUDI, transport, deliberate acts etc. and the details are kept on the Committee's database until required for inclusion in the relevant Annual Report. These cases may be included in reviews in later years where features from cases over a number of years suggest that there may be systemic issues that can be addressed; or
- **Pending further information** – in some cases the Committee requests further information prior to making a decision regarding in-depth review. The majority of cases awaiting further information are deaths attributed to illness or disease or health-system-related adverse events. The medical screening team maintains a high level of scrutiny regarding the circumstances of the deaths of children from these causes, especially where children have received health system services, have had complex conditions requiring a high level of care, or where there has been an interface between medical, welfare and other systems; or

- **Pending completion of investigations** – in accordance with Section 52S (4) of the *Act*, the Committee must ensure that its review processes will not compromise criminal or coronial investigations before it undertakes a review. Criminal investigations are considered to be concluded once any person involved in the death or serious injury of the child has been sentenced, or once South Australia Police have determined they have no further interest in the matter. Investigations conducted by the Coroner are considered to have ended when the Coroner has made a finding into the cause of death or a coronial inquest has been completed; or
- **Awaiting assignment** – in any reporting year, there are also cases ready for review but awaiting assignment of a ‘review team’ to undertake the review.

The number of cases pending investigation or review gradually decreases in any year, as information is obtained, cases are finalised in the criminal and coronial systems, and the Committee makes a determination about further review and undertakes this review.

## 5.7 Reporting requirements

Section 52W of the *Act* outlines the reporting responsibilities of the Committee. It requires the Committee to report periodically to the Minister for Education and Child Development, and also to provide an annual report on the performance of its statutory functions during the preceding financial year.

The Committee submits a report to the Minister for Education and Child Development at the conclusion of each in-depth review. The report contains the Committee’s recommendations about systemic issues that may contribute to the prevention of similar deaths or serious injuries.

## 5.8 The Committee’s classification of cause of death

In Section 3 *Child deaths South Australia 2005–13* the Committee’s classification of the cause of death has been used. In many cases, the Committee has multiple sources of information available about children (including health, welfare and education records) and is not limited to the causes of death recorded in post-mortem reports or death certificates. Accordingly, the Committee’s classification for a particular death may vary from the ICD-10 classification (See Section 3.11 *ICD-10 Coding of Cause of Deaths* for an explanation of this coding).

At the time of classifying a death, the Committee will consider all available information. However in some cases, further information may become available that may give rise to a change in the classification assigned to a particular death or group of deaths. Any changes will be noted as an addendum in the subsequent Annual Report. In addition, the Committee will continue to review its definitional guidelines in the light of available information.

The guidelines the Committee uses to classify deaths to external causes are described below.

### 5.8.1 Transport deaths

Transport deaths include deaths arising from incidents involving a device used for, or designed to be used for, moving people or goods from one place to another. These incidents may involve pedestrians and include railway or water transport. Incidents may occur on public roads or places other than a public road.

## SECTION FIVE: METHODOLOGY

### 5.8.2 Accidents

Accidents exclude deaths attributed to transport incidents, fires or drowning. Also referred to as deaths from unintentional injuries, accidents most commonly include suffocation, strangulation and choking, falls and poisoning.

### 5.8.3 Suicide

The Committee's definition of suicide is:

*Taking one's own life, intending to do so.*

The Committee classifies a death as suicide if, after a thorough review of all available evidence it is satisfied that the young person killed him or herself intending to take their own life.

### 5.8.4 A deliberate act by another causing death

In previous years one of the categories of death due to external causes was known as 'fatal assault.' A 'fatal assault' was defined as "the death of a child from acts of violence perpetrated upon him or her by another person" (Lawrence, 2004, p 842).<sup>20</sup>

From time to time cases were included in that category which did not really fit the definition of a fatal assault. For instance, a death caused by the deliberate administration of a drug to a child without any intention of causing the child's death.

Accordingly the Committee considered that a category known as 'a deliberate act by another causing death' better described a range of deaths, including deaths from acts of violence, where a person, by whatever means, causes a child's death by a deliberate act.

The definition of 'a deliberate act by another causing death' is simple and straightforward, 'A deliberate act by another that results in the death of an infant or child.'

It is the Committee's view that a simple definition avoids the sorts of complications that would inevitably arise if one sought to establish the intent of the person whose deliberate act results in a child's death. For instance in the example of the deliberate administration of a drug to a child, the person's intent could be to medicate the child.

Other examples might include hitting a young child to quieten them, but in such a way that death ensued. Of course in more extreme cases the person's intent might well be to seriously injure or indeed kill the child.

In the eyes of the law a person's intent is obviously relevant to issues of criminal liability but for the Committee's categorisation of deaths there is no need to focus on that issue.

Similarly there may well be cases where the person who causes a child's death does so as a result of mental illness (e.g. postnatal depression or a psychosis), leading to a finding in a Court of mental incompetence. Such cases are also included in this category.

There will be some cases where it is not possible, on the basis of the available evidence, to be certain that a child's death resulted from a deliberate act by another person. For instance a child may have serious head injuries causing death but it is not possible to say that the injuries were deliberately inflicted as opposed to being caused by an accidental fall.

In such cases upon a consideration of all the available evidence, the Committee will decide which is the most likely cause of death. If it decides that deliberate infliction was the most likely it will assign a 'p' (probable) to flag that issue.

<sup>20</sup> Lawrence, R. (2004) *Understanding fatal assault of children: a typology and explanatory theory*. *Children and Youth Services review*, 26, 841-856.

### 5.8.5 Neglect

The Committee defines neglect as a death resulting from an act of omission by the child's carer(s) including:

- Failure to provide for the child's basic needs
- Abandonment
- Inadequate supervision, and
- Refusal or delay in provision of medical care.

This definition can account for both chronic neglect and single incidents of neglect, or a combination of both (Lawrence & Irvine, 2004).<sup>21</sup>

### 5.8.6 Health-system-related adverse events

These deaths have been classified as such by the Committee based on written records which may not necessarily be complete. The Committee places a death in this category based on consideration of preventable aspects in the circumstances of the death and a focus on future prevention strategies rather than an investigation of the cause of death.

### 5.8.7 Sudden Unexpected Death of Infants (SUDI) and Sudden Infant Death Syndrome (SIDS)

Sudden unexpected death in infancy (SUDI) has been described as an 'umbrella' term that is used for all sudden unexpected deaths of infants younger than one year of age.

### *The definition of Sudden Unexpected Death in Infancy (SUDI)*

In December 2007 the Australian and New Zealand national meeting of child death review teams and committees agreed to work towards a common reporting framework that was based on the definition of SUDI proposed by Fleming et al. (2000).<sup>22</sup> The agreed SUDI definition is: Infants from birth to 365 completed days of life whose deaths:

- |             |  |
|-------------|--|
| Criterion 1 | Were unexpected and unexplained at autopsy;  |
| Criterion 2 | Occurred in the course of an acute illness that was not recognised by carers and/or by health professionals as potentially life-threatening; |
| Criterion 3 | Arose from a pre-existing condition that had not been previously recognised by health professionals; or                                      |
| Criterion 4 | Resulted from any form of accident, trauma or poisoning.   |

### *The definition of Sudden Infant Death Syndrome (SIDS)*

The criteria used to determine a death attributed to SIDS continues to be the San Diego definition proposed by Krous et al. (2004, see Table 18). Death rates for SIDS are reported per 100 000 livebirths.

<sup>21</sup> Lawrence, R. & Irvine, P. Redefining fatal child neglect. *Child Abuse and Prevention*, 21, 1-22.

<sup>22</sup> Fleming, P., Bacon, C., Blair, B. and Berry, P.J. (2000) *Sudden unexpected deaths in infancy, the CESDI studies 1993-1996*. London: the Stationary Office.

## SECTION FIVE: METHODOLOGY

**Table 18: Definition of sudden infant death syndrome**

### General Definition of SIDS\*

SIDS is defined as the sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.

### Category IA SIDS: Classic features of SIDS present and completely documented

Category IA included deaths that meet the requirements of the general definition and also all of the following requirements.

#### Clinical

- > 21 days and < 9 months of age;
- Normal clinical history including term pregnancy (gestational age > 37 weeks);
- Normal growth and development;
- No similar deaths among siblings, close genetic relatives (uncles, aunts or first degree cousins), or other infants in the custody of the same caregiver).

#### Circumstances of Death

- Investigations of the various scenes where incidents leading to death might have occurred and determination that they do not provide an explanation for the death;
- Found in a safe sleeping environment, with no evidence of accidental death.

#### Autopsy

- Absence of potentially fatal pathologic findings. Minor respiratory system inflammatory infiltrates are acceptable; intrathoracic petechial haemorrhage is a supportive but not obligatory or diagnostic finding;
- No evidence of unexplained trauma, abuse, neglect or unintentional injury;
- No evidence of substantial thymic stress effect (thymic weight < 15g and/ or moderate/severe cortical lymphocyte depletion). Occasional 'starry sky' macrophages or minor cortical depletion is acceptable;
- Negative results of toxicologic, microbiologic, radiologic, vitreous chemistry and metabolic screening studies.

### Category IB SIDS: Classic features of SIDS present but incompletely documented

Category IB includes infant deaths that meet the requirements of the general definition and also meet all of the criteria for category IA except that investigation of the various scenes where incidents leading to death might have occurred was not performed and/ or >1 of the following analyses were not performed: toxicologic, microbiologic, radiologic, vitreous chemistry or metabolic screening studies.

### Category II SIDS

Category II includes infants that meet category I except for > 1 of the following.

#### Clinical

- Age range outside that of category IA or IB (ie 0–21 days or 270 days (9 months) through to first birthday);
- Similar deaths among siblings, close relatives or infants in the custody of the same caregiver that are not considered suspect for infanticide or recognised genetic disorders;
- Neonatal or perinatal conditions (eg those resulting from pre-term birth) that have resolved by the time of death.

#### Circumstances of Death

- Mechanical asphyxia or suffocation caused by overlaying not determined with certainty.

#### Autopsy

- Abnormal growth or development not thought to have contributed to death;
- Marked inflammatory changes or abnormalities not sufficient to be unequivocal cause of death.

### Unclassified sudden infant death

Includes deaths that do not meet the criteria for category I or II SIDS, but for which alternative diagnoses of natural or unnatural conditions are equivocal, including cases where autopsies were not performed.

### Post resuscitation cases

Infants found in extremis who are resuscitated and later die ('temporarily interrupted SIDS') may be included in the aforementioned categories, depending on the fulfilment of relevant criteria.

\*Krous, H. F., Beckwith, J. B., Byard, R. W., Rognum, T. O., Bajonowsky, T., Corey T., Gutz, E., Hanzlik, R., Keens, T. G. and Mitchell, E. A. (2004) Sudden infant death syndrome and Unclassified infant deaths: A definitional and diagnostic approach. *Paediatrics*, 114, 234 – 238.

## 5.9 Deaths of children with disability 1–17 years old

The definition used to determine inclusion as the death of a child with disability for children 1–17 years old is:

- The child was over one year of age at the time of death,
- The child's daily activities were limited because of their disability, illness, disease or health problem, and
- The child's daily activities were adversely affected for a period of six months or more.

Where the length of time during which the child's daily activities were adversely affected was unknown the case was not included on the Register.

Cases where the child had a chronic health issue (e.g. asthma, epilepsy, diabetes etc) were only included on the Register if other disabilities were present or if the child's daily activities would have been adversely affected for a period of six months or more due to the frequency and severity of the health issue. Furthermore, cases were only included if, despite effective treatment, the child still suffered as a result of their chronic health issue.

Some children had multiple types of disability, for example cerebral palsy and epilepsy. Multiple disability diagnoses were recorded for each child when they were identified. The categories of disability used are provided below.

### 5.9.1 Neurodegenerative diseases, genetic disorders and birth defects

This category included all instances of neurodegenerative diseases, genetic disorders and birth defects, including in-born errors of metabolism where the child's health deteriorates over time.

Children with many of these conditions are likely to die as a result of their disease and they require significant care as their condition progresses.

### 5.9.2 Cerebral palsy

This category included all cases of cerebral palsy, which is a term used to describe a group of non-progressive motor function disorders that arise because of damage to, or dysfunction of, the developing brain. This permanent condition can affect body movement, muscle control, muscle coordination, muscle tone, reflex, posture and balance. It may also cause visual, learning, hearing, speech and intellectual impairments, as well as epilepsy.

### 5.9.3 Epilepsy

Using the guidelines developed to identify disability, this category only included cases where the frequency and severity of the child's epilepsy would have adversely affected their daily activities for a period of six months or more, or the child with epilepsy had associated disability.

Epilepsy is a common disorder that is characterised by recurring seizures or sudden, uncontrolled surges in the normal electrical activity in all, or part, of the brain. While the Epilepsy Centre notes that epilepsy can mostly be controlled by taking medication and restricting daily living activities, epilepsy can be associated with sudden unexpected death.

## SECTION FIVE: METHODOLOGY

### 5.9.4 Heart and circulatory problems

This category included all cases where a condition involving the heart or blood vessels was able to be identified, regardless of whether the condition resulted from an infection or from a birth defect.

Children with conditions such as complex congenital heart defects or cardiomyopathy are, without life-saving surgery such as a heart transplant, at higher risk of dying as a result of their heart or circulatory problems.

### 5.9.5 Intellectual disability

This category included all cases where the available information suggested that the child had some form of intellectual disability. It was identified as a specific category because it is a developmental disorder and people living with such disorders have significantly more difficulty than others in integrating new learning, understanding concepts and solving problems.

### 5.9.6 Autism spectrum disorder

Autism Spectrum Disorder is a lifelong developmental disability that affects, among other things, the way a child relates to his or her environment and their interactions with other people. Where information was available indicating a diagnosis of ASD had been made, a child was placed in this category.

### 5.9.7 Other disability types

This category accommodated all of the remaining disability types in children on the Disability Register. It incorporated cases where the child had conditions such as Epstein-Barr virus, systemic lupus and community acquired pneumonia. It also included cases where the available information was too limited to confidently assign the case to a specified category.

### 5.9.8 Cancer – a disabling medical condition

A death from cancer was noted as a disabling medical condition only if the child had had cancer for a period of six months or more. While not traditionally recognised as a disability, it was included as a specific category because of the debilitating effects that cancer and cancer treatments have on the life of a child.

### 5.10 Deaths of infants with a disability younger than one year

There is a unique set of challenges associated with identifying disability in infants younger than one year and a specifically tailored definition was developed by the Committee. In this reporting period, a series of exclusions were used to identify and report on:

- Infants with a disability including conditions such as hypoxic ischaemic encephalopathy of newborn, Edward syndrome, and congenital diaphragmatic hernia
- Infants with a disabling medical condition such as hypoplasia and dysplasia of lung (excluding pulmonary hypoplasia associated with short gestation), hypoplastic left heart syndrome and other specified congenital malformation of the heart
- Infants with cancer.

**Table 19: Exclusion criteria for determining deaths of infants younger than one year old, with a disability, disabling medical condition or cancer**

<b>CATEGORY</b>	<b>BASIS FOR EXCLUSION</b>
Extreme prematurity only	The underlying cause of death was "prematurity" (ICD-10 codes: P07)
Extreme prematurity and maternal factors	The underlying cause of death was a maternal factor (ICD-10 codes: P00-P04)
Prematurity and/or infection	The underlying cause of death was an infection specific to the perinatal period (ICD-10 codes: P35-P39) or an infectious and parasitic disease (ICD -10 codes: A00-B99)
Prematurity and haemorrhage	The underlying cause of death was a haemorrhage (ICD-10 codes: P50-P55)
Prematurity + digestive issues	The underlying cause of death was a digestive issue (ICD-10 codes: P75-78)
Prematurity and/or respiratory issues	The underlying cause of death was a respiratory and cardiovascular disorder specific to the perinatal period (ICD-10 codes: P20-P29) or a respiratory issue (ICD-10 codes: J00-J99)
SIDS	The underlying cause of death was SIDS (ICD-10 code: R95)
Undetermined cause of death	The underlying cause of death was undetermined (ICD-10 code: R99)
External causes of death	The underlying cause of death was an external cause of death, such as an accident, fatal assault or transport-related death (ICD-10 codes: V01-Y98)

## SECTION FIVE: METHODOLOGY

Once these cases were excluded the following screening criteria were used:

- Infants with disability – “Cause Codes” for the “Underlying Cause of Death” were cross-referenced against a list of ICD-10 Codes that the Disability Review team<sup>23</sup> have confirmed as representing disability. These codes were identified with reference to the codes used to identify disabilities in the 1–17 year age group. In addition a secondary screening exercise was then undertaken to identify any cases where the “Cause of Death” or “Circumstances of Harm” made reference to a condition listed in the National Disability Insurance Scheme’s *List C – Permanent Impairment/Early intervention, under 6 years – no further assessment required*, which is used by the scheme to identify disability in this age group.<sup>24</sup> Finally, each case identified was considered by the Disability Review team prior to inclusion in the Disability Register
- Infants with a disabling medical condition – “Cause Codes” for the “Underlying Causes of Death” were cross-referenced against a list of ICD-10 codes that the Disability Review team agreed represented a disabling medical condition. These codes were identified with reference to the codes used for the 1–17 year old deaths.<sup>25</sup>
- Infants with cancer – “Cause Codes” for the “Underlying Causes of Death” were cross-referenced with a list of ICD-10 codes that have been confirmed by the Disability Review Team as cancers.

### 5.11 Aboriginal and Torres Strait Islander Status

The information received from the Office of Births Deaths and Marriages has an Aboriginal or Torres Strait Islander indicator for each case. The Committee has determined that, in the absence of any other form of reliable indicator of ATSI status, this indicator will be used.

### 5.12 Usual Place of Residence

The information received from the Office of Births Deaths and Marriages indicates the ‘last place of residence’ of each child. This information is taken to indicate the child’s usual place of residence for review and reporting purposes. The Committee acknowledges that this information may have been variously interpreted by the person giving the information and may not reflect a consistent definition of a person’s usual residence.

Each Annual Report records the number of cases where the information from the Office of Births Deaths and Marriages shows that the child’s last place of residence was outside South Australia.

<sup>23</sup> The Disability Review team comprises three members of the Committee and includes a medical practitioner with in-depth knowledge about children with disability, a child psychologist and a social work consultant.

<sup>24</sup> This was achieved by applying text filters (for words such as “syndrome”, “disease”, “disorder”, “trisomy”) to the remaining cases and completing a manual search to identify any cases that appeared in the NDIS’ List C – Permanent Impairment/Early Intervention, under 6 years – no further assessment required.

<sup>25</sup> The Disability Review Team agreed that conditions considered borderline between being considered a disability and a disabling medical condition were put in the Disabling Medical Condition category until proven otherwise.

### 5.13 ARIA+ Index of Remoteness and Accessibility

ARIA stands for Accessibility/Remoteness Index of Australia. The ARIA methodology was developed by the Australian Government Department of Health and Aged Care in 1977. Minor changes have been made to this original methodology, resulting in the ARIA+ index of remoteness. This Index is a distance-based measure of remoteness.<sup>26</sup> It defines five categories of remoteness based on road distance to service centres: Major City, Inner and Outer Regional, Remote and Very Remote. The Very Remote category indicates very little accessibility to goods, services and of opportunities for social interaction. ARIA+ Index is an indicator of the degree of geographic remoteness of an area and is a more accurate indicator of disadvantage than subjective labels such as 'rural' or 'country'.

### 5.14 SEIFA Index of Relative Socio-economic Disadvantage

The SEIFA (Socio-Economic Indexes for Areas) Index of Relative Socio-economic Disadvantage (IRSD)<sup>27</sup> draws on a variety of personal and household characteristics (available from the 2006 Census) to rank household and socioeconomic status. The IRSD is calculated to show the relativity of areas to the Australian average for the particular set of variables which comprise it. This average is set at 1000. Scores below 1000 indicate areas with relatively disadvantaged populations under this measure, and scores above 1000 indicate areas with relatively advantaged populations. In this report SEIFA IRSD scores are divided into five quintiles, with the least disadvantaged populations represented in quintile 1 and the most disadvantaged in quintile 5.

### 5.15 Death rates

Death rates have been calculated using Australian Bureau of Statistics (ABS) population projections (There were 3 159 874 estimated resident South Australian population of children aged 0–17 in the period 2005–2013).<sup>28</sup> Children who died in South Australia but whose usual residence was outside of the State are included in all calculations except for the total number of deaths per year where death rates for only those children resident in the State at the time of death are included.

The death rates for Aboriginal children were calculated using the Estimated Resident population of South Australian Aboriginal children aged younger than 18 years. (12 212 Aboriginal children – 2006 Census, 12 551 Aboriginal children – 2011 Census). This figure is based on the 2006 and 2011 Census and has been adjusted by the ABS to take into account the under reporting of Indigenous status.<sup>29</sup> For the death years 2005–2008 the 2006 Census estimate is used and for 2009–12 the 2011 Census is used.

The Infant Mortality Rate (IMR) is calculated according to the deaths of children younger than one year old per 1000 live births in the same year. For the purpose of comparison in the tables in this report, the IMR is represented as the deaths of children younger than one year old per 100 000 live births in that year. The South Australian Maternal, Perinatal and Infant Mortality Committee provided data about live births. In 2013 there were 20 116 live births in South Australia (provided as provisional data on 14 October 2014).

<sup>26</sup> AIHW (2004) Rural, regional and remote health: a guide to remoteness classifications. AIHW Cat no PHE 53, Canberra: AIHW <http://aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442459567> Accessed September 2014.

<sup>27</sup> ABS SEIFA Indexes 2011 <http://www.abs.gov.au/ausstats/abs@.nsf/mf/2033.0.55.001>. Accessed September 2014.

<sup>28</sup> Australian Bureau of Statistics (2012) Australian Demographic Statistics <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3101.0Mar%202014?OpenDocument> Last accessed Oct 2014

<sup>29</sup> Advice received from Public Health Information and Development Unit, University of Adelaide, September 2010. Australian Bureau of Statistics. Table Builder <https://www.censusdata.abs.gov.au/webapi/jsf/selectTopic.xhtml> Accessed October 2014

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The rates of death for children whose families have had contact with Families SA are calculated by dividing the number of children dying whose families had contact with Families SA by the total population of children in SA. The Committee defines 'contact with Families SA' to be any contact in the three years prior to the child's death. It would be preferable to use the denominator 'all children whose family had had contact with Families SA' to calculate the death rate as this would enable a comparison of the rate of death for children whose family had had contact with Families SA and those who had not. However, this information about the number of children who had contact with Families SA from 2005–12 is not readily available. A prevalence rate only is presented in this report for the purposes of comparison over time of the death rates of children whose families have been in contact with Families SA.

The Poisson distribution is used to investigate whether there are trends in the number of deaths due to various causes. The Poisson distribution describes the occurrence of rare events. A p-value of less than 0.05 denotes a significant increasing or decreasing trend.





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