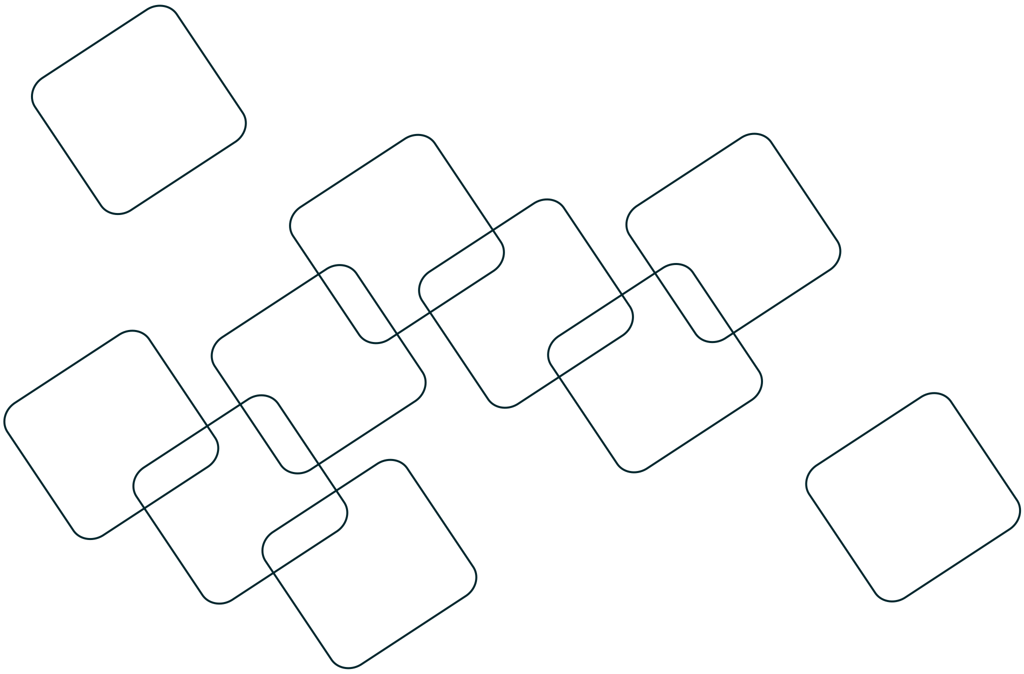

reviewable deaths annual report

2003 - 2004

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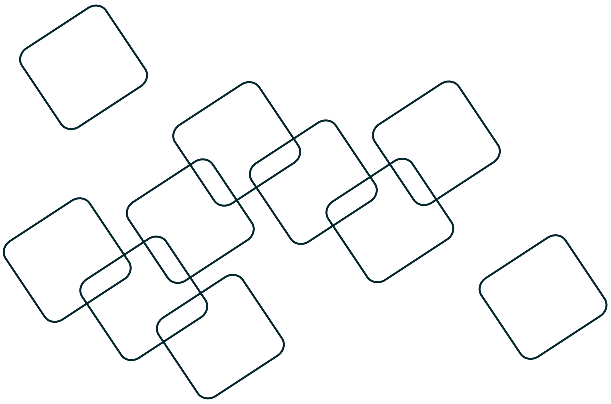

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November 2004

The Hon Meredith Burgmann MLC
President Legislative Council
Parliament House
Macquarie Street
Sydney NSW 2000

The Hon John Aquilina MP
Speaker Legislative Assembly
Parliament House
Macquarie Street
Sydney NSW 2000

Dear Madam President and Mr Speaker

I am pleased to present to the NSW Parliament the first annual report on our reviews of deaths of children in care and certain other children, and persons with disabilities in care.

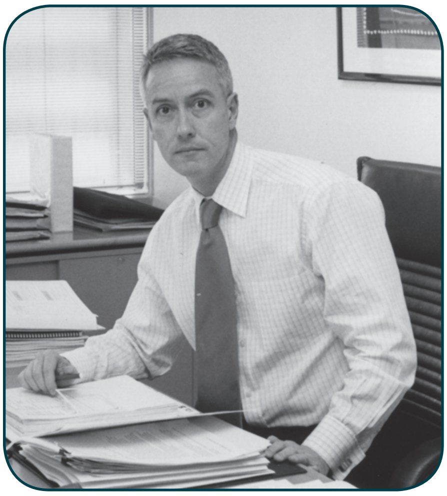
The report contains an account of our work and activities and is made pursuant to s43 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993*. The report includes data collected and information relating to reviewable deaths that occurred in the period ending December 2003, our recommendations, and information with respect to the implementation or otherwise of previous recommendations.

The report includes material on developments and issues current at the time of writing (July-November 2004).

Yours sincerely

Bruce Barbour
Ombudsman

ombudsman's message



BRUCE BARBOUR,
NSW OMBUDSMAN

This is the first report of reviews of the deaths of certain children and those people with a disability who died in care.

Reviewing the deaths of people for whom the government accepts at least some responsibility through the provision of services for their safety, welfare and wellbeing is an extension of the core work of an Ombudsman's office. Our role is not only to ensure that agencies within our jurisdiction comply with the law, but also that they provide services ethically, fairly and to the standard expected by the community. Our review of the circumstances in which people died has allowed us an opportunity to assess the level and kind of services provided and to make recommendations for improvements.

The development of this new function has been challenging, not only because of all the administrative issues associated with setting up a team and establishing the best ways to approach the work, but because of the subject matter itself. We are mindful of the impact of any death on those who loved or cared for the person who died.

Deaths of people with a disability

We believe the formal establishment of a statutory function reviewing the deaths of people with disabilities is a first in the world. We recognise that the group within our jurisdiction, those people living in care, are a very small percentage of the people with disabilities in our community. Many people with disabilities are cared for by their families, with support in various forms provided by agencies. However, the lessons to be learned from the review of the deaths of the group within our jurisdiction are relevant to the wider community.

Our review of the deaths of people with disabilities reveals no surprises. Our work confirms that coordinated individual health care plans are an essential component of appropriate services. There is a clear need for these plans to be monitored and updated. There is little value in specialist assessment if recommended follow up or assistance is not provided. Without accurate and proper documentation of health care needs, the capacity of carers to provide for the often complex needs of people with disabilities is reduced. Training and support of workers in accommodation services is undeniably important.

Our review of the deaths of people with disabilities includes residents of licensed residential centres (boarding houses). While the percentage of reviewable deaths of people living in boarding houses was relatively high, no conclusions can be drawn because of the very small overall numbers. What has become apparent to us are the often different needs of these people. We will record and investigate any trends or patterns that emerge over the next few years.

The most clearly preventable deaths of people with disabilities are those resulting from the unintended consequences of decisions about necessary levels of supervision. The conduct of those who make these decisions is often more appropriately examined by the Coroner. And yet it is clearly an area where our focus on policies and procedures intended to guide the work of service providers may be of assistance in improving those policies and procedures.

The development and application of policies and procedures that reflect legislated standards of service provision is where we have directed our recommendations in this first year.

Deaths of children

In this first year our examination of the deaths of children focuses on the work of the Department of Community Services. We are mindful that the department is only one of the agencies involved in the work of ensuring the safety, welfare and wellbeing of our children, but it is the lead agency.

We are also mindful that the department steps in when parents and families fail to provide adequately for their children and that this is an enormous responsibility with a small margin for error. The deaths of children from abuse, neglect or in suspicious circumstances are a problem for our whole community. In many child deaths we reviewed, there are a number of contributing factors, things that could have been done better. Our analysis is directed at where the system failed and children were left in situations of risk.

The Director-General of the department has pointed out that the lives of the children who died were similar in many respects to hundreds of other children, and that it is not possible to identify in advance those who will die. And yet, patterns of neglect and risk that did not receive appropriate protective intervention are evident from our work and we believe the department needs to respond effectively to what we are reporting and the recommendations we have made.

Much attention has been paid in recent years to the increased numbers of reports made to the department about risk of harm to children. Many millions of dollars are being spent to improve the services provided. It is clear to us that money alone will not resolve the problems. For example, we are concerned that the department has failed in a number of matters to take advantage of the support and resources of other agencies and adopt a cooperative interagency approach to protective intervention. We recognise that the department cannot by itself protect all children at risk, but neither is it expected or required to do so.

Improving the systems

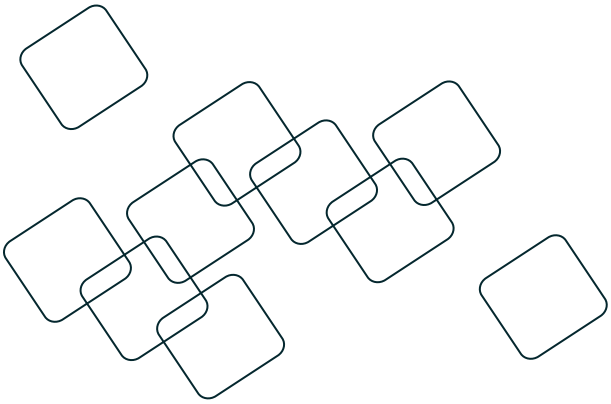
Our review of the circumstances leading up to the deaths of some of the most vulnerable people in our community identifies many challenges. What we have sought to do is to report our analysis and make recommendations arising from that analysis to the agencies that are able to make improvements to the system. We have already sought and received feedback from those agencies and this is incorporated into the report.

I would also be pleased to receive feedback and comments from the wider community in order that we can make any changes necessary to improve our important work in this area in the future.

B. A Barbour

Bruce Barbour
Ombudsman

introduction



Reviewable deaths

In December 2002, the Community Services (Complaints, Reviews and Monitoring) Act 1993 (CS-CRAMA) was amended and the former Community Services Commission was amalgamated with the NSW Ombudsman. One of the changes made was to formally establish a death review function, pursuant to Part 6 of CS-CRAMA.

The deaths of the following persons are reviewable (s35 CS-CRAMA):

(a) a child in care,

(b) a child in respect of whom a report was made under Part 2 of Chapter 3 of the Children and Young Persons (Care and Protection) Act 1998 within the period of 3 years immediately preceding the child's death,

(c) a child who is a sibling of a child in respect of whom a report was made under Part 2 of Chapter 3 of the Children and Young Persons (Care and Protection) Act 1998 within the period of 3 years immediately preceding the child's death,

(d) a child whose death is or may be due to abuse or neglect or that occurs in suspicious circumstances,

(e) a child who, at the time of the child's death, was an inmate of a children's detention centre, a correctional centre or a lock-up (or was temporarily absent from such a place),

(f) a person (whether or not a child) who, at the time of the person's death, was living in, or was temporarily absent from, residential care provided by a service provider and authorised or funded under the Disability Services Act 1993 or a residential centre for handicapped persons (in this Part referred to as a "person in residential care"),

(g) a person (other than a child in care) who is in a target group within the meaning of the Disability Services Act 1993 who receives from a service provider assistance (of a kind prescribed by the regulations) to enable the person to live independently in the community.

A child is defined as a person under the age of 18 years.

Prior to this, the NSW Child Death Review Team (NSW CDRT) had reviewed the deaths of all children in NSW while the former Community Services Commission reviewed the deaths of people with a disability in residential care. A brief overview of the history of reviewing deaths is at appendix 1.

Complementary changes were made to the Coroners Act 1980. All reviewable deaths of children and people with a disability are now examinable only by the State Coroner or a Deputy State Coroner.

The focus of Part 6 of CS-CRAMA is largely on systemic issues arising from reviewable deaths, reviewing trends and patterns and recommending changes to policies and practices that might prevent or reduce untimely deaths. As the function has been established in the Ombudsman's office it has become clear that we also have the capacity and responsibility to review deaths not only at a systemic level but also to review, and as necessary inquire into, the circumstances of individual deaths.

The Ombudsman's key functions

The Ombudsman's key functions in this area are:

(a) to monitor and review reviewable deaths,

(b) to formulate recommendations as to policies and practices to be implemented by government and service providers for the prevention or reduction of deaths of children in care, children at risk of death due to abuse or neglect, children in detention centres, correctional centres or lock-ups or persons in residential care,

(c) to maintain a register of reviewable deaths occurring in New South Wales after a date prescribed by the regulations classifying the deaths according to cause, demographic criteria or other factors prescribed by the regulations,

(d) to undertake research or other projects for the purpose of formulating strategies to reduce or remove risk factors associated with reviewable deaths that are preventable.

The Ombudsman is required to make a report each year on the work and activities related to the review of deaths. This report is to include data collected and relevant information, recommendations and information about the implementation or otherwise of previous recommendations.

All the agencies whose work is referred to in this report were given an opportunity to comment prior to publication. None made any critical comment about the content of the report. Where updated information was provided, it has been incorporated.

Monitor and review of deaths

Our role is not simply to research and report on systemic issues revealed through review of individual deaths. The function includes keeping reporting systems under scrutiny, undertaking detailed review of information relating to reviewable deaths, analysing data to identify patterns and trends, and consulting with people with relevant expertise.

The relevant statutory provisions and the Second Reading Speech indicate clearly that the function is intended to be one of oversight or scrutiny, but that the Ombudsman's independence and strong investigatory powers allow for more in depth work if necessary.

The range of powers available for the exercise of functions in reviewing deaths includes all the powers of investigation available to the Ombudsman for the investigation of complaints. This includes the power to require information or documents, powers under the Royal Commission Act that enable us to require people give evidence under oath and produce relevant material. We have unrestricted access to the records of the State Coroner and any other government agency or service provider in relation to the review of deaths. We are also able to report at any time to service providers or other appropriate agencies on issues arising from reviews. The Ombudsman has a unique opportunity to respond to individual matters and to assist service providers to address specific aspects of their service provision.

Using information obtained through the reviews we are able to make specific recommendations about improving the delivery of services to children and people with a disability. Recommendations arising out of our review of deaths appear at the end of each relevant chapter in this report.

Differences between the Coroner's role and that of the Ombudsman

Broadly speaking, the Coroner's investigation is focused on determining the manner and cause of an individual's death. Only the Coroner is entitled to make this determination for reviewable deaths and so death certificates for these individuals can no longer be signed by any other person. Coronial processes (or subsequent criminal proceedings) tend to focus on events immediately relevant to the death. The Coroner may hold an inquest to examine underlying or systemic issues surrounding a death, but this is done in only a small proportion of cases.

The Ombudsman, by contrast, looks not so much at the cause of death, but at the circumstances in which the death occurred in order to identify the potential for preventing these deaths. With the cooperation between the two agencies there is maximum opportunity to use information from individual deaths to monitor and review services and influence changes to systems and practices. Coordination is obviously essential.

More details about coronial processes can be found at appendix 2.

Registration of deaths

Work in this area is initiated by notification of a death. Section 37 of CS-CRAMA provides that the Ombudsman must be informed about a reviewable death:

(1) The Registrar of Births, Deaths and Marriages must provide the Ombudsman with a copy of death registration information relating to a child's death not later than 30 days after receiving the information.

(2) The Director-General of the Department of Ageing, Disability and Home Care must provide the Ombudsman with copies of any notification received by the Director-General relating to a reviewable death not later than 30 days after receiving the notification.

(3) It is the duty of the State Coroner to notify the Ombudsman of any reviewable death notified to the State Coroner not later than 30 days after receiving the notification.

The above information forms the basis of the register the Ombudsman is required to keep of reviewable deaths.

In the year under review, 271 deaths were determined to be in jurisdiction and were registered. This includes 110 deaths of people with a disability, and 161 children. The deaths of 24 of these children were not reviewed because not all the relevant information was available.

Protocols for accessing databases

The information received from the above sources does not identify whether children or their siblings have been reported to DoCS. We have access to the databases of DoCS in order to identify these children and to discharge other relevant functions. We also have access to the NSW Police COPS database.

Further information from these and other agencies is requested as necessary.

Advisory committees

We have set up two advisory committees to assist in the review of deaths and relevant activities. The membership of these two committees is set out in appendix 3.

Since December 2002, the reviewable child death advisory committee has met on nine occasions. The reviewable disability death advisory committee has met on seven occasions.

These committees provide us with valuable advice on complex child or disability death matters, policy and health practice issues. Both committees have participated in the preparation of this report, providing advice and feedback.

Coding of cause of deaths

Each reviewable death registered during the year was coded in line with the Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) developed by the World Health Organisation. The purpose of this classification is ‘to permit the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries or areas and at different times’ (WHO(1993) Vol 2, p2).

Expert members of our advisory committees completed this coding.

Additional work done during the period under review

During 2003-2004 and in relation to individual matters, we:

- started five investigations under s.16 of the Ombudsman Act
- conducted three preliminary inquiries under s.13AA of the Ombudsman Act
- made risk of harm reports to DoCS in relation to 11 children, siblings of children whose deaths we reviewed
- notified DoCS of the death of a child in very similar circumstances to the previous death of a sibling
- referred four matters to the State Coroner for further consideration.

We undertook a number of educational activities over the period of time. This included:

- seven seminars across NSW with staff from the Coroner’s Office to inform non-government disability service providers about the new requirements for reporting deaths in their services
- an address to the Interchange Respite Care State Conference
- briefing dietitians at the Metro Residences Rydalmere and social workers at Westmead Hospital on our death review functions
- delivering two seminars on deaths of people with a disability and epilepsy management issues.

Review of the deaths of 37 people

In March 2004 we completed a paper analysing health issues arising from the review of 37 deaths of people with a disability who died between 1 July and 31 December 2002. This analysis included thirty deaths that occurred before the commencement of the reviewable death function in the Ombudsman’s office and completed work begun by the former Community Services Commission. The issues paper was a way to ensure that key issues arising from these deaths were identified and recorded.

The 37 deaths were analysed to identify trends and patterns and to determine if there were any issues that warranted further examination. The deaths were classified according to demographic criteria, cause of death and underlying health conditions.

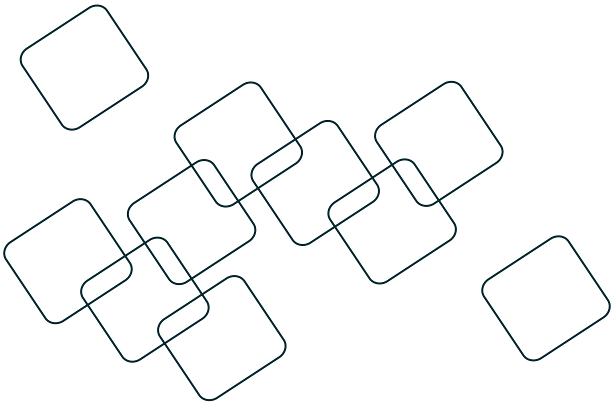
The majority (31) of the 37 individuals were identified as having an intellectual disability, with 15 reported as having a severe or profound disability. Our analysis identified a number of issues:

- Respiratory illness was a common cause of death, with 12 deaths being related to respiratory illness.
- Gastro-oesophageal reflux disease (GORD) and indications of poor oral hygiene were present. Both are linked to respiratory disease. Of the 12 deaths related to respiratory illness, nine of the people had either symptoms and/or a diagnosis of GORD.
- There were low immunisation rates across the review group.
- Complications had arisen from enteral nutrition regimes (providing food through a tube). Ten of the group of 37 individuals had a form of gastrostomy at the time of their deaths, with two deaths being directly related to the placement of the gastrostomy device.

As part of the review process, we convened a meeting of representatives from DADHC, NSW Health, the HCCC and a representative from our advisory committee to discuss a draft paper and to canvass ways to improve the services provided to people with a disability in care. Following input from the agencies we finalised the issues paper, identifying a number of matters warranting further consideration and action. The proposals we put forward focussed on agencies working to ensure that appropriate policies, procedures and training are in place to assist disability service staff and health personnel to provide adequate services to people with a disability in care.

The responses from DADHC and NSW Health have been included in this report where appropriate.

deaths of people with a disability



Department of Ageing Disability and Home Care

DADHC was established in 2001, bringing together the former Ageing and Disability Department (ADD), Disability Services provided by the Department of Community Services (DoCS), and the Home Care Service of NSW. DADHC is responsible for the full range of services for older people, people with a disability, and their carers, in NSW. In 2002 DADHC began implementing a regional structure, which is now complete. Under the new structure, each region is responsible for the administration, planning, delivery and monitoring of DADHC operated and funded services in its area.

It is a legislative requirement that DADHC, on behalf of the Minister for Disability Services, monitors the agencies it funds and provides to ensure they are delivering services in accordance with the *Disability Services Act 1993*. Further, DADHC is responsible for providing guidance to services to assist them to meet their service delivery obligations.[1] Through the Commonwealth, State and Territory Disability Agreement (CSTDA) DADHC funds approximately 200 community organisations to provide accommodation support services to people with a disability.

In August 2004, DADHC released *Future Directions*, a paper that outlines pressures impacting on the disability service system and the department's immediate priorities for action. These priorities include:

- the closure of large residential centres and relocation of residents to community housing arrangements
- working with other agencies to develop support options for people with high and complex needs
- improving prevention and early intervention strategies, including work with NSW Health to improve diagnostic and assessment services.[2]

The Minister has requested that DADHC make available more detail about its plans for each of the priority initiatives (including timelines), and provide regular updates of achievements against these plans.[3]

Reporting deaths

The Disability Death Review Team (DDRT) of the former Community Services Commission had agreements with ADD (in respect of funded accommodation services) and DoCS (in relation to government accommodation services) about the notification of deaths of service users. Services were to inform the relevant department, who would in turn forward the information to the DDRT.

From July 1999 with the publication of *Standards in Action*, non-government services completed a form entitled Client Death Notification (CDN). DoCS used their own amended version of this form. In either event, the form was completed and forwarded to the respective department by the agency. The department then forwarded the CDN to the DDRT for assessment and review. The agency was required to cooperate with these processes and to provide full and unrestricted access to records and personnel if requested by the DDRT. Following the formation of DADHC, the existing arrangements for provision of information to the DDRT continued.

This CDN included minimal information. Beyond personal details, agencies were asked to give date and cause of death and duration of last illness as well as some information about the notification of certain people. Attachments to the CDN included any related incident reports and any briefings to the department. Each department also advised the DDRT of any investigation or review of the death, including any reports or findings.

In order to have all relevant information for a review of the death, it was the practice of the DDRT to call for individual client files. In that way, they were able to access the client's current health care plan and any recent critical incident reports.

Following the legislative changes of December 2002 the Ombudsman was required to establish a register of reviewable deaths occurring in NSW after 1 December 2002. This included deaths of residents of licensed residential centres, more commonly known as boarding houses. DADHC agreed to provide Disability Client Death Notification forms for residents of DADHC accommodation and the CDN forms received from non-government disability accommodation services. It was agreed, however, that the two forms should be revised and standardised.

The CDN form was redeveloped in collaboration with DADHC. This form captures additional information as well as requiring the automatic provision of relevant documents. In this way, information necessary for the register was obtained without extensive negotiation over each matter notified.

The revision was generally supported by DADHC as a way of standardising death notification processes across funded and licensed disability accommodation services as well as those operated by DADHC. In mid 2003 we began sending out an interim form 'supplementary CDN' to services who were reporting deaths using the old CDN. The supplementary CDN sought additional information. The Deputy Director-General expressed some concern that while the Ombudsman was clearly entitled to the additional information, it was likely to only be available from DADHC services and that this might perpetuate the inconsistencies in the reporting of client deaths across the disability sector. However, the revised form was endorsed by the Director-General in June 2003 and released to DADHC operated services in February 2004.

In August 2004, DADHC finalised a policy called *Response to the Death of a Client and Reporting Reviewable Deaths*. It provides operational procedures for responding to and reporting the death of a person with a disability, for all DADHC operated, funded and licensed accommodation services, including completion of the CDN. The policy was released to all DADHC operated services in September 2004. It is now available, with the CDN, on DADHC's website. DADHC advises that it is currently developing a strategy for distributing and promoting the policy to funded and licensed services.

It is proposed that the CDN will be reviewed in the next reporting period.

Prior to the change of legislation licensed residential centres were not within the jurisdiction of the DDRT. The need to notify a death and complete a CDN is a new requirement for boarding house proprietors.

Defining the scope of our work

This chapter details information about the people who died and the circumstances of their deaths. Because this is the first year for which this information has been collected, we have focused on a broad, largely descriptive analysis of the group of people who died while in care. In the future we intend to look at trends and patterns in some depth and focus on issues highlighted through our review of data. It is however possible to identify some areas where more work is clearly warranted.

In this period we received notification of 114 deaths. Four of these people were not within our jurisdiction because they were not living in residential care as described in the legislation; they were therefore not included on the register. Six of the reported deaths were of children with disabilities who were also determined as being reviewable child deaths. These deaths therefore appear in the child death data as well.

The following analysis is of the 110 deaths recorded on the reviewable deaths register. It includes information on demographic factors and accommodation types and a number of other issues often associated with death in this population. This includes not only cause of death and contributory factors, but type of disability and any related health issues.

We have also reviewed a group of 33 of the 110 people who died, focusing on respiratory illness. This work follows the analysis of 37 deaths finalised in April 2004.

A further ten deaths were reviewed in detail, using not only the information from the CDN and accompanying documents but also service files and relevant medical records. Priority for detailed reviews was given to deaths that occurred as a result of a 'sentinel event'– 'an unexpected event that results in death or serious physical or psychological injury, or risk thereof'.[4] These reviews allowed us to examine in some detail events leading up to and surrounding the deaths. Some of these detailed reviews are summarised as case studies in this report.

Twenty-two (22) of these deaths were of people living in licensed residential centres. They are included in this review because they are within jurisdiction, but in a number of respects these people are different from the larger group. For example, three of the people who died did not have a disability. Where it is more useful to do so, the deaths of people who lived in boarding houses are reported as a separate group.

In the analysis and the review, we refer to a number of DADHC policy documents. Some of these documents were introduced after the review period had commenced, and some are required only in DADHC operated services. The key policies referred to are:

- *Managing Client Health*. We acknowledge that this policy was only endorsed in May 2003 and is currently only required policy in DADHC operated services. DADHC has advised that it is reviewing *Managing Client Health* with a view to making it available to the non-government sector.[5] The *Managing Client Health* policy was preceded by the Department of Community Services' document *6.15 Healthy Lifestyles* in the *Policies for Working with People with Disabilities Version 2 1996*. Reference is also made to this document where relevant.
- *Ensuring Good Nutrition*. This policy was released by DADHC in October 2003 for all disability accommodation and centre-based respite services funded or directly operated by DADHC. The roll-out of the policy to non-government organisations (NGOs) was completed in mid-2004.

Demographic Information

Age

The age range in the group of 110 was 8 – 93 years.

Six of the people (6%) who died during the reporting period were children (ie under 18 years of age). Two of the deaths in the under 18 age group occurred while the child was accessing respite care.

The average age at the time of death of the group of 110 was 52 years with 59 deaths (54%) occurring between the ages of 45 and 74 years. The median age for the whole group at time of death was 54 years, with the median for the 46 women who died being 50 years and for the males being 54 years. The median age at time of death for boarding house residents was 65 years. This is compared with life expectancy in Australia for the general community, which is 76 years for males and 82 years for females (ABS *Australian Social Trends* 15 June 2004). The median age of people using disability accommodation services nationally was 40 years for males and 41 years for females.[6]

Gender

There were 64 (58%) males and 46 (42%) females in the group. This reflects the gender proportion of people using disability accommodation support services in Australia.[7]

As can be seen in the chart below, in three age ranges there were more deaths of males than females. Of the 59 deaths in the age groups 45 to 74 years, 39 deaths (66%) were of men.

Service type

The reviewable deaths are of those people with disability 'in residential care'. The types of residential accommodation are categorised on the CDN and are as follows:

- group homes – of less than seven people
- small residential centres of between seven and 20 people
- large residential centres of more than 20 people
- licensed residential centres, more commonly known as boarding houses, where the number of residents depends on the licence conditions
- respite care (group homes or large residential centres).

The numbers of deaths in each type of facility, as reported on the CDN, is set out in the bar graph below.

Figure 1: Age and gender

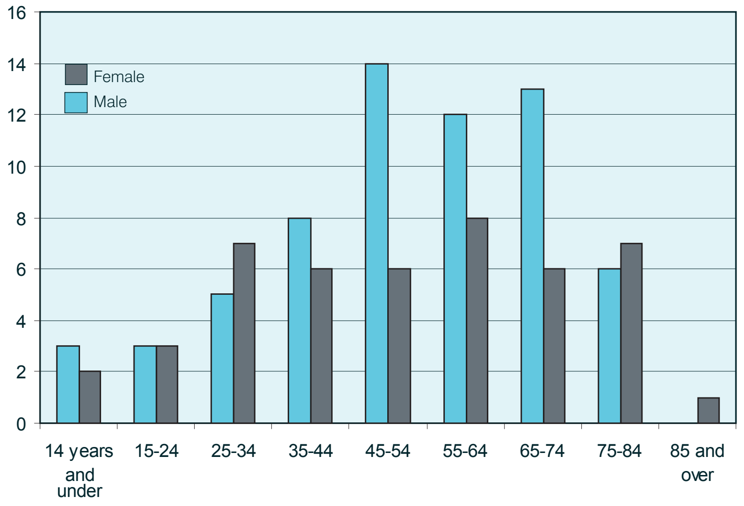
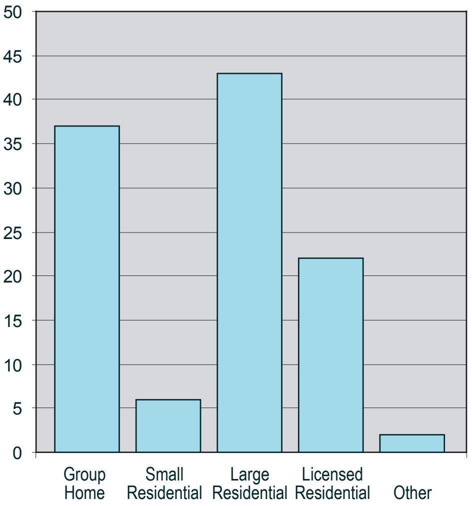


Figure 2: Numbers of deaths in different types of facility



Indigenous status

Four service users (4%) were recorded as being of Aboriginal or Torres Strait Islander (ATSI) origin.

NESB status

Eight service users (7%) were reported as being from a non-English speaking background. Five were reported as having a first (or preferred) language other than English.

Accessibility/remoteness

Most people were resident in a major city at the time of death (58) with only two people living in an outer regional or relatively inaccessible or remote area.

One death occurred in what the service described as a 'transitional accommodation service'. This fits into none of the service types set out above, but is nonetheless in jurisdiction. The second facility in the 'other' category was respite care.

While not all relevant figures are available at the time of writing, some idea of the numbers of people living in the different types of facilities compared with the numbers of deaths is useful. Direct comparisons are not possible because the reviewable deaths are from the calendar year 2003 plus December 2002, while the number of people accommodated is based on a snapshot report of May 2002 collated by DADHC.

Figure 3: Number of people with a disability living in different types of residences

Type of residence	Number of people accommodated*	Number of deaths	Percentage of population who died	Percentage of reviewable deaths
Group homes (DADHC)	1218	19	1.5	17.3
Group homes (funded/licensed)	1585	18	1.1	16.4
Small residential centre (DADHC)	16	0	N/A	N/A
Small residential centre (funded/licensed)	70	6	8.5	5.5
Large residential centre (DADHC)	1278	25	1.9	22.7
Large residential centre (funded/licensed)	563	18	3.1	16.4
Licensed residential centre	1072**	22	2.0	20.0
Other (funded/licensed)	Not available	2	Not available	1.8

* source: data collected by DADHC for Commonwealth/State Disability Agreement Minimum Data Set 2002 (CSDA MDS)
** these are licensed beds. No centralised information is kept on occupancy rates.

Thirty nine percent (39%) of reviewable deaths were of people who lived in large residential centres. It is not possible to draw conclusions from this data as the group is small and there are difficulties in comparing mortality rates of people living in community and institutionalised settings.[8]

Nonetheless, it is interesting to note that 20 per cent of the deaths were of residents of licensed residential centres. No conclusions about this are inferred here since more detailed work would be necessary in order to make any valid observations.

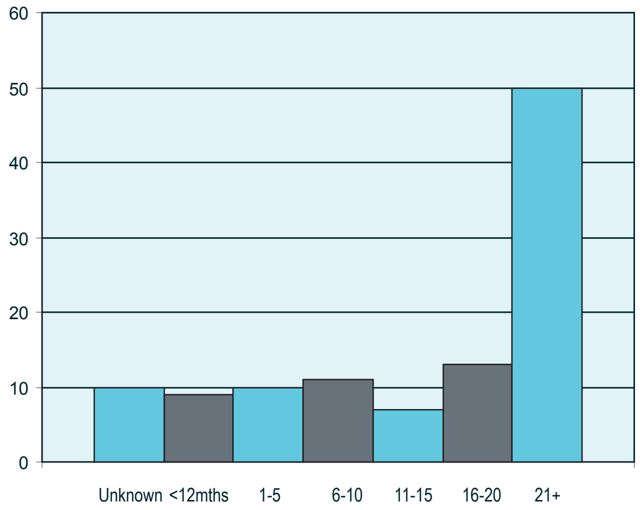
Time in residential care

Nearly 46 per cent of the people in the total group had spent more than 21 years in residential care. The age of these people ranged from 31 to 93 years with the median age at time of death being 57 years.

Services are asked to report on the CDN the length of time the person had lived in their place of residence. Ten people had lived in their residence for less than 12 months at the time of their death. Of these, two had been in residential care for less than 12 months, while seven others had been in residential care for more than 16 years.

One of the issues about the movement of people between services, or even between residences within a service, is the importance of the new service provider being able to access accurate, current and well-documented information about their new service user. Particularly when people have critical or complex health issues, relevant information needs to be immediately available, for example an epilepsy management plan, or plans to manage chronic health problems. One of the issues we have come across during the year is the paucity or poor quality of available information or plans (see section on health management for more detail).

Figure 4: Total lifetime years spent in care



Disability type and levels of support need

The CDN reports the known disabilities (or impairments) for each person and these are represented in figure 4.

The CDN does not report on ‘primary’ disability. Eighty-four people (76%) were reported as having an intellectual disability. Of the 84 people reported as having an intellectual disability, 55 were reported as also having other disabilities or impairments.

Figure 5: Disability Types

Disability	Number
Developmental	1
Intellectual	84
Physical	49
Psychiatric	31
Neurological	11
Sensory	37
None	3

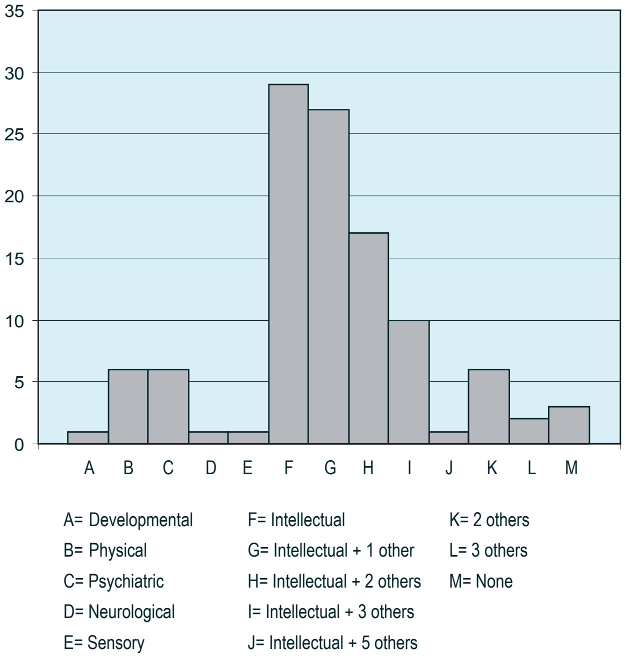
* Each person may have had one or more disability types and so may appear in more than one catetory.

Figure 6: Disability types and frequency

Frequency	No.	Percent
Developmental	1	0.9
Intellectual	29	26.4
Physical (Cerebral palsy/specified other)	6	5.5
Psychiatric	6	5.5
Neurological	1	0.9
Sensory (sight, hearing/specified other)	1	0.9
None*	3	2.7
Intellectual & Physical	10	9.1
Intellectual & Psychiatric	9	8.2
Intellectual & Neurological	1	0.9
Intellectual & Sensory	7	6.4
Intellectual & Physical & Psychiatric	2	1.8
Intellectual & Physical & Sensory	6	5.5
Intellectual & Psychiatric & Sensory	6	5.5
Intellectual & Physical & Psychiatric & Sensory	4	3.6
Intellectual & Physical & Neurological & Sensory	1	0.9
Physical & Psychiatric	1	0.9
Physical & Sensory	2	1.8
Neurological & Psychiatric	1	0.9
Neurological & Sensory	2	1.8
Intellectual & Physical & Neurological	1	0.9
Physical & Psychiatric & Neurological	1	0.9
Intellectual & Physical (2) & Sensory	4	3.6
Neurological (2) & Sensory	1	0.9
Intellectual & Physical (2)	2	1.8
Intellectual & Sensory & Neurological & Physical (3)	1	0.9
Intellectual & Psychiatric & Sensory (2)	1	0.9
Total	**110**	**100**

*Three residents of licensed residential centres were reported as having no disability. They were aged 65 years, 73 years and 80 years of age.

Figure 7: Intellectual and other disabilities



The presence of more than one disability or impairment is likely to impact on the level of support required by each person in one or more areas. Other health and related factors may also contribute to the need for additional support. Of the 63 people reported as having two or more disabilities, 44 people (70%) were reported as having urinary and/or faecal incontinence, 46 people (73%) were reported as having limited mobility, 37 people (59%) were reported as needing assistance with meals, 38 people (60%) were reported as having swallowing problems and 22 people (35%) were reported as having epilepsy.

Just as disability type and presence of multiple impairments is likely to impact on the level of support required by each person, ‘level’ of intellectual disability may result in the need for support in particular areas of daily living, such as communication and decision-making. The CDN reports the level of disability for those 84 people reported as having an intellectual disability, represented in the table below. Documentation supporting the reported level of intellectual disability was not sought. For this reason, and given the limitations of this measure as a sole indicator of support need as well as problems with its reliability, this data should be treated with caution.

Figure 8: Level of intellectual disability

Level of intellectual disability	No. of people	Percent
Mild	15	13.6
Moderate	34	30.9
Severe	21	19.1
Profound	11	10
Unspecified	3	2.7
Not Applicable	26	23.6
Total	**110**	**100**

The CDN also reports if the cause of the intellectual disability has been diagnosed. Chromosomal abnormalities were reported as the most common cause, including 17 people with Down syndrome, two people with Prader-Willi syndrome and one person with Fragile X syndrome. The cause of intellectual disability was reported as unknown for 33 people while eight CDNs did not include any information.

While it is not uncommon for the cause of intellectual disability to be unknown, a definitive diagnosis, where possible, would generally assist in health care planning, given known health risks associated with some syndromes.

Deaths of people with Down Syndrome

Down syndrome is the most commonly inherited cause of intellectual disability and in Australia it accounts for approximately 15 per cent of all cases of people with intellectual disability.[9] As indicated above, 17 of the total group of 110 deaths (15 %), representing 20 per cent of the group of 84 reported as having an intellectual disability, were identified as having Down syndrome.

In the whole group of 110 reviewable deaths, the median age at death was 54 years. Median age at death for the four women with Down Syndrome was 48 years, while the median age at death for the men was 51 years.

Recent research found median life expectancy for people with Down syndrome to be 58.6 years. In this study, 75 per cent of the 1332 people who died had lived to 50 years of age, 50 per cent had lived to 58.6 years, and 25 per cent had lived to 62.9 years. The median life expectancy was greater for males than females by 3.3 years.[10]

Disability and health care coordination

As indicated above, more than half of the group of 110 people had two or more disabilities. A high proportion of these had existing health issues. Many in the group were perceived to have severe or profound levels of intellectual disability. These factors indicate that the support required by some people with a disability to maintain optimum health is likely to be high or complex, requiring a well-coordinated response. Support arrangements include a number of elements such as support hours, resources and tools to assist people in care and the staff who support them, and expert advice and assistance in relation to treatment.

Among the group of 110 deaths, we found many instances where failures in health-related support and coordination featured. For example, we found:

- delays in identifying some health conditions, such as osteoporosis, because the person had not been screened for the condition
- delays in implementing specialist recommendations, such as dietary recommendations where significant weight loss resulted
- delays and, in one case, lack of referral to a relevant health specialist
- delays and lack of follow up on recommendations for referral back to specialists for further review.

This suggests there are at least three factors that are essential for maintaining optimum health care for people with a disability living in care:

1. regular assessment or health screening and review: more frequent screening and review may be required for people with complex health needs or known health factors.
2. access to specialist services to address health conditions.
3. implementation and follow up of specialist recommendations.

For all three to occur, clear policy and procedural guidance is needed for support staff, and staff need to be aware of policy and well-versed in their responsibilities.

DADHC has advised us that within DADHC operated services, key workers are responsible for integrating all health care services for individual service users.[11] In its policy for DADHC accommodation services, *Managing Client Health*, a key worker is defined as a worker within the accommodation unit who is the service user's primary contact and who is responsible for development, implementation, management and documentation of that person's individual plan. Procedural guidance for health care planning, within the context of individual planning, is set out in this policy.

DADHC has advised that it is reviewing *Managing Client Health*, and that it will consider the inclusion of the policy principle of a key worker when the policy is extended to funded services.[12]

One DADHC program in the Illawarra area is an example of health care management that may be particularly relevant for people with medical needs who require a complex service response. The program uses clinical nursing specialists to work with services developing health care plans for service users, coordinating health care services and attending medical appointments. It was evaluated as being a successful model by independent reviewers who submitted their findings to DADHC in May 2000. DADHC's response to that review and its recommendations is unknown.

In addition to clear guidance for support staff, health services, which are alert and responsive to the needs of people with a disability in care, are also required to ensure their optimal health is maintained.

NSW Health advises it has a number of current and proposed initiatives that it considers will enhance health service delivery to people with a disability in care. These include the following:

- contracting the Centre for Developmental Disability Studies (CDDS) to develop a training strategy and information resources for general practitioners and other health care providers, to increase their disability awareness and skills in managing people with intellectual disability
- the Primary Health Care Capacity Building pilot project, which is aimed at building the capacity of general practitioners to take a lead role in managing the primary health needs of people with intellectual disability by strengthening local networks between GPs, allied health professionals and disability service providers
- development of guidelines for hospital staff, *Responding to the needs of people with disabilities during hospitalisation*, and associated training program
- improvements to discharge planning which specifically address the needs of people with a disability living in residential care, and
- exploring the possibility of extending the oral health training program provided by the United Dental Hospital to support staff in government and non-government services.

case study 1

A person with severe intellectual disability and cerebral palsy was admitted to hospital for treatment of a fractured elbow. Due to an infection of the wound the person stayed in hospital for a number of weeks. Although the wound improved to a point where hospital notes record a discussion with service staff concerning discharge plans, later that same day the person's health suddenly deteriorated. Two days later surgery was required for a massive faecal impaction and a few days later the person died.

According to information on the files, the person had experienced a number of health problems in the previous year. These included chronic constipation, increasingly challenging behaviour and two other fractures. Hospital notes indicated that the person was aggressive and sometimes refused treatment during each of the admissions in this period.

There was no documentation on the files reviewed that the service had provided information to the hospital about the person's general health care needs, including the chronic constipation, nor guidelines on how to manage the difficult behaviour.

Causes of death

The following table identifies the primary cause of death in 90 of the 110 deaths, categorised according to ICD-10 codes. At the time of writing, the Coroner had not made a determination of cause of death for the other 20 deaths in this group.

Figure 9: Numbers of deaths in each ICD-10 cause of death category *

ICD-10 Cause of death category	No. of deaths
Certain infectious & parasitic diseases (A00-B99) Diseases generally recognised as communicable or transmittable, for example, tuberculosis, tetanus, meningococcal septicaemia, viral meningitis but excluding HIV, diseases related to perinatal period, influenza & other acute respiratory infections.	3
Neoplasms (C00-D48) A new and abnormal growth, any benign or malignant tumour often referred to as cancer.	6
Diseases of the blood & blood-forming organs and certain disorders involving the immune mechanism (D50-D89) For example, iron deficiency anaemia, protein deficient anaemia, disease of the spleen.	1
Endocrine, nutritional & metabolic diseases (E00-E90) Diseases that can affect the production of hormones, breakdown of substances which can in turn affect the growth and functioning of the body. For example, hypothyroidism, diabetes mellitus, malnutrition, testicular dysfunction, obesity, phenylketonuria.	1
Diseases of the nervous system (G00-G99) This includes diseases that can cause a decrease in body activity by affecting the nerves and their function. For example, cerebral palsy, meningitis, encephalitis, Parkinson's Disease, Alzheimer's disease, epilepsy, hydrocephalus.	4
Diseases of the circulatory system (I00-I99) This includes disease of the heart and blood vessels needed for the transport of nutrients and oxygen and removal of waste products. This includes pulmonary heart disease, hypertension, pulmonary embolism, subarachnoid haemorrhage, cardiac arrest, haemorrhoids.	17
Diseases of the respiratory system (J00-J99) This includes diseases of the combination of organs and tissues needed for breathing and hence includes the nasal cavity, pharynx, larynx, trachea, lungs and other associated muscles. For example, influenza, pneumonia, bronchitis, asthma, pneumonitis, pulmonary oedema.	36
Diseases of the digestive system (K00-K99) Diseases that affect the breakdown of food for absorption by tissue in the body, for example, gingivitis and periodontal disease, xerostomia (dry mouth) oesophagitis, gastro-oesophageal reflux, haematemesis.	4
Diseases of the skin and subcutaneus tissue (L00-L99) Diseases that can result in poor control of hydration, infection, senses (touch, pain, temperature). It also includes nail disorders, dermatitis, hair loss, acne, decubitus ulcers (pressure ulcers).	1
Diseases of genitourinary system (N00-N99) This pertains to diseases that affect the reproductive system (male and female) and also the urinary system including renal failure, cystitis, amenorrhoea (failure to start menstruation).	2
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99) This includes disorders present at birth whether they are inherited or caused by an environmental factor. For example, microcephaly, congenital hydrocephalus, spina bifida, malformations of the heart, cleft lip & palate, Down Syndrome, Fragile X Syndrome.	1
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99) This includes signs and symptoms, abnormal results of clinical or other investigative procedures, and other conditions not classifiable elsewhere. Examples include, dyspnoea, asphyxia, respiratory arrest, sudden death, dysphagia, senility.	7
Injury, poisoning and certain other consequences of external causes (S00-T98) Traumatic subdural haemorrhage, crushing injury of the larynx & trachea, foreign body in respiratory tract, drowning.	5
External causes of morbidity and mortality (V01-Y98) Where environmental events and circumstances have caused injury, poisoning and other side effects. For example, fatal blood levels of medication, pedestrian injured in collision with vehicle.	2

* table only includes categories in which deaths of this group of people were coded

Diseases of the respiratory system were the primary cause of the largest group of deaths (36). This was not unexpected, as respiratory illness is known to be the most common cause of death of people with intellectual disabilities.[13] Our specific review of deaths from this cause can be found below. Other significant causes of death were diseases of the circulatory system (17) and neoplasms (6).

People with Down syndrome are at increased risk of some health problems, including congenital heart defects, increased susceptibility to infection and respiratory problems.[14] Nine of the 17 people in this group (53%) died of respiratory illness. Four died of diseases of the circulatory system and for two the cause of death is not yet known.

External cause deaths

ABS[15] reports that in 2002 external causes (accidents, poisonings and/or violence) were responsible for 5.8 per cent of all deaths registered. For this group, taking together the two categories relating to external causes, it is 6.3 per cent. This is a significantly lower percentage than that reported in 2001 by the former Community Services Commission in its review of the circumstances of the death of 211 people with disabilities. In that review 12 per cent of deaths were due to external factors, with drowning being the largest single external cause of death. Although the figures are extremely small, it is interesting to note that in the group under review neither drowning nor falls were prevalent to the same degree.

The circumstances of death for the people in the current review were as follows:

- alleged murder (during the night while residents were unsupervised)
- fall (while staff members moved a person from a bed to a shower trolley)
- pedestrian accident while leaving a workplace
- fatal medication level in blood (of medication not prescribed to that person)
- choking (on food taken from another service user)
- drowning (two – one in a swimming pool and one in a bath tub).

All seven deaths classified as resulting from external causes could be attributed to the person being unsupervised at the time of, or in the period leading up to, death. Where coronial or other legal proceedings are not finished it would not be appropriate to publicise any details about the circumstances of death. For example, the alleged murder is still before the courts so any discussion of the matter might prejudice the outcome of criminal charges. While it is easy to observe that these deaths were probably the most immediately preventable in the group, it is necessary to look at the circumstances of each death in order to assess whether they were preventable.

The pedestrian accident occurred in the dock area of a supported workshop. There had been changes made to pedestrian routes on the site on the day of the death but no assessment of the ability of this person to move around the site safely and independently.

The death from a fall was of a person whom two workers were preparing to move from a bed to a shower trolley. The Coroner found that the person had died as a result of an accidental fall, but did note that the mobility management plan had not been followed.

Both of the deaths by drowning raise issues about supervision. In one case, a man with a mild intellectual disability, epilepsy and a history of challenging behaviour, absconded from the service in which he was living in order to go to a swimming pool of his choice. A worker followed him and tried to stop him from entering the pool but retreated when the man became annoyed and began throwing rocks. The worker returned to the service saying s/he would return shortly. The man was found drowned about 30 minutes later. The autopsy could not rule out the possibility of him having had a seizure leading to him drowning. The Coroner dispensed with an inquest.

External causes of death and prevention

While it may be reasonable to assess that deaths from external causes such as falls, drowning and choking, can be prevented by increased supervision, there are significant issues that services have to contend with in determining and ensuring adequate levels of individual supervision. Broadly, these issues relate to perceived tensions between balancing people's rights to privacy and taking calculated risks that allow for the development of competencies and independence (often described as 'dignity of risk') with the requirements of services to meet their duty of care to service users. This tension is most evident in cases where a decision needs to be made as to whether a person is capable of undertaking activities alone, or to what degree they require supervision.

The *NSW Disability Services Act 1993* (DSA) and related Disability Services Standards require the planning and delivery of services based on individual needs. Thus, broad or blanket guidelines that relate to particular disability types or support issues, such as compulsory supervision of people who have epilepsy, may be inconsistent with the standards and the principles of the DSA. Similarly, the objects and principles of the DSA focus on the provision of services that promote the competence and independence of people with a disability. Thus, guidelines that do not appropriately recognise and support these concepts, while ensuring people are adequately supported and safe, are likely to be inconsistent with the DSA.

Standards in Action (1998) provides guidance to DADHC operated and funded services in this regard. Standard 2 (Individual needs) sets out minimum standards and practice requirements for planning and delivering services based on individual needs of service users. Standard 10.2 (Duty of care and dignity of risk) sets out minimum practice requirements, including the development of policy and procedures by each agency for ensuring that appropriate care is taken to '*minimise risk of harm, illness, injury and death*' of service users, balanced with the right of people with disability to take risks.

In addition, disability accommodation services and licensed residential centres are required to comply with the *Occupational Health and Safety Act 2000*. This Act requires employers to ensure the health and safety of employees and any others who are on the employee's worksite, including service users.

In this context, it is essential that any strategy to minimise the risk of injury or death due to external causes includes regular review to assess risk to individuals and requirements for supervision, and procedures to ensure that such supervision is consistently provided.

In most instances, assessment and decisions about supervision, or risk management, will require the input of several parties, including the service user (or their representative), the service provider, and someone suitably qualified to provide expert advice where necessary.

Tension can arise between privacy issues and safety considerations, often described as tensions between 'the dignity of risk' and 'duty of care'. The *Disability Services Act 1993* and *Standards in Action* enshrine in law and practice the right of people with disabilities to the same basic human rights as other people. This includes the right to privacy, dignity and confidentiality. This is not to say that these rights override the need for a high level of safety, which is clearly fundamental. In a case before the ACT Coroner in 2001, a person drowned in the bath while unsupervised. A key focus of the inquest was the identified tension between policies of supervised bathing and the right of an individual to privacy and dignity. The Coroner noted that the balance between the two principles of safety and privacy could have been found by a proper assessment of risk to an individual. He found that it was not for individual staff members to make such decisions, but for an appropriately qualified person to give clear and unambiguous instructions about the level of supervision necessary to ensure safety while still affording as much privacy as possible.[15]

case study 2

A person who choked to death had Prader Willi syndrome.[18] The person had been living in a group home for many years and had a reasonable level of independence, including managing personal shopping and banking with support.

Staff reported that they had left the person alone for about ten minutes on the day of the death, but on their return the person was unconscious and going blue. The person had asphyxiated on snack food taken from another resident's room.

It seems from the records that this was not the first time this person took food from another resident's room. The staff, while limiting and monitoring the person's food intake, were doing so in a framework of supporting appropriate choices and decisions. A requirement that residents' rooms be locked or that all food items be removed and stored centrally would have limited all residents. Balancing the needs of a person with Prader-Willi Syndrome with those of other residents of a group home who do not need food restrictions is clearly a challenge.

The *Managing Client Risk* policy for DADHC operated services requires a client risk profile (CRP) to be completed for each service user, and regularly reviewed in the context of their individual plan. The policy also requires that support plans to manage identified risks are developed and implemented through the individual planning process. While *Managing Client Risk* does not include any specific requirement for ensuring expert advice is sought in the development of risk management plans, this is a minimum practice requirement under the standard for meeting individual needs.

The *Managing Client Health* policy for DADHC operated services also notes '*There can be a tension between person's individual choices and duty of care. This tension should be worked through between the client (where possible), staff and family or other advocate, with professional advice, and all decisions documented.*'[17] As noted elsewhere in this report, DADHC has advised this office that it is currently reviewing *Managing Client Health* with a view to extending it to non-government services.

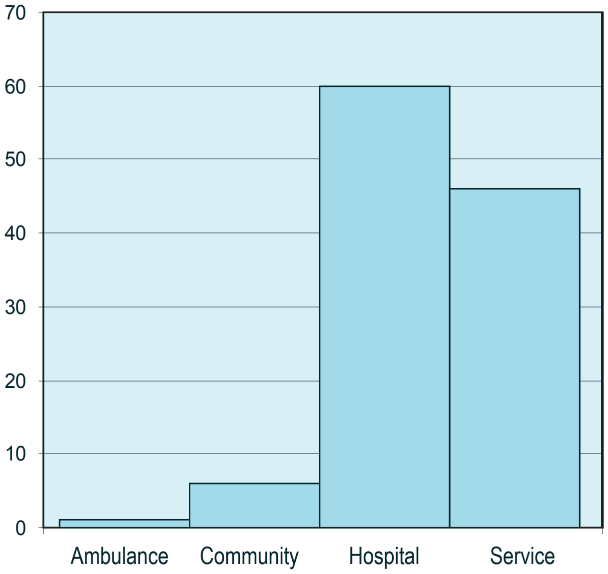
A further and related issue indicated by our reviews is that of placement issues and compatibility of individual support needs. Some people living in care have identified risk factors relating to behaviour that require management through environmental controls. How such risks can be appropriately and safely managed while respecting the rights of other residents is a challenge across disability accommodation services.

In response to increasing demand for services, DADHC has committed to a range of priorities and longer-term strategies designed 'to achieve a sustainable and equitable system of services and supports' in its *Future Directions* document (released August 2004).

These include development of intake and vacancy management systems and improved assessment arrangements as short-term priorities, and looking at new funding models and service options as a longer-term strategy. In the context of a systemic focus on stabilising current funding and service delivery, it is essential that DADHC ensures clear procedures are in place to inform individual assessments and compatibility issues in disability accommodation services, with clear guidance for decision making about placement decisions.

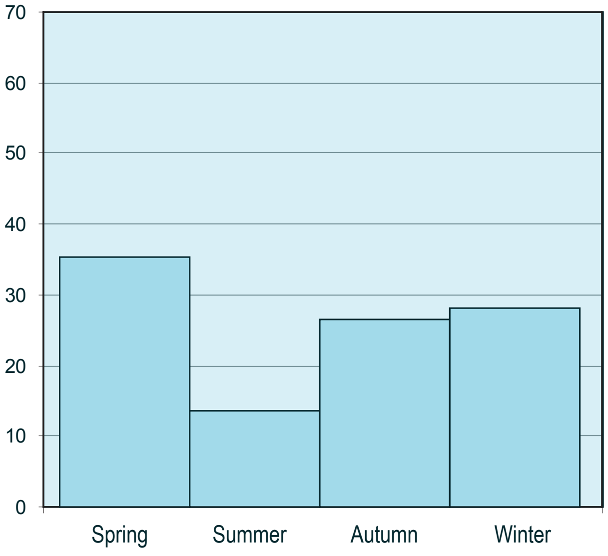
Place and season

Figure 10: Place of death



Most of the deaths under review occurred in hospital (55%). A further 39 per cent occurred at the person's residence.

Figure 11: Seasonality of death



Note: Nine deaths occurred in December 2002 and have not been included in this analysis of seasonality of death.

Thirty six deaths (33%) occurred in the spring months of September, October and November 2003 compared to 25 per cent occurring in the winter months of June, July and August. The data for the respiratory group was not dissimilar and is discussed in that section. It is, however, worth noting that this data does not reflect published information that more deaths in Australia occur in the winter months, coinciding with outbreaks of influenza and other respiratory infections. The NSW GP Sentinel Surveillance 1999- 2003 of Influenza-Like-Illness (ILI) of NSW Health shows a peak for GP consultations in July 2003.[20]

Weight and nutrition

Services were asked to provide information on the last record of height and weight of the person before their death. Body mass index (BMI) was calculated from this data.[21] Research indicates that there is an increased rate of mortality for individuals above or below the healthy weight range. Underweight individuals have increased risk of respiratory disease, tuberculosis, digestive disease, osteoporosis and some cancers. Overweight individuals are at an increased risk of developing cardiovascular disease, gallbladder disease, high blood pressure, diabetes, osteoarthritis and some cancers.[22]

It should be noted that BMI is one of many parameters that can be used in the nutritional assessment of an individual.[23] It is a good starting point but has some limitations in this context. It can be difficult to assess healthy weight for some people with disabilities. For example, it can be difficult to accurately measure weight and height for people with severe scoliosis (spine curvature) or those unable to stand still to be measured. In addition, interpretation of BMI results also needs to consider loss of muscle tissue in certain health conditions.

Within the group of 110, there were six children under 18 years of age. BMI figures for children are determined differently from those for adults. Using growth charts, BMI-for-age percentiles can be used to determine underweight and overweight in children.[24] Using this measure, two females and two males were below the 5th percentile BMI-for-age. That is, four out of the six children were severely underweight.

There were 30 adults over 65 years of age in the group of 110. BMI is calculated differently for this group to take into consideration physical ageing factors. Three people in this group were severely underweight with BMI < 17. Four of this group had severe obesity with BMI > 30. The upper limit of a healthy weight range for this age group is 27.[25]

BMI for those people in the total group who died aged 18 to 64 years is reported in the table below.

Figure 12: BMI category – 18 to 64 years

	Number	Percent
Outside age range *	24	21.8
Very underweight (<16.99 kg/m^2)	4	3.6
Underweight (17-18.4 kg/m^2)	2	1.8
Healthy weight range (18.5-24.9 kg/m^2)	22	20
Overweight (25-29.9 kg/m^2)	14	12.7
Obese (30-34.9 kg/m^2)	11	10
Severe Obesity (>/= 35 kg/m^2)	6	5.5
Unavailable**	27	24.5
Total	**110**	**100**

* Twenty four people were not aged between 18-64 years
**Data for either or both weight and height for this age group was unavailable for 27 people (25%).

Twenty percent of people who died were in the healthy weight range. All of those people in the very underweight category died from respiratory illness. Only one of them was receiving enteral nutrition. On the data available, severe obesity did not directly lead to the death of any of these people.

It is worth noting that, of the total group of 110, there are more people in the overweight and obese groups (28.2% of the group) than in the underweight groups (5.4% of the group). This may be a reflection of the general Australian population, where the proportion of adults who are overweight or obese continues to increase.[26]

The *Ensuring Good Nutrition* policy for all disability accommodation and centre-based respite services funded or directly operated by DADHC includes the *Nutrition in Practice Manual,* which provides comprehensive guidance for nutrition management for people in care, including those assessed as underweight and overweight. The manual includes the Nutrition and Swallowing Checklist for use in individual assessment and review. DADHC advises that training in the nutrition policy and its resources has now been provided across the state. In addition, regional support groups are being established to assist with implementation of the policy and an assessment tool is being developed to monitor that implementation. This monitoring will be critical for effective evaluation of the policy and identification of, and response to, the need for refinements.

Health management

Standards in Action provides practice guidance for all DADHC operated and funded accommodation services, and is the current benchmark for compliance with the NSW Disability Service Standards.

Standard 2 (Individual Needs) includes minimum standards and practice requirements for planning and implementing supports designed to meet the individual needs of service users. Standard 10.4 (Nutrition and Health) includes minimum practice requirements for regularly monitoring of the health of service users and for ensuring appropriate intervention occurs as required. This means that all residential services should have documented plans for each of their service users.

The requirements are different for licensed residential centres, but they are still required, in accordance with licence conditions, to keep records of service users' details and medications.

The CDN asks services to report on the existence of health management documents and to attach copies of the documents advising when they were prepared. The guidelines for completing the CDN describe a health care plan as '*a comprehensive overview of a person's health assessments and reviews, the goals of their health care, actions to be taken, person/s responsible, time frames, relevant support plans and contact details for medical and dental service providers*'. Relevant support plans are for specific health issues such as epilepsy or asthma management.

The existence of health management documentation as reported is set out in the table in figure 13.

A number of services reported that the person who died did not have a health care plan, but did have plans developed to address specific health needs such as epilepsy, nutritional needs or swallowing difficulties. While acknowledging the importance of these plans, the value of comprehensively assessed and coordinated health management cannot be underestimated. This being so, it is of concern that 31 of the whole group did not have a plan that gave a comprehensive overview of their health and actions to be taken to address issues.

DADHC's *Managing Client Health* policy provides for the development and regular review of Health Care Plans for every service user, to be developed in conjunction with Individual Planning processes. Health Care Plans are described as outlining '*the nature and level of support the client requires to maintain a healthy lifestyle and minimise risks associated with health issues*'. The policy provides detailed guidance for developing and implementing the plans. Only two residents of DADHC operated services who died after June 2003 still did not have Health Care Plans.

The provision of comprehensive policy guidelines for meeting the individual health needs of all service users is very important.

In addition, a robust mechanism for monitoring the provision of services is critical to ensuring the individual needs of service users, including their health needs, are met and for identifying areas for policy and service improvement.

Figure 13: Health care planning documentation

Type of service	Health Care Plan Only	Health Care Plan and other care plans	Other Care Plans only	No Plans
DADHC operated service	0	40	4	0
Funded service	13	6	11	14
Licensed residential centre	1	1	3	17
Total	**14**	**47**	**18**	**31**

Consent provision

Standard 10.4 (Nutrition and Health) includes minimum practice requirements for seeking valid consent for medical and dental treatment from service users, and for identifying who can consent to treatment where the service user is not able to consent themselves.

Services were required to report on the CDN on who was responsible for providing consent for medical and dental treatment. Twenty-five service users were reported as providing their own consent, including more than half of those living in licensed residential centres. The majority of service users (60%) had a family member identified as responsible for providing medical and dental consent. Legal guardians had been appointed for 16 people, with the Public Guardian being appointed in 14 of those cases.

In the context of the development of Health Care Plans, the *Managing Client Health* policy provides guidance for obtaining appropriate consents and for identifying the 'person responsible' for decisions about medical and dental treatment. It also refers to DADHC's *Decision Making and Choice* policy for further guidance in this regard. As noted previously, DADHC is reviewing *Managing Client Health*, with a view to its application in the non-government sector.

Consent to treatment and related decision-making

Our detailed case reviews raised a number of critical issues in relation to consent to treatment and related decision-making.

Issues relating to consent to medical treatment for children living in voluntary care have also been reported by the former Community Services Commission.[27]

We note that DADHC's *Action Plan for Improving Services to Children and Young People with a Disability* includes various strategies that may assist in this regard. For example, *Children's Standards in Action* has been publicly released. The document includes some guidance in relation to decision-making and care for children and young people with a disability.

case study 3

The death of a child in voluntary care was preceded by his family's refusal to consent to medical treatment on a number of occasions. Our review found that although there were repeated recommendations for the treatment by medical practitioners, and the (non-government) service attempted to discuss the treatment with the family on several occasions, the child was not reported 'at risk' under the *Children and Young Persons (Care and Protection) Act 1998*. While reporting the child and his situation may not have changed the outcome in this case, there was sufficient information on his file to suggest that a report to DoCS may have been warranted. In this case, it was not apparent that the service provider had a clear understanding of the role of various bodies in relation to resolving consent issues.

DADHC's *Child protection policy and reporting procedures for DADHC and DADHC funded services* has also been released, which provides guidance for reporting risk issues. We have been advised that briefing sessions are currently being provided for DADHC service monitoring staff and non-government services in relation to these initiatives. DADHC plans to evaluate the impact of the briefing sessions and use the information gathered to inform the development of specific monitoring tools to support the *Children's Standards in Action.* We are monitoring these activities.

In the deaths of two adults who died while in hospital, decisions to cease treatment, including Not For Resuscitation (NFR) orders were made.[28] There was no evidence on file that the individuals concerned had input to the decision, although this input may not have been possible. In one case, files indicate that family were directly involved in treatment decisions in consultation with medical practitioners. However, in the other case, it does not appear that a 'person responsible' was involved in the decision.

Figure 14: Consent providers

	Type of Facility					
Consent provider	**Group Home**	**Small Residential**	**Large Residential**	**Licensed Residential**	**Other**	**Total**
Person themselves	4	1	6	13	1	25
Family	25	4	30	6	1	64
Guardianship Private	2	0	0	0	0	2
Guardianship Public	5	0	7	2	0	14
Other	1	0	0	0	0	1
No Response	0	1	1	0	0	2
Total	**37**	**6**	**42**	**21**	**2**	**110**

NFR orders are a clinical decision, in which doctors are guided by policy (which in Australia generally includes consultation with patients and their families), their own clinical judgment and any legal obligations. However, research indicates that there is little known about the process that leads to decision making and action, and the factors that determine who makes treatment decisions, what influences treatment choice and how treatment is carried out are not clearly understood.[29]

Perceptions of 'quality of life' are likely to be contributing factors in end of life decision-making. Given the sensitivities of this concept, it is critical that guidance be provided to those involved in end of life decision-making for people with a disability living in care to ensure they are afforded the same considerations as other people.

It is important to note that the *NSW Guardianship Act 1987* is not clear about consent obligations with regard to withdrawing or refraining from treatment where a person is unable to consent themselves, and has no 'person responsible'.

In 2000 NSW Health released *Dying with Dignity: Revised Draft Guidelines for Clinical Decision Making at the End of Life.* The guidelines emphasise the importance of discussion with the patient and their family (or advocate) and documentation of decisions. However, they are silent in circumstances where there is no 'person responsible'. The interim guidelines have been under review since September 2002.

Documentation and record keeping

A significant issue identified in service user files was the extent of poor record keeping and documentation in both DADHC operated and funded services. Issues included:

- missing or lost files or parts of files
- Nutrition and Swallowing Checklists and action plans not completed
- weight records not being maintained
- incomplete service user financial ledgers
- lack of clarity in files regarding currency of documents (documents undated and unsigned)
- unclear recording of critical information, for example a family's 'Not for Resuscitation' request and an individual's medication administration record.

There are a number of requirements that relate to appropriate record keeping, use and disposal. These include the *State Records Act 1998*, the *Privacy and Personal Information Protection Act 1998*, the federal *Privacy Act 1998*, which applies to some service providers, and *Standards in Action.*

Good documentation of a service user's needs, service responses, regimes and plans are critical to promoting consistent and appropriate care, and it is of significant concern that poor record keeping appears to be prevalent. DADHC advised us in July 2004 that it was reviewing and standardising record keeping and archiving across the whole department.

case study 4

A mobility management plan for the person who died had been recently updated. There was a handwritten addition to the plan outlining a further precautionary measure. As this notation was neither signed nor dated, it is impossible to determine when it was added to the plan and whether staff would have been aware of the precaution.

After the fatal incident, the service conducted a review of events leading up to the death. The report of that review was lost. A further review was conducted months later and changes were recommended to ensure a similar accident did not occur. These included an audit of mobility management plans and associated documents by senior staff, regular review of those plans and education sessions for all staff on mobility management.

Respiratory Illness Group Review

The percentage of deaths due to respiratory disease amongst people with intellectual disabilities is significantly higher than that in the general population. In the general Australian population, pneumonia and influenza were the underlying cause of death for 2.35 per cent of people in 2002, and respiratory system diseases were responsible for almost 10 per cent of deaths of persons aged 65 and over, reflecting the incidence of respiratory diseases with advancing age.[30]

As noted above, of the 110 deaths that were reviewable, the Coroner had made a determination of cause of death in 90 cases. Forty nine (54%) of these 90 people had a primary or underlying cause of death related to respiratory illness. Thirty three (67%) of these respiratory related deaths were identified as being potentially preventable and so have been reviewed as a group ('RI review group').[31]

Respiratory illness was the primary cause of death of 31 of the 33 people in the RI review group and the underlying cause for two others. An autopsy was completed on 18 people in the group.

Methodology

This group review is based on information drawn from several sources:

1) detailed health profile provided by the service provider in the CDN and one or more of the following:
    - client service files;
    - hospital records;
    - general practitioner files;
    - final post mortem report;
    - Police report of death to Coroner;
2) cause of death coding (completed by a member of the advisory committee).

Cause of death

The cause of death, as determined by coding, for people in the RI review group was:

- Pneumonia (24), including aspiration pneumonia, bronchopneumonia, pneumonitis due to food and vomit, pneumonitis due to oils and essences, hypostatic pneumonia, lobar pneumonia
- Pulmonary embolism (3)[32]
- Other respiratory related conditions (6)

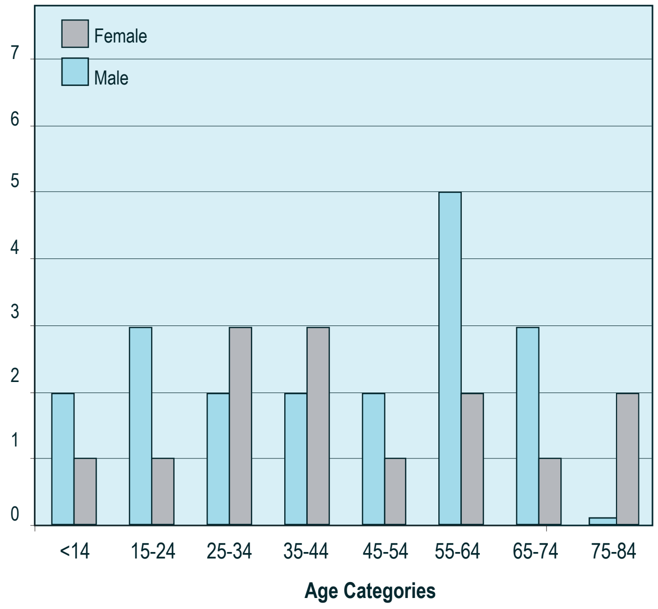
Figure 15: Cause of death

Cause of Death	No. of people	Percentage of group
Pneumonia	24	72.7
Pulmonary embolism	3	9.1
Respiratory failure	2	6.1
Respiratory disorder (unspecified)	2	6.1
Other (with respiratory related underlying cause of death)	2	6.1
Total	**33**	**100**

Gender and age

We reviewed 19 males and 14 females in this group. The age range at the time of death was 13 to 78 years with the largest group of deaths occurring in the 55-64 age range. While respiratory system diseases are more prevalent with advancing age in the general Australian population, the number of deaths in our review decreased after the age of 64 years.

Figure 16: Age by gender



Disability

Twenty-six people (79%) had an intellectual disability, with 16 diagnosed as being in the range of severe to profound level of intellectual disability, and 10 in the mild to moderate range. Eleven of those with an intellectual disability had one additional type of disability and four had two additional types of disability.

Overall, 13 people in the group had one disability and 20 had multiple disabilities.

Figure 17: Type of disability

Disability	No.of people	Percentage of group
Physical	3	9.1
Psychiatric	2	6.1
Neurological	1	3
Intellectual	7	21.2
Intellectual + 1 other disability	11	33.3
Intellectual + 2 other disabilities	4	12.1
Intellectual + 3 other disabilities	3	9.1
Intellectual + 5 other disabilities	1	3
Multiple disabilities (not including intellectual)	1	3
Total	**33**	**100**

Figure 18: Level of intellectual disability

Level of intellectual disability	Number of people	Percentage of group
Mild	4	12.1
Moderate	6	18.2
Severe	9	27.3
Profound	7	21.2
Not applicable	7	21.2
Total	**33**	**100**

The aetiological condition of those people with an intellectual disability (26) was:

- Unknown (16)
- Down Syndrome (6)
- Rett Syndrome (1)
- Cytomegalovirus (1)
- X-linked congenital hydrocephalus (1)
- Post measles encephalopathy (1).

Season of death

Eleven deaths occurred in spring, eight in winter, five in summer and four in autumn.[33]

Figure 19: Season of death (not including December 2002)

Season	Number of people	Percentage of group
Spring	11	39.3
Summer	5	17.9
Autumn	4	14.3
Winter	8	28.6
Total	**28**	**100**

The above results contrast with findings in the general population, where the winter months tend to be the time when more deaths occur. It is possible that these results reflect people becoming chronically ill during winter and then dying at the beginning of the warmer months.[34]

Type of service

Sixteen (48.5%) people group lived in large residential facilities:

- 12 in facilities operated by DADHC
- four in facilities managed by NGOs

Ten (30.3%) people lived in group homes:

- six in group homes operated by DADHC
- four in group homes managed by NGOs.

Five (15.2%) people lived in licensed residential centres.

Two (6.1%) people lived in small NGO run residential facilities.

Individuals living in institutions are at increased risk of developing respiratory infections[35]. Critical factors include:

- the risk of infection increasing due to the number of people residing together
- people living in institutions tending to have higher support needs, this being associated with increased risk of respiratory infection.

Support needs

The majority of the people had high dependency needs indicated by:

- requiring assistance with meals (20 people)
- limited mobility (25 people)
- incontinence (urinary or doubly) (23 people)
- multiple disabilities (20 people).

A high degree of dependency on support for daily living activities has been found to be associated with increased risk of the development of respiratory infections.[36] High dependency is often the result of complex health needs, such as epilepsy, dysphagia, gastrointestinal disorders, and posture and mobility problems, all of which can impact on respiratory health.

History of respiratory illness

Twenty one people (63.6%) had a history of recurrent respiratory illness. For the purposes of this review, recurrent respiratory illness was defined as more than one episode of a respiratory illness in the last 12 months, including pneumonia and upper respiratory tract infections.

Fifteen people (45.5%) had diagnosed chronic obstructive pulmonary disease (COPD), for example bronchitis, asthma, chronic airways limitation, bronchiectasis, croup. Fourteen of these people also had a history of recurrent respiratory illness.

Figure 20: Type of residential service by service provider

		Service Provider			
		DADHC operated	LRC	DADHC funded	**Total (%)**
Type of Service	Group home	6	0	4	10 (30.3)
	Large residential	12	0	4	16 (48.5)
	Licensed residential centre	0	5	0	5 (15.2)
	Small residential	0	0	2	2 (6.1)
Total		**18**	**5**	**10**	**33 (100)**

According to the respiratory specialist on the Advisory Committee[39], it would be best practice for a general practitioner to make a referral to a respiratory specialist if a person:

- has asthma that is not controlled by medication, or oral steroids are needed
- has a 'peak flow' (the rate at which a person can expel air from the lungs) of less than 60 percent
- has a diagnosis of COPD to enable assessment and determination if respiratory damage is reversible, or
- has a disability and an occurrence of pneumonia. This is because of the increase in risk factors for this population of GORD, dysphagia, and mucociliary clearance.

Of those people who had either a history of recurrent respiratory illness (21) and/or a diagnosis of COPD (15):

- 5 had been seen by a respiratory specialist in the three years preceding their death, and
- 14 had two or more disabilities, with attendant increased risk of respiratory illness.[38]

Weight and nutrition

People with disabilities have increased nutritional risk, many because of complex medical conditions, so monitoring weight is a critical component of nutrition management. Sixteen people in the RI review group did not have serial weight charts completed in the 12 months preceding death. DADHC's *Nutrition in Practice Manual* requires its services to maintain serial weight charts. This requirement extended to NGOs as of June 2004.

Weight

It was possible to determine the Body Mass Index (BMI) for 27 people in this group, based on height and weight measurements provided either in the CDN form or on the Coroner's Autopsy Report. The table below sets out these determinations:

Figure 21: Body Mass Index

BMI results	Number of people
Very underweight	3
Underweight	0
Healthy weight range	8
Overweight	4
Obese	2
Severe obesity	2
BMI cannot be determined	6
Outside age range	8
Total	**33**

Underweight people are at greater risk of contracting pneumonia due to their susceptibility to infection as a result of an impaired immune status.[39]

Enteral nutrition

Eight people in the group were reliant on enteral nutrition, which is the delivery of liquid nutritional formula via a tube.

- one had a naso-gastric tube
- five had percutaneous endoscopic gastrostomies (PEGs)
- two had jejunostomies.

When someone is placed on enteral nutrition it is generally a result of an inability to maintain a healthy weight range and/ or swallowing difficulties. Of these eight people:

- BMI could not be determined for the person with the NG tube
- two of the people with a PEG had a BMI that placed them in the healthy weight range, and BMI could not be determined for the other two
- one person with a jejunostomy had a BMI that placed them in the very underweight range; the BMI for the other person could not be determined as the person was outside the age range.

Seven people were nil by mouth (NBM) and one was receiving nasogastric feeds to supplement his oral intake. A person is placed on NBM when a doctor and/or speech pathologist deems it unsafe for a person to receive any nutrition orally due to their health status and possible aspiration/choking risk and so on. A risk of aspiration from saliva and reflux still remains. Some complications of being NBM can be reduced oral hygiene, dehydration, and reduced nutrition.

Gastro-oesophageal reflux disease

Gastro-oesophageal reflux disease (GORD) is a backflow of stomach contents upward into the oesophagus. Stomach contents can also be aspirated into the lungs.

The prevalence of GORD has been identified as considerable amongst people with an intellectual disability in institutional care. One study has indicated that while the prevalence of GORD in the general western adult population is up to 20 per cent, 70 per cent of people with an intellectual disability in institutional care are at risk of developing the disease. This study also suggested that the diagnosis of GORD in this population is frequently overlooked due to the wide range and non-specificity of the symptoms, with diagnosis being further complicated by the inherent difficulties in interpreting behavioural presentations and symptoms amongst some individuals with intellectual disabilities.[40]

In relation to respiratory illness, the respiratory complications commonly associated with GORD include chronic cough[41] and chronic lung disease due to recurrent aspiration. GORD is also associated with death due to aspiration pneumonia.

We were advised[42] that positive management of suspected or diagnosed GORD would include:

- referral for a review by a gastroenterologist
- prescription of GORD medication
- review of eating and drinking by a speech pathologist
- regular observations of weight and temperature and alertness for haematemesis (vomiting of blood) and malaena (blood in faeces).

Information in client files suggested that 24 of the RI review group (73%) had a diagnosis of GORD or were on GORD medications in the previous 12 months.[43] This would seem to indicate a relatively high level of recognition of GORD or symptoms of GORD.

Of those 24 people on GORD medication or with a diagnosis of GORD:

- 7 had been seen by a gastroenterologist within the last three years
- 21 were on GORD medication[44]
- 10 had been referred to a speech pathologist for assessment of dysphagia in the three years prior to their death
- 13 had serial weight charts on file for the 12 months prior to their death. Also, files indicated that seven had had melaena (blood in the faeces) or haematemesis (vomiting blood) identified in the last three years
- 5 were assisted to sleep at an angle, a technique used to manage GORD by decreasing the possibility of gastric contents being regurgitated from the stomach up into the oesophagus.

While two of these four elements of positive management were evident for 17 people (70.8%), file documentation indicated that all four elements of good practice management were apparent for only two individuals.[45]

Dysphagia (eating or drinking difficulties)

Swallowing difficulties

Twenty-four people (73%) were reported to have had swallowing difficulties. Nineteen of them (80%) had a diagnosis of dysphagia. It is well recognised that the risk of developing dysphagia is increased in people with neurological conditions, especially people with severe intellectual disability.[46] It has also been reported that up to 56 per cent of people with a disability have eating and drinking difficulties[47], while other research estimates that 80 per cent or more of severely disabled people will have some type of eating and drinking disorder.[48] Dysphagia is an important risk factor associated with aspiration pneumonia and 12 people in the RI review group had dysphagia as an underlying cause of death or as a significant contributing factor to their death.

case study 5

A person with significant disabilities, including cerebral palsy and a severe intellectual disability, died during the night. The Coroner determined the cause of death to be aspiration pneumonia with cerebral palsy noted as an antecedent cause.

From our review of the person's files, a history of recurrent chest infections and aspiration pneumonia was evident, with the person being admitted to hospital three times in the last year for respiratory related problems. There was, however, no evidence on file of any referral to a respiratory specialist.

Because of the person's difficulties swallowing without aspirating food, an eating and drinking plan had been developed, but no nutritional management plan. The person appeared to be having increasing difficulties getting sufficient nutrition and was quite underweight at the time of death.

Of the 24 people reported to have had swallowing difficulties, 15 had been referred to a speech pathologist for assessment of dysphagia within the last three years. Since speech pathologists can specialise in the assessment, diagnosis and management of eating and drinking / swallowing difficulties it would seem important for all people with swallowing difficulties to be referred. This may reduce the risk of a person developing aspiration pneumonia and/or choking.

Nutrition and Swallowing Checklist

DADHC's *Ensuring Good Nutrition* policy requires all services to 'identify and address individual risks related to food intake, nutrition and nutrition support needs by using an appropriate checklist' such as the Nutrition and Swallowing Checklist which is an appendix in the Nutrition in Practice Manual. The policy also requires the development of individualised health, nutrition and eating and drinking plans. Of the 18 service users in DADHC operated services, only 14 had a Nutrition and Swallowing Checklist completed in the last 12 months.

Of the 24 people with reported swallowing difficulties, 15 had a Nutrition and Swallowing Checklist completed in the 12 months preceding death, and 10 of those checklists had a completed Action Plan. Sixteen of the people with reported swallowing difficulties lived in a DADHC operated service. Of these 16, 14 (81.3%) had a Nutrition and Swallowing checklist completed in the 12 months preceding death.

Licensed residential services are not required to complete an annual Nutrition and Swallowing Checklist and NGO services were not required to do so until mid-2004 when DADHC completed the roll out of its *Ensuring Good Nutrition* policy.

Mealtime plans

Nine people in the RI review group had either a primary or underlying cause of death as pneumonia due to food and vomit (8) or pneumonia due to oils and essences (1).

Of the 24 people with reported swallowing difficulties, only 14 had a mealtime management plan (also known in DADHC's *Ensuring Good Nutrition* policy as an Eating and Drinking Plan). It is important that a range of health care professionals are involved in the development of mealtime plans, such as speech pathologists, dietitians and occupational therapists, to ensure that all relevant factors affecting a person's nutritional intake are considered. Of the 14 existing mealtime plans for people with swallowing difficulties, only six indicated that more than one health care professional had been involved in developing the plan.

Of the 16 people who had a mealtime plan, eight were on fluids of thickened consistency. Of particular concern is that there were four people who were on thickened fluids but did not have a mealtime management plan. In total, 12 people in the RI review group were reported to be on fluids of thickened consistency, 11 of whom had been reviewed by a speech pathologist within the last three years.

Figure 22: Number of people with swallowing difficulties who also had a mealtime management plan

Swallowing difficulties and mealtime management plan	Number of people
No	9
Yes	15
Total	**24**

Having missing or limited teeth may affect a person's ability to safely eat a normal diet, indicating the need for an assessment by a speech pathologist to ensure safety during mealtimes. Twenty people were reported to have some teeth missing, or to have no teeth. Of these 20, only 11 had a mealtime management plan.

Table 23: Dentition status

Dentition	Number of people	Percentage of group
All teeth	12	36
Only some or no teeth	20	61
Not known	1	3
Total	**33**	**100**

Epilepsy

Seventeen people (52%) had a diagnosis of epilepsy. Four of them were not on epilepsy medications and had not had a seizure in over two years.

There is an increased prevalence of epilepsy in people with intellectual disabilities in the order of 10 to 20 percent. Those with generalised seizures are at the greatest risk, with associated pneumonia being the most common cause of death[49]. It has been established that both epilepsy and anti-convulsant medications are known to increase the risk of respiratory problems,[50] and that people can aspirate after a seizure, which can cause aspiration pneumonia.[51]

Fourteen (82%) of the 17 people who had a diagnosis of epilepsy died of pneumonia. A respiratory specialist had reviewed none of these people in the last three years.

Of the 17 people with a diagnosis of epilepsy, there was no evidence to suggest that any had poorly controlled epilepsy (defined by more than two generalised tonic clonic seizures in the 6 months prior to death, without neurological review).[52] One person had epilepsy listed as a significant contributing factor in their death, but there was no one that had a primary or underlying cause of death as epilepsy.

Asthma

Sixteen people had a diagnosis of asthma or were on asthma medication. Although anyone who has asthma should have an asthma management plan, only three of these 16 people (19%) had one in their service files. In the general population, asthma diagnosis and plans are based on peak flow level (litres per millimetre cubed), and it can be problematic to get a peak flow level from someone with a disability that makes it difficult for them to expel air forcefully. In these cases, other measures are required in order to tailor an asthma management plan – such as frequency of wheezing, breathlessness in the morning or night, or needing more than four puffs of Ventolin in one day.[53]

GORD can be present in up to 89 per cent of people with asthma[54], as the presence of oesophageal acid may alter bronchial hyper-responsiveness.[55] Twelve of the 16 people (75%) who had a diagnosis of asthma, or were on asthma medications, also had a diagnosis of GORD or were on GORD medications.

NSW Health informed us that it has contracted the Centre for Developmental Disability Studies to develop an educational strategy aimed at general practitioners. The strategy will be directed at improving general practitioners' understanding of a number of issues relating to providing effective primary health care for people with disabilities, including the link between GORD and asthma.[56]

Oral hygiene

There is an association between poor oral hygiene/care and the development of chronic respiratory disease.[57] Poor oral/dental status has been identified as a major risk factor for the development of aspiration pneumonia: '*optimising oral health may decrease morbidity and mortality associated with aspiration pneumonia'*,[58] emphasising the need to ensure good oral hygiene management within this population. However, maintaining the oral and dental hygiene of individuals with intellectual disabilities in particular those with high support needs can be problematic for a number of reasons including limited self-care skills, difficulties for an individual in expressing pain, resistance to dental care and the lack of skills and resources available to carers.

DoCS' *Policies for Working with People with Disabilities Version 2 1996* recommended that service users have an annual dental check-up, and that the recommended maximum time between dental examinations be two years. DADHC's *Managing Client Health* policy has a requirement that all users of DADHC operated services have dental examinations every six months and that each client has a documented daily oral hygiene routine.

Oral hygiene plans

- 27 people did not have a documented oral hygiene routine
- 15 of these 27 people were accommodated in DADHC operated services.

Dental review in last 12 months

- 16 people had had a dental review in the last 12 months. Ten of these people were users of DADHC operated services.
- 9 people had not had a dental review within the last 12 months. Five of these people were users of DADHC operated services.
- For 8 people it was not possible to determine from information on the client files if they had had a dental review in the last 12 months. Three of these eight people were users of DADHC operated services.

The need for dental/oral care

Periodontal disease is prevalent in people with Down Syndrome,[59] a daily oral hygiene routine is therefore very important. Of the six people with Down Syndrome, none had an oral care plan, and four had been reviewed by a dentist in the 12 months preceding death (two of whom were DADHC operated service users).

The incidence of dental erosion is high for individuals who have GORD. Of the 24 people with a diagnosis of GORD or on GORD medications, 11 had had a dental review in the 12 months preceding death.

The potential for the accumulation of dental calculus has been found to be high among those receiving enteral nutrition, which has been associated with poor oral hygiene due to decreased oral intake.[60] Five of the eight people receiving enteral nutrition had had a dental review in the 12 months preceding death.

We note that while DADHC's *Managing Client Health* policy requires a dental review every six months, the frequency of this treatment could be a problem for people resistant to the review and/or those who need a general anaesthetic. In these cases, it may not in fact be in the best interests of the person to have a dental review this often. The *Managing Client Health* policy does not provide any guidance to services where this is the case.

NSW Health has advised that it is currently exploring the possibility of extending the Oral Health Training program provided by United Dental Hospital to disability support staff, in consultation with DADHC.[61]

Immunisation

Immunisation vaccination is vital in reducing the incidence of vaccine preventable disease among people with disabilities in care. Specific immunisation is recommended for all people who have impaired immunity and who have a chronic disorder of the pulmonary or circulatory system. The Australian Immunisation Handbook also advises that annual influenza vaccinations should be given to those living in nursing homes and other long term care facilities.[62]

The former Community Services Commission (2002) reported that there were inadequate guidelines for service providers and there was a risk that services were generally not aware of the importance of immunisation.

Within the RI review group:

- 15 people (46%) had a current immunisation form (that is, documentation of when immunisations were taken or due to be updated).
- 23 people (70%) were immunised against influenza in the 12 months preceding their death. In six cases, immunisation status for influenza was unknown.
- 13 people (39%) were immunised against pneumococcal in the five years preceding death. In 15 cases, immunisation status for pneumococcal was unknown.

People with Down Syndrome are at a higher risk of pneumonia due to a genetic predisposition to congenital heart disease, ear, nose and throat problems, and immunological factors.[63] Of the six people with Down Syndrome who died:

- three had seen a respiratory specialist in the last three years
- four had had influenza immunisation in the last 12 months
- two had had pneumococcal immunisation in the last five years.

DADHC's *Managing Client Health* policy states that the general practitioner shall review each person's immunisation status annually as part of the annual medical review. The policy requires the key worker to ensure that each client has a detailed vaccination record, and that a detailed immunisation record be kept for each resident. Of the 18 people who lived in a service managed by DADHC, 11 had a current immunisation record form. We note that the *Policies for Working with People with Disabilities vol 2, 1996* did not include a section on immunisation. None of the five people who resided in licensed residential facilities had a current immunisation record, and only four of the ten people who lived in a DADHC funded or licensed service had one.

The immunisation section of the *Managing Client Health* policy is based on the Australian Standard Vaccination Schedule. It does not, however, make reference to the needs of groups with special vaccination requirements, as outlined in the current version of the Australian Immunisation Handbook. DADHC has informed us that it will consider revising this section as part of its review of the *Managing Client Health* policy, which is due to be completed in 2004.[64]

In the *Review of the deaths of 37 people* issues paper, we suggested that NSW Health coordinate the development and implementation of an educational strategy aimed at general practitioners to raise awareness of the immunisation needs of those people with disabilities with special requirements, as outlined in the current Australian Immunisation Handbook. NSW Health's response was that it will ensure that advice regarding vaccinations is incorporated into the information and education strategies for general practitioners to be developed by the Centre for Developmental Disability Studies.

We also note that '*My Health Record*' published by the NSW Department of Health, is available to all people with disabilities. It has a section for recording immunisation information. DADHC's *Managing Client Health* policy states that each resident of a DADHC operated service will have their own copy of this record, and that it is to be taken to each medical, health, or dental appointment and to hospital.

Scoliosis

Sixteen people (49%) had a diagnosis of either scoliosis (abnormal sideways curvature of the backbone) or kyphoscoliosis (abnormal curvature of the spine both forwards and sideways). Two of these people had kyphoscoliosis listed as a significant contributing factor in their death. Kyphoscoliosis is an easily definable cause of respiratory failure, and the degree of spinal deformity has been associated with the development of respiratory failure.[65] A deformity of the spine can result in poor head positioning, which can result in reduced protection of the airways when swallowing, particularly if the head is tilted backwards,[66] thus increasing aspiration risk.

Six of these 16 people also had a diagnosis of GORD. People with scoliosis are at an increased risk of developing GORD because of the increased abdominal pressure that is associated with this condition.[67] Scoliosis and kyphoscoliosis also affect a person's lung capacity.

Smoking

Smoking, or having a history of smoking, can cause certain respiratory illnesses. In the RI review group the prevalence of smoking was low, with only two people reported to be smokers at the time of their death.

Issues arising from review of service files

The reviews of the service files revealed that there were particular issues with missing and poor documentation, and the occurrence of referral recommendations not being followed up.

Missing/ poor documentation

Examples included:

- consultant reports absent from the client's file
- action plans on Nutrition and Swallowing Checklists not completed
- weight records not being kept
- records of medication administration not clear
- records of a new diagnosis made by hospital staff not on the client's file
- poor epilepsy documentation
- poor documentation of 'not for resuscitation' request by parents.

It is possible that these documents were kept somewhere other than the client's service file. If this were the case, it would clearly be more effective for all health care management information to be kept in one central file and therefore more easily accessible by staff.

It was common to find documents in client files that had no date and /or no author named on them. For example, an unsigned eating 'alert', behaviour incident reports not signed, undated Nutrition and Swallowing Checklists, mealtime plans not dated or signed. This can cause confusion as to what is current practice for the person.

Poor follow-up of referral recommendations

It was found that on several occasions specialists had referred service users on to other clinicians/ specialists, but this had not been carried out by the service. For example:

- referral to see neurologist for possible epilepsy
- referral to dietitian for weight management
- referral to speech pathologist for possible dysphagia
- neurologist requests review in 12 months, but client not taken back for review.
- no monitoring of weight management even though a dietician had placed the person on a strict weight reduction diet
- no review of oesophagitis even though the person had grade 3 (erosive – severe) making it potentially cancer forming
- changes in Eating and Drinking Plans not being made although the status of the person had deteriorated significantly.

The failure of a service to follow up on recommendations made by a medical professional can severely compromise a person's health.

Health care management

The review of the group of 33 people who died of respiratory illness confirms what is evident from the analysis of the whole group of reviewable deaths. People with disabilities who live in care may have multiple disabilities and associated health problems. Some may have high medical needs. Coordinated health care management is an essential component of ensuring appropriate medical care and good practice.

Eighteen of the 33 people had a case manager who coordinated their health care. Of the 18 people who lived in a DADHC operated service, 13 had information on their file to suggest they had a case manager who coordinated their health care.

The review findings indicate that people who had a case manager to coordinate their health care needs were more likely to have a health care plan in place. While 89 per cent of those people with a case manager had a health care plan, this fell to 27 per cent for those people without a case manager. In addition, those people who had a case manager were also found to be more likely to have been seen by a respiratory specialist. While 28 per cent of those people with a case manager had seen a respiratory specialist, this fell to 7 per cent of those people without a case manager.

Given the prevalence of deaths as a result of respiratory illness, it is important that support staff are aware of the signs of respiratory illness, and of their responsibilities to act promptly to ensure its management.   We note that in 2003 DADHC Hunter region developed a screening checklist for identifying clients who require regular chest care.

DADHC's *Managing Client Health* policy requires that each client of DADHC operated accommodation services have an annual health review, based on a comprehensive health assessment. This is required to have input from the client, their family, their key worker and GP. This review is then used to inform the person's Health Care Plan. The policy also provides information to staff about a range of health issues, including those that may be risk factors for respiratory illness, such as asthma, GORD, nutrition and swallowing management, and oral hygiene.

While annual health review may assist in the detection and management of health problems, at least on an annual basis, and information about various health factors may provide guidance to staff in specific health areas, *Managing Client Health* does not provide specific information or guidance in relation to identifying and managing respiratory illness. Given the prevalence of deaths as a result of respiratory illness it is likely that clear guidance for identifying and responding to signs and symptoms would benefit those who may be at risk.

Recommendations

We make the following recommendations to the Department of Ageing, Disability and Home Care (DADHC)

1. In the context of the review of the *Managing Client Health* policy, and making the policy available to funded services, DADHC should:

    a. ensure the immunisation section of the revised policy incorporates the recommendations of the current Australian Immunisation Handbook for groups with impaired immunity or who have a chronic disorder of the pulmonary or circulatory system, and in particular the need for pneumococcal and influenza vaccinations

    b. ensure the revised policy includes clear guidelines for identifying persons able to provide consent for medical and dental treatment, and in what circumstances, for people with disabilities living in care

    c. review the Hunter Region's chest care checklist for identifying clients who require regular chest care, with a view to its incorporation in the *Managing Client Health* policy, and/or broader application in DADHC operated and funded services

    d. incorporate and promote the principle that every resident in DADHC operated and funded accommodation services has a clearly identified person responsible for coordinating all their health care services

    e. report on progress towards, or plans to roll out, the *Managing Client Health* policy to funded services, including details of training and resources to support implementation of the policy

    f. report on plans for monitoring and evaluating the implementation of the *Managing Client Health* policy in DADHC operated and funded services.

2. In the context of the review of the *Managing Client Health* policy, and any planned review of policies for individual planning and risk management, DADHC should ensure that adequate guidance is given for:

    a. regular assessment of risk to individual service users as part of individual planning

    b. seeking expert advice for developing plans to meet individual needs

    c. monitoring the implementation of individual risk management plans.

3. In monitoring implementation of the *Ensuring Good Nutrition* policy in DADHC operated and funded services, and in the context of reviewing the *Managing Client Health* policy, DADHC should respond to specific issues identified in this report, particularly

    a. completion of swallowing and nutrition checklists and/or action plans

    b. development of eating and drinking plans

    c. development of oral care plans

    d. keeping serial weight charts

    e. keeping immunisation records.

4. DADHC should advise this office of the progress of roll out to DADHC operated and funded services of the Nutrition Assessment Tool for monitoring the *Ensuring Good Nutrition* policy.

5. DADHC should review the clinical nurse specialist model of health care case management, such as that operating in the Illawarra region, and the potential for wider application of this model in DADHC operated and funded services.

6. In the context of its developmental work on intake and vacancy management systems, DADHC should ensure clear procedural guidance is included for assessment and placement decisions, taking into account service user compatibility issues.

7. DADHC should develop strategies to ensure that staff in DADHC operated and funded services are fully informed of the importance of reliable and accurate records for service users, and are provided with the support necessary to maintain complete and accurate records.

We make the following recommendations to NSW Health

8. In the context of the development by the Centre for Developmental Disability Studies of an educational strategy aimed at general practitioners, NSW Health should ensure it includes advice to GPs on best practice approaches to management of asthma in people with disabilities. It should include guidance on developing an asthma management plan when peak flows cannot be ascertained.

9. In relation to the review of *Dying with Dignity: Revised draft guidelines for clinical decision making at the end of life*, NSW Health should advise us of the timeframe for completion of the review, and what guidance will be provided to medical practitioners about end of life decision making for people with disabilities who live in care, including when there is no identified 'person responsible'.

A response to the above recommendations to DADHC and NSW Health should be provided to the Ombudsman by 28 February 2005.

In addition, we make the following recommendation to DADHC and NSW Health

10. In relation to access to allied health and specialist medical services, DADHC and NSW Health should report on progress towards

    a. shared responsibility for meeting the medical needs of people with disabilities in accommodation services

    b. joint models of support for people with complex care needs.

A response to this recommendation should be provided to the Ombudsman by 28 February, 2005.

Endnotes

1 DADHC *Funding Agreement: A Guide for Community Based Service Providers*

2 NSW Health advises it is currently engaged in negotiations about the possible transfer of diagnostic and assessment services from DADHC to NSW Health (advice dated 24 September 2004).

3 DADHC *Future Directions*, August 2004.

4 Joint Commission on Accreditation of Health Care Organizations, USA

5 DADHC correspondence (15 July 2004)

6 AIHW (2003)

7 AIHW (2003)

8 Janicki, M.P, Dalton, A.J, Henderson, C.M, Davidson, P.W. (1999) pp 284-294.

9 Glasson E.J., Sullivan, S.G, Hussain, R, Petterson, B. A., Montgomery, P.D, Bittles, A.H, (2002) pp 390-393.

10 ibid

11 DADHC correspondence (15 July 2004)

12 ibid

13 Hollins, S., Attard, M., von Fraunhofer, N., and McGuigan, S. Sedgwick, P. (1998) pp 50-56

14 Down Syndrome Fact Sheet (2003), Down Syndrome Association of NSW.

15 ABS (2002b)

16 ACT Coroner (August 2001) Ponting, www.courts.act.gov.au/magistrates [8 December 2003]

17 DADHC 2003, *Managing Client Health* p. 17

18 Prader Willi syndrome is a condition with characteristics that include intellectual disability and an insatiable appetite

19 AIHW (2002)

20 NSW Health Influenza Surveillance Weekly Report No 12: 27 July to 2 August, 2003. Dated 7 August 2003.

21 BMI is defined by the World Health Organisation (WHO) as weight (in kg) divided by the square of one's height (in metres) i.e. kg/m^2. The classification system of Nutrition Australia is based on that of WHO.

22 www.betterhealth.vic.gov.au [12 August 2004]

23 Daniels, L (2003) pp 136-40.

24 Growth charts from the National Centre for Chronic Disease Prevention and Health Promotion (US).

25 Best Practice Food and Nutrition Manual for Aged Care Facilities. Central Coast Area Health Service.

26 ABS (2001)

27 Community Services Commission (2002)

28 We note that NSW Health recommends abbreviations such as NFR are not used and that the correct terminology is ' appropriate to commence cardiopulmonary resuscitation', or not. NSW Health *Dying with Dignity: Discussion Document*, November 2000

29 Waddell, C., Clarnette, R., Smith, M., Oldham, L., and Kellehear, A. (1996) p540

30 AIHW (2004c)

31 Advice provided by Dr Helen Beange, a member of the Reviewable Disability Death Advisory Committee. Relevant factors leading to a death being identified as potentially preventable included staffing levels, supervision, presence and adequacy of dysphagia management, and the adequacy of treatment of recurrent respiratory infection.

32 We were advised by Dr Alvin Ing, a respiratory specialist, to include pulmonary embolism as a respiratory related death

33 Five were not included in this seasonal analysis as they died in the previous year

34 Reviewable Disability Deaths Advisory Committee meeting, July 2004

35 Limeback, H (1998)

36 ibid

37 Dr Alvin Ing, August 2004

38 Advice from Dr Alvin Ing, August, 2004

39 Advice from Dr Alvin Ing, August 2004

40 Bohmer, C et al (2002)

41 Harding, S.M. & Richter, J. (1997)

42 Reviewable Disability Deaths Advisory Committee, August 2004.

43 According to Dr Alvin Ing, there is a current trend among doctors to prescribe GORD medication based on description of symptoms and not necessarily as a result of a conclusive diagnosis (through endoscopy or testing of PH (acidity) levels of gastric juices in the oesophagus).

44 We were unable to ascertain the medication regime from client files for three people where a diagnosis of GORD was evident.

45 Data collected about specialist referrals relates to referrals in the three years prior to the person's death

46 The Joanna Briggs Institute (2000)

47 Reilly, S., Skuse, D. and Poblete, X, (1996)

48 Schwarz et al (2001)

49 Fosgren et al (1996)

50 Tracy, J., & Wallace, R. (2001)

51 Advice from Dr Alvin Ing, August 2004

52 Advice from Dr David Williams, May 2004

53 Advice from Dr Alvin Ing, August 2004

54 Harding, S.M. & Richter, J. (1997)

55 Harding, S.M. (2003)

56 Response by NSW Health to the NSW Ombudsman (2004) Issues Paper *Review of the deaths of 37 people who died in care between 1 July and 31 December 2002*

57 Scannapieco, Papandonatas and Dunford (1998)

58 Dyment, H and Casas, M (1999) p224

59 Chaushu et al (2003)

60 Dyment, H and Casas, M (1999)

61 Response by NSW Health to the NSW Ombudsman (2004) Issues Paper 'Review of the deaths of 37 people who died in care between 1 July and 31 December 2002

62 NH&MRC Guidelines (2003)

63 Hilton, Fitzgerald and Cooper (1999); La Mantia et al (1000); Chaushu et al (2002)

64 Response by DADHC to the NSW Ombudsman (2004) Issues Paper Review of the deaths of 37 people who died in care between 1 July and 31 December 2002

65 McCool, D.F. and Rochester, D.F (1994)

66 Castell, Castell, Schultz and Georgeson (1993)

67 Bohmer et al (1997)

Glossary

Aetiology

The study of causes of disease

BMI

Body mass index

Cytomegalovirus

A member of the herpes group of viruses. It commonly occurs in humans and normally produces symptoms milder that the common cold. However, in individuals whose immune systems are compromised it can cause more severe effects, and it has been found to the cause of congenital disabilities in infants born to women who have contracted the virus during pregnancy.

COPD

Chronic obstructive pulmonary disease

DADHC

Department of Disability Ageing and Home Care

Dysphagia

Eating and drinking/ swallowing difficulties

Endoscopy

Procedure involving use of an instrument to visualise the interior of the gastrointestinal tract

Enteral Nutrition

The provision of nutritional intake either short-term or long-term via tube to the stomach or small intestine

Gastrostomy

A surgical operation that creates an artificial opening into the stomach for the insertion of a tube to provide nutritional intake

GORD

Gastroesophageal reflux disease is a backflow of stomach contents upward into the oesophagus and pharynx

Melaena

Black faeces due to the presence of partly digested blood from higher up the digestive tract

Haematemesis

The act of vomiting blood. Most often arises from bleeding in the oesophagus, stomach or duodenum. Common causes are gastric and duodenal ulcers, and oesophagitis (ulceration of the oesophagus)

Kyphoscoliosis

Abnormal curvature of the spine both forwards and sideways

Mucociliary

The process by which cilia (hairs) move a thin film of mucus from the upper and lower respiratory tracts towards the digestive tract. Unwanted particles of dust and micro-organisms are trapped on the mucus and thereby removed from the respiratory tract.

NG

A naso-gastric tube is passed through the nose into the stomach for delivery of liquid food formula and other fluids or medications, as a temporary means of ensuring nutritional intake

NHMRC

National Health and Medical Research Council

Oesophagitis

Inflammation of the oesophagus

PEG

Percutaneous endoscopic gastrostomy - a tube is inserted through the external abdominal wall and into the stomach, without having to perform an open operation on the abdomen. The tube is kept in place with an internal flange. Food, fluids and medications are delivered via the tube. This is a long-term enteral nutrition procedure.

PEJ

Percutaneous endoscopic jejunostomy – a surgical operation similar to PEG where the tube is located in a part of the small intestine

Post measles encephalopathy

Disease of the brain caused by the measles virus

Rett Syndrome

A disorder affecting young girls, in which stereotyped movements and social withdrawal appear during early childhood. Intellectual development is often impaired

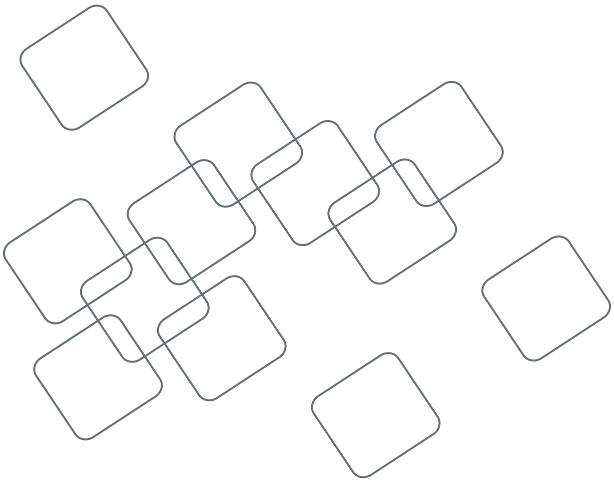
Scoliosis

Abnormal sideways curvature of the backbone

X-linked congenital hydrocephalus

A genetic syndrome with excess fluid on the brain, short flexed thumbs, spasticity, and intellectual disability.

reviewable child deaths



Introduction

Key provisions

Section 35(1) of *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CS-CRAMA) specifies the deaths of the following children (being persons under 18 years) as being reviewable deaths:

(a) a child in care

(b) a child in respect of whom a report was made under Part 2 of Chapter 3 of the *Children and Young Persons (Care and Protection) Act 1998* within the period of 3 years immediately preceding the child's death

(c) a child who is a sibling of a child in respect of whom a report was made under Part 2 of Chapter 3 of the *Children and Young Persons (Care and Protection) Act 1998* within the period of 3 years immediately preceding the child's death

(d) a child whose death is or may be due to abuse or neglect or that occurs in suspicious circumstances

(e) a child who, at the time of the child's death, was an inmate of a children's detention centre, a correctional centre or a lock-up (or was temporarily absent from such a place).

The children[1] whose deaths are reviewable fall into three main categories.

Child 'in care' is defined in s4(1) of CS-CRAMA. The definition of 'in-care' that applies to this work is very broad, and captures most circumstances of children in any form of care provided or funded by the Department of Community Services (DoCS) or the Department of Ageing, Disability and Home Care (DADHC). These are children for whom the government has assumed significant responsibility in order to ensure their safety, welfare and wellbeing. This includes children who are under the parental responsibility of the Minister for Community Services; those for whom the Director-General or a designated agency has day-to-day care responsibility; and those in care arrangements including residential disability services and supported accommodation for people who are homeless. The deaths of children who are in some form of detention are also reviewable for the same kind of consideration.

There are, in addition, those children, or their siblings, who have been brought to the attention of DoCS within three years of their deaths. The inclusion of this group allows for an assessment of whether the intervention by DoCS as a result of reports of child protection issues was appropriate.

While the outcome in all the cases reviewed has been the death of a child, not all children died in circumstances related to abuse or neglect. However, our assessment is that there were common risk factors between this group and children who died of natural causes.

The third group of children are those whose deaths have been identified as being related to abuse or neglect, or in suspicious circumstances that may have been related to abuse or neglect. These children may not have been reported to DoCS or any other agency. Once again, however, the Ombudsman is able to consider the intervention that occurred, or could have occurred.

Defining the scope of our work

A number of important definitional issues have arisen in deciding how to go about our role in reviewing child deaths. This is often the case with new legislation. Some of these issues have been resolved, but further consideration of others may result in changes to our reporting in the next year.

Sibling

The purpose of s35(1)(c) is to ensure that a review of a child's death occurs when the child's siblings have been the subject of an 'at risk of harm' report, but sibling is not defined in the legislation. There are a variety of family structures that involve children who are not necessarily biological siblings but who share the same caregiver, and potentially the same risk. In order to reflect the apparent intention of the section, enabling oversight agencies to review patterns of risk of harm, but without making the definition unworkably broad, the following working definition has been agreed to by the agencies involved:

> *The sibling must share one or more adoptive or biological parents of the child, who is the subject of the report. The sibling must also have the characteristic of ordinarily being a member of the same household as the deceased child on a full or part-time basis.*

This definition was initially designed to assist the police to refer notifiable deaths to the Coroner. It is not a legal definition but has been adopted for operational purposes.

Abuse, neglect or suspicious circumstances

There are no universally accepted definitions of abuse or neglect that leads to the death of a child. We decided, therefore, to adopt the definitions developed by the NSW Child Death Review Team (NSW CDRT) and used in its report *Fatal Assault and Neglect of Children & Young People* as a starting point for work in the area of child deaths and for reasons of consistency. As noted below, these definitions may be amended to provide greater clarity in reporting the work of this function.

Abuse

While assault is obviously not the only way in which a child can be abused, and may not adequately encompass long term patterns of behaviour, it is generally sufficient to describe abusive actions that result in death. In its report *Fatal Assault and Neglect of Children & Young People* the NSW CDRT gave two definitions of fatal assault:

- death [of a child or young person] resulting from acts of violence perpetrated upon him or her by another person. It includes acts by which the perpetrator intended to kill the child and acts from which the child died, even though the perpetrator may not have intended the outcome (NSW CDRT 2003 p1).[2]
- where a child is fatally injured by beating, burning, shaking, stabbing, shooting, poisoning, suffocation, strangulation or other physical means, including homicides and murder-suicides (NSW CDRT 2003 p15).

Neglect

The NSW CDRT developed the following definition of fatal neglect as resulting from

'… an act of omission by a parent or carer that involves refusal or delay in providing medical care; failure to provide basic needs such as food, liquids, clothing or shelter; abandonment; or inadequate supervision' (NSW CDRT 2003: p15).

The NSW CDRT noted that there is no universally accepted definition of neglect and explored the difficulties in arriving at such a definition.

The NSW CDRT definition raises some issues for us, particularly in relation to deaths in the context of 'supervision neglect', which *"involve inadequate supervision at critical moments – the parent or caretaker is absent or unavailable and the child is killed by a sudden arising danger"*(NSW CDRT 2003, p.2).

This would include single incidents of oversight or omission - for example, a pool gate inadvertently left unhinged and a young child accessing the pool area and drowning – which are broad public policy issues best pursued through means such as public education campaigns. These single tragic incidents are less relevant in a framework of review that focuses on monitoring agencies' policies and practices.

An alternative opinion is that neglect necessarily involves more than one occurrence. The Australian Institute of Health and Welfare (AIHW) has previously described neglect as requiring multiple omissions,[2] consistent with a view that some behaviours could be viewed as a chronic pattern of neglect (including lack of supervision). One definition of chronic neglect could be 'a persistent pattern of family functioning in which the caregiver has not sustained and/or met the basic needs of the child which results in harm to the child'[3] (i.e. an 'accumulation of harm').

We will give further consideration as to how neglect should most effectively be encompassed in our review of deaths occurring in 2004.

Suspicious circumstances

For the first year of our work, and in this report, our definition of suspicious circumstances has been in line with that of the NSW CDRT. Deaths in suspicious circumstances are taken to be those '*… where there is insufficient evidence or information in the post-mortem to determine whether the cause of death was or was not clearly due to assault or neglect. Deaths were considered suspicious if there was a history of child abuse and neglect in the child's family background or other concerning circumstances in the context of the death incident*' (NSW CDRT 2003: p16).

We have also incorporated the NSW CDRT's earlier criteria for 'screening' suspicious deaths:

a) the autopsy cause of death is 'unascertained' or 'not determined' but the forensic pathologist had noted that it is possible the child was suffocated or smothered;

b) the autopsy cause of death is SIDS but there is other forensic evidence (eg. blood, bruising, fractures, evidence of old injuries) indicating child abuse and neglect or other contextual information indicating concerning circumstances;

c) the autopsy cause of death is SIDS but there are reports of child at risk of harm or confirmed abuse and neglect in relation to the dead child or the siblings; or

d) the autopsy cause of death is suicide or risk taking behaviour but there are reports of child at risk of harm or confirmed abuse and neglect in relation to the child or the siblings (NSW CDRT 2001, page 27).

This definition differs from that of police reporting to the Coroner, whose use of the term indicates the possibility of a criminal act having been committed. The NSW CDRT often differed from the NSW Police or Coroner in their determination of whether a particular death was suspicious.

We will consider whether changes to the current definition of suspicious are needed in consultation with other relevant parties such as the Coroner.

Register of reviewable child deaths

Information on all child deaths within jurisdiction is included in our register. This includes the coding of these deaths by a member of the Reviewable Child Death Advisory Committee in accordance with ICD-10 codes (see p9 for more details about this coding system). The registered information is largely consistent with the register kept by the NSW CDRT. However, we report on the deaths of children occurring within the reporting period whereas the NSW CDRT reports on deaths registered in a reporting period.[4]

NSW Registry of Births, Deaths and Marriages (BDM) provides the initial information about all deaths of children registered in the previous month. This includes demographic information (such as date of death, child's age, gender, names of parents and last known address).

An initial check of all the children who died is conducted using DoCS' databases (CIS and KiDS) to establish whether the child or his/her sibling(s) had been reported to DoCS and the death is therefore within jurisdiction for that reason.

Information received from the Coroner, includes the NSW Police report of a death to the Coroner, final autopsy report and any inquest decision. This information may indicate that the death is reviewable because it occurred in circumstances related to abuse or neglect, or in suspicious circumstances. A full determination of whether a death is in jurisdiction may take some months.

Analysis of any patterns or trends arising from this information forms the basis of this section of our reviewable deaths annual report.

Additional work

Investigations

The Ombudsman can make preliminary inquiries or investigate matters of his own motion, where the matter arising from the review of a death could be the subject of a complaint under CS-CRAMA. A number of the cases that we reviewed warranted further inquiries and during the year we commenced investigative action in relation to eight of the reviewable deaths, including five investigations using the formal powers of the Ombudsman. These powers can include requiring an agency to provide us with information or documents and answer questions. Matters that are investigated are also included in the review data.

This action was taken where review of a death indicated:

- there may have been serious failings on the part of an agency or agencies, either in relation to circumstances leading up to the child's death or at any time in their prior contact with agencies.
- concerns about agency actions in relation to surviving siblings or family members.

Monitoring previous recommendations

In the context of the transfer of responsibility from the NSW CDRT to the Ombudsman for the review of abuse and neglect related deaths of children, provisions were included in the legislation relating to recommendations made in previous NSW CDRT reports.

This year, we have monitored only some previous NSW CDRT recommendations, generally those targeted specifically to DoCS. DoCS response to the recommendations monitored by us have informed, and been incorporated where appropriate, in this report. All the recommendations we monitored and DoCS responses are reported in the section entitled 'Monitoring recommendations'.

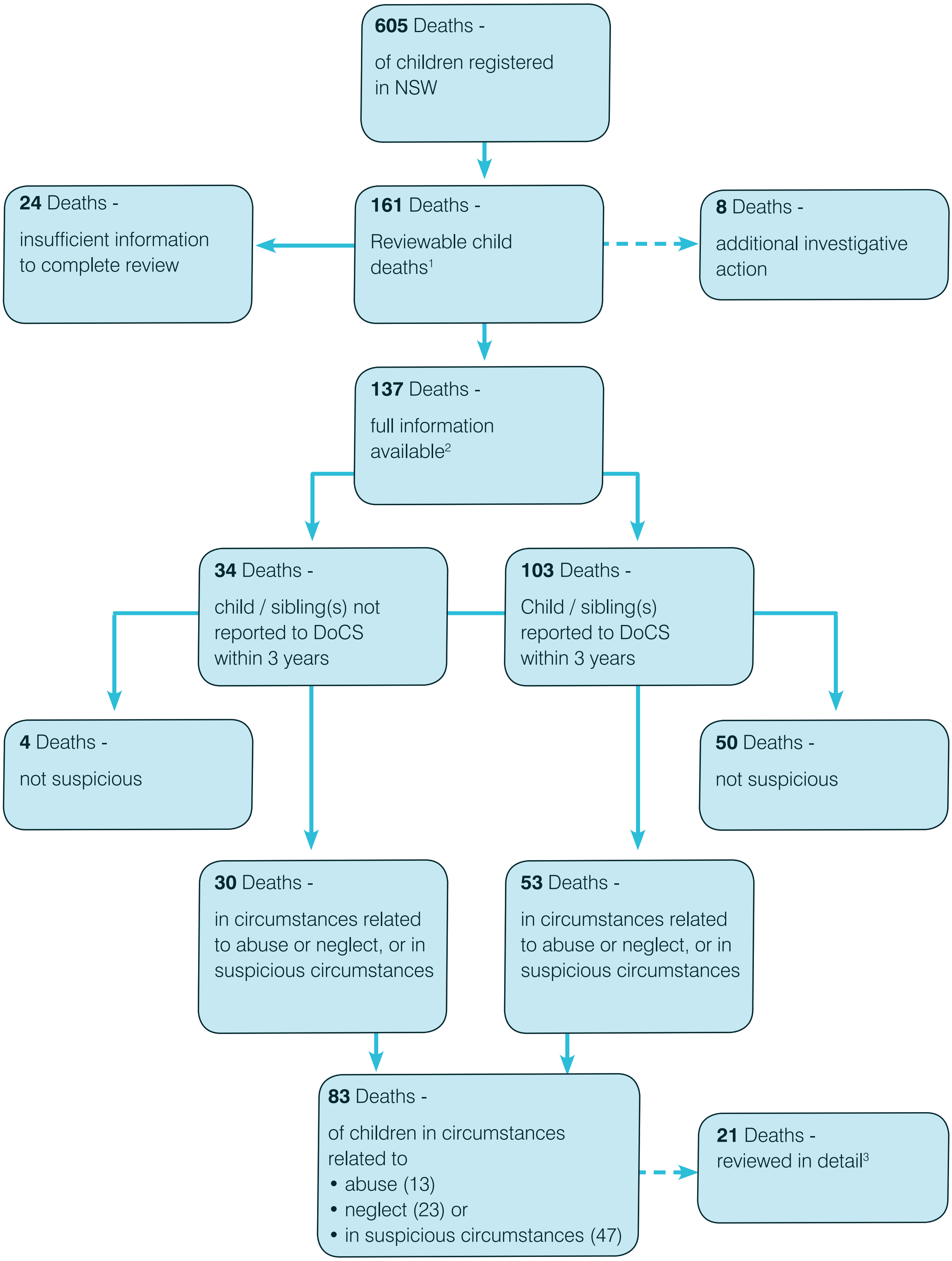
Reviewable child deaths

In summary

For the period 1 December 2002 to 31 December 2003 there were 605 children who died in NSW.[5]

- 161 of the 605 child deaths (27%) were reviewable under the Ombudsman's reviewable deaths function. Age, gender, Aboriginality, place of residence and information about any risk of harm reports to DoCS in the three years prior to the death are reported for these 161 deaths. Information reviewed for these 161 deaths was:
  - BDM records
  - risk of harm reports to DoCS within three years of the child's death
  - coronial information.
- 48 of the 605 deaths were of Aboriginal children
  - 30 of the deaths of Aboriginal children were reviewable
  - 14 Aboriginal children died in circumstances related to abuse or neglect or in suspicious circumstances.
- 137 of the 161 reviewable child deaths were reviewed more closely.[6] Additional information reviewed for these 137 deaths was:
  - NSW Police report of the death to the Coroner
  - final autopsy report
  - coronial findings where available, and inquest decisions.
- 10 of the 137 deaths were of children who died in care:
  - five children in foster care funded by DoCS, three in DoCS placements, and two in NGO placements
  - three children in voluntary care in services funded by DADHC
  - two children in respite care.
- 103 of the 137 deaths reviewed more closely were deaths of children where there had been a risk of harm report to DoCS for the child and/or a sibling of the child within the three years preceding the death. Information recorded on DoCS databases about risk of harm reports and protective intervention for 101 of these 103 children is included in this report.[7]
- 83 of the 137 deaths reviewed more closely were of children who died in circumstances related to abuse or neglect, or in suspicious circumstances:
  - 13 died in circumstances related to abuse (9%)
  - 23 died in circumstances related to neglect (17%)
  - 47 died in suspicious circumstances (34%).
- 53 of these 83 deaths were of children who themselves or their siblings had been reported to DoCS within three years prior to their death.
- No children died in a children's detention centre, a correctional centre or a lock-up during this reporting period.

1 Dec 2002 - 31 Dec 2003



[1] based on information from NSW Registry of Births, Deaths and Marriages, DoCS data bases and coronial documents
[2] additional information available from police reports to NSW Coroner, final autopsy reports and inquest decisions
[3] files from relevant departments accessed

Demographics

We are able to report the following demographic information on the 161 children whose deaths were determined as reviewable in the reporting period.

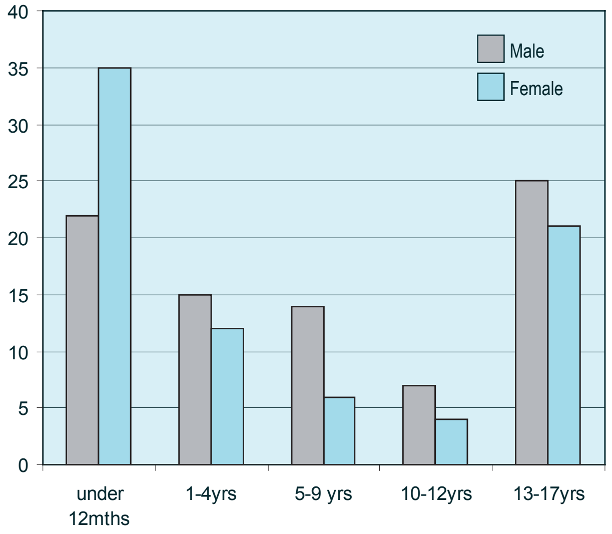
Age and Gender

The age and gender of the 161 children who died is shown in figure 24:

- 84 (52%) deaths were of children aged under five years of age:
  - 57 (35%) deaths were of infants aged under one year
  - 27 (17%) deaths were of toddlers aged one to four years
- 31 (19%) deaths were of children aged five to twelve years
- 46 (29%) deaths were of teenagers aged 13 to 17 years.

Slightly more boys (83) than girls (78) died. More girls than boys died in the under one year age group (35 girls and 22 boys) and more boys than girls died in the five to twelve year age group (21 boys and 10 girls).

Figure 24: Age and gender of children



Place of birth

The majority of children who died whose deaths were reviewable were born in NSW (122 of 161). Five of the children not born in NSW were born in other Australian states or territories and seven were born overseas.[8]

Deaths of children reviewed

As noted above, full information was available for only 137 of the 161 child deaths deemed to be reviewable. This information included that from the NSW Registry of Births, Deaths and Marriages, DoCS databases, NSW Police reports to the NSW Coroner, final autopsy reports and inquest decisions. From this information we were able to ascertain which of these deaths occurred in circumstances related to abuse or neglect, or in suspicious circumstances. The results of this analysis follow.

Circumstances of deaths

In determining circumstances of deaths, we considered the cause of death (essentially the medical determination of the disease or injury which results in death) and the manner in which the child died, that is the events that lead to death. Each death was also coded by a medical practitioner from the Advisory Committee using ICD-10 codes. The categories for manner of death we used are consistent with those used by the Coroner's office but because additional information was sometimes available to us, the results were not always the same. Where the coronial process is still open (50 of the 137) the cause of death has not been categorized.

Eighty-three of the 137 (61%) children reviewed died in circumstances related to abuse, neglect or in suspicious circumstances.[9]

- Abuse – children who died in circumstances related to abuse were stabbed, strangled, suffocated, burned, drowned or shot. The coronial process is still open in more than half these cases.
- Neglect – the circumstances related to neglect in which children died included traffic accidents (for example where the child was not wearing a seat belt or the driver was found to have proscribed levels of alcohol), drowning, and illness (where adequate medical attention had not been sought). The coronial process has not been finalised in one-third of the cases.
- Suspicious circumstances included suicide, overdose and a traffic accident (where there are indications that the collision may have been intentional). Thirteen infants died in sleep incidents where bed-sharing or bedding were factors. The coronial process has not been finalised in approximately two-fifths of the cases.

The Coroner could not determine the cause of death in nine of the 137 (7%) matters. For this reason, these deaths have been determined as suspicious at this point in time.

Fifty-four (39%) of the 137 children whose deaths were reviewed died from natural causes or in circumstances where there were no suspicious circumstances. Health issues were the most frequent cause of death for these 54 children. These children were in jurisdiction because the child and/or sibling(s) had been reported to DoCS within three years of their death or they were in care at the time of death. Other causes of death for this group included SIDS, choking on food despite the best efforts of the carer, falls and traffic accidents (where, for example, the child was passenger in a car whose driver was not responsible for the collision). The coronial process has not been finalised in almost one-third of the cases.

Figure 25 shows the circumstances of death for the 137 children, by gender.

Figure 25: Circumstances of death

	Girls	Boys	Total
Abuse			
Drowning	-	1	1
Shooting	-	1	1
Stabbing/ cut throat	2	-	2
Strangulation	1	-	1
Suffocation	1	-	1
Coronial process not finalised*	3	4	7
Total	**7**	**6**	**13**
Neglect			
Disease	2	-	2
Drowning	1	5	6
Traffic accident	1	6	7
Coronial process not finalised*	4	4	8
Total	**8**	**15**	**23**
Suspicious			
Sleep incidents**	8	5	13
Disease	-	1	1
Shooting accident	1	-	1
Traffic accident	-	1	1
Overdose	-	2	2
Suicide	3	6	9
Coronial process not finalised *	10	10	20
Total	**22**	**25**	**47**
Natural or unexpected deaths (not suspicious)			
Disease	14	17	31
SIDS	-	1	1
Choking and suffocation	-	2	2
Falls/jumps	-	2	2
Traffic accident	2	1	3
Coronial process not finalised*	10	5	15
Total	**26**	**28**	**54**

* as at June 2003

** bedsharing or bedding was a factor in these deaths: autopsy cause of death SIDS (3); autopsy could not determine a cause of death (9); autopsy cause of death asphyxia by bedding (1).

More boys (15) than girls (8) died from fatal neglect (see figure 25) There was little gender difference in the deaths from abuse, in suspicious circumstances or for those who died from natural causes or in unexpected circumstances that were not suspicious.

Eight of the children died in the same incident as a sibling, two children dying in each incident. One incident was a motor vehicle accident and one was a house fire. The other four children were killed by their fathers in two separate incidents.

Age

The age of the children who died is shown in figure 26.

Figure 26: Reviewable child deaths by age

Jurisdictional category	Age in years					Total	
	< 1	1-4	5-9	10 -12	13 -17	No.	Per cent
Fatal abuse	1	4	3	1	4	13	10%
Fatal neglect	2	8	6	2	5	23	17%
Suspicious circumstances	23	5	3	1	15	47	34%
Natural and unexpected deaths (not suspicious)	17	7	7	6	17	54	39%
Total number	**43**	**24**	**19**	**10**	**41**	**137**	**--**
Total per cent	**31%**	**18%**	**14%**	**7%**	**30%**	**--**	**100%**

Place of death

Figure 27 shows where the death occurred. Almost half the children (46%) died at home.

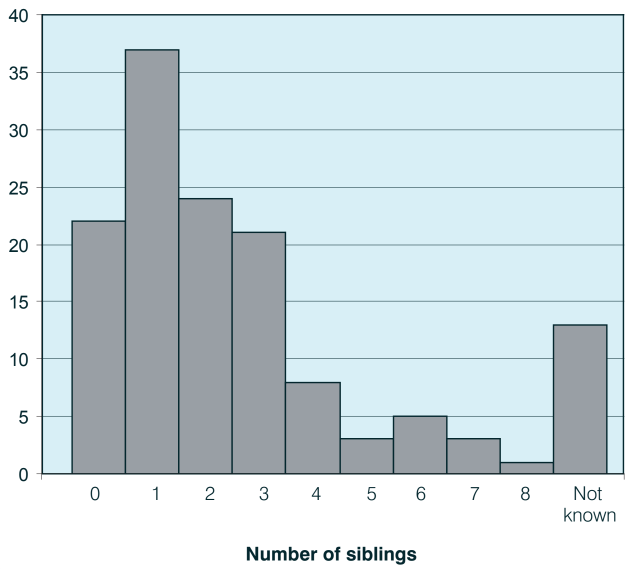
Figure 27: Place where the death occurred

	Type				Total	
Place	Abuse	Neg.	Susp.	Other	No.	Per cent
Child's home	5	10	32	16	63	46
Other home	2	1	3	1	7	5
Hospital or health facility	-	2	1	25	28	20
Residential service	-	-	1	3	4	3
Swimming pool	-	1	-	-	1	1
Natural body of water	1	2	-	0	3	2
Roadway/ driveway	1	6	3	5	15	11
Railway	-	-	3	-	3	2
Other location	4	1	4	4	13	10
Total	**13**	**23**	**47**	**54**	**137**	**100%**

Family Characteristics

The majority of the 137 children came from smaller families (83; 61%). Twenty-two children (16%) had no sibling. Sixty one children (45%) had one or two siblings. Approximately one-third (41; 30%) of children came from larger families with three or more siblings (see figure 28).

Figure 28: Number of siblings in the household



The majority of the children, 113 (82%), lived with at least one biological parent.

Twenty-four children, (18%), were not living with a biological parent at the time of their death:

- eight infants, aged less than 10 weeks, had health complications at birth (prematurity, congenital disease) and were never discharged from hospital
- five children died in a disability accommodation service, three who were permanent residents and two who were in respite care
- five children lived in foster care – three in care provided by DoCS, and two with non government service providers
- two children lived with extended family
- two teenagers lived independently
- one child lived with an adoptive parent
- one child lived in a nursing home
- living arrangements could not be identified for one child.

Two of the children who died in a disability accommodation service died in suspicious circumstances. Of the five children in foster care, one died in circumstances related to neglect, and another in suspicious circumstances. Both children who lived with extended family died in suspicious circumstances. One of the teenagers living independently died in suspicious circumstances.

There had been a prior death of another child in the family in nine cases (7%). In three cases the prior death was due to medical problems, in three cases the cause of death was SIDS and in one case the child died bed-sharing. Two children who died in the same incident had an older sibling who had died some time before, but no details are available about this death.

Risk of harm reports

Of the group of 137 children who died, 103 were children where a report about them and/or their sibling(s) had been made to DoCS within the three years preceding their death.

Risk of harm reports were received within 12 months prior to the child's death in 59 cases. For seven of these children a report was received less than seven days before their death, and for a further seven children, a report was made more than a week but less than a month prior to their death.

Figure 29: Weeks between date of last DoCS report & date of death

	Frequency	Percent	Cumulative Percent
0 - 13 Weeks	32	23.4	23.4
14 - 26 Weeks	16	11.6	35
27 - 39 Weeks	6	4.4	39.4
40 - 52 Weeks	5	3.7	43.1
>52 Weeks	25	18.2	61.3
No DoCS Reports	53	38.7	100
Total	**137**	**100**	

Assessing risk of harm

The *Children and Young Persons (Care and Protection) Act 1998* provides the statutory basis for the care and protection of children and young people in NSW. The Act provides for a person to make a report to the Director-General DoCS if they suspect a child or young person is at risk of harm.

A report may be about a single incident or child; it may be about a number of children in a family or a number of issues of concern. Several reports may be received from the same or different sources about the same child or family.

DoCS has the 'lead responsibility' for providing and coordinating the community response where intervention is necessary for the care and protection of children and young people.[10]

Section 23 of the Act defines a child or young person as being at risk of harm if current concerns exist for the safety, welfare or well-being of the child or young person because of the presence of any one or more of the following circumstances:

- the child's or young person's basic physical or psychological needs are not, or are at risk of not, being met,
- the parents or other caregivers have not arranged and are unable or unwilling to arrange for the child or young person to receive necessary medical care,
- the child or young person has been, or is at risk of being, physically or sexually abused or ill-treated,
- the child or young person is living in a household where there have been incidents of domestic violence and, as a consequence, the child or young person is at risk of serious physical or psychological harm,
- a parent or other caregiver has behaved in such a way towards the child or young person that the child or young person has suffered or is at risk of suffering serious psychological harm.

Under s.25 of the Act, reports of risk of harm may also be made before a baby is born in order to enable the provision of support and assistance to a family to reduce the likelihood of the newborn child being placed in out-of-home care.

Statutory child protection intervention is largely reactive and investigative in nature. It is essential that this intervention occurs within a policy and practice framework that provides coherence and continuity both within DoCS and across agencies with a role in protecting children and providing assistance to families.

This section addresses issues identified through our reviews that relate to the assessment of and response to risk of harm. In 2002, the Legislative Council's Standing Committee on Social Issues inquiry into child protection services (referred to hereafter in this report as Legislative Council inquiry or Legislative Council report 2002) identified a need for alignment between the work of the Helpline and community services centres (CSCs). In this context, we have examined the department's assessment of risk of harm and any subsequent intervention as a '*single, seamless process of service delivery*'.[11] This approach is supported by the department's own risk of harm business rules and framework which state that risk of harm is '*a process that is made up of three distinct but complementary stages*'. These stages are:

- initial assessment, usually undertaken by the DoCS Helpline and the first stage in gathering and analysis of information
- secondary risk of harm assessment, occurring after the initial assessment and usually conducted by a CSC or a Joint Investigative Response team (JIRT)[12]
- risk of harm assessment in the delivery of care and protection services, where assessment continues until the issues leading to the need for care and protection are resolved (Secondary Risk V4.0.doc., Business Help).

The risk of harm framework is an essential starting point for looking at child deaths and our initial work indicates some issues that require more detailed consideration. These issues will form a core part of our work in this area during the next twelve months.

Information was sought from DoCS to provide a context for the data and analysis in this report. We requested information covering the reporting period, 1 December 2002 - 31 December 2003. DoCS advised that it had experienced some difficulties in providing the information because of the changes to its client information system (CIS) in 2002 and the introduction of its new system, KiDS, in October 2003. DoCS advised that reports based on KiDS data could not be released until the department can ensure that the information is consistent and accurate. This was not available at the time of writing this report. In addition, data was provided for the financial year 2002 – 2003, which does not coincide with our reporting period. Where DoCS have provided contextual information, it is reported.

In relation to risk of harm reports, DoCS provided the following data:

- 176,271 reports to DoCS were made in 2002-2003
- of these reports, 146,877 (83%) were about risk of harm concerns 'based on the legal basis of the report as determined by caseworkers at the DoCS Helpline'. These reports concerned 79,612 children

Figure 30: Number of times children were reported

Number of times children were reported	Number	Percent
1	50,737	63.7
2	14,550	18.3
3	6,155	7.7
4	3,161	4
5	1,744	2.2
6 - 10	2,744	3.4
11 - 15	401	0.5
16 – 20	74	0.1
> 20	46	0.1
Total	**79,612**	**100**

Source: Client Information System Annual Statistical Extract NSW DoCS

Risk of harm assessments for children who died

We analysed the risk of harm reports and assessment outcomes recorded on DoCS databases for all children who died in the review period, where there had been a report for the child or the child's sibling in the three years preceding the death. There were103 children who met this criterion.

There was difficulty analysing information recorded in the databases because:

- secondary assessment outcomes were not recorded for a number of reports
- outcomes were recorded for a number of reports where no record of secondary assessment action or report could be located
- terminology used by DoCS to record information has changed over time, for example in response to changes to child protection legislation
- DoCS introduced a new database in October 2003 with new systems for recording information. There were some delays and problems in transferring information from the old Client Information System (CIS) to the new KiDS system. Reports received when CIS was in use may have been finalised after KiDS became operational and information was often difficult to locate
- changes to secondary assessment policy during this reporting period meant that it was difficult to determine whether secondary assessment was conducted as required by policy current at the time the report was made.

A total of 429 reports were made for 103 children in the three years before their death. These reports included risk of harm reports for the deceased child, the deceased child and their sibling(s), or for the deceased child's sibling(s) only.

Nineteen of the 103 children who died had 143 reports that referred to the child's sibling(s) only and are not included in the following analysis. For the remaining 84 children, 286 reports were made in the three years before their death.

Initial risk of harm assessment

The Helpline plays a critical role in determining whether an incoming report constitutes risk of harm to a child and therefore warrants a protective response. When a report is made to DoCS, usually through the Helpline, an initial risk assessment takes into account the urgency of the case and the need for intervention by DoCS. In addition to information provided by the reporter, DoCS advice is that initial assessment at the Helpline includes an examination of the history of the child and family in order to ascertain more accurately any risk of harm.

When the Helpline decides that an incoming report does not require a protective response, reports may be closed at the initial assessment stage. The primary reasons for closure are:

- current care and protection concerns are not evident
- there is no legal basis for the report[13]
- the information is already known, or does not add to information already known to DoCS.

Closed reports may be referred to the local CSC for 'information only' if other issues are still under consideration by the CSC. Information, referral advice or guidance may be also be provided to the reporter.

If care and protection issues are identified, one of four response levels is attributed to the report:

- level 1, requiring a response within 24 hours of referral to the CSC or JIRT. An immediate response may be required if the risk is urgent.
- level 2, requiring a response within 72 hours, due to serious safety concerns
- level 3, requiring a response within 5-10 days
- level 4, requiring a response at some stage after 10 days, generally information only about appropriate services.

The Helpline develops an initial required action plan (RAP) following the initial assessment. The report is then referred to the appropriate CSC or JIRT for action.

Initial risk of harm assessments for children who died

Ninety-eight of the 286 reports were closed at the initial assessment stage at the Helpline.[14] These reports were made in relation to 44 of the 84 children about whom a report had been made.

Ninety-eight reports closed at the initial assessment stage represents 34 per cent of reports received about this group of children. Sixty-six percent (66%) of reports received concerning this group of children were assessed as requiring further assessment or investigation at a CSC or JIRT. This figure of 66 per cent is significantly lower than the 75 per cent of reports that DoCS advised us were assessed as requiring further assessment or investigation across all risk of harm reports received in the period 1 July 2002 to 30 June 2003.

Twenty-nine of those 44 children where reports were closed at the initial assessment stage subsequently died in circumstances related to abuse or neglect, or in suspicious circumstances.

A total of 69 reports were closed at the initial assessment stage for the 29 children:

- 14 children had 1 report closed
- 7 children had 2 reports closed
- 3 children had 3 reports closed
- 3 children had 4 reports closed
- 1 child had 5 reports closed
- 1 child had 15 reports closed.

The nature of the reports made about these 29 children was wide-ranging, with risk from domestic violence (11 children) and neglect (13 children) being most commonly reported.

A total of 83 other reports that were not closed at the initial assessment stage were made in relation to those 29 children, including:

- 16 reports that were closed under Priority One[15]
- 30 reports that were closed after secondary assessment
- 5 reports that remained open and allocated
- 32 reports where we were unable to determine the status of the reports.

Of those 83 reports:

- neglect was included in 37
- physical abuse was included in 30
- sexual abuse was included in 13
- domestic violence was included in 13
- psychological abuse was included in 11
- carer drug and alcohol use was included in 5
- homelessness was included in 5
- carer mental health was included in 4
- carer/adolescent conflict was included in 3.

Closure of reports at initial assessment stage – last action by DoCS

For 24 of the 44 children, closing the report at the initial assessment stage was the last DoCS action prior to the child's death. The report closed at the initial assessment stage was the only report made in relation to nine of these children. Thirteen of the 24 children subsequently died in circumstances related to abuse or neglect, or in suspicious circumstances.

The last report made in relation to those 13 children included the concerns detailed below:

- domestic violence – for three children. Two children died in circumstances related to abuse, and one died in suspicious circumstances.
- homelessness - for two children. One of these children died in suspicious circumstances and one died in circumstances related to abuse.
- physical abuse - for one child. This child's death was related to neglect.
- carer drug and alcohol use – for one child. This child died in suspicious circumstances.
- physical abuse, neglect and domestic violence - for one child. This child died in suspicious circumstances.
- physical abuse, psychological abuse and neglect - for one child. This child died in suspicious circumstances.
- neglect - for one of the children. This child died in suspicious circumstances.
- carer/adolescent conflict - for one of the children. This child died in suspicious circumstances.
- 'other' concerns - for two of the children. The death of one of these children was related to neglect and the other child died in suspicious circumstances.

The high rate of closure at the initial assessment stage of reports about the children whose deaths we reviewed does not of itself demonstrate poor decision making by DoCS. However, it does demonstrate the need for good decisions to be made and that there can be fatal consequences if these assessments are inadequate. Our reviews also show that in just over half the cases the closure decision at the initial assessment stage was the last action taken by DoCS before the death of a child.

As noted previously, closure at the initial assessment stage may occur because DoCS assesses that there are no protective concerns, the report has no legal basis, or the report duplicates information already known. The importance of examining the history of the child and family is indicated by the following case study.

case study 6

A nine-week-old infant boy died of sudden infant death syndrome. A report had been made about this infant when he was three days old. The report concerned his mother's failure to seek appropriate antenatal care, drug use during pregnancy and a recent episode of drug-induced psychosis.

Helpline staff did not conduct a full search of CIS when the report was made. As a consequence, the infant's family history was not considered when determining the level of risk to the newborn infant. This history involved 14 reports to DoCS about the infant's three siblings in the previous three years. Issues raised in those reports included parental drug and alcohol use, lack of parenting ability, inadequate food, inadequate supervision, unsuitable housing and lack of adequate medical attention.

The Helpline recorded the report in relation to the newborn infant as requiring a 'Level 4 information only response'. The report was not transferred to the local CSC.

DoCS advised they were not aware of the infant's death until we sought further information eight months after the infant died.

Assessment of the significance of additional reports about a child is particularly critical in identifying when similar information indicates escalating risk or provides further validation of the need for a protective response. Our reviews indicate that some reports screened out on the basis that the information was already known may, in fact, have been indicators of increasing risk.

case study 7

An adolescent who died after falling from a cliff at the age of 15 had been reported to DoCS 17 times in the three years prior to her death. A number of people, including mandatory reporters, made these reports but they were similar in nature. They concerned carer drug use, parental neglect and abandonment, physical abuse and domestic violence.

Four reports were assessed as intake only or information only. Ten reports were recorded as Initial Assessment, but were closed at the CSC without further assessment. The last report, made five months prior to the girl's death, was assessed as level 4. Proposed action, if future reports were received, was to assess risks and available resources. The report was closed under Priority One policy eight weeks prior to the girl's death.

In the case study above, the escalation in reports in the three years preceding this child's death did not result in recognition of the need for a protective response. The increasing risk to the child was recognised across a variety of situations and environments with reporters from government and non-government agencies, the child's school and her neighbours. The opportunity for DoCS to recognise the escalation was lost when new reports were simply recorded as duplicating information previously provided.

Secondary risk of harm assessment

A Secondary Risk of Harm Assessment is:

…a tightly focused assessment that requires judgements about immediate safety and the consequence and probability of future harm to the child or young person. It is a thorough and systematic process. It is assisted by professional supervision and dialogue with colleagues. Strengths and issues identified in the assessment provide the basis for the development and review of the case plan. (DoCS submission to Legislative Council inquiry, p14).

A secondary risk of harm assessment (or secondary assessment) should occur if the initial assessment process identifies care and protection concerns. Secondary assessment comprises two stages. Stage one occurs prior to field action and stage two occurs after field action. The purpose of both stages is to build on information and analysis already conducted.

DoCS advised us that of the 146,877 reports, 110,423 (75%) were assessed as requiring further assessment/investigation at a CSC and/or JIRT. 1,686 reports were referred to a co-located JIRT.[16]

It should be noted that 'further assessment/investigation' covers a range of work from a single telephone call to full protective intervention.

Secondary assessments for children who died

131 reports for 55 children, indicating multiple reports for some children, were referred to the local CSC for secondary assessment. We were unable to establish the extent of secondary assessment for many of these reports. For example, there were some reports recorded on the DoCS databases as being closed after assessment but a secondary assessment report could not be located. Other reports had an outcome of 'confirmed' or 'not confirmed' recorded but the secondary assessment action could not be identified during our review of DoCS databases.

Thirty-four of these children died in circumstances related to abuse or neglect, or in suspicious circumstances.

The RAP and decisions made at the initial assessment stage guide secondary assessment. However, the Manager Casework at the CSC can override initial assessment decisions. According to DoCS, this includes reports being

> assessed with local additional knowledge of the child or family and prioritised by a local Casework Manager against the other work the office is already dealing with. This may mean a case is allocated a different priority by the Casework Manager to what it was initially given at the Helpline. Because of this local knowledge, some cases assessed as Level 1 at the Helpline will not be accorded the same priority at the CSC and the actions may therefore not fit within the Level 1 protocols (DoCS submission to Legislative Council inquiry p11-12).

Assessment decisions which may be overridden by a CSC include:

- whether there is an immediate safety concern
- risk of harm
- whether the child or young person may be in need of care and protection
- required response
- case focus and/or
- assessment focus (DoCS Practice Bulletin June 2002).

We did not collect information for all reviewable deaths about 'downgrading' by CSCs of responses recommended by the Helpline. However, of the deaths of 21 children reviewed in detail, reports about three children who died were downgraded by the CSC. In one case, the reason for the downgrading is recorded as relating to the delay between the reporter seeing the child and contacting the Helpline (see case study 11). In the other cases, the reasoning is less clear. For one child a report recommended for Level 2 response was downgraded to Intake Only and for another child a recommended Level 3 response was downgraded to Intake Only.

DoCS advised us that due to changes to its client information systems it was unable to advise how many of the reports transferred from the Helpline to CSCs received a secondary risk of harm assessment in this reporting period.

We acknowledge the difficulties generated by changing information systems. However, it is a significant concern that DoCS is unable to provide any indication of the extent to which this critical response to risk of harm has been applied.

Where stage one secondary assessment identifies that further information is required in order to determine whether the child is in need of care and protection, the assessment may then include a home visit or other field action. Field action may involve observing or speaking to the child who is the subject of the report as well as other children in the same household.

Of the 21 children whose deaths we reviewed in detail, 13 reports concerning seven children resulted in further secondary assessment of risk by the CSC:

- In six of these 13 reports concerning four children, secondary assessment did not include a home visit or interviewing the parent or observing/interviewing the child. The secondary risk of harm assessment was limited to contact with the reporter or another agency.
- Both the child and a parent were seen in follow up to five reports for four children.

In addition:

- Three of the 11 children where reports were made in the 12 months prior to death were neither interviewed nor sighted by a caseworker.
- The parents of four of the 11 children where reports were made in the 12 months prior to death were not interviewed by a caseworker.
- In four of these 11 cases neither the child nor the parents were interviewed.

In June 2003 DoCS introduced new practice rules for secondary assessment. Prior to the introduction of these practice guidelines, secondary assessment policy required that '*the subject child must be observed and where possible spoken to*', other than in 'extraordinary circumstances' for example where the child cannot be located (DoCS Secondary risk of harm assessment policy statement, March 2002 in Business Help Procedures Manual).

case study 8

A child was three and a half years old when she was found dead in a neighbour's swimming pool. She was first reported to DoCS four days after her birth, the report of neglect being confirmed and registered.

The child's mother had already had a child removed due to a history of neglect including inadequate food, clothing and supervision, together with reports of chronic domestic violence and alcohol abuse. The risks do not appear to have diminished when this child was born.

In the last 14 months of the child's life, nine reports were made about her, including four further reports including neglect, six of which were closed without assessment. A secondary risk of harm assessment was conducted following the second report about neglect, at which time she was 2 ½ years old.

The allegations of neglect and inadequate supervision were not substantiated by this risk of harm assessment. The caseworker recorded her as '*a small, very thin and pale child…, completely non-verbal during the visit'* and to be *'very keen to climb through the back fence to the neighbours' yard'*. The caseworker also noted that she was a child at risk '*in view of the circumstances of her older sibling*' but concluded that the future risk level to the child was low and that DoCS could monitor the situation by engaging the services of an NGO where the mother attended groups, speech pathology and dietetic services.

The mother was also given information about local childcare centres. No appropriate protection planning meetings with other agencies occurred, even when recommended by the Helpline.

There were eight further reports following the secondary risk of harm assessment. Concerns reported about this little girl were that:

- she was filthy, inadequately dressed, had significantly delayed speech and was cross-eyed but no corrective intervention was occurring
- she was being physically, verbally and emotionally abused by her relatives
- she was left unsupervised in the backyard for long periods of time
- she was regularly seeking food and comfort from neighbours and became distressed when escorted home.

Not all the reports were confirmed and the outcome of some assessments is not recorded. There is however no indication of a re-evaluation of previous conclusions that risk to the child was low.

However, under the June 2003 practice rules, secondary assessment can be finalised at stage one without any observation of the child, or visit to the family, if other information gathered at this stage is sufficient to determine the child is not in need of care and protection. This appears to contradict the requirements of the earlier policy statement (March 2002), which is currently included in the DoCS Business Help Procedures Manual.

Additionally, Priority One policy (refer below) may be used at any time during the secondary assessment process to suspend or close a secondary assessment if there are insufficient resources to undertake or complete it.

A stage two assessment is completed after field action. A determination is made as to whether the child is in fact in need of care and protection, whether care and protection issues have been resolved during the assessment phase or whether further intervention is required. Risk of harm assessment is meant to continue until care and protection issues are resolved.

Case study 8 is sourced from the DoCS internal investigation of the death of the child. That report notes that the assessments of risk to the little girl were based on the '*immediate presenting situation*' and did not examine *'the pattern and history and escalation in risk factors*'.

Priority One

DoCS 'Priority One' policy is a work management tool that allows for prioritisation and closure of incoming risk of harm reports that would otherwise require a response. The intent of the policy is to enable casework managers to prioritise a CSC or JIRT response to the most urgent cases where there are insufficient resources to deal with all incoming work and competing priorities.

According to the policy, a decision not to implement a RAP should be made with reference to the DoCS risk assessment framework, the Interagency Guidelines for Child Protection Intervention, and staff consultation. Matters may be unallocated because of factors such as staff on leave, too few experienced staff available to undertake complex casework, occupational health and safety issues, and technological difficulties with information systems that may limit access to information.

Under the policy, unallocated cases are reviewed every four weeks and cannot be closed until they have been unallocated for one month. The policy states that a recommendation for closure will be based on one or more of the following:

- the mandated reporter has been recontacted
- the caseworker has considered and/or provided feedback to non-mandated reporters
- information is sought to establish the current circumstances
- the validity of an assessment or investigation would be compromised or would be intrusive, or the situational impact has been lost
- information is received that circumstances have changes and the risk is reduced.

While the intent of the policy is clearly to target limited resources to where they are most pressingly required, the legitimacy of a policy that allows closure of, or no immediate action about, cases of risk of harm has been the subject of some debate. The Legislative Council report on child protection services noted that '*the closure of cases initially assessed as at risk of abuse runs counter to the Department's statutory responsibilities to protect children from harm*'.[17] However, the DoCS/PSA Joint Working Party on the 'Demand for DoCS services and Management of the Intake and Casework Process' in 2002 formed the view that while there is a disjuncture between resources and demand for investigative and assessment services, there will be a need for a policy that allows for prioritisation and closure of reports of risk of harm. This view was taken on the basis that if case closure is unavoidable, then it should at least be transparent.[18]

Regardless of whether or not DoCS should manage a statutory function in such a way, our analysis of child deaths indicates that the application of Priority One means that on occasions inadequate or no responses are being made to reports of children being at serious risk of harm. In some of the cases we reviewed there were significant child safety issues that had not been resolved at the time the decision to close the case was made. We also noted that some cases were closed based on incorrect assumptions about the level of risk.

DoCS was unable to provide us with data on the number of cases closed under Priority One during the period under review. In May 2004 DoCS advised us that the system it had developed for state-wide reporting on, and monitoring of, the Priority One policy was never fully implemented. While a system for reporting is in place at the CSC level and was implemented in some regions, the resources required to establish a state-wide system were not available. DoCS advised that 'it is well aware of the current shortcomings in the system for centralised measuring and monitoring of the impact of Priority One Policy.' DoCS further advised that it expects *'reports on unallocated cases and closed cases will be available when the report capability is developed in the KiDS data base'.*

Closure under Priority One for children who died

As noted earlier, the Helpline referred 131 reports about 55 children to the local CSC for secondary assessment. Fifty of those reports, concerning 37 children, were closed under Priority One.

Twenty of these 37 children subsequently died in circumstances related to abuse or neglect, or in suspicious circumstances. The total number of reports made about these 20 children was 132.

Twenty-eight reports were closed under Priority One for these 20 children – eight children had two reports closed under Priority One and 12 had one closed. The nature of these reports was wide ranging.

One hundred and four other reports were made in relation to these 20 children. Of the 104 reports:

- 38 were closed at the initial assessment stage
- 35 were closed following assessment
- 5 were open and allocated at the time the child died
- 3 were open and unallocated at the time the child died
- it was not possible to determine the closure status of the report in 23 cases that were closed.

The nature of these reports was wide-ranging.

For 12 of those 20 children, closing the report under the Priority One case closure policy was the last DoCS action prior to the child's death. The last report made in relation to those 12 children is detailed below:

- domestic violence - for two of the children. Both of these children died in suspicious circumstances.
- sexual abuse, physical abuse, neglect and domestic violence - for one of the children. This child died from abuse.
- physical abuse and domestic violence - for one child. This child died from abuse.
- psychological abuse and domestic violence - for one child. This child died in suspicious circumstances.
- physical abuse, neglect and 'other' - for one child. This child died in suspicious circumstances.
- physical abuse, psychological abuse and neglect - for one child. The death of this child was related to neglect.
- physical abuse - for one child. This child died in suspicious circumstances.
- neglect and 'other' - for one of the children. This child died in suspicious circumstances.
- physical abuse and carer mental health - for one child. This child died due to abuse.
- psychological abuse - for one child. This child died in suspicious circumstances.
- 'other' concern - for one child. This child died in suspicious circumstances.

It is a significant issue that the Priority One policy, while indicating that staff should seek guidance from risk assessment tools, rests on analysis of relative risk and urgency, rather than identified risk to an individual child. This can result in cases with outstanding significant risks being closed. The following case study is an example of this.

case study 9

A young child was reported to DoCS three times by three different mandatory reporters in the six weeks prior to his death. All three reports concerned the mental health of the child's parent, and the parent's threat to kill the child and commit suicide.

The first report was assessed as requiring a level 2 response. DoCS contacted the mental health team and were advised that the team had arranged follow up with the parent, and there were no immediate concerns. DoCS then left two phone messages for the parent to contact them. This report was still open when the child died in circumstances that reflected the concerns reported to DoCS.

The second report, made nine days after the first, reported threats by the parent to harm themselves and the child. This report was not linked to the first as the child's surname was spelt differently and a phonetic check was either not done or failed to link the two names. The address was the same. According to files, the report was closed under Priority One 16 days later – two weeks earlier than prescribed by Priority One policy.

A third report was made to the Helpline three weeks before the child died, again concerning the parent's threat to kill the child and commit suicide. The reporter was told DoCS were aware of and following up the issues. Despite the child not attending pre-school yet, DoCS records note that the family member and the pre-school would contact the Helpline again if they had any '*future and/or major concerns*'. The second report was not identified in the initial assessment of this report. DoCS issued a formal request for information from the relevant mental health team but did not sight the child or parent. No response was received by the time the child died. The third report was closed under Priority One some months after the child's death.

We have been advised by DoCS that, in accordance with recommendations of the Kibble Committee, a 'case closure' policy is being developed that will replace Priority One as a workload management tool.

In the letter dated 14 May 2004, referred to above, DoCS advised in relation to the new case closure policy that it *'will provide staff with clear instructions for closing a case that has been referred as a Risk of Harm report. It will also cover cases that meet DoCS' business criteria, but which cannot be allocated because of lack of available resources.'* The advice continues, *'the operational impact of new instructions to staff on case closure will be tested prior to their introduction statewide. Work on this trial has commenced. In the meantime, the Priority One Policy with some minor modifications related to the Key Information Directory System (KiDS) system, remains in place'.*

The implementation of any future case closure policy will require careful monitoring. Such monitoring might include regular auditing of unallocated cases that have been closed and close scrutiny of closure rates across CSCs.

Other actions undertaken at the CSC for children who died

Of the 131 risk of harm reports the Helpline referred to a local CSC for secondary assessment, 81 reports concerning 33 children received further assessment:

- 61 of these reports concerning 29 children were closed after assessment
- 21 of these 29 children subsequently died in circumstances related to abuse or neglect, or in suspicious circumstances.

As noted earlier, we were unable to establish the extent of the secondary assessment for many of these reports. However, we did ascertain that:

- 17 reports concerning seven children were open and allocated at the time the child died. Six of these children died in circumstances related to abuse or neglect, or in suspicious circumstances.
- 3 reports concerning two children were open and unallocated at the time the child died. Both children died in circumstances related to abuse or neglect, or in suspicious circumstances.

Summary

Our review work indicates that more than 50 per cent of reports to DoCS do not lead to any preventive intervention.

Risk of harm reports raising serious child safety issues were received for children who died in circumstances related to abuse or neglect, or in suspicious circumstances that did not result in a secondary risk of harm assessment. The following case study is one example.

case study 10

A four-month-old infant died in a bed-sharing incident. The Coroner was unable to determine the cause of death. At the time of her death she was sharing a bed with her 15-month-old brother and her mother, who was intoxicated. There was an extensive history of DoCS involvement with the family as a result of long term parental drug and alcohol abuse, neglect and poor parenting. Six other siblings had been placed in relatives' care and one other sibling had reportedly died from 'cot death'.

Four reports concerning neglect, carer drug and alcohol use and parental homelessness were made in the 12 months prior to the infant's death. The family were living on the streets in the weeks leading up to the infant's death. Despite the long history of DoCS involvement with the family and two risk of harm reports in relation to the mother's transience whilst caring for two children under 15 months of age, no secondary risk of harm assessment was undertaken and DoCS provided no assistance to the mother to help establish stable accommodation for her and the two children.

The issues of homelessness, substance use and inadequate parenting skills would have been more readily identified in the context of a comprehensive secondary risk of harm assessment.

The application of the Priority One policy resulted in some children at risk of harm receiving no assessment or protective intervention and remaining at substantial risk of harm. The following case study is one example.

case study 11

A mandatory reporter made a report to DoCS about an adolescent's psychosis and disclosure of possible sexual abuse. The Helpline allocated the case a level 1 priority and forwarded the report to the local CSC and JIRT.

JIRT rejected the referral. The CSC downgraded the response to level 3, on the basis that it could not have been urgent because the reporter had seen the child on a Monday but had not sent a fax to the Helpline until Wednesday. The CSC advised the reporter of this downgrading. The report was subsequently closed under Priority One.

A further report was made in relation to the child's sibling three months later concerning physical abuse and neglect. The report for this child was also closed under Priority One. The adolescent committed suicide, two months later, aged 17 years.

Where secondary risk of harm assessments were conducted for the children we reviewed, those assessments did not necessarily identify the risks to the child. The following case study is one example.

case study 12

A 5 ½ year old boy with global developmental delay, autism and severe epilepsy drowned in the bathtub while suffering an epileptic seizure. No traces of anti-convulsant medication were found in his system at autopsy.

Four reports regarding parental non-compliance with anti-convulsant medication were made to DoCS in the 18 months prior to his death. Three of these reports followed the boy's admission to hospital with seizures. On two admissions, blood tests revealed inadequate levels of anti-convulsant medication in his system, leading doctors to warn that failure to properly medicate the boy placed him at risk of suffering an epileptic seizure and drowning whilst in the bath.

The last report concerning the boy was made 13 months prior to his death, following another hospital admission for seizures. A secondary risk of harm assessment was commenced three weeks later.

The secondary risk of harm assessment noted the boy's vulnerability due to developmental disability, the history of parental non-compliance with medication, the potential for seizures to result in further brain damage and the likelihood of harm continuing. However, the assessment concluded that there was no clear substantiation of risk of harm despite the explicit warning from a medical practitioner about the risk of the boy drowning if he had an epileptic seizure in the bath. The boy's case was subsequently closed because DoCS determined there were no safety, risk or wellbeing issues.

This boy died 12 months after this assessment was concluded.

Due to the inadequacy of the secondary risk of harm assessment and its conclusions concerning no risk of harm, DoCS did not enforce the need for this boy's parents to consistently administer anti-convulsant medication. The failure to administer medication was directly linked to the boy's death.

Where secondary risk of harm assessment was conducted for the children we reviewed and risks were identified, this did not necessarily lead to effective protection for the child. The following case study is one example.

case study 13

A six-week-old infant was found dead face down in his crib. The Coroner was unable to determine the cause of death. Three risk of harm reports were received by DoCS in relation to the infant in the six week period between his birth and his death.

An initial report was made to DoCS when he was six days old, prior to his discharge from hospital. This report concerned his mother's emotional volatility and her difficulties managing the new baby.

Two further reports were made, the first by a mandatory reporter following an incident of domestic violence between the infant's parents. Concerns were the mother's emotional state and her threats to harm the infant. An attempt to sight her and the child failed.

The intake worker at the CSC to which the report was referred upgraded the urgency of the required response because of prior knowledge of the mother's history. A DoCS caseworker and an NGO worker made a home visit. The caseworker did not speak to either of the parents during the visit, only to another family member. The caseworker's later statement included observations that the infant's mother demonstrated '*flat affect consistent with a depressed person*' and that the father did not interact with the infant.

Although the caseworker did not engage with the parents or discuss the child protection concerns, s/he concluded that the infant's welfare was not in jeopardy. S/he did give a family member contact details to enable that person to make direct contact if necessary. After the home visit the caseworker contacted a number of other agencies about possible support for the mother, but there was no follow up action.

When the family member contacted the caseworker about a month later, s/he was told to make a report to the Helpline. The Helpline forwarded that report back to the CSC and an attempt was made to contact the mother. When this failed, the caseworker wrote to the mother offering assistance if she needed it. Another home visit was attempted about a week later, but the mother and child could not be located.

The infant died two days later.

Neglect

We determined that the deaths of 23 children were related to neglect during the 13-month review period.[19] This number is considerably higher than the number of deaths reported by the NSW CDRT, who found 31 neglect related deaths over a three-year period.[20] The exclusion of relevant SUDI (sudden and unexpected deaths of infants) and suicide/risk taking deaths by the NSW CDRT may largely account for the difference in numbers found.

In the current group of neglect related deaths, 15 of the 23 children were boys (65%) and eight were girls (35%). This is similar to the proportion reported by the NSW CDRT, where the majority of deaths related to neglect (61%) were also boys.

Reports of neglect

Neglect was a significant issue raised in reports to DoCS about children who died. Of all the reports to DoCS in relation to the 103 children who died and had been reported to DoCS, 35 per cent included neglect as a reason for the report being made.

Of the 83 children who died in circumstances related to abuse, neglect or in suspicious circumstances, 44 children had one or more reports of neglect made about them.

Figure 31: Number of reports of neglect

No. of reports including neglect	No. of children	Percent	Cumulative percent
1	22	50	50
2	7	15.9	65.9
3	6	13.6	79.5
4	3	6.8	86.4
5	5	11.4	97.7
9	1	2.3	100
Total	**44**	**100**	

Twenty-four of the 100 reports concerning neglect were closed at the initial assessment stage. This represents almost one quarter of all reports where neglect was included as a reason for the report.

Deaths related to neglect where the child was not reported to DoCS

Ten of the 23 children (43%) who died in circumstances related to neglect had not been reported to DoCS in the three years preceding their death.

The age range of these children was from eight months to five years. Seven children were aged five years or less. Three were adolescents aged 14 to 15 years.

- Six children died in circumstances of supervisory neglect – three children drowned, one fell and two were killed by motor vehicles.
- Two children who died were passengers in cars. Their deaths were determined to be due to negligent driving.
- The deaths of two children were linked to the failure to obtain medical care.

Deaths related to neglect: children reported to DoCS

Of the 23 children whose deaths were related to neglect, 13 had been reported to DoCS.

Their ages ranged from eight months old to 14 years old. Six children were aged five years or under.

- Nine deaths were due to supervisory neglect. Seven of these children drowned, including three in swimming pools and two in the bathtub. One child died in a motor vehicle accident while riding his bicycle and one child was run over while unsupervised.
- Two children were passengers in motor vehicle accidents.
- Two children died in circumstances where adequate medical care was not obtained.

Seven of the 13 children also had at least one report of neglect made about them in the three years prior to their death. A total of 21 neglect related reports were made about these seven children.

Responses to reports of neglect

The findings that neglect was a very commonly recorded reason for making a report about a child at risk is consistent with international findings (see, for example, Bloom 2000).

Evidence indicates that neglect not only leads to poorer physical and psychological development but also may well increase the risk of a child being physically abused or killed.[21] There is a considerable body of research that indicates neglect is given lower priority by child protection agencies. A number of theories have been proposed to explain this 'neglect of neglect', but a commonly cited reason is that physical or sexual abuse is more readily identifiable as an immediate risk to a child, while the absence of action to a point where it constitutes neglect, is often a more difficult judgement to make.

In statutory frameworks where considerable evidence must be obtained before action can be taken and where resources are constrained, workers may well underestimate the seriousness of reports of neglect. The threat to the neglected child is seen as less immediate and less urgent and, in the context of high demand, neglect is likely to be given a lower priority against harm that is more readily identified.

Our work this year raises concerns about whether reports of neglect may have required a greater level of assessment and response than was provided.

case study 14

An infant boy was the subject of five risk of harm reports prior to his death at age one year. All five reports indicated that the child's parent was not able to properly feed, supervise and maintain safety in the environment they were living in. There were concerns that the parent was a frequent user of alcohol and drugs and on occasions left the infant unattended or without adult supervision.

The first risk of harm report, made when the infant was five months old, followed the parent's failure to collect the infant from a carer. This report received a Level 1 response. The child was placed in temporary foster care and the parent was assessed. The infant was then returned to the care of his parent and DoCS wrote to the parent with information about obtaining support. The case was then closed.

The second report five months later concerned inadequate care of the child. The report was transferred to the local CSC with a recommendation for a secondary risk of harm assessment. DoCS records indicate no intervention occurred and the case was closed under Priority One.

A third report was made when the child was 11 months of age and was burnt while reportedly alone at home. This report was accorded a Level 2 response. Prior to any action, a further report was received three days later that the child had again been left unsupervised. The report was given a Level 1 response. A pre-assessment plan was developed, and a caseworker interviewed the parent. Ongoing issues were identified, including inadequate supervision and lack of appropriate medical care.

A further report was made three weeks later, again about the child being inappropriately supervised and the parent's heavy drinking. As the case was allocated and work was being done with the parent, this report was assessed as Level 3, not containing new information. It was passed on to the allocated caseworker on the day s/he went on two week's scheduled holidays. The case was not reallocated and no further intervention occurred. The infant died three weeks later in circumstances directly related to inadequate supervision

In a number of cases additional reports and information that may have signalled escalating risk and thus a need to further assess the child's situation may not have been adequately considered.

case study 15

A three year old boy died while he and his sister were in the care of people his mother had only recently met. The history of DoCS contact with the mother indicates chronic neglect, physical and sexual abuse and poor parenting skills, including lack of judgement about suitable carers for her children.

Six reports were made to DoCS in the two years prior to the boy's death. The first two reports were confirmed, referred and closed. The next report was recorded as closed under Priority One and the third report was closed on the basis it was the 'same information as prior report'. The fifth report was closed without further assessment at the CSC. The CSC closed the last report under Priority One.

Five of these reports included neglect as a reason for reporting.

Both children were sexually assaulted. The little boy died in suspicious circumstances four months after the last report.

These cases indicate some of the common errors of reasoning in child protection work that the secondary risk of harm policy expressly warns caseworkers about.[22] Research has shown that professionals may be too slow to revise initial judgements about risk, particularly if newer evidence (reports) indicates a higher level of risk than already assessed. Another issue was that workers may become too '*absorbed in present day issues and fail to stand back and place current events into a longer term assessment of the family. This bias can be very powerful in preserving the current risk assessment by obscuring the pattern of behaviour or the frequency with which small worrying incidents are happening*' (Munro 1999; p754).

The report of this study is included in DoCS' own risk of harm procedures document NSW Risk Assessment Framework Training Package.

Responding to neglect, particularly where there are multiple reports of neglect, is a significant issue that warrants attention by DoCS and all other relevant agencies. At this stage we are unable to provide information about the levels allocated by the Helpline to all reports of neglect for children reported to DoCS whose deaths were reviewable. However, we note the Kibble Report, in relation to level 2 and 3 reports, stated '*it is of great concern to learn that these reports are of children very much at risk and that many serious outcomes (eg. child deaths) come from matters classified as levels 2 and 3*' (p. 48).

In advice provided to us in September 2004,[23] DoCS advised that it has approved a project plan for the development of a policy on neglect, including a policy for the department on working with children and families where neglect is an issue. DoCS indicated completion of the policy is due in 2005.

DoCS has previously acknowledged the need to respond more effectively to reports that may be considered 'less urgent'. According to *DoCS: A Blueprint for change* (2003):

> Current pressures on DoCS mean that caseworkers are almost exclusively focused on dealing with the highest priority cases. Less urgent cases therefore seldom receive a field response. There is evidence that multiple low-level reports can escalate, over time, to become higher priority cases as the child's situation deteriorates. To address this problem, an additional 350 caseworkers will be recruited over the next five years. These staff will be 'quarantined' from other child protection and out-of-home care work and will focus exclusively on cases assessed as less urgent that would benefit from DoCS' intervention before families reach crisis point.

In response to a draft of this chapter, DoCS provided advice about its Early Intervention Program.[24] According to the department, the main outcomes being sought from the program are '*…reduced entry and escalation of children into the statutory child protection system, improved family functioning and positive developmental outcomes for the children in the target group'*. The target group for the program in the first two years will be families who are expecting a child or have children up to eight years of age, with priority of access being given to families with children under three years of age. In the longer term, DoCS states the target group will be families with children up to 14 years of age.

DoCS also clarified eligibility for the program. Eligible families will be those who may have already been reported to DoCS, or are at risk of entering the child protection system. The basis for eligibility will be the presence of at least one vulnerability that, if not addressed, will escalate or impact adversely on children. Vulnerabilities are identified as:

- domestic violence
- parental drug and alcohol misuse
- parental mental health issues
- a lack of extended family or social supports
- parents with significant learning difficulties and/or intellectual disability
- child behaviour management problems.

DoCS indicated that the program would be based on the principle of voluntarism, and that eligibility will be '*evaluated and determined by DoCS, or determined by DoCS based on the advice of the referring non government agency*'.

It appears that the Early Intervention Program will focus largely on building on the existing service system, supported by the establishment of regional services. Funding in this context is being rolled out on a location-by-location basis in 2004-2005. In May 2004, $6.5 million was allocated across the state for early intervention services.

While the program has great potential for positive intervention in cases of neglect and 'low level' risk, coordination and resourcing will be critical issues for the department. For instance, building on the existing service system in relation to target groups such as families experiencing domestic violence, mental health issues or intellectual disability will demand high level involvement of agencies such as NSW Health, DADHC and NSW Police. It will also be critical that the non-government sector has effective infrastructure and sufficient resources to sustain a key role in case management and service delivery.

We will continue to actively monitor progress in this area.

Reviewable deaths of Aboriginal children

We have identified a child as Aboriginal or Torres Strait Islander if any of the records or files obtained from any source indicated that the child or their family identified as Aboriginal or Torres Strait Islander. No Torres Strait Islander children were identified.

Of the 30 reviewable Aboriginal child deaths, full information was available for 24 children. The information not available for the other six children included cause of death and circumstances surrounding death.

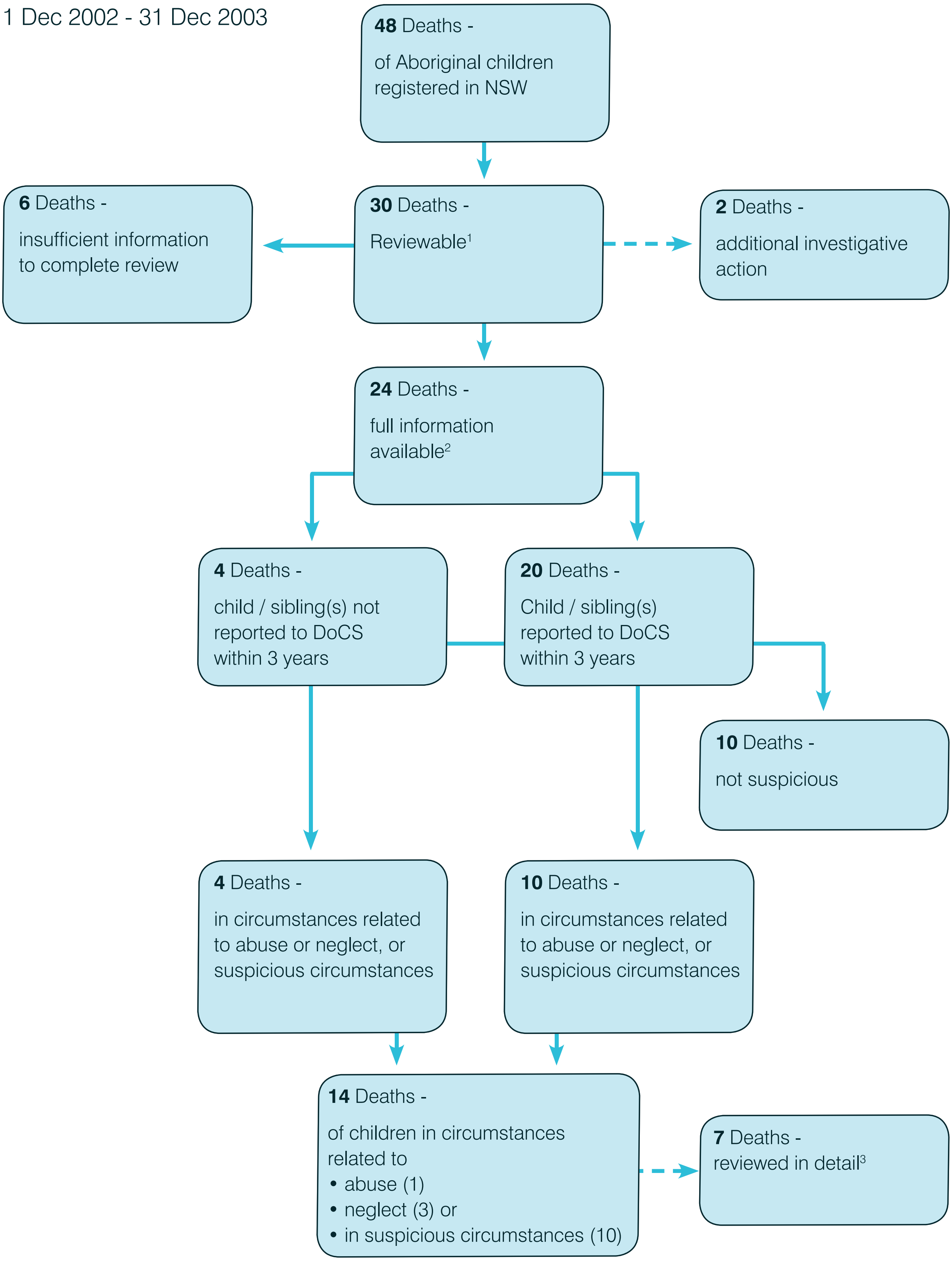
Indigenous children are over-represented in child deaths in NSW. This over-representation of death rates among Indigenous children has been noted in previous NSW CDRT reports and the trend has not changed in the period under review. According to information from BDM, nearly eight per cent of the children who died during this period were Aboriginal children (48 of 605), whereas the data from the Australian Bureau of Statistics[25] indicates that Indigenous children comprise approximately 3.5 per cent of all children in NSW. We have been advised by DoCS that 8.8 per cent of all children reported to DoCS in the period 1 July 2002- 30 June 2003 identified as Indigenous.

Thirty of the 48 deaths of Aboriginal children occurring in NSW between 1 December 2002 and 31 December 2003 were reviewable. This means 62 per cent of all deaths of Aboriginal children were reviewable compared with 23 per cent of the deaths of children who were not Aboriginal.

Seventeen of the 30 reviewable deaths of Aboriginal children (57%) were of infants under the age of 12 months. Five of the deaths were of Aboriginal children aged between 15 and 17 years. Figure 32 sets out the age range.

Aboriginal Deaths

1 Dec 2002 - 31 Dec 2003



[1] based on information from NSW Registry of Births, Deaths and Marriages, DoCS data bases and coronial documents

[2] additional information available from police reports to NSW Coroner, final autopsy reports and inquest decisions

[3] files from relevant departments accessed

Figure 32: Age range of Aboriginal children who died

Under 12 months	1 – 5 years	6 – 10 years	11 – 14 years	15 – 17 years
17	4	2	2	5
57%	13%	7%	7%	16%

Reported levels of abuse and neglect are generally seen as an underestimate of the extent of child abuse and neglect. Research indicates that these underestimates may be even larger for Indigenous children and that the failure to report abuse and neglect of Indigenous children may be due to a number of factors including a fear of reprisal and reluctance to involve statutory child protection agencies.[26]

Recent data indicates that the rate of substantiated cases of child abuse or neglect in NSW is 4.9 times higher in the Indigenous population than in the non-Indigenous population. In the period 1 July 2002- 30 June 2003, 16.7 per cent of child abuse substantiations in NSW were for Indigenous children.[27]

In 20 (67%) of the reviewable deaths of Aboriginal children there were reports of risk of harm to the child and/or a sibling to DoCS within three years preceding their death. In eight cases, both the deceased child and sibling(s) had been reported to DoCS. In five deaths, only the deceased child had been reported to DoCS. In seven deaths, only the child's sibling(s) had been reported to DoCS.

Deaths of Aboriginal children that were not related to abuse or neglect, or occurring in suspicious circumstances

The deaths of 10 of the 24 Aboriginal children were not related to abuse or neglect and did not occur in suspicious circumstances. The deaths of these ten children were reviewable because they had been reported to DoCS (4), or were the sibling of a child reported to DoCS (6), within three years prior to the death. Seven of these ten children were aged six months or younger when they died.

Deaths of Aboriginal children in circumstances related to abuse or neglect or in suspicious circumstances

Of the 24 Aboriginal children where full information was available, 14 (58%) died in circumstances related to abuse or neglect, or in suspicious circumstances.

The death of one Aboriginal child was due to abuse.

The deaths of three Aboriginal children were in circumstances related to neglect. Two of the children had been reported to DoCS in the three years prior to their deaths. A third child, a 15-year-old girl, died in a motor vehicle accident. The child was not wearing a seat belt at the time of the accident and the driver of the vehicle was driving with a proscribed amount of alcohol.

The deaths of ten Aboriginal children occurred in suspicious circumstances. Seven of the children and/or their sibling(s) had been reported to DoCS in the three years prior to their death.

Nine Aboriginal children who had themselves been reported to DoCS died in circumstances related to abuse or neglect, or in suspicious circumstances. The weeks between the date of the last report to DoCS and date of death is as follows:

- 4 children between 0-13 weeks
- 3 children between 14-26 weeks
- 2 children >52 weeks.

Of the ten deaths that occurred in suspicious circumstances, six were infants under the age of six months. Five of these six infants died in sleep incidents from suffocation or strangulation. The cause of death for the sixth infant, who was found face down in bedding, could not be determined at autopsy.

Three of these infants had been reported to DoCS themselves and one was the sibling of a child reported to DoCS. Reasons for the reports to DoCS included carer substance use, carer mental health, neglect and physical abuse. Only one of these four cases was open and allocated to a caseworker at the time the child died.

The other two Aboriginal children who died in suspicious circumstances were aged two years and seven years. The two year old, who had not been reported to DoCS, drowned in a swimming pool. The seven year old, who had been reported to DoCS and who was in informal kinship care at the time of her death, died from pneumonia. The last report about this child was two months before she died and concerned neglect and physical abuse. That report was closed under Priority One.

Two Aboriginal children died in suspicious circumstances. A girl aged 16 years committed suicide and a boy of 17 years died from narcotic overdose. Both of these children had been reported to DoCS in the three years prior to their death.

Child protection issues

In its submission to the Legislative Council inquiry, DoCS made the following statements:

> Servicing ATSI communities in a way that will produce results is a problem for all Australian governments and their agencies. The rhetoric about partnerships and culturally-appropriate approaches is all there, but the on-ground results are less than satisfactory to all concerned (DoCS submission p60).

We have identified a number of cases where DoCS intervention to ensure the safety, welfare and wellbeing of an Aboriginal child was of concern. For example, for four of the seven deaths we reviewed in detail there were confirmed risks of harm to the child who died. In each of these cases we have concerns about the intervention by DoCS. The following case studies are examples.

case study 16

From about the age of 13 years, the boy began exhibiting difficult behaviour, truanted and was then suspended from school, had an itinerant life style and was experimenting with drugs. Six reports of risk of harm were made about him in the following two years, including two mandatory reporters notifying him as homeless, together with information about conflict in the home.

The Kings Cross Adolescent Unit found him at the Cross one night and took him home. They spoke to his mother and provided some financial assistance. The case was then allocated to a caseworker at the local CSC. About two months later, the Kings Cross Adolescent Unit rang that CSC when they received information that he, aged 14 years, was at the home of a suspected paedophile. The caseworker did not accept this as a report of risk of harm and no action was taken by DoCS.

About three weeks later the boy went to a police station saying he did not want to live at home. He was reported as being homeless and DoCS placed him with extended family. The boy continued to exhibit difficult behaviour and was not attending school. About one month later a family member rang DoCS for support and DoCS mailed housing and community health information. Concerns about the boy's behaviour were then reported but this report was closed under Priority One.

The boy was first charged with criminal offences when he was 15 years old, receiving a probation order with requirements to attend Department of Juvenile Justice's (DJJ) Intensive Program Unit and to live at home. Within 10 days, the boy went to the police informing them he had breached his bail because he could not live at home. He was reported to DoCS as being homeless and the police took him to a refuge. The boy was then to go and live with extended family. This was assessed by DoCS as Intake Only.

Having committed further offences while on probation he was held in custody. A juvenile justice officer rang the Helpline to report him as homeless in that he was refusing to go home and would have no accommodation when released from custody. This report was closed under Priority One a month later.

DJJ had provided the boy with access to relevant services, including access to specialised Aboriginal services, and had interviewed members of his family. A report, prepared for the court hearing of his further offences and breach of probation conditions, noted that a further community based order might be setting the boy up for further breaches, and that a control order (that would keep him in custody) would ensure he would only be released '*if he is committed to participating in a case plan which addresses his welfare needs as well as his offending behaviours*'. He was in fact given 18 months probation, conditional on him attending counselling and intensive support programs. He attended an interview with juvenile justice officers the day after the court decision and work on a comprehensive case plan was begun. He died before he was due to attend again.

The cause of death could not be ascertained as his body was not found immediately, but the autopsy report indicated that it could probably be attributed to the 'toxic effects of opiates'.

case study 17

A six year old boy drowned at the beach. In the 12 months prior to his death, there were three risk of harm reports concerning him and his siblings. The reports related to neglect, inadequate supervision, physical and psychological abuse. All three siblings had been under the parental supervision of the Minister for Community Services for a period of time and were restored to the mother's care about two years before the boy's death.

The last report to DoCS was 18 weeks before he died and was in relation to neglect and inadequate supervision of the child and his siblings. This report was closed under Priority One.

There were four risk of harm reports about the boy's siblings following his death. The first of these was less than three week's later when a mandatory reporter rang the Helpline with concerns about inadequate care and hygiene issues at their house. All four reports were closed without protective intervention, including the last, which was made while the mother was being held in custody. At that time the reporter was unaware of the whereabouts of two of the children. The report was closed under Priority One policy about five weeks later.

The recorded initial assessments of these reports do not mention the death of the boy.

We have commenced a formal investigation into the conduct of a number of agencies that were involved with a 14 year old Aboriginal girl in the year prior to her death. Not only was she living a transient lifestyle, but there did not appear to be any adult who clearly exercised parental responsibility for her during that time. From an initial review of documents on file, we found no evidence that either DoCS or the agency supervising her placement with a family member had sighted her during the year. For much of that year she was in a violent relationship with a boyfriend who was ultimately charged with, and convicted of, her murder. Our investigation is focused on the response by agencies to clearly identifiable risks, including alleged assault. Of further concern is the lack of any coordinated interagency response.

Out-of-home care

The Aboriginal child placement principles outlined in the Act stipulate that an Aboriginal child in need of out-of-home care is to be placed with, in descending order, a member of their extended family or kinship group, a member of the Indigenous community to which they belong, a member of another Indigenous community residing in the vicinity of the child's usual place of residence, or a suitable person approved by the Director-General after consultation with members of the child's extended family or kinship group and Indigenous welfare organisations appropriate to the child. A court can override these principles when the best interests of the child would not be served by placement with the child's extended family or kinship group, or with a member of the community to which the child belongs.

In the period under review, three Aboriginal children died while in kinship care.

We are currently investigating one case where an infant and his older sibling were placed with a family member subject to a Temporary Care Agreement signed by the children's mother. The focus of the investigation is on the adequacy of the assessment of the family member as a carer, the adequacy of DoCS support and supervision of the placement and the quality of protective intervention for the children placed in this family. We have also sought reasons from the department for its decision not to apply to the Children's Court for a care order given the extensive child protection history of the two children.

The Legislative Council report noted the possibility that DoCS' inability to recruit Aboriginal foster carers may lead DoCS to leave some Aboriginal children in situations of risk for longer than should be the case (Legislative Council Report 2002, p138).

Aboriginal children may be placed with foster carers but there is evidence of an increasing use of kinship care.[28] While this research was based on a small number of qualitative interviews, it indicated strong support for the benefits to children of placement with kin. The research also indicated that unlike other placements such as foster care, kinship placements were made by caseworkers '*operating with minimal guidelines*'. Departmental guidelines in NSW were reported as being '*extremely limited in important areas of practice such as assessment and training of relative carers, case planning for kinship care, financial assistance, management of contact arrangements with birth parents, and frequency and nature of casework support*'.[29]

case study 18

A seven year old Aboriginal child living with a member of her extended family died at home from acute bronchopneumonia. Numerous head lice, small scars and lesions were noted on her body at autopsy.

Three risk of harm reports were made during the three years prior to her death. These reports were made while she was living with her relative and related to sexual abuse, neglect, psychological harm, inadequate supervision, carer drug and alcohol use, physical and verbal abuse and failure to attend school.

The RAP from the Helpline following the first report included interviewing the child, speaking with the adults in the home and referring the sexual assault allegations to police if appropriate. This report, and the next one, were closed under Priority One.

The Helpline recommended a risk of harm assessment following the third report. A caseworker was allocated who contacted the school and ascertained that the child had been absent from school on more than half of the days she should have been there. School staff advised that at times they had to provide clothes for the child and described her behaviour as follows: '*not too bad… however she does not attend school enough to really tell what she is like or how she is doing*'.

No secondary risk of harm assessment was undertaken. Neither the child nor the carer was interviewed and no home visit was undertaken. The suitability of the placement was not assessed in light of the serious nature of the reports. A letter was sent to the child's carer outlining the importance of adequate supervision and the carer was advised to contact DoCS if she required support in providing consistent care and supervision. The report was then closed under Priority One. The child died two months later.

Submissions were made to the Legislative Council inquiry that supported the '*critical need to support Indigenous kinship carers, who provide the vast majority of out-of-home care'* (Legislative Council report 2002, p139). Ongoing interaction with kinship carers is an essential aspect of ensuring the safety, welfare and well-being of the children placed in these arrangements.

This year DoCS has funded two intensive family based services, one in the Western Region (Bourke) and one in metropolitan Sydney (Redfern). Staff from these services work with families in crisis whose children are at risk of being placed in care. Caseworkers work intensively with families in their home for periods of up to three months.

Interagency coordination and cooperation

For a child protection system to operate effectively, it is essential that all agencies providing services to children and families cooperate: no one agency has all the knowledge, skills and resources necessary to ensure the safety, welfare and well-being of children. The key framework to interagency cooperation in NSW is provided by the *NSW Interagency Guidelines for Child Protection Intervention, 2000*.

The Interagency Guidelines are based on the principle that government agencies will work in partnership with each other, with non-government organisations and with the child and their family to secure and sustain their safety, welfare and well-being. The statutory framework for interagency cooperation is provided in sections 15, 17, 18 and 248(1), (2) and (6) of the *Children and Young Persons (Care and Protection) Act 1998.*

The Interagency Guidelines establish the Department of Community Services as having *'lead responsibility'* in providing and coordinating the community response where intervention is necessary for the care and protection of children. Other agencies with specified roles and responsibilities are:

- NSW Police Service
- NSW Health
- Department of Education and Training
- Department of Corrective Services
- Department of Juvenile Justice
- Department of Ageing, Disability and Home Care
- Department of Housing
- courts and tribunals, and
- various non-government organisations.

The fundamental aim is that all relevant agencies work together to provide a coordinated and comprehensive response to the needs of children at risk of harm. This includes exchanging relevant information, planning for and providing relevant services and responding to requests for services from DoCS where possible and appropriate.

Detailed information about the level of interagency coordination and cooperation was not collected for all reviewable deaths. The following analysis of the effectiveness or otherwise of interagency cooperation is based on our detailed reviews of the deaths of 21 children.

Our analysis is based on the documented use, or not, of several practical options outlined in the Interagency Guidelines: case coordination and protection planning meetings; referrals to and liaison between agencies; information exchange between agencies; and best endeavours requests for service.

Mandatory reporting
(section 3.2 Interagency Guidelines)

Records of 18 of these 21 children indicate that they or their families had had some involvement with NSW human service agencies, other than DoCS, in the 12 months preceding the child's death. Some of that contact between families and agencies resulted in risk of harm reports being made to DoCS, in the main by mandatory reporters.

Figure 33: Reports made by mandatory reporters

Mandatory reporters	Number of reports made
NSW Police	10
NSW Health	6
Child care worker	4
Department of Juvenile Justice	2
SAAP youth service	2
Women's refuge	2
Anonymous*	2
Department of Housing	1
Medical professional (private practitioner)	1
Centrelink*	1
Total	**34**

** it is unknown whether these reports were from mandatory reporters.*

Beyond being recorded as information only, closed after initial assessment or closed under Priority One, action was taken in relation to only 12 of these reports. In five cases DoCS interviewed the parents of the child subject of the report. In three of these cases DoCS saw the child as well.

Protection Planning Meetings
(section 3.4 Interagency Guidelines)

If an assessment and investigation of the needs of a child and his/her family have been completed and a decision made that protective intervention is required, a protection plan should be developed. The purpose of the protection plan is *'to develop a recommended course of action which will ensure that where abuse or neglect has occurred, it is stopped and that the child or young person and their family receive the services, care and support appropriate to their developmental and assessed needs'*(Interagency guidelines 3.4.1).

Protection planning meetings allow all agencies working with the child and their family to be involved in developing a protection plan which draws together the skills, knowledge and expertise of each agency. The meetings can be used to ensure resources are combined and properly coordinated, and that responsibility for certain services or actions is allocated and timelines established. According to the Interagency Guidelines (Part 3.4.2), such meetings are compulsory where a child is at risk of harm and is assessed by DoCS as being in need of care and protection.

For eight of 21 children whose deaths were reviewed in detail, there was at least one report of risk of harm concerning the child and/or the sibling(s) that had been recorded as confirmed in the three years preceding the child's death.

Our review of DoCS records indicate that in only one case was a protection planning meeting held in the three years preceding the child's death, and two such meetings were held about the one child. No protection planning meeting had been held in the remaining seven cases.

Over and above the lack of compliance with the Interagency Guidelines in these cases there is, in relation to some, an obvious question as to why a coordinated approach was not taken. While it is easy to see in hindsight that coordinated protection planning was an obvious option, the situation at the time was undoubtedly less clear. However, as the case study below indicates, for some of these children, a more coordinated approach between agencies may have led to a better outcome.

case study 19

The child was three years old when she was admitted to hospital vomiting and unable to stand up. This was the second admission in three weeks. Her mother told hospital staff the child had had multiple falls, constipation and difficulty sleeping. When medical staff advised the mother that they intended to conduct drug screening, she removed the child from the hospital. This was reported to DoCS.

Less than a month later the child was re-admitted in a critical condition following a respiratory arrest. Hospital staff suspected a narcotics overdose and administered Narloxene. The mother denied the child had access to narcotics, but later disclosed she was on a methadone program. The incident was again reported to DoCS.

Although a secondary risk of harm assessment was conducted, the mother's access to take away methadone continued. When the child died three months later from acute methadone poisoning the police removed a number of small bottles of methadone from the home.

It is not known whether the methadone clinic or prescriber were aware of the earlier indications that the child had access to methadone.

Where one or more agencies are involved with families and young people, clarification of respective roles and responsibilities is essential. Protection planning meetings, with documented agreements, are the recommended starting point. Without this, it is possible that essential information is not shared, and that issues directly impacting on the safety, welfare and well-being of the child are not addressed.

Information exchange between agencies (section 2.5 Interagency Guidelines)

The *Children and Young Persons (Care and Protection) Act 1998* provides for the exchange of information between the Director-General, DoCS and prescribed agencies under s.248. The primary purpose of s248 is to enable the provision and exchange of information between agencies responsible for providing services to ensure the protection of children.

The Interagency Guidelines underscore the need for effective exchange of information in the care and protection of children. Timely provision of accurate information is often critical in assessing and responding to risk of harm reports about children.

case study 20

(also referred to in case study 11)

A young woman committed suicide at the age of 17 years. Two years prior to her death she disclosed that she had been sexually assaulted, and she experienced psychotic episodes in the months leading up to her death.

Since the age of 12 years, the girl had had contact with a number of agencies: DoCS, Police, Health and DJJ. There was significant concern about her carers' mental health and substance use and domestic violence within the home.

The girl left school when she was 14. Her criminal offending increased and she continued to use cannabis chronically. Seven months before her death, while she was in a juvenile detention centre, the girl disclosed previous attempts to kill herself and current thoughts of suicide. She was placed in protective care. Her mental health deteriorated while she was in detention and she was transferred to a mental health unit as an involuntary patient. When the girl returned to the community she received considerable support from a mentor and staff from DJJ and mental health professionals from an area health service. However, the case review notes following her suicide made the following point: '*All present on reflection agreed that to our knowledge [the girl] made no previous suicide attempts and had not indicated suicidal ideation'*.

Two risk of harm reports were made in the 12 months before the girl's death and both were closed by DoCS under Priority One. The last of these reported concerns about her psychological needs being unmet and her disclosure of a further sexual assault.

Suicidal ideation/attempts are a recognised risk factor for further suicide attempts and the information on this young person should have been made available to DoCS.

Government agencies, including NSW Health, have developed policies and procedures to follow when responding to requests for information pursuant to s248 of the *Children and Young Persons (Care and Protection) Act 1998*. For example, NSW Health policies include agreed timeframes in which requested information is to be provided to DoCS. Standard s248 requests for information are to be responded to within five to ten working days.

case study 21

(also referred to in case study 9)

One case was identified where a section 248 request for information was made to a mental health service in the weeks immediately preceding the child's death. The request was made directly to a doctor and not through the Area Health Service central contact point. No response to the s248 request had been received at the time the child died 17 days later. DoCS records indicate that the s248 request was successfully facsimiled to the mental health service and that four follow-up phone calls were made to that agency during the next 17 days. Eventually the report of risk of harm was closed some eight weeks after the child died, without DoCS having received the information requested in the s.248 request.

The information required in the s248 request related to the primary carer's mental health status and was necessary for a proper assessment of the child's safety and well-being. The primary carer was charged with murder following the death of the child. There was no record of the s248 request from DoCS in the primary carer's mental health files provided to us.

DoCS is currently preparing guidelines covering responses to all requests for information, except subpoena issued by courts or tribunals. These guidelines will be based on recent legal advice from the Crown Solicitor and senior counsel. That legal advice was obtained following the Ombudsman expressing the view to DoCS that it had taken an overly restrictive view of its capacity to release information under s248.

Referrals to and liaison between agencies (section 2.4 Interagency Guidelines)

Collaborative responses to vulnerable and at risk families are a part of practice established under the 1997 Interagency Guidelines. The *Children and Young Persons (Care and Protection) Act 1998* legislates for a whole of government response.

While DoCS is the lead agency for child protection work in NSW, there are of course a number of agencies that have responsibility for this work. Where risk factors have been identified in a family, it may not be DoCS responsibility to directly provide services addressing those risks. We noted that reports of risk of harm to the Helpline where referrals to other agencies could have been made included those concerning domestic violence, carer mental health problems or drug or alcohol abuse, the child experiencing mental health problems, drug or alcohol abuse, physical abuse, neglect or homelessness.

As noted in the Legislative Council report:

> Families of parents with a personality disorder are part of a larger group of complex needs families that require both intensive support and coordinated services. These are families characterised by a cluster or pattern of problems strongly associated with abuse and neglect such as drug or alcohol misuse, domestic violence, criminal history, mental illness, poverty, homelessness and social isolation.
>
> Their problems are very entrenched (Legislative Council report 2002: paragraph 8.43, p148).

In two of the detailed reviews we did, the child was experiencing mental health problems in the period preceding their death, including psychosis, suicidal ideation and self-harm.

In another detailed review we found that the child's primary carer had been experiencing mental health problems. Despite the risks in the family being known, we did not find any record of liaison or referral between DoCS and mental health services, or any other agency able to support this family (see case study 22).

Two of these young people subsequently committed suicide. In the third case the young woman was found dead at the bottom of a cliff. The Coroner determined that she had fallen.

case study 22

(also referred to in case study 7)

A child who died at the aged of 15 years had been reported to DoCS 20 times since the age of two years. Reports related primarily to carer drug use, neglect (including being left completely unsupervised for some weeks at the age of 11 years) and domestic violence.

By the time the child was 12 years old, her mother had had two admissions to hospital for drug related psychosis. Our review of the files did not find any evidence of reports to DoCS being made about these admissions. Far from recognising the risk to the child, the hospital social worker who was involved in the mother's discharge the second time noted that she '*supports a 12 year old girl who is her motivation to stop drugs. Apparently manages to care for the child satisfactorily.'*

By 13, this child was homeless and itinerant. Mandatory reporters made further reports, including that she was living in a caravan park with only support from an NGO. The NGO made five reports to DoCS about her risk of harm, including her homelessness and lack of supervision. They also wrote to the relevant CSC asking for assistance to formulate an alternative parenting plan for three young people, including the one who died, to enable them to return to school. DoCS denied the request for a multi-agency meeting. There was no evidence on the files reviewed of any alternative plan being formulated.

A significant number of reports were made about this child from a number of people and agencies. In the last 13 months of her life, eight reports were made. We found no evidence of any attempt, except by the NGO, to comprehensively review this girl's situation or develop a plan to address the problems of her homelessness, neglect and drug taking.

She was staying with friends the night she died. Toxicology revealed 0.l2 g/100ml alcohol and MDMA (ecstasy) in her system at the time of her death. She died from injuries sustained by falling down a cliff.

Our data showed that 96 reports of risk of harm to DoCS in the period under review included concerns about domestic violence. Seven of the children whose deaths were reviewed in detail had been reported to DoCS for concerns about exposure to domestic violence. In none of these cases did we find any evidence of DoCS making referrals to external agencies specialising in providing support to victims of domestic violence or agencies specialising in treatment of perpetrators.

case study 23

Three risk of harms reports related to domestic violence, parent-adolescent conflict and wellbeing concerns were made to the Helpline about one boy in a 12 month period. At one stage the mother took out an AVO against the boy and his father. Two reports were recorded as Intake Only, and one was closed under Priority One. All were closed without assessment.

The boy was convicted of breaching the AVO and given a bond with conditions to be supervised by DJJ. This supervision involved home visits, phone calls and case management. He appears to have progressed well while being supervised, including returning to school. He committed suicide a few months after the expiration of the bond.

case study 24

Three risk of harm reports were made about an adolescent and his siblings in the 12 months before his death. All reports related to domestic violence and substance abuse within the family and all three were closed without assessment. The father was convicted of assaulting the mother and an ADVO against the father was current when the boy died. Our review of DoCS, NSW Police and NSW Health documents indicate that the boy himself became increasingly involved in violence and substance abuse in the months before his death. He committed suicide at the age of 16 years.

There were two matters examined where there had been significant involvement from both DADHC as well as DoCS in the years preceding the child's death, as the deceased children both had significant intellectual disability. One was also significantly physically disabled. Both had complex needs and required support and services from a range of health services.

In one case there was no record of coordinated or joint casework between DoCS and DADHC between 1999 and June 2002, despite the child being in a voluntary care arrangement since 1999.

In both cases the child protection concerns were left largely to DADHC to address. In one case, the DADHC caseworker was specifically asked by DoCS to raise the child protection concerns with the primary carer and the case was closed following this request. In neither case was there coordinated casework between DADHC, DoCS and NSW Health.

One of these children died from bronchopneumonia whilst in DADHC respite care and the other drowned in the bath following an epileptic seizure.

case study 25

(also referred to in case study 12)

A child drowned having had an epileptic seizure in the bath. The forensic pathologist found no traces of anti-convulsant medication in his system at autopsy.

Four reports about his mother's failure to give the boy prescribed anti-convulsant medication had been made to DoCS in the 18 months prior to his death. Following the first report, DoCS asked the DADHC caseworker to raise the issue of non-compliance with medication with the boy's mother. The DADHC file notes contain no record of any such discussion with the mother. After the second report, NSW Health staff advised DoCS that the boy was at risk of brain damage and/or drowning in the bathtub if he was not adequately medicated.

The secondary risk of harm assessment conducted after the fifth report to DoCS indicates that the DoCS caseworker was unclear about the impact on the child if he did not receive his medication. DoCS records indicate that risk of harm was not confirmed - that there were 'no safety, risk or well-being issues'.

A protection plan jointly developed by DoCS, DADHC and NSW Health could have taken into account expert medical opinion regarding epilepsy management and adequately assessed and addressed the risks to this boy. DoCS closed the case due to the ongoing intervention of DADHC, despite the mother's failure to adequately medicate the boy being a child protection rather than a disability issue.

In November 2003 DADHC and DoCS released a memorandum of understanding, which set out the respective roles of the two agencies in providing care and protection to children and young people with disabilities. In the past 12 months DADHC has released a number of policies for its staff that support implementation of the agreement. This includes a policy on child protection and reporting procedures for DADHC operated and DADHC funded services (February 2004).

DADHC has advised that the two agencies have developed local protocols in all regions of NSW to support the memorandum. It has also undertaken an audit of the knowledge and skills of relevant staff to effectively support children with a disability who are at risk of harm.

Best Endeavours Requests (section 2.4.3 Interagency Guidelines)

Section 17 of the *Children and Young Persons (Care and Protection) Act 1998*, provides for the Director-General, DoCS to ask a government department or agency to provide services to a child and his/ her family. Section 18 of the Act stipulates that a government department or agency must use its best endeavours to comply with a request made to it under s17, if that request is consistent with its own responsibilities and does not unduly prejudice the discharge of its functions.

In the detailed reviews we did, we found no records of 'best endeavours' requests.

Given DoCS workload it seems surprising that not more advantage is taken of this opportunity to utilise the resources of interagency partners to ensure the safety, welfare and well being of children who are reported to DoCS.

Adolescents

Of the 161 reviewable deaths, 46 (29%) were deaths of adolescents:

- 21 were aged 13-15 years and 25 aged 16-17 years
- 21 were girls and 25 boys
- 6 were Aboriginal children, 3 boys and 3 girls
- 32 children had been reported to DoCS in the three years prior to their death
- 2 had not been reported to DoCS themselves, but were the sibling of a child who had been.

Full details were available on 41 of these 46 adolescents, including information about cause and manner of death:

- 4 of these children were murdered – three by peers and one by a parent
- 5 children died in circumstances related to neglect, including inadequate medical care, negligent driving and inadequate supervision
- 15 children died in suspicious circumstances:
    - 8 children committed suicide
    - in five cases the manner of death had not been determined by Coroner at the time of writing
- 28 children had been reported to DoCS in the three years prior to their death
- 2 children had not been reported to DoCS themselves, but were the sibling of a child who had been
- 6 children had a history of contact with the criminal justice system.

Youth suicide

There is no doubt that the transition from childhood to adulthood is a difficult time for many young people.

> Although many young Australians are doing well, changes in the social and economic environments have been accompanied by an increase in what is described as 'youth problems' and the growing societal concerns about these problems. These concerns are wide-ranging, including mental and behavioural problems and suicide, transport accidents, drug and alcohol misuse, declining participation in education, the high representation of youth in the justice system and homelessness, to mention a few (AIHW 2003, p293).

The range of issues being faced by adolescents, particularly those with a history of child protection issues, cannot be encompassed by any one agency. The problems that can arise when interagency cooperation fails are particularly evident in our reviews of the deaths of adolescents.

Nine children whose deaths were reviewable committed suicide.[30] Six of these children had been reported to DoCS.

In two cases the child had experienced mental health problems prior to their deaths. Two of the children had developed significant substance abuse problems in the period prior to their deaths and three of them had been involved the criminal justice system. There was no record of ongoing interagency liaison between the drug and alcohol services, mental health services, DJJ and DoCS regarding joint casework or interagency liaison to offer support and services to these children.

DoCS had been intensively involved with the family and the child in the following case study for a number of years. The involvement with the child appears to have ceased when he left his final alternative placement at the age of 14 years despite indications that he was still at risk. Involvement with at least one of his siblings continued.

case study 26

This adolescent and his family had a long history of contact with DoCS, beginning when he was reported at the age of two years as being without adequate supervision. The department provided ongoing support to the family, and coordinated services such as counselling; it also directly funded at least one alternative care placement and respite.

His last alternative parenting plan had resulted in a lengthy placement supervised by DoCS. The service's correspondence with DoCS at the time indicate that his behaviour was becoming unmanageable. He finally left and returned home at which point, after referring the family to a counselling/support service, DoCS ceased to have any contact with this boy. He was by then 14 years old.

There were three further reports to DoCS. The second of these, a month after the end of the placement, was about his violent behaviour in a refuge. No information is available about what happened between him returning home and this point. DoCS found an alternative place for him to stay for two nights but there seems to have been no re-engagement with the boy despite this clear indication of risk. The report was closed as Intake Only. The third report, concerning conflict between the boy and his mother, was about a month before he died; it was closed under Priority One.

At the time he committed suicide he was on bail, directed to live at home but unable to do so because of an AVO against him. He committed suicide prior to the finalisation of the criminal proceedings.

The Legislative Council report recommendation 5 stated:

> In developing a framework for secondary prevention, the Department of Community Services should establish a system for ensuring coordination through formal agreements between relevant agencies, including NSW Health, the Department of Juvenile Justice, the Department of Ageing, Disability and Home Care, the Department of Corrective Services, the Department of Education and Training, and the Department of Housing (Legislative Council report p18)).

The development of these formal agreements should be a priority at both the departmental level and at the local level where service delivery occurs.

Without this approach, services may work in isolation from each other and without full knowledge of the circumstances and risks that the child may be facing at any particular time. Without an effective framework for interagency meetings and exchange of information between services, there is indeed a lack of clarity not only about roles, but also about responsibilities, coordination of services and the overall needs of children.

Improving interagency cooperation

A Child Protection Senior Officers Group (CPSOG) was established in October 2003, reporting to the Human Services Cabinet Committee chaired by the Minister for Community Services. DoCS has advised us that the focus of this group has been on developing a work plan '*that responds to the interagency issues raised in consecutive Child Death Review Committee reports'*. This followed an audit of all CPSOG agencies' initiatives to address NSW CDRT recommendations. CPSOG also consulted with peak NGOs.

Two main areas of work have been identified. One is the need to update the Interagency Guidelines. The first stage of this update will be a correction of factual errors resulting from legislative change and agency restructures. The second, more extensive stage, will result in a new edition of the guidelines following further consultation and a discussion paper. The second area of work targets the need to improve interagency practice, including identifying any barriers to the exchange of information and local initiatives that are fostering local interagency relationships.

In light of the dramatic increase in child at risk reports received by DoCS in recent years, it is essential that DoCS engages in meaningful and effective partnerships with both government and non-government agencies in order to provide support and services to families and to children and young people at risk of harm. Interagency cooperation is an essential component of good intervention with vulnerable families where there are one or more high risk factors such as mental illness, substance use, domestic violence, relationship breakdown, and children or carers with a disability.

As the DoCS submission to the Legislative Council inquiry stated:

> More effective use of referrals to other services would allow for intervention in cases that DoCS subsequently decides not to pursue because of higher priorities. This early intervention may prevent escalation of a problem to crisis level (DoCS 2002, p60).

The submission went on to note that additional caseworkers *'should provide some additional capacity for this task, but we need to determine the changes in protocols, etc to achieve the desired outcome'*. From our review of the deaths in this reporting period, it is apparent that DoCS is still not using other services to the extent that it might.

Recommendations

Assessing risk of harm

Data

It is essential that DoCS information system provide full, accurate and current information in relation to individual children and their families. Further, it should have the capacity to provide a basis for assessment of the effectiveness of DoCS child protection intervention. While we acknowledge the difficulties in introducing a new information system, DoCS must be able to report on critical aspects of its work.

Recommendation 1

DoCS should ensure that KiDS has the capacity to report on:

- risk of harm reports closed without assessment and the reason for closure
- risk of Harm reports closed under Priority One or the proposed case closure policy and the reason for closure
- reports referred by the Helpline to CSCs and JIRTs for secondary risk of harm assessment
- reports that received a secondary risk of harm assessment, including actions taken and outcomes of that assessment.

Recommendation 2

DoCS quarterly data publication should include numbers of reports closed and numbers of reports receiving secondary risk of harm assessment.

Initial assessment

The NSW Audit Office is currently conducting an audit of the DoCS Helpline. The audit will examine the performance of the Helpline in a number of areas, including the assessment, prioritisation and referral of reports that need further action. In this context, we have limited our recommendations to immediate matters that have been clearly identified through our work.

Recommendation 3

DoCS should develop strategies to ensure that in undertaking initial risk assessment, staff adhere to policies regarding:

- consideration of the child protection history of a child and their family
- phonetic spelling searches
- address searches

Recommendation 4

DoCS should develop strategies to ensure that additional reports providing similar information about risk to a child are closely considered to identify any escalation of risk prior to being regarded as ‘information only’.

Overriding a Required Action Plan (RAP)

It is reasonable for a CSC to make assessments about how a report should be responded to, in the context of information provided by the Helpline and additional information held at the local level. However, decisions that downgrade a response identified on a required action plan should be closely monitored and reviewed.

Recommendation 5

DoCS should institute a system to document and regularly review decisions and reasons for decisions by CSCs to override RAPs. Reviews should focus on assessment of the appropriateness of such decisions.

Secondary risk of harm assessment

The Secondary Risk Assessment Framework was introduced in 2002 and aimed to shift the focus of assessment from an incident-based approach to one of guided decision-making based on an analysis of overall risks of harm and consideration of family strengths and supports. We have identified cases where secondary risk of harm assessment did not provide a holistic assessment of, or an effective response to, risk.

Recommendation 6

DoCS should clarify its policy regarding circumstances under which children should be sighted and families/carers should be interviewed. Guidance about this policy should be provided to staff through clear procedural guidelines and training.

Recommendation 7

DoCs should develop and implement strategies to:

- ensure all staff have the key competencies to undertake initial and secondary risk of harm assessment
- monitor the effectiveness of secondary risk of harm assessment, particularly in relation to:
- identification of key risk factors
- protective intervention resulting from identification of risk.

Recommendation 8

DoCS should develop strategies to ensure that in undertaking secondary risk assessment, staff adhere to policies regarding consideration of the child protection history of a child and their family.

Case closure

The Priority One policy allows DoCS to give a relative weighting to reports of risk of harm. That is, a child may be at risk but because of lack of resources and other cases being assessed as higher priority, there will be no protective intervention. Many of the children who died in circumstances related to abuse or neglect or in suspicious circumstances had had reports closed at initial assessment stage or under the Priority One policy. As noted, while the number of reports closed does not necessarily demonstrate poor decision making by DoCS, it does demonstrate how critical these decisions can be to children. We have examples of cases being closed where initial assessment identified significant risk but no further protective intervention was provided. We have also identified cases where secondary risk of harm assessment was commenced but ceased under Priority One in circumstances where the risks had not abated. We saw little evidence of DoCS making referrals to, or requests of, other agencies to provide assistance in cases that were subsequently closed because the department did not have the resources to respond directly.

Recommendation 9

A key principle in child protection intervention should be that where a report raises issues of safety of a child, or a failure to adequately provide for a child's basic physical or emotional needs, it should not be closed until adequate steps have been taken to resolve the issues. In this context, DoCS should work towards a framework for case closure that includes a risk threshold above which cases should not be closed without protective intervention.

Recommendation 10

DoCS should develop strategies to ensure that the child protection history of a child and their family is closely examined and considered prior to decisions to close a case.

Neglect

Assessment of neglect

Neglect is a significant issue in reports about children who died and in relation to the deaths of children. Our work has raised concerns that reports of neglect may have warranted a greater level of assessment and response than was provided. DoCS has advised that it is currently developing a 'policy on neglect'.

Recommendation 11

DoCS should give priority to finalising and implementing its policy on neglect. The policy should be made public.

Early intervention and prevention

DoCS is in the process of establishing an early intervention program. The stated focus is reducing the entry and escalation of children into the statutory child protection system, improving family functioning and positive developmental outcomes for vulnerable families with children who may have been reported to DoCS or are at risk of entering the child protection system.

Recommendation 12

DoCS should provide advice to this office regarding:

- whether the roles and responsibilities of relevant agencies participating in the early intervention program, particularly NSW Health, NSW Police and DADHC have been confirmed, and if so, details of respective roles and responsibilities
- details of the department's project plan to build capacity in non-government agencies to provide the required level of case management and service delivery
- details of program performance indicators and the evaluation framework for the program or, if these have not been developed, plans for development
- details of how the department will determine 'service benchmarks' and establish systems for managing demand for the program.

Aboriginal children and young people

Aboriginal children were highly represented in reviewable child deaths. Of these children, a significant number were known to DoCS and died in circumstances related to abuse, neglect or in suspicious circumstances. Our work has highlighted instances where child protection intervention for Aboriginal children and young people and their families has been inadequate. We are concerned that issues of neglect, parental misuse of drugs and alcohol, and domestic violence in the Aboriginal community are not being adequately addressed. In the area of out-of-home care, we are concerned that children are being placed in kinship placements that are not being adequately assessed, monitored or supported.

DoCS Aboriginal Services Unit has recently been expanded to develop DoCS capacity to respond to the unique needs of Aboriginal people and communities.

Recomendation 13

DoCS should consider the issues raised in this report in relation to Aboriginal children and young people and their families, and report on its proposed strategies to address these issues with particular reference to:

— protecting Aboriginal children where domestic violence, parental drug and alcohol use and neglect are identified risk factors for children

— progressing and implementing a proposal for the provision of support services to relative/kinship carers

— progressing and implementing processes for adequately assessing potential kin carers.

Interagency cooperation

Our work indicates that the Interagency Guidelines for Child Protection Intervention are being under-utilised, and that DoCS could better engage with other agencies in its child protection work. A key component of effective child protection intervention is strong advocacy by child protection caseworkers to ensure implementation of case plans. This is particularly the case where other agencies have identified responsibilities within the case plan. We saw little evidence in the cases we reviewed of such advocacy. We note that DoCS, through the Child Protection Senior Officers Group, has commenced a process of updating and review of the Interagency Guidelines for Child Protection Intervention.

Recomendation 14

DoCS should develop strategies to ensure that case managers comply with interagency guidelines, particularly in relation to convening Protection Planning Meetings where a child or young person is at risk of harm and assessed to be in need of care and protection.

Recomendation 15

DoCS should develop strategies to ensure that its staff engage effectively with other relevant agencies in child protection intervention. In particular, strategies should:

- ensure that caseworkers utilise section 17 and 18 of the *Children and Young Persons (Care and Protection) Act 1998* to provide assistance to promote and safeguard the safety, welfare and well-being of a child or young person.
- promote appropriate referrals to other relevant agencies to address domestic violence issues where these issues are the basis of, or evident in, risk of harm reports
- promote referrals to other relevant agencies to address critical issues impacting on child safety, such as drug and alcohol and mental health services.

DoCS has developed and implemented a formal agreement with DADHC in relation to responding to risk of harm and care issues for children with disabilities.

Recomendation 16

DoCS should advise this office of the steps it has taken to implement recommendation 5 made by the Legislative Council Standing Committee on Social Issues in *Care and Support: Final Report on Child Protection Services*, that the department establish a system for ensuring coordination through formal agreements between relevant agencies.

DoCS role in reviewing deaths

This year, DoCS has established a Child Deaths and Critical Reports Unit. This unit will provide an important central point for responding to child deaths. DoCS has advised us that the unit's role in monitoring practice reviews in the field is currently undetermined.

Recomendation 17

DoCS should clarify the role of the Child Deaths and Critical Reports Unit in relation to practice reviews instituted at local level in response to the death of a child, in particular, the unit's role in:

- monitoring and assisting local reviews, and
- using the outcomes and recommendations from reviews to inform policy development and practice improvement across the department.

Documentation and record keeping

In the course of reviewing the deaths of children, we found many examples of poor record keeping and inadequate documentation of critical information.

Recomendation 18

DoCS should develop strategies and provide appropriate training to ensure that departmental staff improve adherence to documentation and reporting requirements.

Endnotes

1 Child or children in this report refers to children and young people under the age of 18 years.

2 AIHW (2000) '*The Comparability of Child Protection Data'*

3 National Clearinghouse on Child Abuse and Neglect Information 2001, '*Acts of Omission: An Overview of Child Neglect'*

4 A death may not be registered for some time after it occurs and therefore be counted in a different reporting period.

5 The NSW Child Death Review Team publishes an Annual Report on all child deaths in NSW registered in the reporting period. Data in that report may differ as the NSW CDRT considers deaths registered rather than occurring in a given period.

6 The circumstances of death for 24 of the 161 children could not be determined because coronial information was not available at the time of writing. However, these children and/or their siblings had been reported to DoCS within three years prior to their deaths.

7 Technical issues with the reviewable deaths database meant that relevant information for two children was not available at the time of writing.

8 Information in relation to the ancestry of children and their families was often difficult to obtain, as it is not consistently recorded by the Registry of Births, Death & Marriages, in DoCS databases, in NSW Police reports of death to the Coroner, or in coronial records. As a result of this, we have not been able to identify the cultural or linguistic background for over half the group of 137 deaths where full information was received.

9 Suspicious circumstances is used to describe deaths of children who may have died in circumstances related to abuse or neglect but there was not enough evidence in the final autopsy report to clearly determine if they died from abuse or neglect.

10 Interagency Guidelines for Child Protection Intervention 2000, p4

11 Legislative Council report (2002) p55

12 A joint DoCS/Police Team for the investigation of child abuse.

13 This indicates that DoCS do not consider the report concerns risk of harm, or has not reached a threshold of identified risk.

14 This may be an underestimate of the number of reports closed at initial assessment. We were unable to ascertain the point at which risk of harm assessment ceased for 57 reports concerning 35 children, due to difficulty locating or interpreting information on the DOCS databases. It is unclear whether these 57 reports were closed at the initial assessment stage or if they were referred to the CSC for secondary assessment and closed prior to the completion of an assessment.

15 see page 49 and following for a more detailed discussion of the Priority One policy

16 DoCS provided data only for co-located JIRTs

17 Legislative Council report (2002) p89.

18 Report of the Joint DoCS/PSA Working Party (The Kibble Report) 2002, p16

19 Definitions of neglect and inadequate supervision are set out on pages 2-3

20 NSW CDRT (2003)

21 Tomison (1995)

22 The policy includes an article by Eileen Munro entitled '*Common Errors of Reasoning in Child Protection Work*'.

23 Advice was provided in response to our request for an update on implementation of previous NSW CDRT recommendations. This is reported in detail in the chapter on 'Monitoring recommendations'.

24 DoCS response to the draft reviewable child deaths chapter of this report, November 2004.

25 ABS (2002a) census data

26 Stanley, Tomison and Pocock (2003)

27 AIHW (2004a)

28 Spence (2004)

29 ibid

30 One of these suicides was of a boy aged 10 years. He is not included in the group of adolescents because of his age.

Glossary

ABS
Australian Bureau of Statistics

Abuse
fatal assault where a child is fatally injured by beating, burning, shaking, stabbing, shooting, poisoning, suffocation, strangulation or other physical means, including homicides and murder-suicides

Adolescent
a person aged 13 to 17 years

AIHW
Australian Institute of Health and Welfare

BDM
NSW Registry of Births, Deaths and Marriages

Child
a person under the age of 18 years

CIS
Client Information System (DoCS superseded database)

CSC
community services centre, a local DoCS office

COPS
Computerised Operational Policing System, a NSW Police database containing crime information and intelligence

CPSOG
Child protection senior officers group

DoCS
Department of Community Services

DADHC
Department of Ageing, Disability and Home Care

Helpline
Single entry point for all reports of risk of harm and requests for assistance to DoCS

Infant
a child aged under one year

KiDS
Key Information and Directory System (DoCS database that replaces CIS)

Mandatory reporters
A person who, in the course of his or her professional work or other paid employment delivers health care, welfare, education, children's services, residential services, or law enforcement, wholly or partly, to children, and anyone holding a management position in such organisations, is required to make a report if, on reasonable grounds arising during the course of work, they believe a child is at risk of harm

Neglect
an act of omission by a parent or carer that involves refusal or delay in providing medical care; failure to provide basic needs such as food, liquids, clothing or shelter; abandonment; or inadequate supervision

NSW CDRT
NSW Child Death Review Team

P79a
NSW Police report of death to the Coroner

Priority One
DoCS policy that allows for prioritisation and closure of incoming risk of harm reports that would otherwise require a response. Due to be replaced by a case closure policy

PPM
Protection planning meeting – an interagency process providing a forum for pooling the skills, knowledge and expertise of agencies

Protective intervention
Action taken to protect a child from abuse and neglect

RAP
A recommended action plan (RAP) developed by a Helpline caseworker identifying tasks that need to be completed as part of further assessment of risk of harm conducted at a CSC.

Risk of harm
Defined in s23 of the *Children and Young Persons (Care and Protection) Act 1998* a child or young person is at risk of harm if current concerns exist for the safety, welfare or well-being of the child or young person because of the presence of any one or more of the following circumstances:

(a) the child's or young person's basic physical or psychological needs are not being met or are at risk of not being met,

(b) the parents or other caregivers have not arranged and are unable or unwilling to arrange for the child or young person to receive necessary medical care,

(c) the child or young person has been, or is at risk of being, physically or sexually abused or ill-treated,

(d) the child or young person is living in a household where there have been incidents of domestic violence and, as a consequence, the child or young person is at risk of serious physical or psychological harm,

(e) a parent or other caregiver has behaved in such a way towards the child or young person that the child or young person has suffered or is at risk of suffering serious psychological harm.

Risk of harm report
Information provided in accordance with provisions of the *Children and Young Persons (Care and Protection) Act 1998*, by a person who has reasonable grounds to suspect that a child or young person, or a class of children or young persons are at risk of harm from abuse or neglect

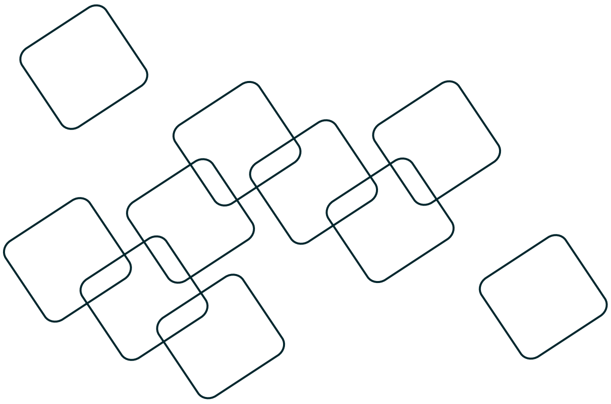
SIDS
sudden infant death syndrome

SUDI
sudden unexpected deaths in infancy

Suspicious circumstances
where there is insufficient evidence or information in the post-mortem to determine whether the cause of death was or was not clearly due to assault or neglect. Deaths were considered suspicious if there was a history of child abuse and neglect in the child's family background or other concerning circumstances in the context of the death incident

Toddler
a child aged one to four years

monitoring recommendations



Reviewable deaths of people with a disability

As noted earlier, information provided by agencies in response to matters raised in the issues paper, *Review of the deaths of 37 people with disabilities who died in care between 1 July and 31 December 2002*, have been included, where appropriate and relevant, in the body of this report.

Reviewable deaths of children

Provisions in the legislation have been made to ensure the Ombudsman monitors and reports on the implementation of previous recommendations relevant to the reviewable death function. This most obviously applies to the recommendations made by the NSW CDRT concerning children who died in circumstances related to abuse or neglect, or in suspicious circumstances.

Section 43(2)(c) of CS-CRAMA provides that the annual report should include *'information with respect to the implementation or otherwise of previous recommendations (as appropriate)'*.

This year the NSW CDRT has continued to monitor recommendations that it identified as being other than those related to DoCS' response to child abuse and neglect. Responses to these recommendations can be found in the NSW CDRT 2003 annual report. As a result, this year, we have monitored only some previous NSW CDRT recommendations, generally those targeted specifically to DoCS.

In response to a draft of the child deaths chapter of this report, the convenor of the NSW CDRT clarified that the team does not intend to monitor recommendations relating to child abuse or neglect or suspicious deaths, regardless of the department involved.

Set out below are details of the NSW CDRT recommendations we have monitored. We requested further information about action taken by DoCS in relation to each of these recommendations. This request, DoCS response and our comments, are also reported.

Recommendation 4 NSW CDRT Annual Report 2000-200	
The Department of Community Services should consider establishing a system for centralising and integrating information from internal reviews of deaths of children with a previous or current history of contact with the Department. The aim is to improve case work within the Department through identifying practice and management issues and sharing lessons throughout the agency.	
Our request	1. Further to the department's response to this recommendation as reported in the CDRT Annual Report 2003-2004, please advise: 1.1 What processes the department has in place to ensure recommendations made in the course of child death reviews are implemented and outcomes monitored. 1.2 What processes the department has in place to ensure findings and recommendations of departmental reviews of child deaths inform change where relevant in departmental policy and procedure. 1.3 The process, if any, by which the department will respond to identified management and practice issues in the handling of individual cases where a child has died.
DoCS response	The Department has a number of processes in place to assess, implement, track and monitor findings and recommendations from various reviews, reports and investigations. Historically, the Department had convened specialist committees to oversee internal reviews or investigations following individual child deaths where there are potential issues of a systemic or corporate nature. A member of the Executive who takes on responsibility for consideration, decision making, ownership and accountability convened such committees. In February 2002 the Department established the Systems Improvement Group as a formal mechanism for oversighting, monitoring and driving systemic service improvement initiatives across DoCS, identified through major internal and external reports, system reviews and critical events. The group now meets on as as-needs basis and maintains the same terms of reference. As a separate process, reviews following the death of a child are sometimes commissioned and managed within individual regions focussing on local practice and systems issues. Responsibility for monitoring any recommendations or findings remains at the local level with either the Regional Director or Director Child and Family. The Child Death and Critical Reports Unit is in the process of being established within DoCS and, as discussed at a meeting with the Ombudsman in July, the Unit's role in monitoring practice reviews in the field is currently undetermined.
Ombudsman comments	DoCS response indicates that there is no clear process in place to review the deaths of children known to the department. This limits the capacity of DoCS to identify systemic policy and practice issues to inform service improvement initiatives. We will closely monitor DoCS response to recommendation 17 in this report, and the development of DoCS response to child deaths.

Recommendation 5.1 NSW CDRT annual report 1997-1998

In developing the capacity of district officers, assistant managers, and child protection specialists, and where training is offered to non-government child protection workers, the Department of Community Services pays particular attention to the neglect of children by:

- Requiring that assessments be undertaken on infants and children, where there are issues of neglect, including ongoing growth measurements and formal developmental assessments and in severe cases of neglect, referring parent(s) and their children for comprehensive psychosocial and parenting capacity assessment;
- Making available as part of initial and ongoing training, specialised training about the effects of severe and especially early neglect on infants' and children's development and well-being. This should include training about the recognition of neglect, and indicators for referral for further assessment. Such training should be carried out for the Department of Community Services staff on a formalised basis across the state by specialists in infant and child development and neglect.

Our request	2. Further to the department's response to this recommendation as reported in the CDRT Annual Report 2003-2004, please advise: 2.1.1 Details of progress on *'research and development of policy specifically relating to working with children, young people and their families to minimize the impact of neglect'* (CDRT Annual Report 2002-2003 p. 87). 2.1.2 Whether current departmental policy requires assessments, as outlined in the recommendation, to be undertaken where issues of neglect have been substantiated. If so, please provide details of this policy. 2.1.3 Whether current departmental policy requires, in cases of severe neglect, referral of children and parents for comprehensive psychosocial and parenting capacity assessment. If so, please provide details of this policy. 2.1.4 Details of progress in work with DoCS community partners in looking '*at issues such as preventing vulnerable children and families from entering the child protection system by providing early support before their problems escalate*' (CDRT Annual Report 2002-2003 p 88). 2.1.5 Details of progress in the establishment of specialist units (CDRT Annual Report 2002-2003 p 88), and how the units have progressed work specifically in relation to identification of, and response to, neglect of children and young people. 2.1.6 Details of specialised training currently provided to DoCS' staff about the effects of neglect and recognising and responding appropriately to neglect.
Docs response	2.1.1 DoCS' earlier response (as reported in the July to December 2002 CDRT Report) refers to preliminary work that had commenced on a literature search on neglect, undertaken as part of the early stages of the development of a policy on neglect. This work had commenced prior to the establishment of the Child Protection and Service Reform Branch in late August 2003 (see 2.1.5), which now has carriage of this policy work. A project plan regarding the development of a policy on neglect has been approved. Work has commenced with a review of the current literature on neglect. The literature review will, among other things, identify current research findings on definitions of neglect, causes and effects of neglect, assessment tools, and service responses that will guide the formation of a policy for DoCs in working with children and families where neglect is an issue. The review will include an examination of issues raised in the Child Death Review Team reports in relation to neglect. The policy is intended for completions in 2005. 2.1.2 There are no explicit departmental policies requiring the types of assessments referred to in the recommendation.

Recommendation 5.1 NSW CDRT annual report 1997-1998	
DoCS response (continued)	2.1.3 In cases of severe neglect, the Act enables DoCS to pursue a range of actions, including the referral of children and parents for comprehensive psychosocial and parenting capacity assessment. Other actions open to DoCS include seeking court orders for independent assessment of the child and/or parent(s), the outcomes of which could include a description of the therapeutic program and other support to be provided. 2.1.4 DoCS has continued development work to establish the Early Intervention Program which provides intensive and targeted support to vulnerable children and their families. The Program is part of the DoCS $1.2 billion enhancement package and will build on and enhance the capacity of the existing early intervention service system. As part of Program development, the External Stakeholders Reference Group, comprised of community partners and DoCS representatives, provides expert advice on prevention and early intervention and key issues relating to the development and implementation of the Program. In May 2004 funding of $6.5 million was allocated to support the rollout of the Early Intervention Program in targeted sites and other areas across the State. This funding supported services providing targeted early intervention programs, such as family workers to give parents extra support. Funding for services under the Early Intervention Program will continue to be progressively rolled out on a location by location basis across NSW in 2004/2005. 2.1.5 The specialist units include an Economics Unit, an Aboriginal Services Branch, a Multicultural Services Unit, and an Operations Support Unit. The Prevention and Early Intervention Branch and the Child Protection Policy and Service Reform Branch have also been established as specialist units, with the latter having specific responsibility for developing a policy on neglect. That Branch will work closely with the other specialist units, in particular, Aboriginal Services and the Economics and Operations Support Units, in developing policy and identifying strategies to improve the DoCS service response to neglect. 2.1.6 Neglect is a topic covered a number of times within the Caseworker Development Course (CDC). Specific attention is paid to neglect within the Dynamics of Child Abuse module, where early brain development and the long lasting impact neglect has on brain development is explored in detail. Issues of neglect are also included within the Assessing Risk of Harm, Alcohol and Other Drugs, Mental Health and Domestic Violence modules. DoCS is currently reviewing some aspects of CDC to more closely align with new categories of Caseworkers namely OOHC, Intensive Support Services and Early Intervention. It is proposed that neglect will have a strong focus within the Early Intervention Stream. DoCS also intends to provide courses on neglect within the Professional Development calendar, so as to provide existing workers with current information on neglect.
Ombudsman comments	It is of significant concern that DoCS is operating in the absence of a policy on neglect. Some three years will have passed between initial policy work on neglect and the proposed completion of a policy. It is critical that DoCS ensure its staff have a comprehensive understanding of neglect and its consequences. Staff also need to be provided with adequate procedural guidance to assist them to respond to neglect consistently and appropriately. We will closely monitor DoCS' response to recommendation 11 and 12 in this report. We will also continue to monitor DoCs' response to neglect, including the implementation of its early intervention and prevention program.

Recommendation 2.1-2.3 NSW CDRT Annual Report 1997-1998

In developing and implementing the new Client Information System, the Department of Community Services ensures mandatory recording on the CIS, during the various stages of the case management process, of:

- All information received in relation to allegations of child abuse or neglect;
- All the child's significant relationships, all names which a client may be known by in a way that allows them to be easily located;
- The reasoning behind decisions;
- A clearly identified summary of key events and details of any child who dies from abuse or neglect or under 'suspicious' circumstances, their familial details and the child's significant relationships.

In developing and implementing the new Client Information System, the Department of Community Services consider how the system will:

- Permit linkage between paper and electronic files and integrate all client information in a comprehensive and accessible manner; and
- Requires a mandatory check at intake of prior Departmental contact with a child, his/her family members, and other significant people in his/her life.

Our request	3. Further to the Department's response to this recommendation as reported in the CDRT Annual Report 2003-2004, please advise: 3.1 Whether the system currently incorporates mandatory reporting of items identified in this recommendation. 3.2 Progress in relation to the Community Services Record Management System project.
DoCS response	3.1 The DoCS replaced the existing client database with the new KiDS system in October 2003. In developing and implementing the new Client Information System, DoCS ensures mandatory recording, during the various stages of case management process, of: • All information received in relation to allegation of child abuse or neglect The Helpline record all contacts including allegations of abuse or neglect. This occurs during the initial assessment phase. The seriousness of the allegation determines what action is then to be taken on the matter. If the matter is referred to the CSC or JIRT and staff undertake a secondary assessment, it is compulsory for this information to be recorded on the KiDS system. This is called a Secondary Risk of Harm assessment. • All the child's significant relationships, and all names which a client may be known by in a way that allows them to be easily located Staff search to see if this is an existing client. If not, staff enter details about the client, family relationships, the contacting person (eg mandatory reporter), persons of interest, persons associated with causing risk and persons causing harm in the persons screen. Staff then add these people as a party to the record of the client. The relationship between the subject and reported, persons of interest, persons associated with causing risk and persons causing harm is automatically created as part of the initial assessment and judgements and decisions record. Significant relationships can be easily viewed on the person's record in KiDS. In addition the person history and person summary reports show all relationships for a client. All names including aliases are recorded in the persons names list and can be searched and retrieved on KiDS. • The reasoning behind decisions Decisions are recorded in initial assessment, all stages of secondary assessment as well as all assessments and various meeting records. • A clearly identified summary of key events and details of any child who dies from abuse or neglect or under 'suspicious' circumstances, their familial details and the child's significant relationships

Recommendation 2.1-2.3 NSW CDRT Annual Report 1997-1998	
DoCS response (continued)	The person history report includes all of the above information that is held in KiDS. Further work is currently underway to improve this section, in particular the presentation of older records which were converted from the former CIS system to KiDS. KiDS allows staff to attach word and other electronic documents to a record. There is the capacity to record paper file location and there is a direction to staff on how to record this. Other work underway in this regard includes a pilot project to allow e reporting for mandatory reporters (expected to commence with some Department of Education staff in the coming year). KiDS ensures that staff check for an existing client, as it will not allow staff to add a new client without undertaking a search. If the search finds a possible match staff are required to generate the Person History report to assist decision making about previous reports and impact on current situation. 3.2 As the DoCS shared provider, NSW Businesslink is undertaking an Electronic Records & Document Management Program on behalf of DoCS and its other client agencies. The Program commenced in October 2003, with the following key objectives: • Ensure regulatory obligations are met as mandated by the State Records Act and DoCS-specific legislation. • Develop policies and procedures for the management of records and documents in Head and local offices. • Implement a Records & Document Management System that complies with State Records Authority requirements. This system will integrate with the newly implemented KiDS Client Management System to ensure that complete client records are maintained and accessible. • Undertake a comprehensive staff education & training program. The Program is progressing on target with the implementation of the Records (File) Management solution (including policies and procedures) scheduled for mid 2005. The initial system to be integrated with the Electronic Records and Document Management System will be KiDS and all other electronic records systems will be integrated thereafter.
Ombudsman comments	The KiDS system has now been in operation for twelve months. We have identified numerous problems in KiDS recording and reporting capacity. DoCS states that KiDS can collect all information in relation to allegations of child abuse and neglect, all significant relationships and names by which a client may be known and can generate summary reports of key events. However our work with KiDS found evidence of incomplete or missing data relating to initial and secondary assessments and outcomes for children. Navigating and searching the new system is difficult and the incorporation of older records from CIS to KiDs has created some problems locating and interpreting information. DoCS was unable to advise us how many risk of harm reports in this reporting period received a secondary risk of harm assessment or how many reports were closed under Priority One policy. It is a significant concern that DoCS is unable to provide such key data. We acknowledge the difficulties in introducing a new information system. However, DoCS must be able to report on critical aspects of its work and provide full, accurate and current client information. KiDS should provide a basis for assessment of the effectiveness of DoCS' child protection intervention. We will closely monitor recommendation 1 in this report with regard to DoCS data collection and the reporting capacity of KiDS.

Recommendation 4.1 NSW CDRT Annual Report 1997-1998

The Department of Community Services develops and implements specific strategies including casework supervision for enhancing the capacity of district officers, assistant managers and child protection specialists to conduct risk assessments. In doing this, the following issues should be addressed:

- Building an accurate picture of the risk to the child;
- The importance of past behaviour and family history in building a picture of the risk factors;
- Seeking independent corroboration of information given by relatives and other notifiers, including interviewing children when appropriate;
- The circumstances where a comprehensive risk assessment is required including referrals for paediatric assessments, developmental assessments of parents and children, psychosocial assessments (including bonding and attachment assessments), drug and alcohol assessments, and mental health assessments.

Our request

4. Further to the Department's response to this recommendation as reported in the CDRT Annual Report 2003-2004, please advise:

4.1 In regard to DoCS' review of the initial assessment system for child protection reports (CDRT Annual Report 2003-2004 p 99), the specific changes made to the initial assessment process, and the outcomes of the pilot trial for the revised initial assessment.

4.2 Whether initial assessment of reports of risk of harm includes a mandatory check of previous contacts with the department in relation to the child, his/her family members, and other significant people in his/her life.

4.3 The circumstances under which caseworkers are required to conduct a secondary risk of harm assessment, and how such decisions are made and approved.

DoCS response

4.1 DoCS has completed the first stage of a review of its initial assessment process. The review examined the current process and various assessment models used in other jurisdictions, such as professional judgement, consensus and actuarial models of risk assessment.

DoCS has determined that an economic analysis is required to assess the feasibility of alterative options for reform before any changes to the existing process. Apart from improving the accuracy of individual assessment, any changes to the process are intended to support the broader reform program now underway in DoCS. Stage 2 of this project is about to commence with a detailed economic analysis of the options for reform.

4.2 The current Initial Assessment is generally completed by caseworkers at the Helpline and requires a 'child protection history' check as an essential component of the process. This check requires the caseworker to check KiDS to determine if the child has been previously reported to DoCS. If the names of any siblings are known they are also checked. The KiDS system also allows for linking of persons to an address. Parties to any records associated with a person or address are then checked to establish a clear child protection history. Helpline caseworkers are trained to search for persons and addresses as part of their training in relation to Initial Assessment. All caseworkers (CSC, JIRT and Helpline) receive KiDS training in this process of Initial Assessment.

Caseworkers in CSCs complete about 10% of all Initial Assessments. They do not receive specific training in undertaking Initial Assessment. A Business Help topic on Initial Assessment is in draft form and is waiting endorsement.

4.3 The process of assessment is an activity undertaken by the caseworker in gathering and analysing relevant information to inform the judgements, decisions and future planning for a child or young person's safety, welfare and wellbeing. This is a process that begins when information is first received as a report, and continues throughout Secondary Assessment and case management to closure. An assessment that a child is in need of care and protection (ie, that action is required by DoCS to protect or care for the child or young person) may be made immediately upon receipt of information if the available information and analysis warrants it. In other circumstances the decision that a child is in need of care and protection may not be made until a thorough assessment has been made of all relevant aspects to their situation.

Recommendation 4.1 NSW CDRT Annual Report 1997-1998	
DoCS response (continued)	If, at any stage in the assessment process, it is assessed that adequate arrangements exist for the care and protection of the child or young person, the case may be reviewed and closed. With the introduction of KiDS in October 2003, an additional component of the Secondary Assessment process was introduced. This is the Secondary Assessment Stage 1 (SAS1). In SAS1 a caseworker is able to obtain additional information via local knowledge, further contact with the reporter or other parties or exchange of information under section 248 of the *Children and Young Persons (Care and Protection) Act 1998.* The additional information obtained is used to assist the caseworker and manager casework to determine the priority for action and what action needs to be taken. This information is then able to be recorded in KiDS and the record and any actions arising out of it, including case closure are approved by the Manger Casework. The Child Protection and Early Intervention Directorate is currently developing a Case Closure policy which will apply to those cases remaining after the daily allocation of cases transferred into a CSC has occurred based on the safety and risk issues and the vulnerability of the child or young person and where the CSC is close to reaching its resource limit for Secondary Assessment Stage 2 (SAS2) field visits. This policy will replace Priority One. A trial to assess its effectiveness will be carried out before its full implementation.
Ombudsman comments	DoCS response indicates that the pilot trial for the revised initial assessment scheduled for December 2003 has not occurred (refer CDRT Annual Report 2003-2004 p. 99). Our work had identified a range of concerns with the application of initial risk of harm assessment and secondary risk of harm assessment processes. We will closely monitor DoCS response to recommendations 3 to 10 in this report in relation to risk of harm assessment. We will also monitor the implementation of DoCS proposed case closure policy.

Recommendation 11.1 NSW CDRT Annual Report 1997-1998

The Department of Community Services, in implementing the Children and Young Persons (Care and Protection) Act 1998, ensures that:

- The clinical assessment procedure for potential adoptive, foster and kinship caregivers be equally thorough, and that all potential carers of children needing alternative placement are comprehensively assessed;
- The well-being of all children placed by the Department or a designated agency in kinship care is monitored; and
- That children be monitored for a minimum of the first 12 months of their placement with relatives to ensure that their well-being and safety needs are met.

Our request	5. Further to the Department's response to this recommendation as reported in the CDRT Annual Report 2003-2004, please advise: 5.1 Details of the clinical assessment procedure for relative carers where relative care is: • by virtue of an order of the Children's Court or under the parental responsibility of the Minister; • by virtue of a temporary placement. 5.2 How, and for what period of time, the well-being of all children placed by the department or a designated agency in relative care is monitored, including in relation to voluntary placements.
DoCS response	5.1.1 DoCS completes a formal assessment (not clinical) of all potential carers including relative carers. This assessment includes a formal authorisation process. This assessment includes the relative carer/s completing a formal application form which includes Working With Children and NSW criminal records checks. Working With Children and criminal record checks are also completed for all household members, 16 years and older. The Working With Children Check includes a check for any Apprehended Violence Orders and any completed child related disciplinary proceedings. DoCS also checks its own records system (KiDS). A formal assessment is completed which includes a home inspection, family interview and review of the original application. The assessment may also include a medical check where there are health concerns in relation to the relative carer. This assessment process applies to all relative carers regardless of the length or nature of care. Where a child or young person is placed in emergency relative care and the completion of the placement assessment is not possible, DoCS checks any information contained on KiDS and in those circumstances seeks information from the Police with regard to any criminal history or if the person is a person of interest to police. Following the initial information gathered and if the emergency placement is likely to continue (even if temporarily) DoCS will complete the formal assessment process. In order to be recognised as a carer by DoCS, carers must be authorised. This information is available to all DoCS staff via a Business Help Topic-Assessment and Approval of Authorised Carer. This process is in place for children or young people in the care of DoCS by virtue of an order of the Children's Court or under the parental responsibility of the Minister. It also covers temporary care under sections 151 and 152 of the Children and Young Persons (Care & Protection) Act 1998. 5.1.2 The review of placements of children or young people in the care of DoCS by virtue of an order of the Children's Court or under the parental responsibility of the Minister with a relative carer is covered by section 150 (2) Children and Young Persons (Care & Protection) Act 1998. At this stage the Regulation prescribing the intervals at which reviews are to be carried out has not been finalised. The current definition of children and young people in OOHC does not include children and young people in relative care unless under a Court Order, as above. Therefore DoCS has no requirements to monitor these placements. DoCS would only remain involved where the carer/s are receiving an allowance for the child or young person. This monitoring would be conducted as part of the allowance review.
Ombudsman comments	Our work has raised some concerns about the adequacy of DoCS' assessment and monitoring of kinship placements. We will closely monitor recommendation 13 in this report and DoCS' assessment and monitoring of placements for children who die while in DoCS direct or funded care.

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appendices

Appendix 1

History of the reviewable death function

The function of reviewing deaths has changed over time and so it is useful to look back at the history in order to understand its current work.

Review of deaths of people with disabilities

The then Minister for Community Services announced the establishment of a Disability Death Review Team (DDRT) in November 1998. The DDRT was established within the former Community Services Commission and was initially funded from DoCS and NSW Ageing and Disability Department (ADD). Following review in January 2000 the DDRT was made a permanent program with recurrent Treasury funding.

According to the minister's media release, the DDRT would operate in a similar way to the NSW Child Death Review Team (NSW CDRT) and would:

- develop and maintain a register of all relevant deaths of people with disabilities in care
- analyse reports and identify where more information was required
- conduct reviews of particular deaths that met identified criteria
- carry out or oversee investigations into deaths of people with disabilities in care where there was sufficient concern or public interest
- identify or research patterns and trends and make recommendations on preventative strategies to improve safety and reduce deaths in care.

The DDRT established a protocol with NSW CDRT to ensure co-ordination and information exchange about the deaths of children with disabilities. It also developed mechanisms and protocols with ADD and DoCS covering the notification of deaths of people with disabilities in care. By 2001 not just DoCS disability residential services, but all disability accommodation services funded under the *NSW Disability Services Act 1993* (DSA) were required to notify the DDRT of residents' deaths .

The strategies adopted by the DDRT were:

- to receive notifications of deaths in care
- to assess and review the circumstances of people in care who had died
- to identify trends and patterns and undertake systemic reviews
- to promote service improvement and prevention strategies.

There was no specific legislative provision for this work. Rather the former commission's existing monitoring and review powers were employed to monitor and review the deaths.

The DDRT reviewed the individual circumstances of people with disabilities who died while in residential care. These reviews were targeted at improvements in individual services. Group reviews were also conducted, including the report into the deaths of eight children and young people at the disability service known as Mannix which drew together common themes and issues from each individual's death. The DDRT gave copies of its assessment and review reports to the relevant minister and department and the service specifically involved in the care of the deceased person. In the case of children with a disability, a report was also provided to NSW CDRT.

The team published three reports on systemic work it did:

- A critical incident at the Grosvenor Centre (2000)
- Disability, death and the responsibility of care (2001)
- Young deaths - children with disabilities in care (2002).

The DDRT examined reviewable deaths from a quality of life perspective and sought to promote service improvement initiatives that would reduce the number of preventable deaths of people in care.

History of review of child deaths

The work of reviewing the deaths of children began more than a decade ago. The NSW CDRT Annual Report July – December 2002 summarised the development of this work in the following way:

> A 1990 report by the Physical Abuse and Neglect of Children (PANOC) Committee identified the lack of a central review mechanism in situations where a child suffers serious physical injury or dies (NSW Child Protection Council, February 1990). It recommended that the NSW Government establish an independent review mechanism to examine cases where a child has been re-injured, or has died, with the authority to recommend changes to policies, procedures, services and training.
>
> This led to the establishment in 1993 of a Child Deaths Review Committee of the NSW Child Protection Council. The Committee reviewed a sample of deaths identified or suspected as being due to abuse or neglect of children up to 14 years occurring in NSW between 1989 and 1991. The aim was to determine their characteristics, causes and contributing factors and to assess the effectiveness of existing policies and practices in dealing with them.

> The resulting report, *Preventing Child Homicide* (NSW Child Protection Council, 1995), recommended that the NSW Government establish a Child Death Review Committee with the specific aim of learning from the facts surrounding the deaths of children, using the findings to educate workers and informing policy and procedure across all areas of work to prevent future child deaths.
>
> In 1995 the Government implemented this recommendation by passing, with bipartisan support, legislation establishing the Team – the *Children (Care and Protection) Amendment Act 1995* (NSW) – a first for Australia and the first of its kind outside the United States.
>
> The Team was funded from the budgets of the various government agencies represented on the Team.
>
> For the first three and a half years the Team was administratively supported by the NSW Child Protection Council with its work overseen by the Department of Community Services (reporting to the Minister for Community Services). When the NSW Commission for Children and Young People was established in June 1999, the Commissioner became the Team's Convener, with the Commission providing research, policy, secretariat and administrative support to the Team.
>
> The Team membership reflects a multi-disciplinary interagency response to promoting children's safety, welfare and well-being. The CDRT consists of independent experts appointed by the Minister for Community Services who have expertise in paediatrics and child health, forensic pathology, mental health and child protection. The Team also has nominees from NSW Government departments concerned with the safety and well-being of children including the Departments of Community Services, Attorney General's, NSW Health, Education and Training, the NSW Police, and the Office of the State Coroner. Currently there are 18 members, including two Aboriginal members.
>
> The *Community Services Legislation Amendment Act 2002 (NSW)* changed the functions of the CDRT. The NSW Ombudsman became responsible for undertaking detailed reviews of deaths due to or suspicious of abuse and neglect that were registered after 1 January 2003. The Team will continue with its broader research focus and the Child Death Register, looking at child deaths from all causes. (CDRT 2002 p.2)

In July 2003, following a review of the legislation governing the NSW Child Death Review Team, amendments were made to formally establish the NSW CDRT within the Commission for Children and Young People. The Minister's second reading speech confirmed the research focus of that team – the prevention and reduction of all types of child deaths in NSW. She noted that the deaths of children due to abuse, neglect or in suspicious circumstances sit more appropriately with the Ombudsman's office with its existing powers and functions in relation to the child protection system in this state.

Appendix 2

Coronial information

Reviewable child deaths examined by the State or Deputy State Coroner

A coroner's role generally is to determine the identity of the deceased person, the date and place of death and the manner and cause of death. A coroner may make recommendations, as the coroner considers necessary or desirable, in relation to any matter connected with the death.

Medical practitioners must not certify the cause of death of a child or a person with a disability if the death is examinable by the coroner under s13AB of the *Coroner's Act 1980*. Deaths reviewable under that section must be reported to the Coroner as soon as possible. An inquest into a reviewable death can be held only by the State Coroner or a Deputy State Coroner.

We have reported deaths to the Coroner where it has appeared to us that this has not already been done. We also provide a monthly schedule of deaths that we have determined as reviewable.

The following record of coronial information is of the status of matters at the time of writing.

Reviewable child deaths

Deaths referred to the State Coroner

Of the 137 reviewable child deaths that occurred from 1 December 2002 to 31 December 2003 and about which full information was available, 33 deaths (20%) were not reported to the Coroner, as required by the new legislation, and a medical practitioner signed a death certificate.

These 33 deaths were determined to be reviewable because:

- the child was reported to be at risk of harm in the 3 years immediately preceding the death (14)
- the child and the child's sibling was reported to be at risk of harm in the 3 years immediately preceding the death (9)
- the child's sibling/s were reported to be at risk of harm in the 3 years immediately preceding the death (9)
- the child was in care (1).

Twenty-nine of the 33 children died in a public hospital, three died at home and one died in a nursing home. All of the children had a chronic or serious illness or a significant physical disability, for example congenital disease, neonatal asphyxia or sepsis.

In relation to children who have been reported to the Department of Community Services and who die in hospital of natural causes, we have instigated discussions with the NSW State Coroner to develop an approach that alleviates the adverse impacts on families and hospital staff of a death being examinable by the Coroner.

Autopsies

In 137 child deaths reviewed by the Ombudsman:

- An autopsy was performed following the order of a coroner in 107 deaths (78%)
- An autopsy was not performed in 27 deaths (20%) as the coroner was either satisfied that the manner and cause of death was established or an autopsy could not be performed due to a delay in reporting the death to the coroner.
- Next of kin objected to an autopsy in three deaths (2%).

Inquests

- At the time of writing, no decision had been made regarding an inquest for 45 of 137 child deaths reviewed (33%
- A coroner dispensed with an inquest in 74 child deaths reviewed (54%)
- A coroner has dispensed with holding an inquest into seven deaths of children who lived in care
- A coroner is still examining three deaths
- A coroner determined to hold an inquest for seven child deaths reviewed (5%):
  - Inquests were held into two the deaths of two infants (both sleep deaths)
  - Inquests are scheduled to be held for a further five deaths (two drowning, one sleep death, one pneumonia, one fall)
- An inquest was terminated and criminal charges were laid in relation to the deaths of eleven children (8%).

Recommendations

No coronial recommendations were made in any of the matters that have been finalised

Reviewable deaths of people with a disability

Full coronial information was not available at the time of writing on all reviewable deaths of people with a disability.

Autopsies

- An autopsy was performed following the order of a coroner in 54 0f 110 deaths (74%)
- Next of kin objected to an autopsy in 12 deaths (11%)
- In two of these 12 deaths, an autopsy was performed.

Inquests

- No decision had been made regarding an inquest for 33 of 110 reviewable deaths of people with a disability
- A coroner dispensed with an inquest in 73 reviewable deaths of people with a disability
- A coroner determined to hold an inquest for three deaths of people with a disability
- An inquest was terminated and criminal charges were laid in relation to one death of a person with a disability
- In one case, the file of the person with a disability who died was closed, but no decision regarding inquest had been received by the Ombudsman.

Recommendations

No recommendations were made in any of the matters that have been finalised

Appendix 3

Membership of expert advisory committees

Reviewable disability death advisory committee

Mr Bruce Barbour Ombudsman (chair)

Mr Steve Kinmond Deputy Ombudsman and Community and Disability Services Commissioner

Dr Helen Beange Clinical Lecturer in Faculty of Medicine, Sydney University. She runs clinics for adults with intellectual disabilities with the assistance of the Centre for Developmental Disability Studies at Royal Ryde Rehabilitation Centre.

Mr Michael Bleasdale Director, NSW Council on Intellectual Disability. Principal Researcher at the Disability Studies and Research Institute. Subject coordinator for a number of units for the Habilitation course at Charles Sturt University

Ms Linda Goddard Course coordinator, Bachelor of Nursing, Charles Sturt University (CSU). Currently working with CSU and DADHC to establish a multidisciplinary health clinic for people with disabilities.

Dr Alvin Ing Senior Visiting Respiratory Physician at Concord Hospital and a Senior Staff Specialist, Respiratory Medicine, at Bankstown-Lidcombe Hospital. Clinical Senior Lecturer, Faculty of Medicine, Sydney University

Dr Martin Kennedy Consultant Medical Specialist. Director, Calvary Rehabilitation and Geriatric Service. Sydney Lecturer, Department of Community Medicine, UNSW. Consultant, Developmental Disability Rehabilitation at St George Hospital, Sydney (resigned June 2004)

Dr Cheryl McIntyre General practitioner. Currently involved in a Community of Practice with Challenge in Armidale to update annual check-up for their patients with developmental disabilities, and improve health interactions for people with disabilities.

Dr Rosemary Sheehy Geriatrician /Endocrinologist, Central Sydney Area Health Service.

Ms Anne Slater Physiotherapist working in paediatric disability for over 30 years, currently at Allowah Childrens Hospital. Co-runs a course teaching health professionals dysphagia management

Dr David Williams Director, Department of Neurology at John Hunter Hospital, and Clinical Senior Lecturer in Medicine at the University of Newcastle.

Reviewable child death advisory committee

Mr Bruce Barbour Ombudsman (chair)

Mr Steve Kinmond Deputy Ombudsman and Community and Disability Services Commissioner

Dr Ian Cameron CEO, NSW Rural Doctors Network based in Newcastle.

Dr Judy Cashmore Associate Professor, Faculty of Law, University of Sydney and Honorary Research Associate, Social Policy Research Centre, University of New South Wales. Chair of the Association of Children's Welfare Agencies, member of the Ministerial Advisory Council to the Minister of Community Services and the NSW Department of Community Services' Research Advisory Council.

Dr Michael Fairley Consultant Psychiatrist and Head of the Department of Child and Adolescent Mental Health at Prince of Wales Hospital and Sydney Children's Hospital

Dr Jonathan Gillis Senior Staff Specialist in Intensive Care and Chairman of the Division of Critical Care and Diagnostic Services, at the Children's Hospital, Westmead.

Dr Bronwyn Gould AM Child protection consultant and medical practitioner. Deputy chair of the Commonwealth Ministerial Advisory Council for Children and Parenting (ACCAP) and Chair NAPCAN advisory council. Member of the International Society for Prevention of Child Abuse and Neglect (ISPCAN) and the Association of Children's Welfare Agencies.

Ms Pam Greer Community worker, trainer and consultant, working in the Northern Territory, Queensland and New South Wales. Ms Greer has worked on projects for the Aboriginal community for a range of government departments and also works extensively in the fields of child protection and domestic violence. Member of the Indigenous Women's Committee through the Women's Legal Centre.

Dr Ferry Grunseit AM Consultant Paediatrician. Former Director of Emergency and Outpatient Services and Head of the Child Protection Unit at the Royal Alexandria Hospital for Children, Camperdown. Formerly, Chair NSW Child Protection Council and the NSW Child Advocate

Associate Professor Judith Irwin Head, School of Social Work and Policy Studies, in the Faculty of Education and Social Work, University of Sydney.

Ms Tracy Sheedy Acting Registrar of the Local Court Family Matters, the Children's Court at St James and a Children's Registrar. Manager, Guardian ad Litem Panel set up for the Children's Court and editor of Children's Law News. Part time member of the Consumer Trader and Tenancy Tribunal.

Ms Alice Silva Aboriginal Senior Consultant for Disability Services, DADHC (resigned April 2004)

Ms Toni Single Senior Clinical Psychologist with the Child Protection Team at John Hunter Children's Hospital, Newcastle