NSW Ombudsman

Report of Reviewable Deaths in 2004

December 2005

CELEBRATING
30 YEARS OF
SERVICE
1975~2005

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December 2005

The Hon Meredith Burgmann MLC
President
Legislative Council
Parliament House
SYDNEY NSW 2000

The Hon John Aqualina MP
Speaker
Legislative Assembly
Parliament House
SYDNEY NSW 2000

Dear Madam President and Mr Speaker

I am pleased to present to the NSW Parliament the second report on our reviews of the deaths of children in care and certain other children, and people 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 2004; 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.

I recommend that this report be made public forthwith.

Yours faithfully

Bruce Barbour
Ombudsman

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CELEBRATING 30 YEARS OF SERVICE 1975~2005

Ombudsman's message

This is our second report of reviewable deaths of certain children and people with disabilities. Our responsibility is to recommend to government and service providers ways to prevent or reduce such deaths.

For the agencies within our jurisdiction, this means we must analyse their role in the lives of the people whose deaths came to our attention.

The work of child protection and care of people with disabilities can be complex, demanding and difficult. At the same time, the community expects high standards of care and protection for some of the State's most vulnerable people.

Deaths of people with a disability

We reviewed the cases of 93 people with disabilities who died in care in 2004. They lived in disability services or licensed boarding houses. They had combinations of intellectual, psychiatric or physical disabilities, and some had complex health problems. This report separately considers the deaths of boarding house residents from those in the disability services. This has allowed us to identify specific problems and draw relevant comparisons.

We have noted in the report the importance of ensuring adequate safeguards for people with disabilities living in boarding houses.

We have continued to highlight concerns about health care management in disability services. For the funded services, we have found a need for more guidance in relation to health care planning for their clients. We have also found other factors affecting health care planning, including long queues for some allied health services and insufficient training for staff dealing with the complex needs of residents.

Recommendations to government and service providers are at the heart of the reviewable death function. Last year we made recommendations to the Department of Aging, Disability and Home Care, and to NSW Health. We do so again now, noting that there has been little progress in addressing some of those earlier recommendations.

Implementing changes in policy and practice takes time, particularly in an area as complex as the one under review. We will continue to pursue our recommendations until we see the changes our analysis has revealed as necessary to improve services to people with disabilities in care.

Deaths of children

Most of the responsibility for protecting and nurturing children lies with their families. If families are unable to do so, the child protection system may intervene, alerted by community members or by mandatory reporters who are themselves part of that system. Responsibility for much of the intervention rests with the Department of Community Services. DoCS, of course, does not create the circumstances that lead to the abuse and neglect of children. What is within the department's control is its response, once such situations are reported to it.

This year we reviewed the deaths of 104 children. Of these, 96 children were either known to the department or were the siblings of children who were known to the department.

We continue to be concerned about the DoCS policy that allows closure of child protection cases on the basis of competing priorities and inadequate resources. In some cases that we reviewed, children that the department considered to be at risk were not subject to any further intervention. We continue, also, to be concerned about what was, at times, narrow assessment of risk.

Our latest recommendations come as DoCS continues to recruit many extra staff as part of a five-year $1.2 billion reform program. Last year we observed that more spending on its own would not resolve the problems of the child protection system. It is vital that the department be able to demonstrate how new approaches, combined with the new funding, will result in adequate risk assessment and appropriate, effective responses at the local level.

DoCS does not work in isolation. NSW Police is the single biggest source of mandatory reports to the Helpline, followed by NSW Health and then the Education Department. As with last year's report, we have identified significant room for improvement in the way agencies work together to protect children.

We have used case studies to illustrate our findings in this report. We believe that a frank account of our work is a prerequisite for constructive debate about the prevention and reduction of reviewable child deaths.

Bruce Barbour
Ombudsman

Introduction

Introduction

Reviewable deaths

Since December 2002, the Ombudsman has had responsibility for reviewing the deaths of people with disabilities in care, and of certain children. This responsibility is legislated under Part 6 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CS CRAMA). Specifically, the Ombudsman reviews the deaths of:

- a child[1] in care.
- a child in respect of whom a risk of harm report[2] was made to the Department of Community Services within the three years prior to the child's death.
- a child who is a sibling of a child in respect of whom a risk of harm report was made to the Department of Community Services within the three years prior to the child's death.
- a child whose death is, or may be, due to abuse or neglect or that occurs in suspicious circumstances.
- 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).
- 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 licensed boarding house.

The focus of reviewing deaths is primarily on identifying systemic issues arising from reviewable deaths; monitoring deaths, particularly in relation to any identifiable trends or patterns; and recommending changes to policies and practices that might prevent deaths. The legislation also provides for application of some parts of the *Ombudsman Act 1974*, which allows for inquiry into the circumstances of individual deaths.

Determining reviewable deaths

To assist in the identification of deaths that are reviewable, section 37 of CS CRAMA requires some agencies to notify the Ombudsman of certain deaths:

(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.

In addition to these legislated requirements, disability service standards require relevant disability services to complete a Client Death Notification form when a client dies. The form is provided to this office through the Department of Ageing, Disability and Home Care. In regard to children, this office has access to the client database of the Department of Community Services and to NSW Police Computer Operated Policing System (COPS).

The Act also requires relevant government agencies and service providers to give the Ombudsman full and unrestricted access to records that he reasonably requires to exercise his functions under the Act. This means that we are able to draw on all relevant documented information about the circumstances surrounding a death.

Advice on reviewable deaths

We have established two advisory committees to assist in our work in reviewing deaths. The membership of these two committees is set out in appendix 1. The committees provide us with valuable advice on complex child or disability death matters, and on relevant policy and practice issues. Both committees have participated in the preparation of this report through provision of advice and feedback.

In the year to December 2005, both the reviewable child death advisory committee and the reviewable disability deaths advisory committee met on three occasions.

Reviewable deaths that occurred in 2004

Under the legislation, the Ombudsman must report to Parliament each year about reviewable deaths. This report is the second annual report prepared by this office.

In 2005, we reviewed the deaths of 195 individuals who died in 2004. In two cases, the death was that of a child with disabilities who lived in care. We have considered these two deaths in both sections of this report. The report therefore relates to the deaths of 104 children and 93 people with disabilities.

All the agencies whose work is referred to in the report were given an opportunity to comment on relevant sections prior to publication. All comments were considered in producing the final report, and where relevant information was provided, it has been incorporated.

The report is divided into two main sections: reviewable disability deaths and reviewable child deaths. Each section provides information about the individuals who died, the findings of our reviews, recommendations arising from those findings, and information about agency progress in implementing our recommendations from our previous report.

The Act requires that we monitor and report on implementation of previous recommendations. The recommendations made in this report take into account our earlier recommendations. Where we have determined that they have not been sufficiently progressed, we have incorporated them into the new recommendations. Where appropriate, we have updated the earlier recommendations to take account of relevant administrative or policy changes. In this way, we intend to fully monitor how agencies respond to our recommendations over time.

Endnotes

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

[2] A report must be made under Part 2 of Chapter 3 of the *Children and Young Persons (Care and Protection) Act 1998*

Reviewable disability deaths

Agencies involved when a person with a disability dies in care in NSW and the death is reviewable

The NSW Coroner

Reviewable deaths are also coronial deaths under s.13AB of the *Coroner's Act 1980*. This means that death certificates cannot be written by a medical practitioner. Rather, the death must be referred to the Coroner. The Coroner will examine the death and may hold an inquest to determine the cause and manner of death. The Coroner is required to notify the Ombudsman of any reviewable death notified to him no later than 30 days after receiving this information.

The Department of Ageing, Disability and Home Care (DADHC)

At the time of the person's death, the service provider completes a Client Death Notification form (CDN), and submits it to DADHC no later than 48 hours after the person's death. At this time, or as soon as possible thereafter, the service provider also sends the associated documents (health care plans, briefing notes, etc) to DADHC, which then forwards the documents to the Ombudsman. DADHC is required to provide the Ombudsman with copies of any notification it receives relating to a reviewable death no later than 30 days after receiving the notification.

The Ombudsman

Using information from the CDN, the Coroner and DADHC, the Ombudsman determines whether the death of a person with a disability in care is reviewable. A register is kept of those deaths that are reviewable.

Reviews are generally based on scrutiny of relevant files and records relating to the person. All NSW government agencies and relevant non-government service providers and licensed services are required to provide the Ombudsman with full and unrestricted access to records that are reasonably required to review a death. Where appropriate, the Ombudsman may undertake inquiries or investigate matters relating to the death of a person with a disability in care under the *Ombudsman Act 1974.*

1. Introduction

1.1 Reviewable disability deaths

Section 35(1)(f) of the *Community Services (Complaints, Reviews and Monitoring) Act 1993 (CS-CRAMA)* specifies a reviewable disability death as being that of '*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*'.[1]

A key reason for reviewing deaths is to identify any lessons to be learned and ways in which those lessons can be applied to prevent future deaths. Key considerations in reviewing the death of a person with a disability in care include:

- whether the death was potentially preventable
- whether the person received appropriate care and support
- whether risks were identified and adequately managed
- whether any systems, policy or practice issues are evident from the case, and whether these things are current.

Where we identify issues, our role is to analyse them and develop recommendations about policies and practices that could be implemented by government and service providers to improve service provision and assist in the prevention or reduction of deaths.

All reviews of the deaths of people with disabilities in care involve consideration of information provided on the Client Death Notification form (CDN) and any related plans sent in with the form. Depending on the individual matter, the process can also involve review of records from the service provider, health facilities, medical practitioners, and other services involved with the person.

1.2 Developments since our last report

In NSW, DADHC has lead responsibility for developing policy; planning and administering programs; and managing and monitoring the delivery of services for people with disabilities. In addition, the department is the largest provider of supported accommodation for people with disabilities, and provides community support services and respite care. NSW Health has lead responsibility for developing policy in relation to health care in NSW, and for planning, delivering and coordinating health services, including public and community health, public hospitals, and acute care. There are areas of overlap between DADHC and NSW Health in the provision of care to people with disabilities.

In last year's report[2] we made ten recommendations, seven of which were directed solely to DADHC, two that were directed solely to NSW Health, and one that was directed jointly to DADHC and NSW Health. The recommendations, and the progress of DADHC and NSW Health in implementing them, are detailed on page 45.

DADHC

Many of the recommendations we directed to DADHC related to DADHC's advice that it intended to review its *Managing Client Health* policy in March 2005. DADHC advised that in early May the policy was ready to be submitted to the DADHC Operations Executive for endorsement. To date, the policy has not been released. The policy was to be rolled out to funded services from August 2005. DADHC has advised that the *Managing Client Health* policy has been updated to take into account our recommendations, but it is deferring consultation to enable the inclusion of sections relating to children and young people in out-of-home care. DADHC has advised that the policy will be available for comment in late November 2005.[3]

A key part of the recommendations concerned the *Ensuring Good Nutrition* policy, and the department's roll out and monitoring of the implementation of the policy and associated tools. DADHC has advised that implementation of the policy by funded services will be monitored through its new monitoring system, the Integrated Monitoring Framework. In addition, the new DADHC client database, the Client Information System, will be used to monitor the presence and quality of nutrition management plans for clients in DADHC operated services.

NSW Health

Our recommendations to NSW Health centred on three key areas: inclusion of asthma management in its education of General Practitioners (GPs), review of the department's *Dying with Dignity* guidelines, and joint projects with DADHC. In response, NSW Health has advised that best practice approaches to the management of respiratory and other illnesses would be included in the Centre for Developmental Disability Studies (CDDS) educational strategy as part of NSW Health's Primary Health Care Capacity Building Project, which also includes education of clinicians such as community health workers and allied health staff. The GP and community health workers training sessions have now been completed.[4]

The information provided by DADHC and NSW Health in relation to joint work being undertaken by the agencies to support people with disabilities was minimal. NSW Health provided details of a number of activities that we had reported in last year's annual report, including development and use of the *My Health Record*,[5] improvements to discharge planning, and the Primary Health Care Capacity Building Project. NSW Health also advised of a number of areas of work that are being done by the DADHC / NSW Health Senior Officers Group (SOG).

Considering the responses to our recommendations, we note that a small number of DADHC and/or NSW Health initiatives have been completed during this reporting period:

- Diagnosis and Assessment Services were transferred from DADHC to NSW Health effective 1 July 2005. Diagnosis and Assessment Services are multidisciplinary teams that work with individuals and their families to identify the cause, origin, and extent of an individual's developmental delay or intellectual disability.
- DADHC released its *Individual Planning for Adults in Accommodation Support Services* policy in October 2004. The policy has been released to both DADHC operated and funded services, although only DADHC operated services are required to implement the specific procedures outlined in the policy. The policy outlines the individual planning process for clients of DADHC accommodation services, and ties together risk assessments, health care planning, and a lifestyle and environment review.
- DADHC developed and piloted its *Nutrition Assessment Tool*, which it has implemented in DADHC operated services.
- DADHC has started using the Redeveloped Disability Client Database for records management to ensure client management plans are developed and reviewed according to set timeframes.
- DADHC has developed and piloted its *Electronic Records Management Procedures for Group Homes* as part of its Electronic Records and Document Management project. It has provided briefings to Regional Managers and System Support Coordinators.
- NSW Health completed and released its *Guidelines for end-of-life care and decision-making* in March 2005.
- CDDS was contracted by NSW Health to develop a disability-awareness training package for hospital staff, and to implement the training in public hospitals across NSW. The project was to support the *People with Disabilities: responding to their needs during hospitalisation* policy directive, and was completed in May 2005.
- NSW Health completed and released its *People with Disabilities: responding to their needs during hospitalisation* policy directive in October 2005.[6]

2. Reviewable disability deaths in 2004

This report focuses on the key themes and concerns we have identified in reviews of deaths that occurred in 2004, and also on work we undertook in 2005.

Our data comes from the CDN forms completed by service providers and information obtained through the course of reviews. We have, where relevant, separated the data relating to the deaths of people in DADHC operated or funded services, together referred to in this report as 'disability services', from that relating to the deaths of people in boarding houses.[7] Although reported together, the separation of these two groups reflects the differences in the legislation and framework for service provision. It also allows for more relevant analysis of the data for each group, and enables comparison where appropriate.

In addition to monitoring and reviewing reviewable deaths, one of our functions under *CS-CRAMA* is undertaking research or other projects for the purpose of formulating strategies to reduce or remove risk factors associated with reviewable deaths that are preventable.[8] Pursuant to this function, we undertook a health care planning review in relation to deaths in 2004, incorporating DADHC operated and funded services. The review followed on from concerns identified in last year's report about management and coordination of health care for people with disabilities in care. In the project we explored the quality of health related plans used by services, examined how funded services plan and coordinate service provision to meet the health needs of clients, and obtained information about the role and levels of confidence of residential support workers in relation to health care. The report from our health care planning review begins on page 23.

Throughout this report we use case studies. We have not identified particular services or the people who died.

The following provides an overview of data from deaths in 2004. Where we have identified significant changes from 2003, this is noted. Appendix 3 provides a detailed description of data from 2004.

2.1 Demographic information

In 2004, 93 deaths of people with disabilities in care were reviewable deaths. Two of the deaths were of children with disabilities, which were also determined as being reviewable child deaths. These deaths are also considered in the child deaths section of this report.

Age

The age range in the group was 15 – 93 years. While the average age at the time of death of the group of 93 was 57.6 years, separating deaths in boarding houses from deaths in disability services provides a slightly different picture. The average age at the time of death for residents of disability services was 54.8 years, while for residents of boarding houses it was 65.7 years.

The average age at the time of death for people with disabilities in care is considerably lower than the life expectancy of the general community in Australia. The Australian Institute of Health and Welfare (AIHW) reports that Australians in the general community can now expect to live for an average of 80 years, with the life expectancy of females being 82.6 years and males 77.4 years.[9] In 2004, people with disabilities in the care of disability services died an average of 25 years earlier than the general population.

Further consideration of the age of people who died in the care of disability services in 2004 indicates that the majority of people in the older age brackets (55 years and older) lived in large residential centres. In converse proportion to the general population, males had a higher average age at time of death (55.8 years) than females (53.1 years).

Gender

In 2004, 63 males (67.7%) and 30 females died. The difference in proportion is higher than 2003 where 59% of the group was male, and higher than the gender proportion of people using disability support services in Australia, where 59% are male.[10]

In the boarding house group the difference was more marked, with 20 males (83.3%) to four females.

Cultural background

Eight service users (8.6%) were reported as being from a non-English speaking background, five of whom were in boarding house accommodation. Six were reported as having a first (or preferred) language other than English. One client was reported as being of Aboriginal or Torres Strait Islander (ATSI) origin.

2.2 Service provision

Service type

In 2004, the split between deaths in DADHC services and those in funded services was fairly even. There were 34 deaths (36.6%) in DADHC services, and 35 deaths (37.6%) in 20 funded services. There were 24 deaths (25.8%) in boarding houses, up from 22 in 2003.

The types of residential accommodation categorised on the CDN are:

- Group homes – fewer than seven people
- Small residential centres – between seven and 20 people
- Large residential centres – more than 20 people
- Licensed residential centres – also known as boarding houses, where the number of residents depends on the licence conditions
- Respite care (group homes or large residential centres).

Number of people with a disability living in different types of residence

Type of residence	Number of people accommodated	Change since 2003*	Number of deaths	Percentage of population who died	Percentage of reviewable deaths	Percentage change since 2003**
Group home (funded)	2120	+535	16	0.8	17.2	+1.4
Group home (DADHC)	1284	+66	13	1.0	14.0	-2.8
Large residential centre (DADHC)	1249	-29	21	1.7	22.6	-1.2
Boarding house	1058	-14	24	2.3	25.8	+4
Large residential centre (funded)	525	-38	18	3.4	19.4	+5.5
Small residential centre (funded)	197	+127	1	0.5	1.1	-4.8
Small residential centre (DADHC)	18	+2	0	0	0	0

* Figures indicate percentage change between numbers of people accommodated in each type of residence from 2003 to 2004.
** Figures indicate percentage change between numbers of reviewable deaths from 2003 to 2004.

The largest proportion of residents died in large residential centres, followed by boarding houses. While most of the people who died in group homes were under 55 years of age, most of the people who died in large residential centres were 55 years and older. Half of the people who died in boarding houses were 65 years and older.

We considered the boarding house deaths against the accommodation categories / sizes assigned to disability accommodation, and found a similar pattern to the disability services group. Most of the 24 people who died in boarding houses in 2004 (21 people, 87.5%) lived in premises that accommodated more than 20 people. Three people lived in premises that accommodated between seven and 20 people, with no boarding house deaths occurring in premises that accommodated less than seven people.

Time in residential care

Total lifetime years spent in care

On average, the people in disability services who died in 2004 had been in care for 32 years. In both large residential and group home accommodation, the majority of people who died had been in care for more than 21 years. This information was largely unavailable from boarding houses, with most having ‘unknown’ recorded against length of time in care. For the seven people where this information was known, most had been in care for over 15 years.

Years at most recent location

On average, the people in disability services who died in 2004 had lived at their most recent location for 17.9 years. On average, the boarding house residents had lived at their most recent location for 5.7 years. While the greatest proportion of boarding house residents had lived at their most recent location for 6-10 years (10 people, 41.7%), only two people had lived there for more than ten years.

When and where people died

While overall the highest number of deaths occurred in spring, the highest number of deaths of disability services residents (21 people, 30.4%) occurred in winter. We have received the cause of death for 18 of the 21 people who died in winter. Most of these deaths (61.1%) were respiratory-related, including pneumonia, bronchopneumonia, respiratory failure, and aspiration pneumonia.

For boarding house residents, spring was the dominant season of death, with 37.5% of the deaths (9 people) occurring during those three months. We have received the cause of death for only two of the nine people who died in spring, preventing analysis of the main causes of death at that time. Diseases of the circulatory system, (eg coronary artery disease), were either the direct cause or a factor in the deaths of both of these people.

For both groups, most people died in hospital. A small number of people, all residents of disability services, died in palliative care units. A small number of boarding house residents died either in the community (eg collapsed on a footpath) or in an ambulance on the way to hospital.

2.3 Disability, primary health conditions, and support needs

Disability

82.6% of people (57) in the care of disability services were reported to have had an intellectual disability, and most were reported to have had a severe or profound level of intellectual disability (56.1%). The aetiology (or cause) of the intellectual disability was recorded for only 20 people, with Down syndrome identified in relation to 11 people.

Notably, there were a small number of residents of disability services who were recorded as not having an intellectual disability, including six residents who had a physical disability, and one resident who had a psychiatric disability.

Most of the disability services group had an intellectual disability in addition to at least one other disability. Besides intellectual disability, the main recorded disabilities were physical disability (47.8%, mainly cerebral palsy), sensory disability (43.5%, mainly sight impairment), and psychiatric disability (23.2%, mainly schizophrenia). The majority of disability service residents had two to three disabilities.

The most commonly recorded disability in relation to boarding house residents was psychiatric disability (50%, mainly schizophrenia), followed by Acquired Brain Injury (33.3%, all alcohol-related brain damage).

More than half of the boarding house residents had some form of cognitive impairment. Four people were recorded as having an intellectual disability (16.7%), with two of these people identified as having a moderate level of intellectual disability. In addition, ten (41.7%) boarding house residents were identified as having other forms of cognitive impairment, with eight people having alcohol-related brain damage, and two people having dementia.

Although most boarding house residents had one disability, seven people had two or more disabilities.

Health conditions

In addition to having multiple types of disability, the people who died in the care of disability services in 2004 also had multiple health conditions. As part of our health care planning review, we examined the number and type of health conditions identified on the CDN by DADHC and funded services. We found that the average number of health conditions for the 69 people in this group was 6.52. The average number of health conditions for people in DADHC services was higher than that of people in funded services, and people in large residential facilities were recorded as having a higher average number of health conditions compared to people in group homes. People living in DADHC large residential centres were recorded as having the highest number of health conditions overall, with an average of 7.82 health conditions per person.

Health conditions most commonly reported for disability services residents

	Percentage
Urinary incontinence	68.1
Dysphagia (swallowing difficulties)	65.2
Faecal incontinence	55.1
Respiratory condition[11]	46.4
Epilepsy	39.1
Constipation	39.1
Weight concerns – overweight or underweight	33.3
Vision impairment	31.9
Gastro-oesophageal Reflux Disease (GORD)[12]	30.4
Mental illness	20.3
Osteoporosis	18.8
Cancer	17.4
Diabetes	15.9
Hypertension	13.0
Hearing impairment	13.0
Asthma	11.6

Many of the above health conditions have the capacity to substantially affect independence, mobility, and quality of life. Incontinence, for example, can cause embarrassment, limit opportunities for access to the community, and lead to the loss of independence and dignity, particularly if poorly managed. The management of incontinence can be enhanced by access to continence consultants, charting bowel movements, and implementing bowel regimes. Weight issues (page 15), dysphagia (page 16), and constipation (page 31) are discussed below.

The common health issues for the people who lived in boarding houses were quite different from the disability services group.

Health conditions most commonly reported for boarding house residents

	Percentage
Chronic Obstructive Pulmonary Disease (COPD)[13]	29.2
Cancer	29.2
Diabetes	16.7
Constipation	16.7
Asthma	16.7
Dysphagia	16.7

A number of these health conditions are discussed in other sections of this report, including COPD on page 19, and broader issues emerging from our reviews of the deaths of people in boarding houses from page 36.

Immunisation

The Australian Immunisation Handbook 8th Edition (2003) indicates that people with disabilities in care should receive annual influenza vaccination, and that people with chronic illness should also receive pneumococcal vaccination.

82.6% of the disability services group had received influenza vaccination, with 62.5% of people in boarding houses receiving this vaccination. Fewer people were reported to have received the pneumococcal vaccine, including almost one third of the disability services group (30.4%) and 12.5% of the boarding house group.

In both groups there were relatively high numbers of people whose immunisation status was either unknown or not recorded. For example, there were 31 people in the disability services group whose pneumococcal vaccination status was either unknown or not recorded, and nine people whose influenza vaccination status was unknown or not recorded.

Although immunisation is not specifically referred to in *Standards in Action*, there are requirements for funded services to ensure health risk screening occurs and appropriate intervention is undertaken. Under the *Managing Client Health* policy, DADHC services are required to keep a vaccination record for each client, and the *My Health Record* provides the means for capturing this information. However, in the deaths we reviewed, we found only two *My Health Record* booklets on file, and both were largely blank.

In response to our recommendation in last year's annual report about including in the revised *Managing*

Client Health policy the recommendations of the current Australian Immunisation Handbook for groups with impaired immunity or who have chronic disorder of the pulmonary or circulatory system – in particular, the need for pneumococcal and influenza vaccinations – DADHC advised that the Handbook's recommendations would be incorporated into the revised policy in 2005 and rolled out to funded services.[14] DADHC has subsequently advised that it has updated the *Managing Client Health* policy to take into account our recommendations; however it is deferring consultation on the policy until late November 2005.[15]

Weight

It was possible to determine the Body Mass Index (BMI) for 51 of the 69 people (73.9%) in the disability services group. It should be noted that the inability to calculate the BMI for some residents was primarily due to their height not being recorded – most had their weight recorded as per *Standards in Action*. The *Ensuring Good Nutrition* policy refers to the need for services to have a dietitian's assessment made when a person's healthy weight range cannot be determined because their height cannot be measured. We saw few examples of this in practice.

BMI figures are calculated differently for children and for people 65 years of age and over. Of the 51 people in the disability services group where weight and height was recorded, 36 people were 18-64 years of age. Most of this group (61.1%) were outside the healthy weight range, with 38.9% above the average weight. Of the 23 people in the disability services group who were aged 65 years and over, most were in the healthy weight range, with one person very underweight, and four people overweight to severely obese. The BMI could be calculated for only one of the two children in the group, and she was below the 5th percentile BMI-for-age, placing her in the very underweight range.

Height and weight were recorded for only seven boarding house residents, with three people aged 18-64 years. Two of the three people were overweight, and the other person was within the healthy weight range. The BMI could be calculated for four boarding house residents aged 65 years and over, with one person underweight, one person severely obese, and two people within the healthy weight range.

BMI category for whole group – 18 to 64 years

	Number	Percent
Very underweight (<16.99 kg/m^2)	6	15.4
Underweight (17 - 18.4 kg/m^2)	2	5.3
Healthy weight range (18.5 – 24.9 kg/m^2)	15	38.5
Overweight (25 – 29.9 kg/m^2)	9	23.1
Obese (30-34.9 kg/m^2)	4	10.3
Severe obesity (>/= 35 kg/m^2)	3	7.7
Total	**39**	**100.0**

We have previously commented on the risks faced by people who are underweight, including increased susceptibility to infection due to an impaired immune status, and these risks were exemplified in the deaths of people of below average weight in 2004. The cause of death has been received for six of the ten people who were either underweight or very underweight. Each of these six deaths was the result of infection, including five deaths related to pneumonia or aspiration pneumonia.

Overweight and obesity were prominent in relation to the people with disabilities in care who died in 2004. Obesity is known to increase the risk of morbidity and mortality, and the prevalence of overweight and obesity in adults with intellectual disability is reported to be higher than in the general population.[16] Obesity is recognised as a risk factor in over 45 diseases, including coronary artery disease and non-insulin dependent diabetes mellitus.

The reason for the prevalence of obesity and overweight may be linked to a range of factors, including the largely sedentary lifestyle of many people with disabilities in care, limited mobility, the effect of medications, and poor nutrition. Research has suggested that effectively addressing this issue will require a multilayered approach, where targeted programs to increase exercise, reduce obesity, and improve nutrition are combined with interventions to address broader social determinants of health.[17] The capacity for people with disabilities to have healthy lifestyles is considerably curtailed by things like transport and staffing constraints, low client income, limited options for physically active recreation in the community, and lack of or limited access to meaningful day activities. Serious consideration needs to be given to many of these social factors affecting people with disabilities in care in order to improve their health and wellbeing.

Swallowing difficulties (dysphagia)

Most of the residents of disability services (45 people, 65.2%) were recorded as having swallowing difficulties, and the majority (30) lived in DADHC accommodation. Most of the people identified as having swallowing difficulties were in large residential centres. Four boarding house residents were reported to have swallowing difficulties.

Enteral nutrition

Six people in disability services were reliant on enteral nutrition, which is the delivery of liquid nutritional formula via a tube. All had percutaneous endoscopic gastrostomies (PEGs). Of these six people, three had a BMI that placed them in the healthy weight range, one was in the underweight range, and another was in the very underweight range. For the remaining person the BMI could not be determined because the height was not recorded. Five people did not receive any food by mouth and relied exclusively on enteral nutrition.

Dentition

60.9% of clients (42 people) in disability services were recorded as having either no teeth or only some teeth. Of these 42 people, 29 were reported to have swallowing difficulties.

The dentition status was known for 17 boarding house residents, and eight of these 17 people (47.1%) had either no teeth or only some teeth. One of these eight people had swallowing difficulties.

Involvement of allied health

Speech pathologists assess and diagnose swallowing disorders, and develop comprehensive treatment regimes based on an understanding of the complete swallowing process, including an appropriate mealtime management plan.[18] Referral to speech pathology is suggested in relation to 14 of the 24 nutrition and swallowing checklist questions, and the *Ensuring Good Nutrition* policy states that good practice calls for the involvement of a speech pathologist in the review of nutritional care plans.

Of the 45 residents of disability services with swallowing difficulties, 27 (60%) had seen a speech pathologist or been to a dysphagia clinic in the 12 months prior to their death. Most of these people (20) lived in DADHC services. However, as 30 people in DADHC services were identified as having dysphagia, this meant that only 66.7% had seen a speech pathologist in the year before their death. For the 15 people from funded services who were identified as having dysphagia, only seven (46.7%) had seen a speech pathologist in the 12 months before death. The relatively low number of people with dysphagia who saw a speech pathologist from DADHC services is surprising given the provision of speech pathology services within the department and established referral process. As part of our health care planning review, funded services advised of significant difficulties gaining access to DADHC speech pathology services. This advice is borne out by information provided by DADHC that indicates that, across the DADHC regions, any person referred for DADHC speech pathology can expect to wait an average of 5.7 months before being allocated a service.[19]

Our reviews this year also indicated that not all funded services are aware of the need to involve allied health professionals where there are identified nutrition and swallowing risks. This is despite the *Ensuring Good Nutrition* policy stating that people who have difficulty swallowing need to have their nutritional care plans reviewed at least six monthly, and that good practice calls for the involvement of a speech pathologist in the review.

None of the four boarding house residents who had swallowing difficulties had seen a speech pathologist in the 12 months prior to death. Two of these people had lung cancer and developed swallowing difficulties in the last stages of their illness.

Nutrition and swallowing checklist

A requirement of the *Ensuring Good Nutrition* policy is to complete nutrition and swallowing checklists, and it is recommended that the checklist be used annually in tandem with the individual planning process. The policy currently applies only to DADHC operated and funded services. When we looked at the people in disability services who had swallowing difficulties, we found that 30 people (66.7%) had nutrition and swallowing checklists completed in the 12 months prior to death, and 27 of these were in DADHC services. Only three of the 15 people with swallowing difficulties in funded services had a nutrition and swallowing checklist (20%). We would expect this number to be higher, given the roll out of the *Ensuring Good Nutrition* policy, although we note that the roll out was not completed in funded services until mid-2004.

Eating and drinking plans

An eating and drinking plan is intended to be an easy to understand record of how to best assist a person to eat and drink. It may provide details on positioning and seating, equipment, assistance required, food and drink preferences, food and drink consistencies, and suggested food items and quantities.[20] The information contained in the plan needs to be updated regularly, depending on the needs of the person.

Thirty-six people (80%) had eating and drinking plans (also known as mealtime management plans) on file.[21] All except three people with swallowing difficulties in DADHC services had an eating and drinking plan, and nine people in funded services had one. Interestingly, more people with swallowing difficulties in funded services had an eating and drinking plan than had a nutrition and swallowing assessment. This suggests that funded services may have used another means of assessing client nutrition and swallowing risks, or the plans outlining how best to support the clients at mealtimes may have been developed without a thorough assessment of all the risks.

In response to recommendations in the 2003-2004 reviewable death annual report, DADHC advised that systems to support the implementation of nutrition and swallowing checklists in funded services had been established. DADHC advised that it would look for evidence that the nutrition and swallowing checklist and eating and drinking plans were being used in funded services through the three-yearly cycle of review in the Integrated Monitoring Framework (IMF). DADHC informed us in September 2005 that the documents relating to the IMF had not yet been finalised.

DADHC has also advised that the department's client information databases (the Redeveloped Disability Client Database and the Client Information System) and the Quality and Safety Framework would identify clients of DADHC operated services who do not have a nutrition and swallowing checklist and/or eating and drinking plan. Regional Quality Committees will oversee implementation of these plans in DADHC operated services.

Consent provider

Most people (58, 84.1%) in disability services were reported as having a 'person responsible'[22] for consenting on their behalf to medical or dental treatment. Family members were the primary people involved in consent decisions, with 44 people (63.8%) having a family member act as person responsible, and four people (5.8%) sharing the decision-making with the family member or other person. All those that did not have a person responsible provided their own consent to medical and dental treatment, either alone or in conjunction with someone else.

For three people, the Guardianship Tribunal was listed as their consent provider, but there was no indication from the information provided that the service contacted the Tribunal about medical or dental treatment decisions for the individuals concerned. Two of these individuals were recorded as having a severe level of intellectual disability, with the other individual having a moderate intellectual disability and receiving medications that fell within the scope of 'major treatment'.[23]

In the boarding house group, a greater proportion of people (12 people, 50%) were recorded as providing their own consent to medical and dental treatment, either alone or with someone else. However, 10 people (41.7%) had family members involved in consent decisions, either acting as the person responsible, or sharing the decision-making with the individual. Despite this, in relation to many of our reviews there was no indication in the boarding house records that the persons responsible were involved in decision-making for medical treatment, or that their consent was sought.

Last year we recommended that DADHC ensure that the revised *Managing Client Health* policy include 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. DADHC advised that this information would be included in the review of *Managing Client Health*, and that there would also be links to a new *Decision Making and Consent* policy by April 2005. In addition, DADHC advised that the Substitute Consent for Medical and Dental Treatment form and Information sheets were redeveloped in 2004, and would be posted on the DADHC internet and released as an attachment to both the *Decision Making* and *Managing Client Health* policies.[24] To date, the *Decision Making and Consent* policy has not been released.

Involvement of health professionals

It was evident in our reviews of the deaths of people with disabilities in care in 2004 that most people saw a GP on a regular basis. In the CDN we ask services when the person was last comprehensively assessed by a GP. This is to identify whether the person was assessed and screened for potential health conditions as well as presenting health concerns. Comprehensive health assessments provide the opportunity for health care planning, early intervention, and preventative work, rather than just reactive treatment. For the 69 people in the disability services group, the majority (58 people, 84.1%) were reported to have had a comprehensive assessment in the year prior to death. Nine people (13%) had no record of a comprehensive assessment in the last 12 months of life.

In relation to the people who lived in boarding house accommodation, less than half of the group (45.8%) had had a comprehensive review by a GP within 12 months of their death. This is despite many boarding houses having a weekly or fortnightly schedule for GP consultations.

3. Cause of death

The following table identifies the primary cause of death in 58 of the 93 people who died in 2004 (62.4%), categorised according to ICD-10-AM codes.[25] At the time of writing, the Coroner had not made a determination of cause of death for the other 35 deaths.

The NSW Coroner provides three possible fields of information in relation to cause of death. The first field is the 'direct cause', which is the disease or condition directly leading to death (eg sepsis). The second field is the 'antecedent cause', which is the morbid condition(s), if any, giving rise to the direct cause (eg bronchopneumonia that led to sepsis). The other field of information that can be provided on the coronial medical report is 'other significant conditions' possibly contributing to the death, but not relating to the disease or condition causing it (eg cerebral palsy).

While diseases of the respiratory system were the most common cause of death for disability services residents, diseases of the circulatory system were the most common cause of death for boarding house residents.

Numbers of deaths in each ICD-10-AM cause of death category*

ICD-10-AM Cause of death category	No. of deaths
Diseases of the respiratory system (J00-J99) This includes diseases of the combination of organs and tissues needed for breathing, including the nasal cavity, pharynx, larynx, trachea, lungs and other associated muscles. For example, influenza, pneumonia, bronchitis, asthma, pneumonitis, pulmonary oedema.	25
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. For example, pulmonary heart disease, hypertension, pulmonary embolism, subarachnoid haemorrhage, cardiac arrest, haemorrhoids.	13
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 and other acute respiratory infections.	6
Neoplasms (C00-D48) A new and abnormal growth, any benign or malignant tumour, often referred to as cancer.	4
Injury, poisoning and certain other consequences of external causes (S00-T98) Traumatic subdural haemorrhage, crushing injury of the larynx and trachea, foreign body in respiratory tract, drowning.	4
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, zerostomia (dry mouth), oesophagitis, gastro-oesophageal reflux, haematemesis.	2
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.	1
Diseases of the genitourinary system (N00-N99) Diseases that affect the reproductive system (male and female) and also the urinary system. For example, renal failure, cystitis, amenorrhoea (failure to start menstruation).	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. For example, dyspnoea, asphyxia, respiratory arrest, sudden death, dysphagia, senility.	1
E**xternal 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.	1
Undetermined	**35**

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

3.1 Respiratory illness

The cause of death for 32 people was related to respiratory illness.[26] This is 55.2% of the 58 known causes of death. Eight people (25%) lived in group homes, 22 people (68.8%) lived in large residential centres, and two people (6.3%) lived in boarding house accommodation.

Of the 30 people in the disability group whose deaths were respiratory related, 13 had aspiration pneumonia, and 13 had pneumonia or bronchopneumonia. Their mean age at death was 50.7, which was lower than the mean age at death of the disability services group as a whole. Both boarding house residents who died from respiratory illness had pneumonia (or bronchopneumonia). They were older than the people who died in disability services at the time of their deaths, aged 72 and 61.

Last year we reported the findings of our group review of people who died from respiratory illness in 2003. In that review we highlighted a number of factors that were common to the group, including high dependency needs (incorporating requiring assistance with meals, limited mobility, incontinence, and multiple disabilities), a history of recurrent respiratory illness, underweight, a diagnosis of GORD, and swallowing difficulties. We considered many of the same factors in relation to the people whose deaths were related to respiratory illness in 2004.

Of the 30 people in disability services whose deaths were respiratory-related, the majority had swallowing difficulties (23 people) and either no teeth or only some teeth (20 people). In addition, most had limited mobility (26 people), and weight outside the healthy weight range, including five people who were underweight. Notably, overweight also featured for the people who died from respiratory illness, with nine people overweight, obese, or severely obese. Most people had been vaccinated against influenza (25 people).

Six of the 11 people who were recorded as having Down syndrome died from respiratory illness, including one person who died from aspiration pneumonia. As indicated last year, people with Down syndrome are at a high risk of developing respiratory illness due to a genetic predisposition to congenital heart disease, ear, nose and throat problems, and immunological factors.

Sixteen people who died as a result of respiratory illness had recurrent respiratory infections, and/or COPD, and/or asthma. As reported last year, it would be best practice for people who have asthma that is not controlled by medication or require oral steroids, people who have a diagnosis of COPD, or people who have a disability and an occurrence of pneumonia to be referred to a respiratory specialist. Of these 16 people, only three had seen a respiratory specialist in the 12 months prior to death.

Aspiration

Aspiration refers to the entry of material (food, liquid or saliva) into the airway. In some people the ability to detect the entry of food into the airway is reduced, or the cough to move the aspirated material back into the throat is weak or ineffective. Over time, damage can occur to the lung. In addition, if a large quantity of food or drink is aspirated it can cause respiratory illness.[27] Deaths related to aspiration are, in many cases, considered to be largely preventable. The involvement of appropriate specialists such as speech pathologists, the development and use of individualised eating and drinking plans, and the provision of appropriate supervision are some factors that can help to reduce the risks of death relating to aspiration. We looked closely at the 13 deaths related to aspiration.

Weight and nutrition

Most of the 13 people whose deaths were related to aspiration required assistance with meals (12 people), had swallowing difficulties (11 people), and had either no teeth or only some teeth (nine people). Three people received enteral nutrition, with two of these people receiving no food by mouth.

Almost half of the group were recorded as being outside the healthy weight range, with half very underweight and half overweight.

Just over half of the group had a nutrition and swallowing checklist completed in the 12 months prior to death, and all were clients of DADHC services. More people (nine people) had an eating and drinking plan or equivalent, and most were clients of DADHC services.[28]

Involvement of health specialists

Eight of the 13 people had seen a speech pathologist or attended a dysphagia clinic in the last 12 months of life. Less than half (six people) had seen a dietitian in the 12 months prior to death. [29] Only one person had seen a respiratory specialist in the 12 months prior to death.[30]

3.2 Cardiovascular disease

Cardiovascular (or circulatory) diseases comprise all diseases of the heart and blood vessels, including coronary heart disease (or ischaemic heart disease), stroke (or cerebrovascular disease), heart failure, and peripheral vascular disease.[31]

The deaths of 21 of the 58 clients (36.2%) whose causes of death we have received were related to cardiovascular disease. Cardiovascular disease is the leading cause of death for Australians, and it was the most common cause of death in 2004 for boarding house residents, affecting two-thirds (eight of the 12) boarding house residents whose causes of death we have received. The deaths of 13 of the 46 disability services residents whose causes of death we have received were related to cardiovascular disease (28.3%).

The major preventable risk factors for cardiovascular disease are tobacco smoking, high blood pressure, high blood cholesterol, insufficient physical activity, overweight and obesity, poor nutrition and diabetes. Evidence suggests that risk factor control significantly reduces morbidity and mortality related to cardiovascular disease.[32]

Of the eight boarding house residents with circulatory related deaths, most had at least two of the above risk factors, with three people being recorded as having three risk factors for cardiovascular disease. Of the 14 people in the disability services group who had circulatory related deaths, most had at least two risk factors for cardiovascular disease, with two people being recorded as having three risk factors, and one having four.

3.3 Sepsis

Nine deaths were related to sepsis in 2004 (15.5% of received causes of death). So far in 2005 there have been two deaths related to sepsis.

Sepsis is an infection in the bloodstream. It is more likely to occur when there is an infection in the body, such as in the lungs, abdomen, urinary tract, or skin. It is also more likely to occur in a person whose immune system is not functioning properly. Sepsis is very serious, and the risk of death is high. An associated condition is septic shock, where the blood pressure falls to life-threateningly low levels as a result of sepsis. Septic shock occurs most often in newborns, people over 50, and people with a compromised immune system. It is more of a risk when white blood cell counts are low, as occurs in people who have cancer or chronic diseases such as diabetes.[33]

Four of the nine deaths were related to respiratory illness, including a 76-year-old man who died of septic shock caused by aspiration pneumonia. Two of the deaths were caused by urinary tract infections, and three were caused by issues relating to the digestive system, including two caused by bowel perforations. The common element for many of the people whose deaths were related to sepsis was that they had a number of significant co-existing health conditions. Our medical advice indicated that a number of these health conditions by themselves would leave a person vulnerable to infection and sepsis.

One factor that may impact on deaths due to sepsis is the ability of the client to communicate. Although only two of the nine people whose deaths in 2004 were related to sepsis were recorded as receiving communication support,[34] eight had an intellectual disability, and at least three of these people were recorded as having a severe or profound level of intellectual disability. Sepsis, if identified at an early stage, can be treated with antibiotics, but a delay in starting antibiotic treatment greatly decreases the chances of survival.[35] Where a client is either unable to or has difficulties in communicating their needs and any episodes of illness, the chances of sepsis being detected at an early stage are reduced. Communication is discussed further on page 30.

3.4 Cancer

Although cancer now ranks second as an overall cause of death for Australians,[36] it was not a common cause of death for the people with disabilities in care who died in 2004, and whose causes of death we have received. The deaths of eight of the 58 people where cause of death was known were related to cancer. The five people in disability services whose deaths were related to cancer were diagnosed with metastatic squamous cell carcinoma, ovarian cancer, colon cancer, non-Hodgkin's lymphoma, and haematological malignancy. Their age range was 52-67 years.

Two of the three people in boarding houses who died from neoplasms had lung cancer, and were aged 46 and 61. The other resident had ovarian cancer, and was 67.

3.5 External causes of death

As with last year, we have combined the two categories relating to external causes. In 2004 there were five deaths relating to external causes (8.6% of causes of death received). The causes of death for the five people were as follows:

- Multiple injuries when hit by a train
- Death due to the inhalation of vomitus
- Three deaths due to drug toxicity or overdose

The three deaths related to medications are discussed on page 29.

4. Issues arising from reviews of deaths in 2004

Through our reviews of the deaths of people with disabilities in care, we aim to identify strategies for individual services or the service system that may assist to reduce or prevent premature death. By identifying, reporting, and making recommendations in relation to issues of service practice concerning people with disabilities who died in individual services, we aim to provide information that can help improve service provision and promote practices that will minimise more such deaths in those services. Our reviews and analysis of the register of deaths enable us to identify systemic issues and develop recommendations about policies and practices that could be implemented by government and service providers to improve broader service provision and assist in the prevention or reduction of deaths. The following pages highlight some of the issues we identified this year.

4.1 Health care planning and coordination

Our reviews of the deaths of people with disabilities in care repeatedly highlight the importance of services undertaking a planned and coordinated approach to meeting the health care needs of clients. Ensuring that health needs are identified early, appropriate services are coordinated to meet those needs, and there is adequate monitoring and follow-up is a key strategy to reduce premature deaths of people with disabilities in care.

Last year we raised concerns about the management of the health care of people with disabilities in care, and emphasised the importance of health care coordination. NSW Health also stated in its *NSW Chronic Care Program* that the key components in providing and enhancing care for people with chronic illness include care coordination, care planning and ongoing review, multidisciplinary care and rehabilitation.[37]

However, our reviews of deaths in 2004 continued to reveal problems with health care coordination in both disability services and boarding houses, including:

- lack of health screening
- services failing to identify the need to involve specialist services
- delays in following through on identified referral needs
- lack of implementation of specialist or allied health recommendations
- lack of, or only partial, implementation of health related plans.

A number of the identified issues concerning health care coordination from our reviews of the deaths of people in 2004 are discussed in more detail below.

Involvement of specialist services and follow-up of referrals

Our concerns about the coordination of health care extended to the referral for specialist care of people with conditions such as dysphagia, epilepsy, respiratory and gastrointestinal conditions. Many referrals depend on the general practitioner assessment of client health, which in turn is at least partly dependent on the accuracy, quality and timeliness of information available at the time of consultation or full health review. When referrals are made, service providers have a role in ensuring that specialist appointments are kept and recommendations implemented.

While not all people with disabilities in care require referral to specialists, we found a number of instances where specialist involvement was warranted but not sought. In some cases, the need for a referral to specialists did not appear to be recognised. In other cases, the need for specialist intervention was recognised, but referral action was not taken, as in the case study below.

CaseStudy1

A 36-year-old woman who lived in a large residential centre was transferred to hospital after refusing meals, becoming dehydrated, and responding unusually slowly to staff. She died in hospital three days later.[38] She had a severe intellectual disability, Trisomy 18, scoliosis and contractures of the limbs. She was very underweight, and her health issues included recurrent respiratory infections, GORD, constipation, double incontinence, and dysphagia.

Although her most recent health care plan had been in place for five months at the time of the woman's death, few of its contents had been put into practice. Part of the plan was referral to a respiratory specialist for her chest infections. She had five bouts of respiratory infections in the last 12 months of her life, including two episodes after the health care plan was developed, yet there was no indication that a referral was made, or that the possibility of such a referral was raised with her treating GP.

In relation to the woman's dysphagia, the health care plan noted that a referral was required to a specialist (speech pathologist), and referral to the Dysphagia Clinic had been discussed at a case conference a year earlier. However, there was no indication that the referral was made after either the case conference or the development of the health care plan.

During the woman's last hospital admission, a member of hospital staff contacted the service to ask about her eating habits, and stated that she had aspirated. Although she had a current eating and drinking plan, it did not appear to have been provided to hospital staff.

We advised the service of our concerns. In response, the service advised that it had updated protocols on how to conduct clinics for visiting health professionals to include a stringent monitoring process and revised its referral process including monitoring of a referral register. The service said it had also amended its individual planning process to ensure implementation of health care planning, and was finalising a Shared Services Agreement with two Area Health Services for matters such as information sharing and accessing services after discharge.

There are a number of licence conditions that relate to the health care of boarding house residents. These include licence condition 1.4 that requires the licensee to ‘ensure the health, comfort, safety and proper care of persons with disabilities’, and licence condition 6.5.5 that states that ‘each resident has the right to be assisted by the licensee to maintain his or her optimum physical and mental health’. However, the wording of the conditions is broad and can be open to interpretation. Consequently, it can be difficult to define the specific responsibilities of licensees, licensed managers, and boarding house staff in relation to health care management. This lack of clarity may not serve the best interests of boarding house residents.

Some boarding house residents had correspondence from medical professionals on their files that included recommendations for treatment; however, there was little record of follow-up. We noted a lack of clarity in relation to responsibilities for arranging transport, organising appointments, and coordinating support to meet appointments. A lack of case management services, such as those designated under the Boarding House Reform Program (BHRP),[39] and limited staffing in boarding houses appeared to impact on the coordination of health care for these residents.

Approach to health care – boarding houses

In our reviews of the deaths of people in boarding houses, we noted a tendency for medical consultations to be on a scheduled basis with the visiting GP. GP consultations in a number of boarding houses appeared to be set on a weekly or fortnightly basis, and it seemed that residents saw the GP according to that timing rather than their health needs. As a result, some residents were unwell for several days while they waited for the next GP scheduled visit. In some cases, the late diagnosis of significant health conditions was at odds with the frequency with which they were reported to have seen their GP.

CaseStudy2

A 61-year-old man died 13 months after moving to a boarding house from an aged care home. He had been screened in on the basis that he could mobilise independently and was capable of managing his own medication and health care needs. His health conditions were listed on the screening tool[40] as COAD (chronic obstructive airways disease) and non-insulin dependent diabetes mellitus. The CDN listed the man’s disability as ‘alcohol abuse’ and contained no mention of any health conditions. At autopsy the primary cause of death was found to be severe coronary artery disease, with antecedents of chronic alcoholism, diabetes mellitus, and chronic airways limitation.

Health records revealed that during the man’s 13 months at the boarding house, he was sometimes unsteady on his feet, had four falls, two of which resulted in bone fractures, and had five episodes of chest pain. He had ambulance and emergency department presentations, and admissions to four different hospitals during the last year of his life, as well as regular GP consultations. One medical test dated four months before his death found cardiac problems and contained recommendations for investigations and further examinations.

The records also indicated that the man was aggressive and violent towards other residents resulting in injury, and, in one case, hospitalisation of another resident.

A multidisciplinary care plan prepared by the man’s GP addressed the areas of personal care, optometry, depression, and impaired glucose intolerance. However, there was no record of follow-up of recommendations for further investigation of his cardiac episodes, or consideration of referral to a cardiac specialist, and none of his medications were for a cardiac condition.

He provided his own consents to medical treatment, but had become increasingly dependent on staff to respond to frequent episodes of illness. According to hospital records he had difficulty providing accurate reports of symptoms and history.

The man’s hospitalisations and deterioration in health and self-care ability could have resulted in the use of the screening tool to reassess his suitability to stay at the boarding house. The screening tool is intended to lead to referrals for further assessment and the identification of services additional to that provided by the boarding house. This process may have prompted a coordinated response to his increasingly complex health care needs.

At the time of writing this report, we had not concluded our review of this man’s death.

4.2 Health care planning in funded services

In the context of the findings about health care management in our 2003-04 annual report, and our queries as to how funded services were coordinating the health care of clients, we decided to review health care planning in disability services. We conducted an audit of all CDN forms received in 2004 for DADHC operated and funded services; reviewed the health care planning practices within ten funded services where people had died; and surveyed staff in eight of those services. The methodology for the review is provided in Appendix 4.

Framework

The Disability Services Standards (and the *Standards in Action* manual) require that DADHC operated and funded organisations provide services that are tailored to meet the individual needs and goals of clients (Standard 2.0 *Individual Needs*, and Standard 2.1 *Individual Planning and Review*). These organisations are also required to 'promote practices which establish and enhance service users' health and well-being' (Standard 10.4 *Nutrition and Health*). These include:

- having a mechanism for regularly monitoring the health of clients (such as a health checklist developed in consultation with appropriate practitioners) and for ensuring that appropriate intervention occurs when required
- ensuring that regular nutrition and health risk screening and monitoring of clients is carried out by appropriate practitioners, and that intervention occurs when required
- ensuring that records are kept of this process and of interventions recommended and implemented
- ensuring that any significant health conditions of clients are recorded, and all staff are made aware of this information
- ensuring that clients are supported to access specialist health clinicians as needed.

Individual plans provide the framework from which supports and services are planned and coordinated, action is specified, and responsibilities are allocated, for meeting individual needs. *Standards in Action* does not prescribe how services should monitor the health of clients, ensure the appropriate intervention occurs, and implement recommendations.

DADHC's *Managing Client Health* policy (2003) provides for the development and regular review of health care plans for all clients of DADHC operated accommodation services, to be developed through the individual planning process. Health care plans are described in the policy 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 guidance for developing and implementing the plans. The policy has not yet been rolled out to funded services.

The above frameworks for health care planning and coordination do not exist for boarding houses. Although there are licence conditions that specify requirements with respect to health care, they are not supported by detailed policy and practice requirements clarifying the licence condition's requirements. Consequently, our health care planning review did not include boarding houses.

(i) Audit of health conditions and plans in DADHC and funded services

Our findings in relation to health conditions, including the average number per person / type of residence, and the most common health conditions, have been reported in section 2.1. The key information to reiterate here is that residents in DADHC services had a slightly higher number of health conditions than those in NGO services, and people living in large residential centres had a higher number of health conditions than people in group homes or small residential centres.

Quality of health related plans

Our measures of plan quality are based on what we consider to be important information for staff to know to meet the health needs of clients. That is, what action needs to be taken, when it needs to be done, who is responsible, as well as when the health condition and plan need to be reviewed.

When we considered the plans provided with the CDN, and health related plans on file, we included not only plans specifically identified as 'health care plans', but also documents such as nursing care profiles, multidisciplinary care plans, individual plans, and plans developed for specific health issues, such as plans for epilepsy management, mealtime management, palliative care, and nutrition and swallowing checklists. 67 out of the 69 people who died in 2004 (95.7%) had some form of health related plan or document. The other two people may have had plans, but none were provided with the CDN. The plans ranged from one-page documents that listed the health condition and gave a brief outline of medications used, to detailed plans that outlined the health condition, what it meant for the client, what action needed to be taken by staff to support the person, and when the action needed to be taken.

Overall, the results for each aspect of plan quality were of concern:

- 41% of plans described what actions or strategies needed to be taken in order to meet the needs of the client's health conditions.
- 36% of plans indicated timeframes for when action should occur.

- 20% of plans indicated timeframes for the medical or clinical review of the client's health condition(s).
- 14% of plans indicated who was responsible for actions.
- 12% of plans indicated when the plan itself would be reviewed.

Overall, DADHC plans were more likely to describe actions, indicate timeframes, and indicate when plans would be reviewed than the plans of funded services.

We found that clients with dysphagia had plans that were more likely to outline what staff needed to do to support the person than plans for other health conditions. This may be associated with the *Ensuring Good Nutrition* policy development and roll out to both DADHC operated and funded services,[41] and the involvement of speech pathologists in developing the plans in many cases. The difference in plan quality between DADHC operated and funded services in relation to dysphagia was negligible. However, where there had been policy development by DADHC, but this had not been rolled out to NGO services (for example, epilepsy or asthma management), there was a noticeable difference in plan quality. To illustrate, while 75% of DADHC plans in relation to asthma described what staff needed to do to meet the client's needs associated with that condition, this occurred in only 25% of NGO plans.

While the plans developed in relation to dysphagia had the highest degree of quality in relation to our set benchmarks, it was still low considering the policy development and roll out. This information points to the importance of monitoring policy roll out to ensure that it is being implemented across the board.

The generally poor quality of health related plans identified in this audit raises questions about how key health conditions are managed by services – particularly by funded services. In the absence of comprehensive plans, it is not clear how staff would know what to do to support people with particular health conditions. The absence of timetables to review the plans raises questions about how staff would know when to review the plans to see if they continue to reflect current health needs.

(ii) Review of health care planning in funded services

The funded services involved in the review

The ten selected services were split evenly between those operating group homes and those operating large residential centres. Four out of the five large residences had at least one registered nurse (RN) on every shift. One service operating group homes had an RN working across two residences, but otherwise the group home services were staffed by non-medical staff. Few of the services had staff working in a key worker role.[42] Each of the services was based in, or close to, a metropolitan area, with one service operating outside of the Sydney area.

Findings

How services plan or coordinate general health care

We found that very few of the services had a clear framework to manage and plan to meet the health care needs of clients. Most used a combination of various health related documents that were not necessarily tied to a comprehensive assessment or review of the person's health needs. While seven of the 10 services incorporated health care into the individual planning process in some way, very few (2) appeared to tie this to an adequate assessment or review of the person's health needs. As a result, it was difficult to see how the health needs of the clients were considered in any comprehensive way with the view to early intervention. Rather, health needs appeared to be considered in isolation and only in response to presenting issues. In general, the way that the ten funded services managed the health care needs of clients appeared reactive rather than planned.

In line with the results of the audit, we found that few of the services had plans to guide staff as to what needed to be done to meet the identified health needs of the client. This was of particular concern to us in the context that most of the services advised us that they had used casual staff at some point. In addition, there were a number of other elements that were missing, which would make it difficult for staff to ensure that they were meeting client health needs. For most of the services, this missing information included:

- Identification of the person responsible for providing consent to medical and dental treatment (applicable to the majority of clients), or the specialists / allied health clinicians involved in the care of the client
- Identification on the client's file of their existing health conditions
- Identification of when the client's health conditions should be medically or clinically reviewed.

Health assessment / review

While the services appeared to respond to presenting health issues, including changes in the client's health status and episodes of ill health and injury, earlier health screening and assessment were not as evident.

Standards in Action requires services to have a mechanism for regularly monitoring the health of service users, for ensuring that health risk screening and monitoring of clients is carried out, and for recording this process. However, in our review it was hard to tell in the majority of services whether regular assessments or reviews of client health were undertaken. While it was evident that clients had regular contact with GPs, it was not clear how comprehensive the GP visits or assessments were as there were few health screening or review documents on files.

The ten services did record the more routine visits to GPs (that is, in response to presenting health issues); however, the outcomes of these health checks or assessments were rarely turned into plans for meeting the client's identified health needs. In one of the services it was evident that dietitian advice was translated into a plan for meeting the person's nutrition needs, but this was an infrequent occurrence.

Development, implementation, review, and monitoring of health related plans

In the majority of services it was not clear who contributed to health related plans. Other than mealtime management or eating and drinking plans, which commonly had the involvement of a speech pathologist or dietitian, most plans appeared to have been developed by unnamed staff in the service. Where health care was tied to the individual planning process, it was easier to see how clients, persons responsible, or families may have contributed to the development of health related plans. Otherwise, their input was unclear.

It is important that implementation, review, and monitoring of health related plans does not occur in isolation. There is little point in continuing to implement a health related plan if what is done is not working, or no longer meeting the client's changing needs. We found that, in the main, expert recommendations (including those made by GPs, allied health clinicians, and specialists), and the actions outlined on health related plans, were implemented by all services. However, only half of the services had reviewed health related plans in the 12 months before the client's death.

It was difficult to establish from file information how plans were monitored to ensure that they were being implemented and reviewed. Services indicated that responsibility for monitoring the implementation of plans rested with different positions, depending on the service, including Registered Nurses, Manager, Coordinator, and Team Leaders. The fact that actions on plans (where they existed) were implemented suggests that monitoring of this aspect of the plans occurs in practice. However it is not clear how other aspects are monitored, including plan quality and review.

Challenges for funded services in undertaking health care planning

In our meetings with service management, we asked about any challenges faced by their service in managing and planning to meet the health needs of clients. The information provided by the funded services involved in the review is provided below, but it should be noted that these are the views of those services and have not been tested as part of the review.

General Practitioners

- Services indicated that it can be difficult to locate GPs who are prepared to complete the service paperwork (for example, annual assessments, or recording the outcome of the visit), and allow extra time for the consultation, even where a double-appointment has been booked.
- While some services advised that it is difficult to find GPs who have knowledge of disabilities, others reported that there can be benefits in seeing GPs who do not have a disability background or do not have a long history with the client as they can have an approach that does not necessarily centre on the client's disability. For example, one service noted that in some cases where the same GP has been involved with the client for an extended period of time, they can tend to see 'challenging behaviour' in terms of the person's disability, rather than considering if it is caused by health problems.
- Services advised that it can be difficult to get some doctors to seek consent for medical treatment from the person responsible rather than from service staff. Services said that there is a need for more education of GPs and hospital staff about issues of consent.

NSW Health has advised that its Primary Health Care Capacity Building Project is due to be completed in October 2005. The project involves CDDS providing education about people with developmental disabilities to GPs, community health workers and allied health staff.[43]

Our Advisory Committee has advised that, while the Medical Benefits Schedule currently covers annual assessments of people over 75 and Aboriginal and Torres Strait Islander people over 55, as well as assessments of residents of aged care facilities, it does not provide an item for an annual comprehensive health assessment for people with disabilities. The Committee has indicated that the way Medicare assessment items are structured means that it is a disincentive to conduct lengthy examinations / assessments for people with disabilities. We were advised that, while there is a Medicare item number for a 'care plan', an assessment is also required, and should be done by GPs who are trained in the disability area. The Committee has indicated that mental health is the precedent for this type of model, where GPs are required to receive additional training as a prerequisite to link to the Medicare assessment item numbers.

Staffing and resources

- Most of the services with registered nurses on staff expressed concern about those staff members approaching retirement, and the challenges associated with trying to attract nursing staff to large residential environments.

The broader Australian picture mirrors this view. Current research indicates that the health workforce is ageing, and that the female nursing workforce in particular has aged rapidly.[44] Research also indicates that nursing health professionals have negative attitudes about residents who have disabilities so they avoid working with them. However researchers suggest that clinical placement and provision of information about people with disabilities can help change attitudes.[45]

- Many services advised that some residential support workers are not highly educated or skilled, yet face significant responsibilities and demands. This is particularly the case in supporting the health needs of residents. Services expressed concerns that even though most residential support workers do not have medical backgrounds, they are required to take on increasing responsibilities around health care planning, with limited access to training.
- Most services stated that health care planning is made more difficult because funding is not adjusted to take account of the costs associated with the increasing health needs of residents, particularly for those who are ageing. Services advised that it is increasingly difficult to meet the financial costs of the greater health needs of ageing residents, and support workers are finding the challenge of meeting those increased needs difficult with their level of knowledge and training.

The Commonwealth Department of Health and Ageing established an Aged Care Innovative Pool in 2001-02. The Pool funds a number of projects designed to test new approaches to providing aged care, including ‘disability pilots’ that look at aged care and disabilities. This has involved a number of pilot projects examining how to meet the needs of ageing people with disabilities who are at risk of being admitted to aged care because their increasing care needs cannot be met through disability support services alone. There are four such pilot projects underway, with DADHC a stakeholder in three. Health and Ageing has recently extended the timeframe for the pilots until June 2006, with evaluation of all four to be completed by the end of 2005.

DADHC employs a small number of community nurses within its Community Support Teams. The support of the community nurses is available to residents of DADHC operated and funded services where the resident meets the eligibility criteria and where the funded service is not funded to provide that service. Community nurses are in a good position to provide advice and assistance to service staff concerning health care issues for the people with disabilities in their care. Last year we recommended to DADHC that it 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 to DADHC operated and funded services. DADHC has advised that this model is being reviewed as part of the *Managing Client Health* policy review, and that the newly established DADHC Health Care Review Team[46] will review the model for broader application in regions.

Hospitals

- Many services expressed concerns that, in the main, generalist hospital nursing staff do not appear to be adequately skilled in working with people with disabilities, and do not understand their needs. Services expressed concern about the skills of nursing staff in relation to general disabilities, as well as specific needs associated with disabilities such as spinal cord injury, dual diagnosis, and cerebral palsy.
- Most services advised that when clients are transferred to hospital, nursing staff request that service staff stay with the client and continue to provide care. Services advised that this often blurs staff roles, with service staff having to assist the client with personal care (including showering, toileting and meals), as well as health related tasks that nursing staff are trained in. Services queried why service staff are required to provide ongoing mealtime assistance, for example, when other people without disabilities in hospital who need help with meals may receive this assistance from nursing staff.
- Services advised that although they may forward information with the client to hospital, including eating and drinking plans, this information can fail to stay with the person when they are moved within the hospital, for example from the emergency department to a ward. Consequently, service staff are sometimes contacted by nursing staff asking for information on how to assist the person with meals, raising service concerns about whether the client is receiving adequate support while in hospital.
- Some services expressed concern that the provision of critical information by service staff to nursing staff about supporting the client is not always heeded. Although service staff are acknowledged to have the necessary knowledge about clients (and hence are requested to provide ongoing in-hospital support), their information is sometimes not heeded when it relates to health care.

NSW Health has advised that it has developed a *People with Disabilities: responding to their needs* *during hospitalisation* policy directive to assist hospital staff to respond more effectively to the needs of people with disabilities. The policy directive was released in October 2005.[47] NSW Health has further advised that it contracted the Centre for Developmental Disability Studies (CDDS) to develop a disability-awareness training package for hospital staff and to implement the training in hospitals across NSW. The project was completed in May 2005 and was designed to support the *Hospitalisation of People with Disabilities* guidelines.[48]

Access to allied health and specialist services

- The majority of services advised that, while eligible, clients are unable to get DADHC speech pathology services due to prohibitive waiting lists. As a result, services are having to use private speech pathology services, at the expense of the client. Services also advised that no information is provided by DADHC to indicate the approximate length of time until service provision, making it difficult to determine whether to continue to wait for assistance or take steps to seek private consultation.
- Services indicated that it is also difficult to engage DADHC's Behaviour Intervention Service, again due to extensive waiting lists.
- Services advised that it is difficult to locate psychiatrists who have an understanding of intellectual disability or are prepared to see clients with dual diagnosis.

DADHC has advised that there is no waiting list for the Statewide Behaviour Intervention Service as a result of expansion of the team and a reorganisation of the work processes.

However, it is a different story for speech pathology services. DADHC has provided information that indicates that, across all regions, the average length of time between requesting DADHC speech pathology services and being allocated a service is 5.7 months. There are currently 3606 people on the waiting list for DADHC speech pathology services, with only 180 clients of this group from DADHC operated services.[49]

In its final report to DADHC in September 2003, the DADHC Nutritional Health Expert Advisory Group recommended that DADHC monitor the level of demand for allied health professionals and the ease or difficulty of access to these services as part of its monitoring of the implementation of the *Ensuring Good Nutrition* policy. The final report also identified systemic problems including a lack of professional nutrition (dietetic) services employed in disability services, and inadequate speech pathology services in disability services. The Advisory Group recommended that DADHC work collaboratively with NSW Health to promote the access of people with disabilities and nutrition problems to generic and specialist health services, and closely monitor the level of access to allied health professionals. NSW Health had indicated to the Advisory Group that it was developing an Allied Health Strategic Plan, with a draft to be available in December 2003. To date, this strategic plan has not been released. NSW Health had also indicated to the Advisory Group that it had commenced mapping of nutrition service delivery of health services.

In response to our 2003-2004 annual report recommendations, NSW Health advised that it was working with DADHC through the DADHC / NSW Health Senior Officers Group to map existing specialist and generic services provided by either agency. In addition, NSW Health advised that it was '*identifying workforce issues and strategies to address these*' in relation to allied health staff. The department said the issues would be addressed through implementation of the NSW Health Workforce Action Plan.[50] DADHC advised that in addition to mapping existing services with NSW Health, both departments were identifying models of care to improve access to services and increasing the capacity of existing services.[51]

(iii) Survey of residential support workers

We surveyed 19 residential support workers in eight funded services. The survey was prompted by anecdotal information suggesting that workers are required to take on a significant amount of responsibility and undertake numerous tasks in health care planning with a relatively low level of knowledge and training.

Most of the services operating group homes have non-medical staff, and most services expressed concern about the responsibilities and demands being placed on these staff in relation to health related tasks. Most of the staff involved in the survey were drawn from the services operating group homes. In considering the results of the survey it is important to note that the number of participants was small, and we relied on service selection of staff members, which may have skewed the confidence levels reported. In addition, the workers' statements were not verified (eg sighting a first aid certificate).

We found that while most residential support workers are involved in implementing health related plans, fewer than half of the workers surveyed indicated that they are involved in developing them. Most reported that responsibility for the more complex tasks of developing plans, and coordinating access to health services, rests with people in more senior positions, including case managers and RNs. Residential support workers indicated that the health care tasks they are most commonly involved in include attending medical appointments with clients, identifying and notifying superiors when a client is unwell, and recording health information (eg seizures and weight).

We asked workers to consider one of the clients they provide support to, and to advise of the number of health issues the client has, and how they would rate their support needs (low, medium, or high). We found that the number of health issues did not necessarily equate to the level of support needed. For example, clients with 2-4 health conditions were variously reported as having medium or high support needs, and clients with 4-6 health conditions had mixed levels of support from low to high.

We asked workers to rate their level of confidence in undertaking eight health related tasks, on a scale from 0-10, with 0 being 'not at all confident' and 10 being 'very confident'. The health related tasks included meeting the health needs of their clients, developing and implementing health related plans, interacting with GPs and specialists, completing nutrition and swallowing assessments, recognising illness, and knowing what to do when a client is unwell. The reported levels of confidence were fairly high and consistent across the tasks, with the average being a score of 8 for all tasks other than developing health related plans, which scored a lower average of 7.

We asked workers whether they had any tertiary qualifications, and whether they had a current first aid certificate. Around half the workers surveyed had tertiary qualifications (including Community Welfare Certificate and Social Science degree), and all but two workers reported having a current first aid certificate.

Conclusion from the review

The health care planning review indicated that the management of client health needs in funded services is largely reactive rather than planned or comprehensive. As client health needs become apparent, services appear to be taking action to address those needs and implementing any identified actions or recommendations. However, it is not evident from our work that services are actively identifying health problems before they become urgent, or trying to prevent health problems.

When health issues are identified, we found a failure to consistently keep accurate and timely records. Failure to identify the client's existing health issues on their file, and to document what actions, if any, need to be taken means that all staff working with the client may not have the information necessary to act on the client's needs. This is particularly concerning given the comments of services regarding the skill level of support workers, their lack of medical knowledge, and the increasing health needs of ageing clients.

In order to effectively meet the health needs of a client group that, in general, has a high number of often complex health conditions, there needs to be a shift towards the sharing of resources, training, and knowledge between DADHC operated and funded services. Our review suggested that where there had been the development and implementation of policy in a particular area (such as nutrition), the quality of the response to that issue was higher (for example, clear plans for nutrition management). The review raised questions about whether *Standards in Action* is a sufficient guide to funded services on the coordination of client health care. Funded services would benefit from greater guidance about health care management for people with disabilities in care, and may find it more difficult to move towards good practice without greater input from DADHC. This input extends to policy direction, implementation guidance, and access to training. The lack of monitoring of funded services by DADHC in recent years has implications for service quality and practice,[52] and health care management is one area that requires attention.

The importance of monitoring policy roll out was identified in the review. Although DADHC has developed and rolled out *Ensuring Good Nutrition*, we found gaps in the quality of the plans relating to dysphagia. Monitoring of service implementation of the policy and tools is necessary to identify and act on areas of concern, to evaluate the roll out, and to inform further policy and practice. The quality of health related plans in DADHC operated services suggests that monitoring of the roll out of *Managing Client Health* is also necessary in DADHC services.

The ability of funded services to meet the health needs of clients is contingent upon the availability of outside services, including the availability and quality of health services. It appears to be increasingly difficult for funded services that have clients with swallowing difficulties to consult allied health clinicians, particularly speech pathologists, through DADHC. The adequacy of this service allocation needs consideration. In addition, services are dependent on hospital staff to meet the needs of clients during their admission; yet services indicate that there is not always effective coordination between service and hospital staff to do so.

The concerns raised by services about the increasing support needs of people with disabilities in care who are ageing appear well founded. People with disabilities are generally living for longer, and increasing numbers are living to old age. Our information suggests that many people with disabilities in care are remaining in the care of disability services as they age. Ageing for people in the community is often associated with an increasing number of health concerns, greater dependence on others, increased risks from falls, susceptibility to illness, and the possible onset of dementia. People with disabilities in care face the same ageing process as the broader community, but there can also be added factors such as experiencing ageing effects earlier in life, and increased complexities associated with multiple health conditions. Ageing in place[53] has significant implications for both clients and the services providing support, including the need for later-life planning to ensure that changing health, support and lifestyle needs can be met. There are also implications for the funding of disability services, as supporting people who are ageing can change the support levels that were the basis of original funding arrangements, and greatly impact on the responsibilities of services.

Last year we made a number of recommendations to DADHC about health care coordination and management. They included the incorporation and promotion of 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, and that DADHC should review the clinical nurse specialist model of health care case management and the potential for wider application in DADHC operated and funded services. A number of the recommendations to DADHC concerning health care coordination and management depended upon the department's review of its Managing Client Health policy and the roll out of this policy to funded services. DADHC has advised us that, while it has updated the policy to take into account our recommendations, the document will not be available for comment until late November 2005.[54]

4.3 Medications

Many of the people with disabilities who died in the care of disability services in 2004 were reported to be on multiple medications for a relatively high number of health conditions. Side effects of medications can influence weight, balance, swallowing, and respiratory function. Certain medications, including antipsychotics and antidepressants, are classed as major medications by the Guardianship Tribunal, and require consent from a legal guardian or person responsible.

We looked at those people reported to have received more than one of the following types of medication in the last 12 months of life: antipsychotics, antidepressants, anti-anxiety agents (anxiolytics), anticonvulsants, and sedatives.[55] In the disability services group, most of the people receiving one of more of these medications (59) were receiving two types, with a small number of people (10, 17%) receiving three or four types. Of the 19 people in the boarding house group who were receiving at least one of these medications, most (13, 54.2%) were receiving only one type.

Of the 69 people living in disability services, 19 (27.5%) were receiving antipsychotic medication. Not all of those receiving antipsychotic medication were reported to have had a psychiatric illness.

There were six people who were receiving antipsychotic medication that were not reported to have had a psychiatric illness, and most of these people (5) had an intellectual disability. Three of the six people were not reported to have had 'challenging behaviour' in the 12 months before death. Although all had seen a GP, half were not reported to have seen a psychiatrist in the 12 months before death.

Of the 24 people living in boarding houses, 13 were receiving antipsychotic medication. Eleven of these 13 people were reported to have had a psychiatric illness. Two people were receiving antipsychotic medication but were not recorded as having a psychiatric illness or an intellectual disability. One was not reported to have had any challenging behaviour in the 12 months prior to death, and neither was reported to have seen a psychiatrist in the same period.

It was of concern to us that some people who did not have a reported psychiatric illness or specialist input were receiving major medications, and some were receiving multiple major medications.

Three deaths in 2004 were related to drug toxicity or overdose. In each of these matters the Coroner has not yet determined whether an inquest will be held, and at the time of writing this report we had not concluded our reviews of these deaths. The three matters were:

1. A 72-year-old man with a mild intellectual disability and schizophrenia, who lived in a large residential centre, died from Sertraline toxicity.
2. A 49-year-old man with chronic schizophrenia, who lived in a group home, died from a Clozapine overdose.
3. A 43-year-old man with a severe intellectual disability, who lived in a large residential centre, died from toxicity due to Citalopram, Olanzapine, and Tramadol.

Our reviews of these deaths involved consultation with medical professionals. The matters are not straightforward, and the potential preventative strategies are not obvious. In two of the cases, the clients lived in departmental large residential centres, where nurses handle the storage and administration of medication. GPs and psychiatrists regularly reviewed each of the clients, and where there were medication changes, there was good communication between service, GP and psychiatrist.

What these cases emphasise is the vulnerability of people with disabilities in care to adverse events as a result of medication. As reported earlier, 83.9% of the people with disabilities in care who died in 2004 were receiving at least one form of major medication. Most of the people in the disability services group were receiving more than one type, and some were receiving multiple types of major medications. The Commonwealth Department of Health and Ageing has outlined a number of risk factors known to predispose people to medication related adverse events. They include taking five or more regular medications, taking more than 12 doses of medication per day, significant changes made to medication treatment regimen in the last three months, medications requiring therapeutic monitoring, patients attending a number of different doctors, and discharge from a hospital within the last four weeks. Many people with disabilities living in care readily come under some of these risk factors.

Domiciliary Medication Management Reviews (DMMR), also known as Home Medicines Reviews, are available to people living in the community who are '*at risk of medication misadventure because of their co-morbidities, age or social circumstances, the characteristics of their medicines, the complexity of their medication treatment regimen, or because of a lack of knowledge and skills to use medicines to their best effect*'.[56] Under this service, a GP assesses a patient's medication management needs and, following that assessment, refers the patient to a community pharmacy for a DMMR, providing relevant clinical information with consent. The GP then discusses the results of the DMMR with the reviewing pharmacist, and develops a written medication management plan after discussion with the patient (or person responsible). The GPs service may be directly billed to Medicare, or the patient can claim a Medicare rebate, as with any other consultation. The Commonwealth Government pays the pharmacist to undertake the DMMR.

The involvement of Domiciliary Medication Management Reviews for people with disabilities in care would be an additional safeguard in relation to medication management. Although GPs may currently review the medications of clients, the involvement of a pharmacist provides more expertise about drug interactions and effects, and an additional safeguard.

4.4 Communication support

Twenty-five people (36.2%) in disability services received some form of communication support, such as sign language, picture communication, and adjusted verbal language. One person who lived in a boarding house was recorded as receiving communication support. He had a mild intellectual disability, was deaf, and was unable to speak. It is important to note that the CDN captures whether the person *received* communication support, not whether they required it but may not have received it. As a result, communication may have been an issue for more people than those reported.

Being unable to communicate effectively impairs a person's general quality of life; it can diminish the capacity to make choices, to be involved in decision-making, and to have one's needs met. It also has significant implications for client health, as it can affect identification of illness, pain, and recognition of adverse effects of medications. The importance of communication is illustrated throughout this report, including in relation to such areas as sepsis, end-of-life decision-making, medication use, and constipation.

Without communication supports, clients who are unable to communicate independently rely heavily on staff noticing changes and correctly interpreting behaviour in order to ensure early diagnosis and intervention. Consequently, it is imperative that clients get appropriate communication supports, staff are trained to use the supports, and there is adequate monitoring of health conditions and changing health needs.

CaseStudy3

A 53-year-old man with a profound intellectual disability and a hearing impairment lived in a group home. He used basic gestures and vocalisations to communicate. In 2001, his individual plan identified the need for a communication dictionary, yet by the time of his 2003 individual planning meeting this had not been obtained.

The restrictive practice of a lap belt was used to manage the man's mobility and epilepsy when adequate staff supervision was not available. Documentation relating to the use of the restrictive practice indicated that, at times when the lap belt was used, he would react with protests, shouting, rocking, and by thumping or biting his hand. The restrictive practice documentation also outlined the need to collect data on his reaction to the use of the lap belt, but there was no evidence of data collection in his file. A health care plan checklist completed by group home staff two months before the man's death listed communication as 'N/A'. No communication strategy or dictionary was found on his file.

The service had guidelines in place relating to communication support systems that referred to the need for all persons with an intellectual disability and complex communication needs to have access to appropriate and effective communication systems. The guidelines also highlighted the integral role communication strategies and systems have to play in the development and implementation of behaviour support programs. There was no indication that the guidelines were followed in relation to this man.

In response to our review of this man's death, the service advised that its Network Managers were addressing the issue of communication support in group homes by ensuring all clients have appropriate referrals for clinical support. The service also advised that it had established a Residential Support Worker Level 3 position in each group home, and that this position would be important in developing an understanding of the processes used to access other services. In addition, staff in group homes would be receiving targeted training and support.

4.5 Provision of information by services to hospitals

Sixty-one of the 93 people with disabilities in care who died in 2004 died in hospital (65.6%). A number of reviews raised questions about what information is provided by services, including boarding houses, to hospitals when clients are admitted for treatment.

In most cases a verbal account of the client's health condition/s and history appears to have been provided to hospital staff when the client was admitted, by the client themselves and/or service staff. This account necessarily tended to focus on the immediate health concerns that led to the client's hospitalisation. However, many of the people with disabilities in care who died in 2004 had ongoing health and support needs that required specific management and staff knowledge. Our reviews indicated that this important information was not always provided by services to hospital staff, potentially compromising the health and wellbeing of the client.

The cases highlighted by the reviews varied from situations in which clients were placed at risk as a result of the lack of information, to scenarios in which client care would have been simplified if information about support needs, likes and dislikes had been provided to hospital staff during admission. For example:

- Although a woman had a current mealtime management plan, service staff did not give this plan to the hospital when she was admitted. The woman had a choking incident during a meal provided by the hospital and aspirated.
- A man with limited verbal communication who was a heavy smoker became increasingly disruptive and difficult to manage in hospital due to withdrawal from cigarettes. This basic information had not been provided to hospital staff when he was admitted. When the issue was identified and nicotine patches used, his behaviour became more manageable.

DADHC's *Managing Client Health* policy includes guidelines on supporting clients during hospitalisations. The policy requires staff to give the hospital the relevant medical history and the client's *My Health Record.* If the client remains in hospital, staff are required to supply the hospital with information about the client's nutrition and swallowing needs, medication, personal care needs, communication needs and other support needs such as activities of daily living, through provision of the health care plan and lifestyle and environment plan. We found only two examples of the *My Health Record* during our reviews, and these copies were incomplete.

Problems with the provision of information to hospitals were also evident in funded services. Our reviews found little evidence that management or care plans had been given to hospitals by DADHC operated or funded services to guide client care. As noted previously, services involved in the health care planning review identified additional concerns about the provision of information to hospitals. Some services advised that although they may forward information with the client to hospital, including eating and drinking plans, this information can fail to stay with the person when they are moved within the hospital.

We found few examples in boarding house or medical records of boarding houses providing written or verbal information to hospitals when residents were admitted. Boarding houses keep fewer records, and have no licence conditions or policies to guide their actions in the provision of information to hospitals. Boarding houses may keep a register of resident information, as required by licence conditions, but this would provide limited information to guide hospital staff in their support and provision of care to the client.

4.6 Constipation and bowel health

Our reviews found constipation to be a significant health issue for the people with disabilities in care who died in 2004. For many people it was an identified ongoing health issue, and in three cases it was identified as a contributing factor to death.

Constipation can cause pain and discomfort, haemorrhoids, carcinoma, faecal impaction and megacolon.[57] It can be congenital or acquired, acute or chronic. Sometimes looser faecal matter will overflow around a faecally impacted colon, masking the presence of constipation due to its resemblance to diarrhoea. Megacolon was a factor in two of the deaths we reviewed.

Elimination of bodily waste products is a valuable gauge of overall health and wellbeing, and constipation can be an indicator of a range of deficits (eg dietary) and conditions. Its identification can be complicated by difficulty in recognising and communicating symptoms, and its sometimes paradoxical presentations, such as overflow diarrhoea.

Causes of constipation

There are many causes of constipation, including iatrogenic factors (i.e. caused by medical treatment); side effects of such medications as antipsychotics, iron supplements, narcotic analgesics (e.g. codeine, morphine); neurological disorders such as Parkinson's disease and cerebral palsy; spinal cord injuries resulting in paraplegia and quadriplegia; congenital conditions such as Hirschprung's disease; carcinoma; depression; lack of exercise; immobility associated with hospitalisation or prolonged bed rest; confinement to a wheelchair; poor muscle tone; poor/low fibre diet, and inadequate fluid intake.

Many people whose deaths we reviewed had one or more of the risk factors; for example, a person with cerebral palsy or quadriplegia may have been confined to a wheelchair resulting in poor muscle tone, and have been taking medications that had constipation as a side effect.

Incidence of constipation

Constipation was identified as a health issue for 32 people in 2004 (34.4%). Twenty-one people were on medications known to have constipation as an adverse reaction and four were on two or more different kinds of such medications. Twenty-five people had been prescribed laxatives in the 12 months before death, and eight of those people were having three or more (and up to six) different laxative preparations in that time. Seven people with constipation were not prescribed any laxatives in the last 12 months before death.

Twenty-six of the 32 people with constipation were identified as having mobility problems, and 21 of these used a wheelchair.

Iatrogenic faecal retention, megacolon and drug side-effects were found at autopsy to have a direct causal link to the death of the man who is the subject of the case study below.

CaseStudy4

A 58-year-old man with an intellectual disability and schizoaffective disorder lived at home with his mother until entering a group home ten months before his death. He had swallowing difficulties and required supervision during mealtimes. He was receiving antipsychotic medication, which was changed during his time at the group home due to an increase in his symptoms.

During the eight months leading up to this man's death, he was seen by his doctor for ongoing problems with his stomach and bowels, which included long periods of time spent in the toilet, and alternating bouts of diarrhoea and constipation.

Following the doubling of the dosage of his new antipsychotic medication, service notes indicated that problems of constipation escalated. Two weeks later the man was admitted to hospital with abdominal pain, and he died four days later of aspiration pneumonia and pulmonary embolism. He was found at autopsy to have megacolon. The autopsy report stated that the antipsychotic medication that was prescribed for this man can cause bowel dysfunction, including severe constipation.

Managing and treating constipation

There are many ways in which bowel health may be managed, including consulting specialists such as a dietitian or continence consultant, maintaining bowel regimes, including charting bowel movements, and educating clients in relation to toileting habits. In addition, there are multiple means of treating constipation, including:

- preventative supplements such as psyllium husks (Metamucil) and fruit concentrates
- use of laxatives
- dietary measures (fruit and vegetables, high fibre) and increased fluid intake
- enemas
- manual disimpaction (sometimes under general anaesthetic)
- engaging in physical activity.

The presence of multiple risk factors combined with communication deficits can hamper some people with disabilities in conveying their level of discomfort and their needs. This compounds the difficulties associated with identifying and managing bowel problems.

Maintaining optimal bowel health is dependent on accurate assessment and identification of any problems. Its management is multifaceted, drawing on input from the client, carers, family and advocates, medical practitioners and specialists such as dietitian and continence consultants. It can become a problem quite quickly unless accurate records are kept and reviewed and information is shared, particularly when someone goes to hospital or has some other change in their regular circumstances.

For this reason it is very important that bowel health is not overlooked by staff in the daily monitoring of client health, or by the GP conducting the annual health review, and that its management is incorporated into health care planning by services. This is particularly important in the case of the relatively high proportion of people with severe mobility deficits, which puts them at the greatest risk of constipation, faecal impaction and potentially life-threatening medical conditions such as megacolon.

The nutrition and swallowing checklist provides a trigger for DADHC operated and funded services to consider constipation. The assessment procedures that accompany the checklist clearly outline concerns related to constipation and what services can do in response.

4.7 End-of-life issues

Decision-making and not for cardiopulmonary resuscitation (CPR) orders

In response to the recommendations made in the 2003-2004 reviewable death annual report about completion of the review of the *Dying with Dignity* guidelines, NSW Health advised that it has completed the *Guidelines for end-of-life care and decision-making*. These guidelines outline a process for reaching decisions about the use of life-sustaining treatments, including CPR, in patients with and without decision-making capacity. NSW Health advised that the guidelines emphasise that such decisions should be informed by the person's medical condition and prognosis, values and wishes (where known), and that these decisions should be non-discriminatory, for example decisions about the use of CPR based on age or disability are inappropriate.[58]

The guidelines indicate that the senior treating clinician is responsible for summarising discussions held with the patient, family, and treating team in the patient notes; the notes must clearly state the medical facts leading to the decision (including prognosis), the persons involved in the discussion, a statement of the patient's wishes (where known), the goals of treatment, and details about the medical treatments to be provided, the timeframe before review, or details about treatments to be withdrawn or withheld. The guidelines were released in March 2005, so were not available to health practitioners in the period we reviewed.

Reference is made to the *Guardianship Act* and Guardianship Tribunal in end-of-life decisions for adults without decision-making capacity. Where the guidelines relate to patients that lack decision-making capacity, there is no reference to patients who may not have a family member or person responsible, or the potential need to involve the Guardianship Tribunal in decisions concerning end-of-life care for those individuals. In its response to the draft of this report, NSW Health advised on 1 November 2005 that the guidelines are due for revision in five years, and this particular issue will be added into the guidelines at the first available opportunity. In the meantime, NSW Health has advised that, while the guidelines do not specifically comment on the situation where there is no person responsible, they do refer to NSW Health Circular 2004/84 on Patient Information and Informed Consent that provides more detailed information on consent provisions. However, again, this information is not linked to the specific section of the guidelines that refer to patients without decision-making capacity.

At least 21 of the 61 people who died in hospital in 2004 (34.4%) had 'no CPR'[59] order decisions made during the last admission. In considering these deaths we noted the following:

Parties involved in the decision

It was evident from the majority of the matters that family members were consulted prior to a decision being made concerning no CPR. In most cases, the people consulted were the identified persons responsible for providing consent to medical treatment on behalf of the patient. However, in some cases, the medical team consulted the family member(s) connected to the patient regardless of whether there had been recent or regular contact, including estranged children, and, in one case, the patient's former wife.

From the medical records it was difficult to see how any of the patients themselves were involved in the decision-making process regarding the no CPR order. For some of the patients this would have been impossible given their condition or ability to communicate at that critical point (for example, intubated, unconscious and/or sedated). In the other cases, it appears consultation with the patient could have occurred.

Decision-making process

In many cases it was clear that there was a genuine consultative process that occurred, with families consulted at various points to establish their views and reach agreement. In these cases it was evident that the decision regarding no CPR was not taken as a once-only or final decision. As the patient's condition changed, discussions were again held with the family to explain the current circumstances and prognosis, and to clarify the decision.

In a small number of cases it appeared that the medical team made its decision in isolation, and their decision was then communicated to the family members, as in the following case study. The decision regarding no CPR is largely a clinical one, and families and patients are obviously reliant upon the expert advice and opinion of the treating medical team. However, such decisions also involve social and individual factors, and need to be made in consultation with the patient, or with their families / significant people in their lives where they lack capacity to make that decision themselves. The decision regarding no CPR needs to take into account the patient's diagnosis, prognosis, known wishes, and best interests, and this can only be achieved where true consultation has taken place.

CaseStudy5 (our emphasis)

A 37-year-old man who lived in a large residential centre had a full teeth extraction, and was admitted to hospital two days later with hypoxia and hypotension after oral haemorrhage. The day after the man's admission, the ICU doctor noted that 'considering his pre-morbid status, I feel (as does Dr ____) that escalation of therapy above ward level medical treatment and 1:1 nursing would be inappropriate and unlikely to lead to a long-term improvement of his quality of life. Likewise initiation of CPR in the event of cardiac or respiratory arrest would be inappropriate but we need to contact the family *to inform them of the decision*'.

Later that day, a different member of the hospital staff (position not recorded) noted that the man's deteriorating condition and current treatment was discussed with his mother. The staff member noted that the man's mother was 'in agreeance not for escalation of therapy above current management. Usual premorbid status – total dependence on others requiring 24 hour nursing care. In the event of cardiopulmonary arrest, patient is not for resuscitation'.

Documentation

While the decision 'in the event of cardiopulmonary arrest the patient is not for cardiopulmonary resuscitation' (or similar) was documented in patient records, there was not always a reason(s) provided for this decision. Examples included:

- A doctor had a discussion with the patient's brother and noted that 'after careful consideration it is his decision that in the event of cardiorespiratory arrest, active resuscitation should not be attempted'.
- 'In the event of cardiorespiratory arrest this man should not have CPR'.
- 'After discussions with the guardian it was decided that in the event of further deterioration that he should not be resuscitated'.

Palliative care

At least 18 people with disabilities who died in care in 2004-05 received palliative care, including three people from boarding houses. The palliative care varied from formal involvement of a palliative care team to ongoing palliative management of their condition. Palliative care involves the prevention and relief of suffering of people with life-threatening illness and their families through early identification, assessment, and treatment of pain and other problems.[60]

Location in which palliative care was provided

Palliative care was primarily provided within the person's residence. It was particularly the case that disability services (and primarily DADHC services) made clear attempts to support the person at their residence for as long as possible, with the involvement of the Area Health Service palliative care team. While some people moved to a palliative care unit for their last days, this was at a point that the service indicated the person required more intensive support than it was able to offer, and was done with the assistance and agreement of the palliative care team.

Boarding house residents also received palliative care within their home environment, although in some cases it was not always clear whether this was appropriate given their need for increasing levels of support. In two reviews, the boarding house residents diagnosed with advanced incurable cancer were discharged from hospital without a screening tool assessment. In one of these cases, the person returned from hospital to a room he shared with three other residents, with no sick and quiet room, or alternative space for him to convalesce in or use when managing his health care needs. This situation also raised questions about the choice given to the other residents who shared the bedroom, and what support was offered to them during this time.

Involvement of client and consideration of consent

Palliative Care Australia released the fourth edition of *Standards for Providing Quality Palliative Care for all Australians* in 2005, and commented that, in relation to adults who do not have the capacity to make informed choices, '*in addition to the legal and moral requirement to obtain proxy consent and direction, patients should be afforded every possible opportunity to contribute as far as they are able to the care planning and decision-making process*'.[61] Research evidence '*disputes the notion that individuals with intellectual disabilities do not or cannot understand the concept of death*'.[62]

Where there was a person responsible or guardian indicated to provide consent for medical treatment, it was evident that they were involved in decisions concerning palliative care. However, for people who did not have a 'person responsible', it appeared that the decision to treat the person palliatively was made without consent, and similarly there was no consent for the resulting palliative care plan. Illustrations of this are the cases of two residents of a DADHC large residential centre. One man was aged 80 and the other 82. The Guardianship Tribunal was recorded as being the substitute decision-maker for both residents, yet there was no indication that the Tribunal was contacted regarding the decisions to treat their deteriorating conditions palliatively. Similarly, there was no record of consent in relation to either of the palliative care plans that were developed, which included the decisions that there was to be no CPR and they were not to be hospitalised.

In the majority of matters the involvement of the persons themselves in the decision-making process was not clear – either in the initial decision to treat palliatively, or in any palliative care planning discussions. Records provided evidence of discussion with family members, including involvement in case conferences, but the same efforts to facilitate involvement were not seen in relation to the people directly affected.

Coordination of palliative care

Palliative Care Australia noted that '*recent studies and other feedback indicated that lack of coordination of care and services increases the stress experienced by the patient, their caregiver/s and family and that alleviation of this would add significantly to their quality of life*'.[63] NSW Health's *Palliative Care Framework* (2001) identifies one of the key elements for effective palliative care as 'an inter-disciplinary team approach to coordinate medical, nursing, allied health, pastoral care, volunteer and community services to the patient and their carers'.[64]

For residents of DADHC or funded services, there was generally evidence of the provision of well-coordinated palliative care. This included good liaison between the disability service and the palliative care team, regular visits to the client by palliative care nurses, ongoing monitoring of the client's condition, development and review of palliative care plans, and inclusion of families. In addition, it was evident that the expertise of palliative care teams in relation to pain management was drawn on by disability services to meet the needs of clients.

CaseStudy6

A 67-year-old man with a moderate intellectual disability lived in the care of a large residential centre. He was diagnosed with cancer of the oropharynx in March. The decision to treat palliatively was made in view of the 'advanced and aggressive nature of the disease'.

A palliative care case conference was held three days later, involving the man's cousin (who was also his 'person responsible'), key service staff (including the Nursing Unit Manager, case manager, psychologist, social worker, and Senior Medical Officer), and a Clinical Nurse Consultant in the area health service's Palliative Care Team. Discussion at the meeting included pain management, likely progression of the disease and proposed treatment at each point, and location of treatment.

The man was not present at the case conference, but the minutes noted that he had 'so far been unwilling to engage in further dialogue about his condition and likely prognosis'. The psychologist had identified possible ways to support the man, including the development of a 'social story', grief counselling, and involvement in decisions where possible.

Although his condition deteriorated rapidly, the palliative care plan was reviewed twice before this man's death. He continued to receive palliative care at home, and died there in May.

For two of the three residents of boarding houses who received palliative care, it did not appear to be well coordinated or regular. Illustration of this poor coordination, and its impact on the residents, is provided in the following case study.

CaseStudy7

A 45-year-old resident of a boarding house in metropolitan Sydney was diagnosed with lung cancer while in hospital. He was discharged back to the boarding house, with community palliative care follow-up. While records indicate that the manager of the boarding house was keen to support the man to continue to live in his home environment, the man was not assessed by the palliative care team until after discharge, and he did not have a palliative care plan.

We also identified gaps in the coordination of necessary services. The man was supposed to continue with chemotherapy post-discharge, to slow down the progression of the cancer. However, the delayed assessment of his palliative care needs meant that he missed his chemotherapy appointments due to transport not being organised by the boarding house or another service. Errors in his medication were not picked up by the boarding house or palliative care team until it began to adversely affect him. In addition, questions about whether the boarding house had the capacity to provide adequate support for his increasing needs were not addressed before his death.

This case study contrasts with that of another boarding house resident who was diagnosed with incurable lung cancer. He remained in hospital until he could be transferred to a palliative care facility. In this case, the client had a palliative care plan that clearly documented his diagnosis, medications, and palliative care needs, and made plans for foreseeable problems. The plan was also revised as his needs changed. This man was the only boarding house resident to have a legally appointed guardian responsible for providing consent to medical treatment.

DADHC has advised that its *Palliative Care* policy has been redeveloped to apply across DADHC operated and funded services, and is now in draft form. The policy has not yet been released, and is unlikely to apply to boarding houses.

In its response to the draft of this report, NSW Health advised that Palliative Care Services vary in structure and resourcing across the state, and that it has developed a role delineation model to assist in the strategic planning of palliative care services at area, regional and state levels:

> *'The model consists of a Working Together Framework which describes the roles of specialist and non-specialist care providers and a Resource and Capability Framework which outlines a number of levels of specialist palliative care services. The model is to undergo mapping throughout the state and publication of the document is due in late 2005. It is envisaged that the use of this model will assist in the provision of a consistent level of palliative care service across the state'.*[65]

4.8 Boarding Houses

Some matters relating to people who lived in boarding houses have been dealt with earlier. This section considers topics that are specific to the boarding house model of accommodation for people with disabilities.

The 24 deaths in 2004 of people with a disability who were residents of boarding houses represents 26% of the deaths in jurisdiction, and 2.3% of the boarding house population. There are currently 57 boarding houses within the licensed sector, accommodating 1058 people. The 24 deaths occurred in 11 premises.

There were a high number of deaths in the boarding house group (16, 66.7%) that were retrospectively referred to the Coroner by the Ombudsman.[66] This included deaths that were not reported to the Coroner by the boarding house, hospital or police (12), and deaths that were not identified by the Coroner as 13AB deaths (3).

Licence conditions and guidance

The boarding houses referred to in this report are those licensed by DADHC under the *Youth and Community Services Act 1973* (YACS Act). Each boarding house is subject to a set of licence conditions that specify the requirements expected of the licensee, licensed manager, and staff of the boarding house. There is current debate about the enforceability of licence conditions, that is, whether some licence conditions may be beyond the power provided by the YACS Act ('ultra vires') and therefore unenforceable. In 2004 the Ombudsman completed an investigation into DADHC's monitoring of standards and enforcement of licence conditions in boarding houses. We found the conduct of DADHC to be unreasonable in failing to take prompt action to overcome legal barriers to enforcing the full range of standard licensing conditions through seeking amendments to the YACS Act or by other means. DADHC commenced a review of the YACS Act in 2003. It is yet to be finalised.

In August 2003, DADHC finalised the *Licensed Residential Centres – Licensing, Monitoring and Closure* policy for DADHC staff undertaking the regulation and monitoring of boarding houses. The policy implies that compliance with all licence conditions is expected. However, feedback received from DADHC through reviews and the Ombudsman's work in relation to Official Community Visitors indicates that the department's operational approach sometimes contradicts this policy position, and that doubts about the enforceability of certain licence conditions are taken into consideration when staff undertake monitoring activities. The following case study illustrates the effect of the 'ultra vires' debate in relation to monitoring.

CaseStudy8[67]

Three residents of one boarding house died within the course of nine days in 2004. Our reviews of these deaths identified concerns about the boarding house's record keeping procedures and the licensee's ability to demonstrate how residents' individual needs were met.

During our meeting with DADHC we asked about the boarding house's compliance with the relevant licence conditions. We were advised that DADHC did not require the licensee to produce either the record of efforts made to facilitate the integration of residents into community activities, or evidence of the program of activities and care to ensure the individual needs of residents were met.

When we discussed the matter with the licensee, the 'ultra vires' issue was raised as the reason for why these records were not kept. In addition, the licensee advised that, since boarding houses do not receive any funding, record keeping was an onerous expectation.

In this matter, the uncertain status of the licence conditions resulted in compromises in the requirements expected of the boarding house that were not in the best interests of the residents.

As boarding houses are not covered by the *Disability Services Act 1993*, they are not subject to policies and standards that govern disability services. With one exception,[68] the licence conditions are not supported by detailed policy and practice guidance clarifying the scope of the conditions. DADHC has provided boarding houses with the following documents to guide service practice:

- Circular 97/10: *Guidelines for handling medication in community based health services and residential facilities in NSW*, NSW Health (1997)
- *Food Book for Licensed Residential Centres, Hostels and Group Homes* (2000)
- *Providing Quality Services for People with a Disability. A Staff Sample Handbook* (2001).

However, unlike the practice requirements set out in *Standards in Action* and DADHC policies for DADHC operated and funded services, these guidelines are not directly linked to YACS Act legislative requirements. In contrast to funded services, operators of boarding houses operate without comprehensive guidance. Boarding houses also frequently do not have access to the information sessions that often accompany the roll out of policies directed at DADHC operated and/or funded services. Such forums provide an opportunity for staff training and continuous quality improvement.

As part of our information collection for the annual report, we wrote to DADHC asking whether it intends to provide the *Managing Client Health*, *Support of Clients with Epilepsy*, or *Ensuring Good Nutrition* policies to boarding houses. DADHC advised that the *Managing Client Health* and *Support of Clients with Epilepsy* policies are yet to be ratified, and the *Ensuring Good Nutrition* policy and manual are encouraged as good practice, with their availability flagged on the DADHC website. DADHC noted in its response that boarding houses have no legal obligation to comply with *Ensuring Good Nutrition*.

The Residential Care Association has raised concerns with this office about the difference between the boarding house sector and funded disability services in terms of the capacity of boarding houses to meet various expectations about service provision, and compliance cost issues in relation to licence conditions. Many of those service provision and compliance issues have direct relevance to the health needs of boarding house residents.

This office considers that timely resolution of issues associated with boarding house standards is critical because it will provide a clear framework for determining the services to be provided for the health and wellbeing of residents.

Record keeping and meeting resident needs

Most of our reviews of the deaths of people in boarding houses identified record keeping as a significant concern. The problems related to the adequacy and accuracy of records kept by boarding house staff, as well as the impact of poor record keeping on the ability of boarding house staff to meet individual client needs. Record keeping is one area that is affected by the current lack of resolution concerning the enforceability of licence conditions.

The licence conditions that refer to resident records[69] include:

- The register of information on each resident (licence condition 4.4). The register is to include details such as the resident's name, date of birth, name and telephone number of doctor, any serious illness, allergies, assistance with medication, assistance with personal care needs, and legal guardian or person responsible.
- Where applicable, records of pro re nata (prn)[70] medication (licence condition 4.5). The record system is to include details such as the name and dosage of the prn medication administered, date and time at which the prn medication was administered, and the reason for the prn medication being administered on that date.
- The case management plan for persons on psychotropic prn medication (licence condition 4.6). The plan is to be prepared in consultation with the resident's case manager and/or prescribing doctor.
- A record of efforts made to facilitate the integration of residents into community activities either recreational or therapeutic (licence condition 4.7).
- A register of the entry of all residents which identifies those residents who have been assessed using the Licensed Boarding House Entry Screening Tool and the name and contact details of the officer from the designated agency who completed the Screening Tool (licence condition 10.2).

Of the 24 deaths reported, in only seven cases (29.2%) did boarding houses provide client records to us for review. The type of information provided included hospital admission records, health plans and progress notes. While this additional information provided details of the client's circumstances, it did not include examples of the records specified by the identified licence conditions.

When we review the death of a person with a disability in care, we regularly call for service records in order to establish the client's support needs and assess the care provided. In matters involving the deaths of boarding house residents, it was apparent that the information in boarding house service records was generally insufficient to provide an adequate picture of an individual's support needs or care provision. In most cases we received minimal notes to indicate what care was provided, what services or medical professionals may have been involved, or what the individual needs of the resident were.

As a result of the poor standard of record keeping in boarding houses, it was difficult to determine whether residents were provided with opportunities and support for their individual needs. It was often unclear whether opportunities and supports were facilitated and/or provided by the boarding house or external service providers.

CaseStudy9[71]

A 77-year-old man with a mild intellectual disability and schizophrenia had lived in a boarding house for over eight years. The progress notes provided by the boarding house consisted of two pages for a 27-month period. There was very little information available to determine what the man's health conditions or support needs were, or how these needs were being supported. There were no support or care plans, and the register of information required by the licence conditions did not include the phone number of the GP, details of the man's illnesses, or details of what assistance he needed with medication or with personal care. Four days prior to this man's death, he saw his GP for a cough and a wheeze. His treatment plan was to use a Ventolin inhaler prn and a Seretide inhaler once a day. No prn medication record was kept.

In some cases there appeared to be a lack of coordination of care and review by boarding houses and/or external parties involved with residents. For example, where actions were required and documented in resident files by the treating GP or an alternative external service provider, it was common to find no reference to whether these actions were implemented. Where recommendations for health care management were made that were beyond the capacity of the boarding house to deliver, it was not clear who had responsibility for ensuring that an appropriate referral was made to another service so the resident's needs could be met. If this coordination of care was occurring, it was not being documented by the boarding houses.

CaseStudy10[72]

A letter from a hospital specialist to a resident's GP was found within the resident's file provided by the boarding house. This letter documented a number of recommendations relating to the resident's future health care. It noted that the resident had Type 2 diabetes, which required daily monitoring of his blood sugar levels by boarding house staff. It also noted that his feet were in 'poor condition' and needed review by a podiatrist. While the presence of the letter in the resident's file made it clear that the boarding house and GP had been informed of the recommendations, there was no record of any actions taken to implement them.

The notice of licence conditions for boarding houses requires a register of the entry of all residents. Although we requested boarding house records in relation to a number of reviews, no copies of this register were provided. Where examples of the register of resident information were found, it was common for this information to be out of date. Few boarding houses appeared to have procedures in place for reviewing and updating resident information. The absence of records identified in our reviews raises questions about what records are kept by other boarding house operators, and the extent of monitoring activities undertaken by DADHC in relation to licence conditions.

Staffing issues

The licence conditions specify that at least one member of staff '*shall in the case of an accident or sudden illness, be qualified in the opinion of the Director-General, to render first aid pending the arrival of medical aid*'. However, in a number of our reviews, first aid either did not appear to be administered to residents when they were in critical situations, or it was inconsistent with best practice first aid principles. Our reviews indicated that not all boarding house staff had current first aid certificates or alternative relevant training, and were therefore not 'qualified'.

CaseStudy11[73]

In relation to the three residents who died within nine days of each other at one boarding house mentioned in an earlier case study, information provided in records obtained from the boarding house and health providers raised concerns about the first aid response of boarding house staff to the critical incidents of two of the residents. The first aid provision to these residents appeared limited, focusing on moving the resident to a chair and calling an ambulance. One of the residents was found to be without pulse or respiration upon the arrival of the ambulance, and CPR had not been performed.

As part of our review of the deaths of the three residents, we met with the licensee and licensed manager of the boarding house, the Official Community Visitor,[74] and representatives of the DADHC regional office. During the meeting the issue of first aid was discussed, and we emphasised that at all times there needed to be at least one staff member qualified in first aid available at the premises to render first aid.

The boarding house agreed to investigate the availability of a first aid course and to ensure that the untrained staff members completed the course. We understand that this has now occurred.

Our reviews also raised questions as to whether sufficient levels of staff supervision were provided to some residents who had significant health conditions. While licence condition 5.4 states that the licensee and licensed manager shall ensure that the staff are '*sufficient in number and competent to perform all duties necessary for the proper care of the residents at all times*', it is unclear what benchmarks are used in determining these requirements.

The Boarding House Reform Program

In 1998 the NSW government announced a Boarding House Reform Program (BHRP) that included three key initiatives: the relocation of around 310 residents whose high support needs were not being met in boarding houses, the provision of support services to those people with a disability remaining in boarding houses,[75] and the development of a screening tool for entry to boarding houses. The BHRP is administered by DADHC, and a key objective of the program is to ensure that the boarding house population is comprised of people with disabilities who only have low support needs.

The screening tool was developed as a 'gate-keeping' process to prevent the recurrence of inappropriate placement of high need residents in boarding houses.[76] The screenings are completed by Aged Care Assessment Teams, and lead to a decision as to whether the resident is sufficiently independent such that referral to a boarding house is appropriate, or whether referral to other services or for further more detailed assessment is required. In its user guide for the screening tool, DADHC indicated that it was introduced on a pilot basis, and was to be reviewed by the department in 2002 to ensure that it was '*well understood and…effective*'. DADHC has yet to undertake the review of the tool and its objectives.

From the original group of boarding house residents with high support needs who were identified for relocation, DADHC has advised that only 29 remain in boarding house accommodation. The department has said that its work towards moving these individuals out of boarding houses is a priority, recognising that no people with high support needs should be in that model of accommodation.

None of the 24 boarding house residents who died in 2004 were among the 310 people with high support needs who were identified for relocation in 1998, nor had DADHC otherwise identified them for relocation.[77] Nevertheless, our reviews identified people with chronic health conditions, some residents with multiple health conditions, and others with deteriorating health who required higher levels of support.

As indicated in the health care planning and coordination section, our reviews have raised concerns about the capacity of boarding houses to effectively coordinate and manage the health care needs of residents. Placement of people with high support needs into an environment where their health care needs are not assured of being met or followed up presents a significant risk and can have serious consequences. As a result, it is important that, through the appropriate application of the screening tool, people with high support needs are not placed into boarding houses. There is also the need to ensure that people whose support needs become high do not remain in boarding houses.

Application of the screening tool

A number of our reviews raised questions about the accuracy of the screening tool assessment. That is, in the assessments that we saw, some did not appear to accurately reflect the residents' existing support needs. In some cases, discrepancies between the screening tool assessments and existing resident support needs noted in the disability death reviews suggested that support needs were under-assessed. For example, a man was assessed in a screening tool as being able to maintain his own medication regime. However, a file note attached to the screening tool assessment noted that, while the client wished to manage his own medications, his wardrobe was 'stashed with pills' and he was unlikely to comply with his medication being maintained via a medication aid such as a Webster-pak®.

The screening tool can also be used to re-assess suitability for boarding house residency if a current boarding house resident's health condition deteriorates, if they are admitted to hospital, or if they are absent from the boarding house for more than two months. The rationale behind these provisions is '*to ensure that a resident is screened if his/her condition has significantly deteriorated such that his/her dependency has increased. In this situation the boarding house would have to provide additional support, perhaps beyond its capabilities*'.[78]

However, six of the reviews identified residents who were admitted to hospital and then discharged back to the original boarding house. Among these six people there were 18 separate hospital admissions within the 12-month period before their deaths. Only one of these hospital admissions resulted in a screening tool assessment.

Among the six residents identified above, there was one person who had advanced ovarian cancer, two people who were recommended for palliative care, and one person who was deaf, unable to speak, and suffering from congestive cardiac failure. Three of these six people were discharged with referrals initiated by the hospital for either community palliative care or community nursing support. However, in each case it was not clear whether these services were sufficient to supplement the services available from the boarding house, as no screening tool assessment had been completed.

For these six people, the length of time between their last hospital discharge and their death was short. Three people died within six months of discharge, one died within two weeks, and two died within three days of discharge from hospital.

Involvement of additional support services

The screening tool is also intended to be a process leading to referrals for further assessment and the identification of services additional to that provided by the boarding house. However, there was little evidence of this identification and referral process occurring through the screening tool assessments we identified.

CaseStudy12[79]

A 59-year-old man with an organic brain syndrome and chronic memory loss who lived in a boarding house was diagnosed with advanced lung cancer following a hospital admission. A screening tool assessment was recommended before the man's discharge from hospital due to concerns over whether his care needs had progressed beyond that which the boarding house could provide.

The screening tool assessment took place nine days after the man had been discharged back to the boarding house. Despite documented evidence of chronic memory loss and aggressive behaviour, which according to the guidelines would exclude a person from re-entry to a boarding house, the screening tool assessment stated that he did not exhibit aggressive behaviour and that he could initiate and manage his own health care needs.

Despite his diagnosis of lung cancer, there were no recorded referrals made to any service, general or specialist, to support the man or to assist the boarding house to support him.

Five months later, the man was admitted to hospital with a diagnosis of secondary malignancy of the bone, an indication that his cancer had spread from his lungs. Our review of boarding house and health records indicated that he did not receive any cancer treatment in the intervening period. The man was again discharged from hospital to the boarding house, this time with a referral for community palliative care, but no screening tool assessment was completed. From the palliative care team records, the palliative care support the man received appeared to be limited as he indicated that he did not want their support. However, it is documented that the man had chronic memory loss, and had no recall of his diagnosis of cancer. He died one month later. We are continuing to review this man's death.

Given the private-for-profit arrangements of many boarding houses and their unfunded status, there are limits to what can be provided by boarding houses alone. The BHRP was designed to provide additional supports to people in boarding houses, including provision of case management, health services, personal care, and access to community-based activities. However, we saw little evidence of the involvement of BHRP services in the matters we reviewed. Where records existed of residents having contact with external service providers such as Community Health Teams, it appeared that this involvement occurred on an ad hoc basis. We found no evidence of the consistent involvement of caseworkers, despite some residents having had ongoing high support needs and significant health issues, and case management services being a funded component of the BHRP.

The additional support services that can be provided under the BHRP potentially provide a further safeguard for boarding house residents. In addition to the adequate provision of these support services, it is important that there is ongoing and effective monitoring by DADHC. Rigorous monitoring of boarding house service provision and licence conditions is required to enable the needs of existing and future boarding house residents to be adequately met. It provides the means to establish whether additional supports are required to enable boarding houses to meet the needs of residents, whether there are particular residents at risk who require relocation, and whether action needs to be taken by the department to promote the safety and wellbeing of residents. We are interested in looking at how monitoring of boarding houses is currently taking place, and propose to inquire into DADHC's monitoring of boarding houses in more detail in the new year.

5. Recommendations

Review and roll out of the Managing Client Health policy

A number of the recommendations in the 2003 report related to DADHC's review of its *Managing Client Health* policy, and the roll out of the policy to funded services. The review of the policy has not yet been finalised.

1. In the context of its review of the *Managing Client Health* policy, and its roll out to funded services, DADHC should:
    a) Report on progress towards rolling out the policy to funded services, including details of training and resources to implement the policy.
    b) Report on plans for, and progress towards, evaluating the implementation of the policy in funded services.

Consent

Issues concerning identification of the person responsible for providing consent to medical and dental treatment continued to be identified in 2004. DADHC has indicated that it will include clear guidelines for identifying persons able to provide consent for medical and dental treatment, and in what circumstances, in the revised *Managing Client Health* policy, and more detailed information would be provided in the *Decision Making and Consent* policy under development.

2. DADHC should report on progress towards finalising its *Decision Making and Consent* policy, including details of planned roll out and training.

Chest care

Respiratory illness continued to be a prevalent cause of death for people with disabilities in care in 2004. DADHC has indicated that, in its review of the *Managing Client Health* policy, it will consider the Hunter Region's chest care checklist for identifying clients who require regular chest care, with a view to its incorporation in the policy, and/or broader application in DADHC operated and funded services.

3. DADHC should report on the outcome of its review of the Hunter Region's chest care checklist for identifying clients who require regular chest care.

Review of Illawarra region clinical nurse specialist model of health care case management

In 2003 we identified a DADHC program in the Illawarra area that provided an example of health care management that may be particularly relevant for people with medical needs who require a complex service response. The program used clinical nursing specialists to work with services in managing the health needs of residents. It was evaluated as being a successful model by independent reviewers who submitted their findings to DADHC in May 2000. DADHC has advised that the DADHC Health Care Review Team is currently reviewing this model along with other models being used in NSW and other jurisdictions, with the outcome likely to be available by the end of 2005/06.

4. DADHC should:
    a) Report on the outcome of its review of the Illawarra region's clinical nurse specialist model of health care case management.
    b) Advise of the department's view as to the potential for wider application in DADHC operated and funded services.
    c) If the department considers that the model does have potential for wider application, outline what action DADHC intends to take.

Individual planning and risk assessment

The identification and management of risks are critical to meet the health needs of people with disabilities in care, and reduce preventable deaths. DADHC has advised that risk assessment is part of the *Individual Planning* policy and the *Managing Client Health* policy. In addition, DADHC advised that it would be releasing a revised *Managing Client Risk* policy to funded services in 2005. This policy has not yet been released.

5. DADHC should report on progress towards releasing the revised *Managing Client Risk* policy to funded services, including details of training and briefings for staff.

Communication issues and health care

This report has highlighted implications for client health where communication support is absent or inadequate, including issues concerning the identification of illness, pain, recognition of adverse effects of medications, and involvement in end-of-life decision-making.

6. In the context of its review of the *Managing Client Health* policy, DADHC should ensure that adequate guidance is provided in the revised policy on:
    a) the importance of considering resident communication issues in relation to health care needs
    b) when referral for a communication assessment is required.

Monitoring of health care planning / implementation of the *Ensuring Good Nutrition policy*

The health care planning review highlighted the importance of monitoring health care planning and the implementation of policies such as *Ensuring Good Nutrition*. DADHC has advised that in relation to DADHC operated services, the key means of monitoring health related plans are:

- the Redeveloped Disability Client Database
- after September 2005, the Service Review Instrument (SRI) of the IMF
- the Quality and Safety Framework
- the Client Information System (database).

In relation to DADHC funded services, the key means of monitoring health related plans is the SRI.

7. In the context of its monitoring of health care planning and policy implementation in DADHC operated and funded services, DADHC should provide advice as to:
    a) the 26 key performance indicators that form the basis of the Quality and Safety Framework in DADHC operated services
    b) the terms of reference of the DADHC Health Care Review Team, with particular reference to the role of the team in monitoring implementation of the *Ensuring Good Nutrition* policy
    c) what specific aspects of health care planning in funded services are monitored in the SRI, including nutritional health management practices.

Provision of health care information to boarding houses

A key section of this report considered issues that are specific to the boarding house model of accommodation for people with disabilities. We noted that boarding houses are not subject to policies and standards that govern disability services, and operators of boarding houses largely operate without comprehensive guidance. There are clear implications for the provision of care to boarding house residents in relation to health needs.

8. DADHC should provide relevant information to boarding houses concerning good practice in health care, including provision of good practice information contained within policies such as *Ensuring Good Nutrition, Managing Client Health, Palliative Care, Managing Client Risk*, and *Decision-Making and Consent.*

Screening Tool for entry to licensed boarding houses

Application of the screening tool was identified as an issue in 2004, including the accuracy of the assessments, application following admittance to hospital, and identification of additional services.

9. In relation to the screening tool for entry to licensed boarding houses DADHC should:
    a) review current application of the screening tool to determine whether it is being used in line with existing guidelines. A component of this review should be an audit of the quality and accuracy of the assessments
    b) at the completion of the review evaluate the findings and advise what action, if any, it intends to take in relation to the effectiveness and ongoing use of the tool.

Record keeping in boarding houses

Record keeping in boarding houses was identified as a significant concern in this report. The concerns related to the adequacy and accuracy of the records kept by boarding house staff, as well as the impact of poor record keeping on the ability of boarding house staff to meet individual client needs.

10. In order to improve the adequacy of records kept by licensed boarding houses, DADHC should:
    a) undertake a review of record keeping practices in licensed boarding houses
    b) implement the results of the review
    c) evaluate and report on the outcomes of the review.

Hospitalisation of people with disabilities

Issues relating to the hospitalisation of people with disabilities in care were raised by funded services in the health care planning review, including the separation of responsibility between hospital staff and service staff. In addition, our reviews identified concerns about the quantity and quality of information provided to hospital staff by services when residents are admitted. NSW Health released the *People with Disabilities: Responding to their needs during hospitalisation* policy directive in October 2005, which is to be used in the development of local policies and procedures. CDDS provided disability-awareness training to hospital staff in May 2005 to support the policy directive.

11. NSW Health should evaluate the implementation of its *People with Disabilities: Responding to their needs during hospitalisation* policy directive, and provide details as to how it intends to monitor the development and implementation of local policies and procedures in NSW Health services.

Discharge planning

The importance of discharge planning is evident in this report in relation to palliative care provision to people with disabilities in care, questions as to the appropriateness of boarding house accommodation for some people with higher needs following hospital admission, and the complex health needs of some people with disabilities that require the involvement of numerous health services following discharge. NSW Health has advised that it has developed a draft Effective Discharge Planning Framework, but it has not been endorsed for release.

12. NSW Health should report on progress towards finalising its Effective Discharge Planning Framework, including details of planned roll out, training, and evaluation.
13. DADHC and NSW Health should discuss how the screening tool for entry to licensed boarding houses may be incorporated into the Effective Discharge Planning Framework.

End of life decision-making

In 2003 and 2004 we identified issues relating to end-of-life decision-making for people with disabilities in care, including questions about the involvement of people with disabilities in the decision-making process. NSW Health issued its *Guidelines for end-of-life care and decision-making* in March 2005.

14. NSW Health should evaluate the implementation of its *Guidelines for end of life care and decision-making*, and advise how this will be undertaken.

Palliative care

The provision and coordination of palliative care, including the involvement of the resident in decision-making, were identified as issues for residents of DADHC operated, funded and licensed accommodation services in 2004. Given the sensitive and critical nature of any decision-making on this issue, it is important that there is clear guidance for services in relation to palliative care, including considerations and responsibilities.

15. DADHC should report on progress towards finalising its *Palliative Care* policy, including details of consultation, planned roll out and training.
16. DADHC and NSW Health should commence joint work on the coordination of palliative care for people with disabilities in care.

Comprehensive health assessments

The 2003 and 2004 reports have both highlighted the importance of comprehensive health assessments in ensuring that the health care needs of people with disabilities in care are identified and met. Our Advisory Committee has reported that, while the Medical Benefits Schedule currently covers annual assessments of people over 75 and Aboriginal and Torres Strait Islander people over 55, as well as assessments of residents of aged care facilities, it does not provide an item for an annual comprehensive assessment for people with disabilities. The Committee has indicated that the way the current items are structured means that it is a disincentive to general practitioners to conduct lengthy examinations or assessments for people with disabilities.

17. NSW Health should advise of its view of the matters raised in this report relating to Medical Benefits Schedule assessment items. This should include advice as to whether the department has raised the issue with the Commonwealth Government, or whether there are plans to do so.

Training of health providers on providing health care to people with intellectual disabilities

18. In relation to the Primary Health Care Capacity Building Project, NSW Health should:
    a) evaluate the project and report on the outcomes
    b) following completion of the evaluation, advise what further action, if any, it intends to take in relation to providing training to health workers on health care for people with intellectual disabilities.

First aid

As highlighted in this report, many people with disabilities in care have increased susceptibility to respiratory illness, have swallowing difficulties that place them at risk of choking, and are otherwise prone to serious health conditions. As a result, first aid knowledge is critical in the provision of support to people with disabilities in care. Issues relating to the provision of first aid were noted particularly in relation to boarding houses in 2004.

19. DADHC should require that the services it operates, funds or licenses have at least one staff member on each shift with current first aid qualifications. DADHC should provide assistance to funded and licensed services to achieve this requirement.

Medication reviews

We have identified that people with disabilities in care are vulnerable to adverse events as a result of medication, such as drug toxicity. The involvement of Domiciliary Medication Management Reviews may provide an additional safeguard in relation to medication management.

20. DADHC should develop a system for ensuring regular reviews of medication in DADHC operated and funded services. As part of this work, DADHC should give consideration to Domiciliary Medication Management Reviews.

Access to allied health

Access to allied health, particularly DADHC speech pathology services, was identified as an issue in 2004 in the health care planning review, and confirmed by information provided by DADHC that the average waiting period for its speech pathology services is 5.7 months.

21. In order to improve access to speech pathology services, DADHC should:
    a) negotiate with NSW Health to access alternative services
    b) work with disability agencies to determine priorities for access
    c) track, monitor, and report on the average waiting periods for access to DADHC speech pathology services.
22. NSW Health should provide advice as to how its Workforce Action Plan will address workforce issues in relation to allied health staff.

Progression of DADHC / NSW Health joint work

In 2003 we recommended that DADHC and NSW Health report on progress towards shared responsibility for meeting the medical needs of people with disabilities in accommodation services, and joint models of support for people with complex care needs. We were advised that a number of areas of joint work had commenced to improve equity of access to, and the quality of, medical and health care for people with a disability.

23. DADHC and NSW Health should:
    a) report on outcomes of discussions on the DADHC Complex Care Needs model of supported accommodation for identified clients relocating from large residences who require full-time nursing support
    b) report on progress towards mapping specialist and generic services provided by DADHC and NSW Health, and advice as to how this information will be used
    c) advise what the work on ‘identifying models of care to improve access for people with intellectual disability and the management of their health care issues’ involves, and what progress has occurred to date
    d) outline any other joint projects on the current agenda of the DADHC / NSW Health Senior Officers Group, and advise what progress has occurred to date.

6. Monitoring recommendations

Section 43 (2) (c) of *CS (CRAMA)* requires us to provide information in our reviewable deaths annual report with respect to the implementation or otherwise of previous recommendations (as appropriate). Following are DADHC and NSW Health's responses to our recommendations from 2003-2004.

Response from DADHC

DADHC's first response to our recommendations was provided on 11 March 2005. The information provided by the department in relation to most of the recommendations was either inadequate to indicate what action it intended to take in response to the recommendations, or provided insufficient detail to determine timeframes. Consequently, we wrote again to DADHC, seeking clarification and further advice in relation to recommendations 1, 2, 3, 4, 5, 7, and 10. The following table lists our recommendations in bold type, followed by DADHC's response. In some cases we have summarised the response. Our comments follow DADHC's response.

A number of the recommendations related to DADHC's review of its *Managing Client Health* policy, and the roll out of the policy to funded services. DADHC intended to review the policy in May 2005, and to roll it out to funded services in August 2005. However, subsequent advice provided by the department indicates that, while it has updated the policy to take into account the recommendations from the 2003-2004 reviewable death annual report,[80] it is deferring consultation on the policy to enable the inclusion of sections relating to children and young people in out-of-home care. DADHC has indicated that the policy will be available for comment in late November 2005, but has not provided any further details around the updated likely timeframe for roll out of the policy.

Recommendation 1	
DADHC response	**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** • The current Australian Immunisation Handbook will be incorporated into the *Managing Client Health* policy. **(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** • Information will be included in the review of the *Managing Client Health* policy. This policy will include adequate information for staff to determine the next most appropriate person to provide consent. • The *Managing Client Health* policy also refers staff to the *Decision Making and Consent* policy, which provides detailed information to identify the next appropriate person to provide consent for a range of issues in addition to medical and dental treatment, and the circumstances where this may be required for people living in care. The *Decision Making and Consent* policy will be finalised by August 2005. • The Substitute Consent for Medical and Dental Treatment form and information sheets were redeveloped in 2004 in collaboration with the Alliance of NSW Divisions of General Practitioners, the Office of the Public Guardian, Carers NSW, and the Australian Medical Association of NSW Ltd. The Substitute Consent Form and information sheets will be posted on the DADHC Intranet and Internet and released as an attachment to the *Decision Making and Consent* and *Managing Client Health* policies. **(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** • The checklist will be considered in the review of the *Managing Client Health* policy, which will be rolled out to operated and funded services.

Recommendation 1 (Continued)	
DADHC response	**(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** • The *Individual Planning for Adults in Accommodation Support Services* policy has been released for implementation in DADHC operated and funded services. DADHC operated and funded services will receive briefings on the policy. The briefings will emphasise the 'key worker' model. **(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** • DADHC will provide a progress report about the roll out of the *Managing Client Health* policy to funded services including details of training and resources to implement the policy in August 2005. • A communication and briefing strategy has been developed, and the Service Development and Planning stream of DADHC will brief funded services in each of their Regions. A notice will also be published in the DADHC Connections Newsletter informing funded services of the policy. The policy and briefing package will be published on the DADHC website. The training package is currently being developed by the DADHC Learning and Development Unit for operated services and will be available to funded services via the DADHC website. **(f) Report on plans for monitoring and evaluating the implementation of the *Managing Client Health* policy in DADHC operated and funded services.** • As part of the review of the *Managing Client Health* policy a Quality Audit Tool will be developed to monitor the implementation of the policy. The tool will be a checklist to ensure that clients have their relevant health care plans in place, and will be developed by September 2005. • DADHC Quality and Standards stream has developed the Integrated Monitoring Framework (IMF)[81] that has been piloted and will commence on 1 July 2005. The IMF monitors the implementation of policies in DADHC operated and funded services. • Accommodation and Respite Branch is in the process of negotiating with the Centre for Developmental Disability Studies (CDDS) to evaluate the implementation of the *Managing Client Health* policy in DADHC funded services.
Our Comments	Progress towards implementing the above recommendations has been stalled due to the delay in completing the review of the *Managing Client Health* policy. Although DADHC has indicated that it has updated the policy to take into account the recommendations from the 2003-2004 reviewable deaths annual report, no further information has been provided to indicate what updates have been made, and whether the work on the policy to date has included review of the chest care checklist. To date, the *Decision Making and Consent* policy has not been finalised, and the Substitute Consent Form and information sheets have not been posted on the DADHC website. DADHC has advised that Phase 1 of the IMF (application to funded services) is being rolled out, and the department is now moving to develop an implementation strategy for DADHC operated services. However, DADHC has also advised that it has not yet finalised the documents relating to the IMF, including the Service Review Instrument, which is the key tool used by DADHC to conduct service reviews and develop action plans for service improvement.
Recommendation 2	
DADHC response	**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** • Risk assessment is part of the individual planning process re: *Individual Planning* policy. Training materials to support the *Individual Planning* policy are currently under development and should be available for DADHC operated services in the first quarter of 2006. A briefing package which will be available to government and non-government operated services will also be available in the first quarter of 2006. Briefings will include regular assessment of risk to individual service users as part of individual planning, and seeking expert advice for developing plans to meet individual needs.

Recommendation 2 (Continued)	
DADHC response	– A revised *Managing Client Risk* policy will be released to DADHC funded services in 2005. – *Individual Planning* policy training will be delivered to staff of DADHC operated services and to new staff as part of the induction package, and training and briefing materials will be posted on the DADHC website for use by DADHC funded services. • The *Managing Client Health* policy includes a *Client Risk Profile* that is administered as part of the individual planning process. **(b) Seeking expert advice for developing plans to meet individual needs** • The *Managing Client Health* policy gives responsibility to the key worker for engaging appropriate health care specialists in the health care planning so they receive expert advice when developing plans to meet individual needs. **(c) Monitoring the implementation of individual risk management plans.** • Monitoring the implementation of the individual risk management plans is part of the Individual Planning process and the *Managing Client Risk* policy. Training and briefing for staff will occur in 2005, with the timeframe to be advised after discussion with Learning and Development. • DADHC's Redeveloped Disability Client Database (RDCD) also records all client management plans and produces reports for staff to ensure that all plans are current. The due date of each client's plans is reported to management.
Our Comments	No timeframe has been provided for the release of the revised *Managing Client Risk* policy to funded services. While the *Individual Planning* policy has been placed on the website, no training materials have been posted. While our recommendations in relation to risk management and individual planning appear to be in the process of being implemented, we have received no information to indicate that the intended strategies have been completed.
Recommendation 3	
DADHC response	**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** ***For DADHC funded services:*** • The IMF will review how funded services are performing against the terms of their funding agreements. This framework will also be used to work with DADHC operated services as the key organisational approach to monitoring the quality of service delivery. • The key monitoring and review tool for determining service performance under the IMF is the Continuous Improvement Matrix (now known as the Service Review Instrument, or SRI). The SRI will be used to determine the extent to which services are meeting funding requirements including issues of risk for clients. This includes reviewing practices in regard to nutritional health management in accommodation services. • The IMF will address common systemic issues identified in DADHC funded services and work with the sector to address improvement initiatives. In addition, the framework will provide DADHC and the sector with information on priority areas of improvement.

Recommendation 3 (Continued)	
DADHC response	***For DADHC operated services:*** - DADHC has developed and piloted a Nutrition Assessment Tool that has been fully implemented in DADHC operated services and is available for use in funded services. - The RDCD requires staff of DADHC operated services to enter types of client management plans, the date they were developed and the review date. The RDCD will report when the plans are due for renewal. After September 2005, the SRI will also identify individuals who are clients of DADHC operated services who do not have a current Individual Plan including a Nutrition and Swallowing Checklist, Eating and Drinking Plan, Oral Care Plan, Weight Chart, and Immunisation records. - The Quality and Safety Framework[82] will also identify clients of DADHC operated services who do not have the necessary plans and all their components and records in place. The Quality and Safety Framework requires Regions to complete quarterly reviews to ensure that all necessary plans are in place. If clients are identified as not having the required plans, the Regional Quality Committee (RQC) will request that the Manager of the unit where the client resides submit a plan to redress this to the RQC, with timeframes. The RQC will monitor the implementation of the plan until completion. - The State Quality and Safety Committee for DADHC operated services will address systemic issues identified and consider additional initiatives in relation to (a) to (e). **(e) Keeping immunisation records.** - The *Managing Client Health* policy will be amended to include the Australian Standard Vaccination Schedule from the Australian Immunisation Handbook 8th Edition 2003 and guidelines for those who are at increased risk of infection.
Our Comments	Monitoring of the implementation of the *Ensuring Good Nutrition* policy is at the initial stages. DADHC has indicated that the IMF will look for evidence that practices in relation to (a) – (d) are in place at funded services as part of the three-yearly cycle of review. Although the roll out of the IMF has commenced in relation to funded services, the documents have not yet been finalised. This will affect progress towards monitoring implementation of the *Ensuring Good Nutrition* policy. DADHC has subsequently advised that the issue-specific monitoring tools, such as the Nutrition Assessment Tool, have now been merged with the generic components of the SRI. We have received no advice to indicate what aspects of the Nutrition Assessment Tool will be retained in the SRI.
Recommendation 4	
DADHC response	**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.** In its response to this recommendation, DADHC advised that the Tool had been fully implemented in DADHC operated services and was available for use in funded services. DADHC stated that the Tool would be incorporated into a service specific component of the SRI by September 2005. DADHC also advised in its responses that it is developing a new Client Information System (CIS) that will be the system by which nutrition management plans will be assessed and managed, amongst other aspects of support for clients in DADHC operated services. The indicators developed in the Assessment Tool are being incorporated into the CIS. Stage 1 roll out of the CIS will take place in July 2005.
Our Comments	Monitoring of the implementation of the *Ensuring Good Nutrition* policy is at the initial stages. As indicated in our comments in relation to Recommendation 3, DADHC has subsequently advised that the service specific components of the SRI have now been merged with the generic components, so there are no issue or service specific tools. We have received no advice to indicate what aspects of the Nutrition Assessment Tool will be retained in the SRI.

Recommendation 5	
DADHC response	**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.** DADHC advised that this model would be considered in the review of the *Managing Client Health* policy in April 2005. A Health Care Review Team (HCRT), consisting of a panel of DADHC officers and external representatives with expertise in the health care of people with a disability, will be established by the Accommodation and Respite Branch to look at the quality of health care, planning and implementation. The HCRT will be established as part of the review of the *Managing Client Health* policy by April 2005. The HCRT is currently reviewing the clinical nurse specialist model along with other models being used in NSW and other jurisdictions. The outcome of this review should be available by the end of 2005/06.
Our Comments	Review of the clinical nurse specialist model of health care case management and its potential for wider application has recently commenced, and a timeframe for completion has been provided.
Recommendation 6	
DADHC response	**In 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.** • In March 2003, *Placement of Clients in Group Home Vacancies – Interim Policy Pending Development of a Whole of Sector Vacancy Management Policy* was endorsed. • In 2003, each DADHC region developed localised Vacancy Management Systems for the management of vacancies in both DADHC operated and funded supported accommodation services. • In each region, Government and non-government service providers worked with DADHC and other key stakeholders to develop processes for vacancy management. The processes differ for each region, although all regions have a placement committee with representation from DADHC regional staff, service providers, and independents. The Committee considers applicants for vacancies and makes recommendations on the match of applicants to vacancies to the Regional Director for endorsement. Service user compatibility issues are considered. • DADHC's Community Access Branch is currently developing statewide vacancy management principles for DADHC operated and funded services. The principles will provide a consistent framework for regional policies and complement existing regional procedures. The timeframe for the policy is the end of November 2005.
Our comments	The timeframe for the development of the *Statewide Vacancy Management* policy / principles is end of November 2005. The Systemic Projects and Inquiries unit of the NSW Ombudsman is continuing to monitor DADHC's progress towards developing procedural guidance for assessment and placement decisions.
Recommendation 7	
DADHC response	**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.** • The Electronic Records Management Procedures for Group Homes has been developed and piloted in the Southern Region. It is being completed as part of the DADHC-wide Electronic Records and Document Management (ERDM) project. This project will provide staff at all levels with the tools and the capacity to create and manage records in a manner compliant with International and State Records Authority standards. The implementation has focused on paper-based records, but will move to the corporate ERDM System when improvements and capacity allow. • The implementation has already commenced with briefings, and will progress to training for System Support Coordinators and then staff at the group home level during 2005.

Recommendation 7 (Continued)	
DADHC response	• While the scope of the Records Management Procedures for Group Homes Project was confined to the group homes, it is the intention of DADHC to undertake an analysis and review of the large residential and respite sectors during the July to December 2005 period as part of the preparation for the roll out of the file management system in early 2006. • The rollout of the revised Records Management Procedures for Group Homes has been deliberately aligned with the Quality and Safety Framework in DADHC. A review will be undertaken in early 2006 to identify and address issues relating to implementation and support. • Preliminary discussions have occurred with staff in Accommodation and Respite Branch in relation to DADHC funded services. As part of the ERDM Program, Business Process Integration Project advice will be provided to DADHC to assist in the development of record-keeping in accordance with Department standards by DADHC funded services.
Our comments	While the records management project is not yet completed, and currently applies only to DADHC operated group homes, we consider that the department is taking active steps to address the issue of records and file management. We intend to consider records management and examine progress towards addressing this recommendation through our review work.
Recommendation 10	
DADHC response	**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.** DADHC advised that it would continue to collaborate with NSW Health on these issues. The department's response to this recommendation was inadequate, and did not report on any progress towards the two identified areas of shared work. As a result, we asked DADHC to provide further advice regarding: **(i) Whether DADHC and NSW Health are currently collaborating on any initiative(s) that relates to shared responsibility for meeting the medical needs of people with disabilities in accommodation services, or joint models of support for people with complex health care needs. If so, please provide details. If not, please advise if there are any defined plans to do so.** **(ii) Whether DADHC and NSW Health have any formal and regular mechanisms by which health issues for people with disabilities in accommodation services can be discussed and addressed. If so, please provide details.** In response, DADHC advised that: (i) Discussions continue with NSW Health on the identification of a set of joint projects for meeting the medical needs of clients in DADHC operated accommodation services, and (ii) There are currently two forums in which health issues for people with disabilities in accommodation services can be discussed, the DADHC/NSW Health Directors-General meetings and the DADHC/NSW Health Senior Officers Group. These meetings are held every two months. On 26 October 2005, DADHC advised that it had commenced early work with NSW Health on: • A project designed to map existing specialist and generic services for people with a disability with a view to identifying models of care to improve access for people with an intellectual disability and the management of their health care needs. • Building the capacity of existing services to better meet the needs of people with intellectual disability. • Identifying systemic issues in the delivery of healthcare to people with an intellectual disability. • Identifying workforce issues and strategies to address these in relation to allied health staff.
Our comments	This response is again inadequate and provides no detail on the joint projects that have been identified for meeting the medical needs of people with disabilities in accommodation services.

Response from NSW Health

NSW Health's response to our recommendations was provided on 31 May 2005. The information provided by NSW Health, particularly in relation to recommendation 10 concerning joint work with DADHC, lacked sufficient detail to enable us to determine what progress had been made on key initiatives. Consequently, we wrote again to NSW Health, seeking clarification and further advice in relation to the three recommendations.

The following table lists our recommendations in bold type, followed by NSW Health's response. In some cases we have summarised the response. Our comments follow NSW Health's response.

Recommendation 8	
NSW Health response	**In the context of the development by the Centre for Developmental Disability Studies (CDDS) 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 flow cannot be ascertained.** • NSW Health advised that it will ensure that advice is included to GPs on best practice approaches to management of respiratory and other illnesses in people with intellectual disabilities with particular emphasis on issues relating to limited patient cognition, communication and case management. • The timeframe for the completion of the Project, which incorporates the strategy, guidelines and assessment tool for General Practitioners, is October 2005. The first of the GPs training sessions are scheduled for 18 and 23 August and will be held on the Mid North Coast and in South Eastern Sydney. CDDS will coordinate the GPs and the Community Health Workers training. Training sessions have been arranged for the Community Health Workers in two Area Health Services. • In its response to the draft report, NSW Health advised on 1 November 2005 that the GP training sessions have been completed. The CDDS will identify the lessons learnt and the limitations of the educational methods trialled in their Final Report.
Our comments	While the NSW Health response did not specifically mention asthma, we consider that it would be covered in advice regarding best practice approaches to the management of respiratory illnesses.
Recommendation 9	
NSW Health response	**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'.** • NSW Health has revised and released the guidelines, entitled *Guidelines for end of life care & decision-making*. The revised guidelines outline a process for reaching decisions about the use of life-sustaining treatments, including CPR, in patients without decision-making capacity. This model is a shared decision-making one aimed at building a consensus between the treating team and family or those close to the person about the best possible treatment for the person at that time. The Guidelines emphasise that such decisions should be informed by the particular person's medical condition and prognosis, values and wishes (where known) and that these decisions should be non-discriminatory, such as blanket decisions about use of CPR based on age or disability are not appropriate. Reference is made to the *Guardianship Act* and Tribunal in end of life decisions for adults without decision-making capacity and to decision-making for children who are subject to a care order. • Education forums have commenced, with sessions held in metropolitan Sydney and Coffs Harbour, and upcoming sessions in Wagga Wagga and Bathurst. As well as DADHC staff, the forums are directed at individuals and professional bodies who are responsible for palliative and aged care, legal, ethical and bio-ethical issues. • Where the individual is in a DADHC residence, DADHC staff will be responsible for noting the decision-making process in the *My Health Record* booklet, consistent with the Guidelines.
Our comments	Reference is made in the Guidelines to the *Guardianship Act* and Tribunal in end-of-life decisions for adults without decision-making capacity. However, where the Guidelines relate to patients that lack decision-making capacity, there is no reference to patients who may not have a family member or person responsible, or the potential need to involve the Guardianship Tribunal in decisions concerning end-of-life care for those individuals.[83]

Recommendation 10

NSW Health response

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

In relation to recommendation 10, NSW Health and the Department of Ageing, Disability and Home Care (DADHC) are working together on a number of initiatives to improve access of people with disabilities to allied health and specialist medical services including the following:

- The transfer of Diagnostic and Assessment Services from DADHC to NSW Health.[84]
- The use of the *My Health Record* for clients in DADHC operated services.
- The development of the NSW Health *Hospitalisation of People with Disabilities* Guidelines to assist hospital staff in responding more effectively to the needs of people with disabilities including those from supported accommodation. The Guidelines have been completed and approval to release the Guidelines is being sought. Following approval the Guidelines will be circulated throughout the NSW Health System as a Policy Directive, and Area Health Services will provide appropriate training.[85] Further to this, CDDS was contracted by NSW Health to develop a disability-awareness training package for hospital staff, and implement the training in public metropolitan and rural hospitals across NSW. This project was to support the *Hospitalisation of People with Disabilities* Policy Directive and was completed in May 2005.
- The NSW Health Effective Discharge Planning Framework specifically addresses the needs of people with a disability living in residential care, and a draft Framework is being used in NSW Area Health Services. The final version has not yet been endorsed for release.
- The NSW Health Primary Health Care Capacity Building Project aims to improve the skills and confidence of GPs and community health staff in working with people with intellectual disabilities.
- The DADHC Complex Care Needs model of supported accommodation for identified clients relocating from large residences who require full-time nursing support is on the agenda of the DADHC / NSW Health Senior Officers Group (SOG). The SOG is discussing the role of NSW Health in this model of care.
- The Comprehensive Health Assessment Program (CHAP) Tool is being implemented for use by GPs with supported accommodation clients with intellectual disabilities.
- The DADHC Nutrition Health Expert Advisory Committee has developed overarching policy and standards for all DADHC-funded accommodation services.

NSW Health and DADHC will continue to work together to improve equity of access to and the quality of medical and health (care) for people with a disability by:

1. Mapping existing specialist and generic services provided by NSW Health and DADHC. The mapping exercise is being progressed through the SOG and will be completed by the end of 2005. Availability of services will be outlined in this exercise. Detailed information regarding wait lists is not part of the mapping exercise.
2. Identifying models of care to improve access for people with intellectual disability and the management of their health care issues. This project has been identified as a key responsibility of the SOG and is currently being actioned by this group.
3. Building the capacity of existing services to better meet the needs of people with intellectual disability through the Primary Health Care Capacity Building Project. This project is aimed at enhancing the skills and confidence of clinicians (including GPs, Community Health workers, and allied health staff) in communicating with and treating people with intellectual disabilities.
4. Identifying and addressing systemic issues in the delivery of health care to people with intellectual disability. Both the Primary Health Care Capacity Building Project and the NSW Health Guidelines, *Hospitalisation of People with Disabilities* are strategies targeted at improving the capacity of the NSW healthcare system to identify and address systemic issues in the delivery of health care to people with intellectual disability. In addition, NSW Health, in collaboration with the Clinical Excellence Commission is working in partnership with others to achieve improvements. The Safety Improvement Program aims to ensure the provision of safe and appropriate care to the highest of standard for all people in NSW. This will be achieved through the effective management of incidents including investigation using the Root Cause Analysis methodology.
5. Identifying workforce issues and strategies to address these in relation to allied health staff. The Department's Workforce Development Leadership Branch is responsible for allied health workforce issues. Recruitment and retention of all health staff will be addressed through implementation of the NSW Health Workforce Action Plan.

Recommendation 10 (Continued)	
Our comments	A number of strategies put forward in NSW Health's response had already been reported as current or proposed initiatives in the reviewable death annual report. Namely, the NSW Health *Hospitalisation of People with Disabilities* policy directive; improvements to discharge planning; the Primary Health Capacity Building project; and the CDDS training for hospital staff. In addition, the DADHC Nutritional Health Expert Advisory Committee referred to by NSW Health concluded in 2003. In terms of progress, the Effective Discharge Planning Framework is yet to be released. In relation to the Primary Health Care Capacity Building Project, the scope appears to have been limited to two regions for GPs and two area health services for Community Health workers. No further information has been provided to clarify what the joint work around 'identifying models of care to improve access for people with intellectual disability and the management of their health care issues' involves.

Endnotes

[1] In the legislation, 'residential centre for handicapped persons' means: a) premises declared to be a residential centre for handicapped persons under section 3A of the *Youth and Community Services Act 1973*, or b) premises licensed under Part 3 of the *Youth and Community Services Act 1973*. These premises are also known as 'licensed residential centres', and more commonly known as 'licensed boarding houses'.

[2] NSW Ombudsman (2004) *Reviewable Deaths Annual Report 2003-2004.*

[3] Advice from DADHC in letter to NSW Ombudsman 29 August 2005.

[4] Advice from NSW Health 1 November 2005.

[5] *My Health Record* is a NSW Health booklet designed to record an individual's personal details, emergency contacts, key health and other service contacts, appointments, health problems and diagnoses, medications, allergies and vaccinations, health management plans, and other key information.

[6] At the time of writing this report, we had not had the opportunity to review this policy directive.

[7] For ease of reporting, we refer to licensed boarding houses as 'boarding houses'. The boarding houses referred to in this report are those licensed by DADHC under the *Youth and Community Services Act 1973* ('YACS Act'). Each boarding house is subject to a set of licence conditions that specify the requirements expected of the licensee, licensed manager, and staff of the boarding house. Boarding houses do not receive any funding for their operation, and in most cases operate as private-for-profit businesses. As such, the *Disability Services Act 1993* and its associated principles and standards does not apply to them, nor do the majority of DADHC policies for disability services.

[8] s36(1)(d).

[9] AIHW – *Australia's Health 2004*.

[10] AIHW – *Disability Support Services 2003-04*, August 2005, p2.

[11] This figure includes health conditions termed recurrent respiratory infections, bronchitis, and respiratory illness, but does not include Chronic Obstructive Pulmonary Disease (COPD).

[12] GORD is a backflow of stomach contents upward into the oesophagus. It is associated with respiratory complications including chronic lung disease and aspiration pneumonia.

[13] COPD is a long-term lung disease marked by shortness of breath that initially occurs with exertion and becomes progressively worse over time. It is a major cause of mortality, illness, and disability. Tobacco smoking is the strongest risk factor for COPD.

[14] DADHC advice 11 March 2005.

[15] DADHC advice 29 August 2005.

[16] Melville, C.A., Cooper, S.A., McGrother, C.W., Thorp, C.F., & Collacott, R (2005) *Obesity in adults with Down syndrome: a case-control study*, in Journal of Intellectual Disability Research, Vol 49, Part 2, pp125-133, February 2005.

[17] Emerson, E (2005) *Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England*, in Journal of Intellectual Disability Research, Vol 49, Part 2, pp134-143, February 2005.

[18] DADHC *Nutrition in Practice* manual (October 2003).

[19] DADHC advice 12 September 2005. In its comments on the draft of this report on 26 October 2005, DADHC advised that the average score can be distorted by extreme scores at either end of the frequency distribution. DADHC also advised that the median waiting time was 2.7 months, meaning that half the number of cases waited no longer than 2.7 months, and half waited longer than 2.7 months for speech pathology services.

[20] DADHC *Nutrition in Practice* manual (October 2003).

[21] We included speech pathology reports that included instructions for staff around mealtime management.

[22] 'Person responsible' is a legal term within the *Guardianship Act 1987* (s33A). It refers to someone who has the authority to consent to treatment for an adult who is unable to give a valid consent to their own medical or dental treatment.

[23] 'Major treatment' is classified by the *Guardianship Act 1987* as requiring the consent of a guardian, person responsible, or the Guardianship Tribunal.

[24] DADHC advice 11 March 2005.

[25] *The International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification*.

[26] The number of deaths 'related to' respiratory illness is higher than the number in the above chart as it includes primary cause of death as well as antecedent and/or other significant conditions.

[27] DADHC *Nutrition in Practice* manual (October 2003).

[28] We note that the roll out of the *Ensuring Good Nutrition* policy to funded services was only completed in mid-2004.

[29] A dietitian assesses a person's nutritional status and nutritional requirements. Referral to a dietitian is suggested in relation to 17 of the 24 questions in the nutrition and swallowing checklist, and the *Ensuring Good Nutrition* policy states that services should facilitate the involvement of a dietitian or an appropriate health care professional as needed.

[30] Our Advisory Committee has advised that one episode of respiratory illness should be treated by the GP, a second episode should be treated by the GP with a possible referral to a respiratory specialist, and it is imperative that a third episode results in referral to a respiratory specialist.

[31] NSW Health (2004) *NSW Chronic Care Program: Phase Two 2003-2006*.

[32] Therapeutic Guidelines Ltd (1999) – *Therapeutic Guidelines: Cardiovascular*.

[33] Sourced from *The Merck Manual of Medical Information* (1997).

[34] Communication support may be necessary if a person has limited expressive and/or receptive communication skills. Support examples include hearing aids, signing, pictures, and electronic devices.

[35] Sourced from *The Merck Manual of Medical Information* (1997).

[36] AIHW – *Australia's Health 2004*.

[37] NSW Health – *NSW Chronic Care Program Phase Two 2003-2006*.

[38] The coronial cause of death has not yet been received.

[39] The BHRP is administered by DADHC, and includes the provision of support services to people with a disability remaining in boarding houses. The Resident Support Fund component of the program consists of funding for personal care via the Home Care Service, Primary and Secondary Health Services, the Active Linking Initiative, and case management services.

[40] The screening tool is used to assess a person's suitability for boarding house residency. It is completed by a member of the Aged Care Assessment Team, and is required before an individual can be accommodated in a boarding house. The screening tool is also used to re-assess suitability if a current boarding house resident's health condition deteriorates, if they are admitted to hospital, or if they are absent from the boarding house for more than two months.

[41] DADHC completed roll out of *Ensuring Good Nutrition* to funded services in mid-2004.

[42] The identification of staff members as 'key workers' is a feature of DADHC's *Managing Client Health* and *Individual Planning* policies. This typically involves a staff member being allocated a client or group of clients to work with, and having the responsibility for ensuring certain tasks are completed for those clients. For example, organising the individual planning meeting and developing the health care plan. Not all NGO services use this model.

[43] NSW Health advice 5 August 2005.

[44] AIHW, *Australia's Health 2004*, pxiii.

[45] Johnston, C., and Dixon, R (1998), *Nursing students' attitudes towards people with disabilities: can they be changed?*, paper presented at Australian Association for Research in Education conference.

[46] DADHC has advised that the Health Care Review Team (HCRT) will be established as part of the review of the *Managing Client Health* policy, and will conduct audits and quality reviews of DADHC health care plans and their implementation. The HCRT will consist of a panel of DADHC officers and external representatives with expertise in the health care of people with a disability.

[47] NSW Health advice 1 November 2005. At the time of writing this report, we had not had the opportunity to review the policy directive.

[48] NSW Health advice 5 August 2005.

[49] DADHC advice 12 September 2005. In its comments on the draft of this report on 26 October 2005, DADHC advised that the average score can be distorted by extreme scores at either end of the frequency distribution. DADHC also advised that the median waiting time was 2.7 months, meaning that half the number of cases waited no longer than 2.7 months, and half waited longer than 2.7 months for speech pathology services.

[50] NSW Health advice 5 August 2005.

[51] DADHC advice 12 September 2005.

[52] NSW Ombudsman (2004) *Monitoring of disability services in NSW*.

[53] Ageing in place refers to people ageing in their usual residence – that is, not moving to aged care accommodation.

[54] DADHC advice 29 August 2005.

[55] A number of people were receiving more than one medication in each type, for example two types of anti-psychotic medication. Those numbers have not been considered in this annual report.

[56] Department of Health and Ageing, *Home Medicines Review*, www.health.gov.au

[57] Megacolon is an abnormal enlargement of the colon, often associated with chronic constipation.

[58] NSW Health advice 31 May 2005.

[59] Documented in medical records variously as DNR (Do Not Resuscitate), NFR (Not For Resuscitation), and not-for-CPR. We have used 'no CPR' as it is consistent with the terminology used by NSW Health in its 2005 *Guidelines for end-of-life care and decision-making*.

[60] From the World Health Organisation website: www.who.int/cancer/palliative/definition/en

[61] p16

[62] Janicki, M.P., & Ansello, E.F (2000) *Community Supports for Aging Adults with Lifelong Disabilities*, p185.

[63] Palliative Care Australia (2005); *Standards for Providing Quality Palliative Care for all Australians*; p28

[64] NSW Health (2001); *NSW Palliative Care Framework*; p6

[65] Advice from NSW Health 1 November 2005.

[66] Retrospective referrals are where the Ombudsman reports the death of a person with a disability in care to the Coroner because the Coroner has no record of the death.

[67] This case is also highlighted in case studies 9 and 11.

[68] DADHC *Response to the death of a client and reporting reviewable deaths* policy (2004) applies to DADHC operated, funded, and licensed services.

[69] Licence conditions also specify records relating to the operation of the licensed premises. For example, records must be maintained with respect to fire evacuation drills (licence condition 4.3), and all financial transactions between residents and the licensee (licence condition 8.2).

[70] Pro re nata means 'when necessary'. Prn medication is given to an individual only as needed. For example, Ventolin inhalers may be prn medication that is only taken by the person when they experience difficulty breathing.

[71] This case is also highlighted in case studies 8 and 11.

[72] This case is also highlighted in case study 12.

[73] This case is also highlighted in case studies 8 and 9.

[74] Official Community Visitors are people appointed by the Ministers for Community Services and Disability Services to attend places providing accommodation services for children, young people and people with a disability. Their role is to inform the Ministers and the Ombudsman on the quality of the services being provided; encourage the promotion of legal and human rights of residents; act on issues raised by residents, staff, or other people; provide information to residents about advocacy services; and help resolve complaints.

[75] The Resident Support Fund component of the program consists of funding for personal care via the Home Care Service, Primary and Secondary Health Services, the Active Linking Initiative, and case management services.

[76] DADHC *User's guide to the Screening Tool for entry to Licensed Residential Centres*.

[77] DADHC written advice 6 May 2005.

[78] DADHC *User's guide to the Screening Tool for entry to Licensed Residential Centres*.

[79] This case is also highlighted in case study 10.

[80] No further information has been provided to clarify what updates have been made.

[81] The IMF is the new system developed by DADHC to monitor DADHC operated and funded services. It is being developed in two phases. Phase 1 focuses on the application of the IMF to funded services, and phase 2 will focus on its application to DADHC operated services. Key elements of Phase 1 include a service provider self assessment of their performance against elements of the service review, a service provider annual return, onsite service reviews that address provider performance and adherence to the key elements of the funding requirements, and possible action plans to address areas requiring further improvement.

[82] The Quality and Safety Framework involves DADHC Network Managers conducting quarterly audits and collecting data in all DADHC operated group homes against twenty-six key performance indicators, including nutrition and swallowing checklists. A report is generated from the data collected and presented to the Regional Quality Committee, which is comprised of Regional Managers, the Occupational Health and Safety Advisor, the Regional Executive Officer, and the Regional Director.

[83] In its response to the draft report, NSW Health advised on 1 November 2005 that it would add this particular issue into the Guidelines at the first available opportunity when they are reviewed in five years' time. In the meantime, NSW Health advised that, while the Guidelines do not specifically comment on the situation where there is no person responsible, they do refer to NSW Health Circular 2004/84 on Patient Information and Informed Consent that provides more detailed information on consent provisions. However, again, this information is not linked to the section of the Guidelines that refer to patients without decision-making capacity.

[84] The transfer of these services occurred on 1 July 2005.

[85] In its response to the draft report, NSW Health advised that it has released the *Hospitalisation of People with Disabilities* policy directive.

Reviewable child deaths

Agencies involved when a child dies in NSW and the death is reviewable

Registry of Births, Deaths and Marriages

Funeral directors are responsible for registering a death with the Registry of Births, Deaths and Marriages (BDM). The Registry is required to give the Ombudsman a copy of death registration information relating to a child's death within 30 days of receiving the information.

The NSW Coroner

Reviewable deaths are also coronial deaths under section 13AB of the Coroner's Act 1980. This means that death certificates cannot be written by a medical practitioner. Rather, the death must be referred to the Coroner. The Coroner will examine the death and may hold an inquest. The Coroner is required to notify the Ombudsman of any reviewable death notified to him not later than 30 days after receiving this information.

The NSW Ombudsman

Using information from BDM, the Coroner and the Department of Community Services (DoCS), the Ombudsman makes a determination about whether the death of a child is reviewable. A register is kept of child deaths that are reviewable.

Reviews are based on scrutiny of all relevant files and records relating to the child. All NSW government agencies and relevant non-government service providers are required to provide the Ombudsman with full and unrestricted access to records that are reasonably required to review a death. Where appropriate the Ombudsman may undertake inquiries or investigate matters relating to a child's death under the Ombudsman Act 1974.

Child Death and Critical Reports Unit, Department of Community Services

The CDCRU is a DoCS unit that may conduct a review of the death of a child known to the department. The CDCRU advises the Ombudsman where it intends to conduct a review, and provides the Ombudsman with a copy of the review report.

The NSW Child Death Review Team, Commission for Children and Young People

The purpose of the Child Death Review Team is to prevent or reduce the number of child deaths in NSW. The Team maintains a register of all child deaths; classifies deaths according to cause, demographic criteria and other relevant factors; identifies patterns and trends relating to those deaths; and undertakes research focused on prevention or reduction of child deaths. The team does not undertake reviews of reviewable deaths, but may include a reviewable death in research.

1. Introduction

1.1 Reviewable child deaths

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

i. a child in care[2]
ii. 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
iii. a child who is a sibling[3] 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
iv. a child whose death is or may be due to abuse or neglect or that occurs in suspicious circumstances
v. 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).

For ease of reporting, we refer to (ii) as a child 'known to the Department of Community Services (DoCS)' or 'known to the department', and (iii) as a sibling 'known to DoCS / the department'. Abuse, neglect and suspicious are defined in section 2.4 below.

The legislation focuses on children who were either in care or detention, or whose vulnerability was likely to require the attention of DoCS and other agencies. Under the legislation, the main purpose of reviewing the deaths of these children is to reduce and prevent such deaths. To do this, it is important to consider the overall responses of government agencies to reports of risks to children. Our approach is based on the premise that improving the child protection system is one of the best ways to reduce or prevent the deaths of children at risk.

1.2 Overview of our findings in 2004

While it is widely acknowledged that the safety and well-being of children is a whole-of-community responsibility, DoCS has the statutory responsibilities that place it at the forefront of this work.

Given the definition of 'reviewable' in the legislation, there will be an over-representation of children known to DoCS among child deaths in our jurisdiction. This year, we reviewed the deaths of 72 children known to the department. Last year, we reviewed 84 such deaths.

In many cases, the child's death had no connection to child protection concerns. In others, the type of intervention that could be made by DoCS may have made little difference. However, in some cases we reviewed, more effective intervention could have lessened the risks that were evident prior to a child's death. This year, we determined that for 19 of the children known to DoCS, the concerns reported to the department about them were relevant to the circumstances of their deaths.

It is important to note that we reviewed deaths that occurred in 2004. The child protection history we considered in these reviews often related to DoCS and other agencies' handling of child protection matters in 2004 or earlier. 2003/2004 was also the first year of funding under a five year, $1.2 billion reform package, designed to improve capacity across DoCS. The package incorporates staff recruitment and initiatives for service improvement. It is being systematically implemented to 2008. We acknowledge that changes that have been made, or are planned, may address some of the problems we identified through our reviews.

DoCS' lead responsibility for providing the care and protection necessary for the safety and wellbeing of children who are the subject of reports of risk of harm does not mean that all such reports are responded to. From our reviews in 2004, we found that high-risk cases were at times closed without allocation to a caseworker for a full risk assessment. In the areas we have focused on in this report, including responses to risk of harm reports about unborn children, children involved in domestic violence incidents and adolescents, our reviews identified that a high number of reports were closed without assessment by a local DoCS office.

The basis for closure is lack of resources, and relative urgency of cases at an individual local DoCS office. Cases can be closed at any time. Closure of cases without assessment is the result of demand for DoCS' services outweighing capacity. In the face of stretched resources, DoCS has little alternative but to apply a workload management tool that aims to prioritise high risk cases. While we acknowledge this difficulty, we believe the practice of determining whether a response to a report can be provided based on relative, rather than actual, risks to a child is a critical public policy issue. Enhancement of DoCS' capacity to respond to reports of risk of harm will be an important outcome of DoCS' reform package.

Our reviews of deaths in 2004 also raised some concerns about the quality of casework where reports were allocated for assessment.

In some cases, we found that assessment was not holistic, as required under the department's framework for assessing risk. Rather, it was at times focused on investigation of a particular incident or single issue, regardless of the child protection history of a family. We found this happened even where families had previously had a child removed from their care, and the same risk factors that led to that removal were evident. In some cases we found inadequate analysis of risk and lack of objective evidence on which to base decisions about a child's welfare.

Our reviews provided limited evidence of coordination with, and use of, the resources of other agencies to provide support and assistance to children or their families. In this context, we note that the *NSW Interagency Guidelines for Child Protection Intervention* are currently under review. Some of the concerns we identified in our work are being considered in this process.

We found that some strategies used to protect children were ineffective. One of the strategies that concerned us was the use of informal undertakings or agreements between DoCS and parents, that the parents would refrain from certain behaviour, particularly the use of illicit drugs. In most circumstances, these undertakings were not monitored and were often breached without consequences.

Our reviews also highlighted problems with agency responses to specific risk factors such as carer substance abuse; domestic violence; and parental actions affecting unborn children. Our assessment of agency responses to adolescents and to Aboriginal children and young people indicated some deficiencies in these areas of the child protection system.

DoCS has told us that it is working to identify problems in its casework and business practices, and to establish systems for quality assurance. It is critical that DoCS be able to demonstrate how these management strategies, along with enhanced funding, will result in local offices having the capacity to respond adequately to reports of risk of harm and, where necessary, ensure sustained and effective child protection intervention.

2. Reviewable child deaths in 2004

2.1 Children who died in 2004

This report focuses on the central themes and issues of concern we have identified in reviews of deaths that occurred in 2004, and also on work we undertook in 2005. This work included detailed investigations of children who died in 2003.

In 2004, 540 children died in NSW.[4] Of these, we registered 104 (19%) as reviewable deaths. Two deaths were of children with a disability in care. These two deaths are also considered in our report of disability deaths. In another 28 cases, we were unable to determine whether the death was reviewable in time for this report, as coronial processes had not been finalised.

Twenty-four of the 104 deaths were determined to be due to abuse or neglect, or were suspicious of abuse or neglect.

The primary focus of our reviews this year has been those children known to DoCS. Given the definition of 'reviewable' in the legislation, there will be an over-representation of children known to DoCS among child deaths. This is irrespective of whether or not there was any direct link between DoCS' involvement with the family and the death of the child.

We have also had regard to the critical role of NSW Police in reporting incidents of risk of harm and responding to domestic violence. NSW Health plays a crucial role in recognising and reporting children at risk of harm, and providing services to children and families where abuse has occurred. NSW Health also has a significant responsibility in supporting young people and/or their parents or carers who are dealing with substance abuse problems or who may be mentally ill.

2.2 Investigations of child deaths

While we review all child deaths, *CS-CRAMA* and the *Ombudsman Act 1974* provide for a range of additional powers to support the reviewable death function. Fourteen of the cases that we reviewed in 2004-05 warranted the use of these additional powers, and we subsequently initiated 19 investigations into 11 of the cases. The focus of the investigations was the adequacy of child protection services provided to the child and/or their siblings. In all cases, DoCS was the subject of investigation and in some instances we also investigated the conduct of other agencies such as NSW Police and NSW Health.

Where we have identified unreasonable conduct, we have made recommendations to address the issues raised. Recommendations have been targeted to local, regional and state levels. Agencies have been keen to ensure any lessons learnt through the investigations inform future practice, and recommendations have generally been well accepted by agencies. We monitor the implementation of all recommendations made.

We refer to some of our investigations in this report.

2.3 Developments since our last report

It is widely acknowledged that child protection is a community responsibility. While the NSW government recognises the responsibility of all relevant agencies to protect children, DoCS has lead responsibility for providing and coordinating the community response where intervention is necessary.[5] A critical role for most agencies is to recognise and report suspected risk of harm to DoCS. Once a report is made, the department can respond using its broad statutory powers under the *Children and Young Persons (Care and Protection) Act 1998.*

Our first report on reviewable deaths was released in 2004.[6] In that report, we raised a range of concerns about the child protection system. We said that:

- assessment of, and response to, reports of risk of harm was at times inadequate
- cases were being closed even though children were at risk
- the response to Aboriginal children at risk of harm was in some instances inadequate
- in responding to risk of harm reports, the *NSW Interagency Guidelines for Child Protection Intervention* were being under-utilised.

We made 18 recommendations, all of which were directed to DoCS. The recommendations, and DoCS' progress in implementing them, are detailed in section 9. In 2004, DoCS stated its acceptance of all of our recommendations, and has since provided information about how the department intends to implement them. Strategies detailed by the department link closely to the implementation of the NSW government's $1.2 billion DoCS reform package, which is being rolled out incrementally to June 2008. The changes include the recruitment of an additional 875 caseworkers over the five years from 2003/04. A significant enhancement in 2005/06 will be the recruitment of 125 new caseworkers for child protection and early intervention services.[7] DoCS has told us that there are specific strategies being developed to improve quality assurance in casework decision making; that the Interagency Guidelines are being reviewed; and that the Early Intervention Program is being rolled out and will improve the department's response to 'lower level' reports of risk of harm.

These are significant initiatives to improve the State's response to children at risk of harm. Section 9 provides a full discussion of DoCS' progress in implementing recommendations from our 2003/04 report.

2.4 Definitional changes

We have modified our definition of deaths due to neglect and abuse, and deaths that raise suspicions of abuse or neglect. In our first report, we adopted the definitions of the NSW Child Death Review Team. The Team had responsibility for reviewing deaths due to fatal assault and neglect until this function was transferred to the Ombudsman in December 2002. Difficulties in applying these definitions to the new function were noted in our first report.

Our modifications are intended to:

- more closely align our definitions of 'suspicious' with those used by NSW Police and the Coroner
- screen out deaths as being due to 'neglect' if they relate to a single incident of inadequate supervision and there is no evidence of chronic or reckless neglect.

Definitions we have adopted to determine whether deaths are due to abuse or neglect or occurred in suspicious circumstances are:

Deaths due to abuse:

An act of violence by any person directly against a child or young person that causes injury or harm leading to death.

Deaths due to neglect:

Conduct by a parent or carer that results in the death of a child or young person, and that involves:

- failure to provide for basic needs such as food, liquid, clothing or shelter
- refusal or delay in providing medical care
- intentional or reckless failure to adequately supervise
- a reckless act.

Suspicious deaths:

Deaths where there is some evidence or information that indicates the death may have been a result of abuse or neglect. Deaths would be considered suspicious if:

- police identify the death as suspicious at the time of the death or any time subsequent to the death and there is some evidence that indicates the death may have occurred in circumstances of abuse or neglect (as defined above)
- the autopsy cause of death is undetermined and there is an indication of abuse or neglect
- the autopsy cause of death is a treatable illness and there is an indication that unjustified delay in seeking treatment may have contributed to the death.

Table 1: Reviewable child deaths January 1 – December 31 2003 – Comparison of data using revised definitions

	2004 definitions	2005 definitions
Reviewable child deaths	148	128
Deaths due to abuse	17 (12%)	17 (13%)
Deaths due to neglect	26 (18%)	18 (14%)
Deaths in suspicious circumstances	43 (29%)	8 (6%)
Children who died as a result of abuse, neglect or in suspicious circumstances – number of deaths where the child or the child's sibling(s) were known to DoCS	54 of 86 (63%)	32 of 43 (74%)
Children where the child or the child's sibling(s) were known to DoCS – number of deaths as a result of abuse, neglect or in suspicious circumstances	54 of 114 (47%)	32 of 114 (28%)

Appendix 5 provides updated information about the deaths of children in 2003.

To provide some comparison between deaths in 2004 and 2003, we re-assessed the latter according to our new definitions.

At the time of reporting last year, we identified 161 child deaths in NSW as being reviewable. To provide a comparative base of twelve months, however, Table 1 above excludes 13 deaths that occurred in December 2002.

Table 1 provides information using our earlier definitions, and the changes that would result had we applied the new definitions to deaths that occurred between January 1 to December 31 2003.

2.5 Data about reviewable child deaths in 2004

The following provides an overview of the deaths we reviewed.

The data used in this report is drawn from agency and client files, with the main data sources being the DoCS' client database, the Key Information Directory System (KiDS); DoCS and NSW Health client files; NSW Police Computer-operated Policing System (CoPS) database; and coronial information.

The information about risk of harm reports and DoCS' intervention for a child comes primarily from KiDS. We have encountered significant problems in gathering consistent information from KiDS, and this difficulty is in part reflected in the nature of the data we are able to provide in this report. It was often difficult for us to track actions in relation to a particular report. Despite these difficulties, we are confident the data we present is an accurate reflection of the response to risk of harm reports for children who died.

Case studies

Throughout this report we use case studies. The cases relate to children who died and/or their siblings. We have used each case only once in the report.

We have not included cases where we believe inclusion may be prejudicial to court proceedings.

While all of the statistical data in this report relates only to children who died in 2004, in three cases we discuss children who died in 2003, and in two cases, the children died in 2005. We have done this where a case clearly illustrates ongoing systemic problems identified through reviews in 2004.

Overview of reviewable child deaths in 2004

We determined that the deaths of 104 children in 2004 were reviewable. At the time of writing this report, we had insufficient information to determine the reviewable status of a further 28 child deaths.

Aboriginality

Twenty of the 104 reviewable deaths (19%) were Aboriginal children.

Age

Age grouping	Number of children (%)
0–12 months	35 (34%)
1–4 years	30 (29%)
5–9 years	10 (10%)
10–12 years	7 (7%)
13–17 years	22 (21%)
Total	104 (100%)

Why the deaths were reviewable

The following table shows why the deaths of the 104 children were reviewable. The groupings are not exclusive, and relate to the definitions in section 2.4 above.

Reason for reviewable status	*Number of children, percent and additional information*
Death resulted from abuse	7 (7%)[8]
Death resulted from neglect	6 (6%)
Death occurred in circumstances suspicious of abuse or neglect	11 (11%)
The child, or the child's sibling, was reported to DoCS in the three years prior to the child's death	96 (92% of reviewable deaths): • 72 of the children were reported to DoCS. These children were the subject of a total of 310 reports of risk of harm. A further 189 reports were made about the children's siblings. • 24 of the children were the sibling of a child reported to DoCS. The siblings were the subject of a total of 96 reports of risk of harm.
The child died while in care (as defined in the *Community Services (Complaints, Reviews and Monitoring) Act 1993*)	8 (8% of reviewable deaths)

Appendix 6 provides further detail about the data.

2.6 Children known to DoCS

Of the 104 children who died, 96 (92%) were reviewable because the child or their sibling had been the subject of a report to DoCS in the three years prior to their death:

- The deaths of 72 children (69%) were reviewable because the child had been reported to DoCS. For these children, the status of their case with DoCS at the time of their death was:
  - Open and allocated for 19 children
  - Open and unallocated for 16 children[9]
  - Open, with allocation status undetermined for two children
  - Closed at the time of their death for 35 children.
- The deaths of 24 children (23 per cent) were reviewable because their siblings had been reported to DoCS. That is, the child themselves had not been the subject of a report. It is notable that for children who died whose deaths were reviewable because of sibling-only reports, ten were under the age of 12 months at the time of their death.

Relevance of reported issues in relation to the child's death

We considered whether reports to DoCS about a child had any relevance to the circumstances of their death. To do this, we analysed the issues reported to DoCS that were recorded as primary and secondary issues, and the narrative of reports, against the circumstances of death. For example, we would consider the reports to have relevance to the circumstances of death where a child died in a car driven by their parent or carer while under the influence of alcohol and/or drugs, and carer substance abuse had been previously reported to DoCS.

In most cases where a child was known to DoCS before they died, the child's death was unrelated to care and protection concerns. However, in our assessment, 19 of the 72 children (28%) died in circumstances where the issues that had previously been reported to DoCS bore some relevance. In six of these cases, the children died as a result of abuse, neglect or in suspicious circumstances.[10] The 13 remaining deaths included three young people who had been reported as being at risk of suicide who died as a result of suicide, and two young people who had been the subjects of reports about risk taking, alcohol and other drug use and other related issues who died in traffic accidents that involved speeding, alcohol and drugs.

Identifying risk factors in other cases

We reviewed the child protection histories of children who died in circumstances that were unrelated to child protection issues. We also considered information relating to the siblings of some children who died. Where these reviews have identified systemic issues, and in the context of our role in formulating strategies to reduce or remove risk factors relating to reviewable deaths, we have included relevant analysis of these cases in this report.

2.7 Children not known to DoCS

In 2004, eight of the 104 (8%) reviewable child deaths involved children who were not reported to DoCS in the three years prior to their deaths.[11] These eight deaths are reviewable because the children died from abuse (five children), neglect (one child), in suspicious circumstances (one child), or were in the care of a service provider at the time of death (one child). The child who died in care was living in a disability service and died of natural causes.

In 2003, children not known to DoCS represented 36 out of 161 (22%) reviewable child deaths. Differences in the numbers across the two reporting periods can be accounted for by definitional changes, as described in section 2.1 above.

Of particular concern are the seven children who died from abuse, neglect or in suspicious circumstances who had not been reported to the department. The seven deaths represent seven per cent of 2004 reviewable child deaths. It is important to consider the deaths as a group, to identify whether any patterns are evident that may assist in identifying children who are most at risk.

Our 2004 data for this group is consistent with previous studies[12] in that:

- the children were very young
- persons charged in relation to the death were biological relatives or living in the household with the child
- in a number of cases there was a carer history of mental health problems
- two of the persons charged in relation to the deaths had a history of violence and assault
- other risk factors, such as high stress levels, family breakdown/changes in family composition, and low income/financial problems were indicated.

Profile of the children who died

Where children die as a result of a single fatal episode and have not had a previous history of involvement with government agencies, it is often difficult to gain information that could provide insight into the circumstances of the child and family leading up to the deaths.

None of the seven children who died as a result of abuse, neglect or in suspicious circumstances were identified as being Aboriginal or Torres Strait Islander.

Six of the children were under four years of age, with two of the children being less than 12 months old. One child was 11 years of age. This is consistent with studies into fatal child abuse, indicating that the majority of children who die as a result of maltreatment are under four years of age.

Circumstances of the deaths

An autopsy was performed in all seven cases. The Coroner has determined that five of the seven children's deaths were due to homicide. The coronial process is still open for the remaining two children, with no formal decision yet as to the manner of death.

Charges of murder have been laid in relation to three of the seven deaths. No charges have been laid in relation to the remaining four deaths (two of the four children died in a murder-suicide incident and charges would therefore not be relevant). In one case, an individual who has been charged with the murder of a child in 2004 has also been charged with the death of another child a number of years previously.

Mental health issues

It has been noted that studies of child deaths have found that often, there is no evidence of previous abuse in child homicide cases, and further that:

> *One of the important differences between child homicides and child maltreatment is that parents who seriously injure or kill their children are more likely to suffer from psychiatric disorders than are maltreating parents who do not seriously injure their children.*[13]

In four of the seven deaths, we found evidence that the person charged or identified as being responsible for the child's death was experiencing mental health issues at the time. These included depression and adjustment disorder and obsessive-compulsive disorder. None of the adults involved was receiving treatment from a mental health service provider at the time of the deaths. In two cases, there was a history of attempted suicide.

This is an area that warrants detailed examination in the future.

3. Assessing reports of risk of harm for children who died

The scope of DoCS' work is extremely challenging. In 2003/04, there were 185,198 reports made to the department.[14] DoCS expects that this figure will grow to 210,000 in 2004/05 and 230,000 in 2005/06. [15]

Of the 185,198 reports, 154,713 (84%) were identified at the DoCS Helpline as raising risk of harm concerns. DoCS has advised us that three-quarters of these reports (74.5%), involving 71,425 children and young people, were referred to a DoCS Community Service Centre (CSC) or a Joint Investigative Response Team (JIRT)[16] for further assessment or investigation.

Most children (69%) were the subject of one report in this period. Children were the subject of two reports in 17 per cent of cases, and three reports in seven per cent of cases.

For children whose deaths were reviewable in 2004, there was a total of 595 reports made to DoCS in the three years prior to their death. This includes 310 reports made about 72 children, and an additional 285 reports made about the child's sibling(s) only. Reports for siblings only are not included in the analysis below, unless otherwise indicated. [17]

3.1 Initial Risk of Harm Assessment

Anyone who has reasonable grounds to suspect that a child or young person may be at risk of harm can make a report to DoCS. Reports can also be made about an unborn child where a person believes the child will be at risk after birth.

The DoCS Helpline is the entry point for receiving and assessing these reports, and referring reports needing further assessment or investigation to a CSC or JIRT. Not all reports made to the Helpline are assessed. For example, caseworkers may decide that a report does not indicate current care and protection concerns, or the report provides information that the department is already aware of.

Where a report is assessed, the Helpline considers the reported information and any available history and makes an assessment of the level of risk posed to a child. If the Helpline determines that a child may be in need of care and protection, a plan is developed and sent to a CSC or JIRT. The response categories given by the Helpline to a report requiring further assessment or investigation were previously referred as:

- Level 1 (immediate response required within 24 hours), for extreme safety concerns and high future risk level.
- Level 2 (response required within 72 hours), for serious safety concerns and medium future risk level.
- Level 3 (response required within five to ten days), if there are no current safety concerns and low future risk level. [18]
- Level 4 response (required at some stage after ten days), but noted as being equated informally with 'information only' and 'intake only').[19]

DoCS advised us that the Helpline no longer uses this system. The Helpline refers reports with an assessment of:

- Risk level (high, medium, low); and
- Required response time (within 24 hours; within 72 hours; within ten days).

A significant number of reports that are discussed later in this report were referred to a CSC or JIRT under the earlier rating system, and the reference to 'level' one, two or three remains common in documentation we have reviewed.

Handling of reports by the Helpline

In 2004, we raised some concerns about accuracy in the Helpline's recording of reports, and how well new reports were linked to previous reports about the child and/or family. Linking of reports is critical to understanding a family's child protection history, which in turn is critical for what DoCS policy calls holistic risk assessment. Our reviews indicated that while the Helpline generally referred reports promptly and with instructive initial assessments, there were some continuing problems in this regard.

CaseStudy1

We reviewed the death of a baby who drowned after being left unsupervised in the bathtub. The baby's siblings had been the subject of five reports in the three years before the baby's death. The fifth report related to an incident of domestic violence, and received a response level of 'information only' at the Helpline. When assessing the report, the Helpline recorded that a sibling had 'no prior child protection history', despite the fact that the sibling had been the subject of all four previous reports. This report was not forwarded to the CSC.

At times, history was not accessible due to inaccuracy of recorded information. If the recording of reports is not accurate, the capacity for an effective assessment of, and comprehensive response to, risk is likely to be compromised.

Information we gained from KiDS and client files indicates that the Helpline dealt promptly with most reports for children who died, particularly those assessed as requiring a response within 24 hours. However, some reports were not. Of 593 risk of harm *reports we considered, 123 (21%) were assessed more than three days after being received at the Helpline. Ninety-two of these reports were not assessed for more than a week after receipt, with some not being considered for up to three weeks. We also found that once assessed, some reports were not promptly referred to CSCs:*

CaseStudy2

A 15-year-old girl died in a motor vehicle accident that occurred in the early hours of the morning. She was reportedly not wearing a seatbelt and the driver of the vehicle was over the legal limit for alcohol. Speeding was also indicated as a factor. The girl and her siblings were the subject of 13 reports to DoCS in the three years prior to her death. The reports related to concerns about domestic violence, physical abuse, and drug and alcohol abuse by carers. The eighth report related to a domestic violence incident resulting in physical harm to the mother, witnessed by the children. The report was assessed by the Helpline as representing a 'medium' level of risk, and recommended a response to the report within 10 days. According to KiDS records, however, the Helpline did not refer this report to the CSC for a period of fourteen weeks. The documented reasons for not undertaking secondary assessment activities included the delayed transfer of the report to the CSC. At the time of the girl's death, she was living away from home with extended family.

Casestudy 3

We reviewed the death of a baby who died as a result of prematurity. A report was made to DoCS in relation to parental drug and alcohol use, domestic violence, and the emotional state of the mother. The report was in relation to an 18-month-old sibling. The mother was pregnant at the time the report was made. The Helpline recommended a response time of less than 10 days. However, the report was not entered into the KiDS system until four months after the report was received, when another report was made in relation to the sibling.

CaseStudy4

In one matter, an initial report was received in relation to a young girl, concerning possible neglect. Medical neglect had already been investigated and substantiated by the department some two-and-a-half years earlier. The report was taken as information only, but was not approved and forwarded to the CSC until eight weeks later. A second report about medical treatment not being provided was made a day following the initial report. The second report was assessed as high risk, with a recommended response time of within 72 hours. It was approved and referred to the CSC four days later. The CSC did not act on the second report. The girl died eight weeks later. Three days after her death, the Helpline sent the initial report to the CSC.

In June 2005, the NSW Audit Office released a report of the office's performance audit of the DoCS Helpline. The report indicated that DoCS had improved the overall performance of the Helpline. It also identified some issues requiring further attention, including delays in approving reports about lower levels of risk.[20] DoCS has committed to a number of measures to deal with these issues.[21] The stated measures include review of the initial assessment process to increase reliability and consistency; ongoing upgrades to KiDS; and commencing a 'Handle Times' trial to measure the time taken to process calls and faxes. The Audit Office has also recommended a number of strategies to DoCS, including that the department continue to review and restate minimum requirements for conducting and recording the review of a child's protection history; and that KiDS be enhanced to better support Helpline's assessment of risk and the recording of decisions.

In 2004, DoCS advised us that history, phonetic spelling and address checks were being continually reinforced through training and procedural improvements.

Referral of reports to JIRT

A review of the death of a child identified a lack of consistency in DoCS procedures and practices for referring certain types of information contained in risk of harm reports to NSW Police or JIRT. Our review found two risk of harm reports that indicated a criminal offence may have occurred: a possible sexual assault and the carer's possession of firearms. The reports were not referred by the Helpline to NSW Police or JIRT.

In reviewing this matter, we looked at various DoCS policies and sought advice from the department about the types of matters that should be referred. We found the policies and advice to be at times conflicting. In relation to JIRT referrals, DoCS policy states that staff should refer any reports of sexual abuse of children where the offender is over the age of 10 years. Another policy indicates that if staff receive *'information that an offence has been committed, the Police must be informed'*.[22] A more recent policy—not in place at the time of the reports we were considering—instructs staff to refer matters to JIRT *'if a criminal offence is suspected'* and initial assessment of the report indicates it meets the criteria for referral to JIRT.[23] DoCS' response to our request for advice on this issue did not resolve the problem. The department told us that, in general, *'matters are referred to the Police and/or JIRT where there is clear evidence or information on which Police might act'* and further, that in practice, *'DoCS refers or seeks advice from Police where offences have been substantiated by a DoCS/JIRT investigation'*.[24]

DoCS has provided further advice that it is currently negotiating a memorandum of understanding with NSW Police, and that this would assist in clarifying matters that should be referred to NSW Police.[25] We will continue to monitor the department's response to the issues we have raised.

CaseStudy5

A 15-year-old girl died in a motor vehicle accident, in a car driven by a young person and where speeding was a factor. In the three years before her death, the girl had been the subject of 16 reports to DoCS, all from mandatory reporters. The reports raised concerns about sexual harm, basic physical needs not being met, alcohol use by the child and inappropriate sexual behaviour. Her history indicated she was particularly vulnerable to harm due to her intellectual disability, her carer's limited parenting skills, and her contact with older males, from whom she was receiving alcohol and cannabis and with whom she was reportedly sexually active.

One report a year before her death related to a disclosure by the girl of sexual assault. The allegation was not reported to police. The reporter made initial contact with the Helpline, but due to queues, the call could not be taken immediately. There was a delay of three weeks before the Helpline contacted the reporter to obtain details. The Helpline subsequently assessed the report as indicating low risk of harm and recommended a response time of less than 10 days. The report was not referred to JIRT. Four weeks later the report was transferred to a CSC and a caseworker noted 'given her age, allegation of rape, developmental delay and escalation of risk taking behaviours it is recommended that this file be transferred to JIRT for possible allocation'. The report was not referred to JIRT and the file was closed due to current competing priorities.

The last report of risk of harm was made nine months prior to her death, but was assessed by the Helpline two months after contact by the reporter. We were unable to identify the reason for this delay. The main reported issue was that the girl was at risk of sexual harm through her involvement with an older male. Concerns were also raised about her vulnerability, her family's inability to provide direction and protection for her, and possible drug use. The report was not referred to JIRT and was subsequently closed with no further assessment due to current competing priorities six weeks after being referred to the CSC.

Other reviews have identified a lack of consistent application of policy with regard to the referral of allegations of criminal conduct to NSW Police and/or JIRT. Cases include allegations of physical harm and sexual abuse.

Lack of clarity about how staff should respond to reports that include serious allegations increases the potential for inconsistent and/or ineffective responses to children at risk.

3.2 Secondary Risk of Harm Assessment

Reports requiring further assessment or investigation are referred to a CSC or JIRT for secondary risk of harm assessment ('secondary assessment'). Secondary assessment aims to provide a holistic assessment which substantiates risk of harm or confirms the safety of a child. If risk is substantiated, assessment identifies the level of risk and the protective strategies required to ensure a child's safety.

Secondary assessment is divided into two stages:

- Stage 1 (SAS 1). This precedes any field action and is the process of gathering additional information and making inquiries to determine whether further assessment is required. Stage 1 initial assessment can include any of the following: considering any history held by DoCS; making phone calls; requesting information from other agencies; using local knowledge to inform decision-making; or where relevant and approved by the Manager, contacting parents or carers by telephone.

- Stage 2 (SAS 2). Consists of a home visit or other field action to assess the child's need for care and protection and the action required of DoCS.

At either stage, cases may be closed for a number of reasons, including competing priorities and lack of resources.

Some of our reviews provided examples of the effective application of the secondary risk of harm assessment framework. Others identified a lack of secondary assessment for children who may be at risk of harm, or raised concerns about the scope and quality of secondary assessment where it was undertaken. These issues are illustrated throughout this report. Here, we provide a summary of our concerns.

The scope of secondary assessment

DoCS has advised us that in 2003/04, 115,295 reports relating to 71,425 children and young people were referred from the Helpline to a CSC or JIRT. Due to data quality problems as a result of changes to DoCS' client information system, including the introduction of KiDS, DoCS was unable to provide information about the response times recommended by the Helpline in relation to those reports, or whether the reports received secondary assessment at a CSC or JIRT. DoCS expects this data to be available in late 2005.

In effect, DoCS has not had comprehensive data about how reports of risk of harm are responded to, or the outcome of risk of harm assessment, since it introduced the secondary risk of harm assessment framework in 2002.

Secondary assessment for children who died

DoCS policy on Secondary Risk of Harm Assessment states:

> *Harm or risk of harm may be present for any child or young person who is assessed during initial risk assessment as 'may be in need of care and protection'. For this reason every child or young person in this category must be the subject of the secondary risk of harm assessment.*

However, DoCS has consistently argued that workload demand is such that allocation of all reports to a caseworker is not achievable, and that *'DoCS workers are required to make professional judgements on the information available and prioritise matters in line with perceived risk'.*[26] This means that a case that is open and subject to secondary assessment may be closed if it is considered there are more urgent cases needing attention. Case closure policy is discussed in section 4 below.

While acknowledging the constraints facing the department, our reviews have shown that the current lack of capacity to conduct secondary assessments means that children's safety is potentially being put at risk.

No secondary assessment was conducted for 30 of the 72 children who had been the subject of one or more reports to DoCS. Twenty-seven of the 72 children received an assessment that involved field action, such as sighting or interviewing the child and/or relevant others.[27] In these cases:

- 16 children were sighted
- 11 children were interviewed
- the parents/carers of 24 were interviewed.

CaseStudy6

A 16 year old girl died following an accident. She was intoxicated at the time and received no medical attention for her injuries. Her family had a history with the department, with 12 reports being made about her or her siblings over the ten years prior to her death. In the three years before her death, six reports were made about her and/or her siblings. The reports related to concerns about parental alcohol abuse, mental health, conflict/behaviour management, inadequate supervision and poor school attendance. The last report before her death raised issues about her being assaulted, and she and her sibling being intoxicated. No secondary assessment activity was undertaken in relation to any report about the family, with all reports being 'rolled forward' and/or closed.

Other case studies throughout this report also illustrate our concerns that in many of the cases we reviewed, some reports that appeared to be serious were unable to be allocated for secondary assessment. See for example case study 11 on page 69; case study 19 on page 83**;** case study 25 on page 92.

Secondary assessment and the Helpline rating

CSCs and JIRTs are expected to review Helpline ratings and to use local knowledge to adjust them accordingly. In some cases we reviewed, we found that this was not always the case. As noted earlier, the categories of 'levels' (1-4) to determine a required response to risk of harm reports are no longer used.[28] Rather, '*decisions on cases that undergo Secondary Assessment Stage 2 are based on response level, level of risk and available* *resources'*.[29] Our reviews have indicated that the response time given by the Helpline often plays a significant role in determining whether a report receives a secondary assessment. While this is understandable, there is the need to ensure that assessments of risk level are given appropriate weight.

CaseStudy7

We reviewed the death of a baby who had been the subject of a pre-natal report. The baby died within 24 hours of her delivery following an emergency caesarean. The baby's sister had a history of reports to DoCS over six years, indicating chronic and ongoing concerns arising from domestic violence, carer substance abuse, physical abuse and neglect. We made further inquiries in relation to the sister.

In a ten-month period, the Helpline forwarded eight reports about the child to a CSC for assessment. The reports related to domestic violence, physical harm, and carer drug and alcohol abuse. Six of these reports were subsequently closed under the case closure policy and at the time of review, one had not been allocated for assessment.

One report related to an observed injury and some indication that the injury may have been the result of deliberate harm, which the Helpline determined required urgent assessment. The Helpline assessed risk as 'high' and urgency of response as within 72 hours. The report was closed due to 'current competing priorities'. A later report also alleged physical abuse of the child and carer drug use. In analysing the issues, the caseworker recorded that 'severity of harm' was high due to reported bruising, and 'likelihood of harm' was high. The Helpline referred the report as a medium risk, with a required response of within ten days. The report was subsequently closed without assessment due to competing priorities.

Although both reports were assessed by the Helpline as indicating high risk, both were closed without further assessment by the CSC. After further reports were made, DoCS commenced a secondary assessment.

CaseStudy8

The Helpline received a report about the emotional state of a baby's carer. The baby was in hospital at the time, but the report indicated ongoing concerns about the mother's capacity to cope. The Helpline assessed risk of harm as 'high' and recommended a response within 72 hours. The Helpline noted that further assessment was required 'promptly' to ensure the baby was safe and to assess the mother's mental health, and whether the mother was capable of providing safe and appropriate care. The Helpline phoned the CSC to advise of the need for a prompt response. The CSC advised that they were not accepting 'prompt within 72 hour responses' to be phoned through. The Helpline was advised by the CSC that management had determined that if reports needed to be responded to promptly, 'they needed to be made within a 24 hour response.' According to KiDS records, no further assessment was done.

The significance of the Helpline's required response time in determining which matters are considered at a CSC is illustrated by the response of one DoCS region to high workloads. An investigation we conducted found that the region had decided to streamline responses by not allocating or reviewing reports assessed by the Helpline as 'Level 3' and subsequently closing these without review. This procedure was current at late 2004. We asked DoCS to confirm whether this practice continued in this or any other region. DoCS' response noted only that the region, and regions in general *'conforms generally to the Department's policy as described in the Priority One policy and KBR (Kids Business Rule) 179'*.[30]

The adequacy of secondary assessment

Last year, we stated that in some cases we reviewed, secondary risk of harm assessment did not provide a holistic assessment of, or an effective response to, risk. We have also found this in our reviews of deaths in 2004.

In some cases, the secondary assessment did not appear to provide an adequate basis upon which to determine current or future risk to a child.

CaseStudy9

We reviewed the case of a four-year-old girl who died as a result of natural causes. The girl had five older siblings aged between five and 14 years. There were 21 reports about the children in the three years before their sister's death. The concerns reported to DoCS included physical harm, carer mental health issues, neglect and risk of sexual abuse. DoCS records describe six secondary risk of harm assessments for the children in the period before the death. Two of the earlier assessments resulted in the removal of two of the children, with one child being placed in long-term care.

Following these assessments, one of the child's siblings, then aged five, was reported as being at risk of sexual abuse. She was reported to be constantly talking about sex and who she would have sex with. Action resulting from the secondary risk of harm assessment consisted of a feedback letter to the mandatory reporter, requesting that they monitor the situation. The girl was neither seen by DoCS caseworkers, nor were her parents interviewed.

Just over a month later, another report was made for the same child. The report alleged the girl had bruising and had disclosed to the reporter that her mother had bitten her. The recorded secondary assessment consisted of a letter sent to the mother regarding inappropriate discipline, and a feedback letter to the mandatory reporter. Once again the girl was not seen, and her parents were not interviewed or spoken with.

Following the death of the four-year-old child, a comprehensive secondary risk of harm assessment was conducted for the children, and support services put in place.

Last year, we recommended that DoCS clarify its policy regarding the circumstances under which children should be seen and/or families interviewed. In August 2005, DoCS advised that revised procedures for secondary assessment, due in October 2005, would include a procedural requirement that children and young persons subject to secondary assessment Stage 2 must be sighted.[31] In response to a draft copy of this report, DoCS noted that *'The revised Business Help topic on Secondary Assessment will state that caseworkers need to sight a child and interview where possible.…The topic also provides clear pointers on vulnerabilities and what constitutes sighting the child'.*[32] As we have not sighted the new procedure, we are not in a position to form an opinion as to whether the revised procedure addresses our recommendation.

In a number of cases, we found that secondary assessment was not comprehensive enough to provide a sound basis for decisions about necessary protective intervention. This included cases where decisions were made about children who had not been sighted and about whom little was known, and where a case plan was developed but not implemented.

CaseStudy10

We reviewed the death of a baby who died of natural causes. In the course of the review, we considered a secondary risk of harm assessment that was conducted for the baby's six siblings prior to her birth. The reports that led to the assessment included concerns about carer alcohol and drug abuse, physical harm and risk of physical harm, domestic violence, and inadequate supervision. The assessment was conducted over a nine-month period, during which five further risk of harm reports were received. Our review found the assessment was inadequate, with little evidence that it accorded with the secondary risk of harm assessment framework. There was no holistic assessment of the circumstances of the children. Investigation was limited and little objective evidence was sought to inform the decisions made about the children's welfare. For example:

- Judgements and decisions were made about four children who were not seen or spoken with, and without consultation with other agencies that may have held relevant information about the children.
- During the assessment, DoCS received four reports about one of the children. At least three of these reports related to inadequate supervision. The assessment noted that the child was at risk of harm due to lack of parental supervision, that he wandered the streets and was in trouble with police. The caseworker's comment was that they had *'…no casework contact with (the child) from a DoCS point of view.'* In making judgements about the child's safety, the assessment report made no reference to inadequate supervision.
- Three of the children – aged five, four and one year - were assessed as being at a 'higher level of risk of harm continuing' due to their age and dependency. However, for all three children, none of whom had been observed or spoken with, the 'harm consequence' was determined as 'nil'; 'harm probability' as 'unlikely'; and 'future risk level' as 'low'.
- The secondary assessment stated that one child was at risk of ongoing abuse, but did not substantiate physical harm for that child. While the child was assessed to be in need of care and protection, there appeared to be no comprehensive assessment of other issues for him, or identification of how he and his family could be further supported to address the concerns about his wellbeing.

Secondary assessment where children had been previously removed

If DoCS has taken Children's Court action in relation to a family, this should be a key indicator of concern and a critical factor in further assessments of risk in that family environment.

For three children who died, we found that the department had previously taken court action in relation to their families resulting in court-ordered removal of a child from home. In each case, the child that had been removed had not been restored to the family by the time their sibling died. The autopsy report for two of the three children identified the cause of death as undetermined or unascertained. The other child died from a serious but treatable illness. Our reviews found that in two of these cases, the risk factors that had resulted in the earlier removals were apparent in the reports subsequently made to DoCS about the child who died and/or their siblings. In these cases, we found that the family history was not adequately considered in determining protective measures for the children.

In 2004, we also conducted one investigation and one detailed review into deaths that occurred in 2003, where the child who died had siblings in court-ordered care. We had concerns about the degree to which family history was considered when assessing the current circumstances of the family.

We found in our reviews that at times, assessments about the likelihood of harm attached significant weight to the parents' account that their circumstances had changed, rather than on evidence that risk factors had been addressed. For example, in one case, parental drug use was a main ground in the earlier removal of a child. Despite a long-term history of drug abuse, subsequent reports for the child's siblings were dealt with through informal undertakings in which the parents agreed to refrain from using illicit drugs. These undertakings were not met and we found no evidence of action by DoCS in relation to these breaches. Voluntary or informal undertakings are discussed further in section 6.1.

In these cases, despite the existence of a well-documented child protection history, assessment did not fully consider the possible risks to a child.

Our reviews indicate the lack of capacity to undertake comprehensive risk assessment as envisaged in DoCS' risk of harm assessment framework is, to a significant degree, the result of constrained resources coupled with high demand and high workload. It is also apparent in some cases that a critical issue is the inexperience of caseworkers. Inexperience may be because they are new caseworkers, or that they are dealing with families who present with complex social and/or clinical problems that are beyond their current capacity. Poor supervision of caseworkers in their decision making has also at times been evident in our reviews.

The continued roll out of DoCS enhancement funding and resultant additional casework capacity should over time improve the department's capacity to apply its secondary assessment framework more comprehensively.

4. Case closure due to competing priorities

4.1 Priority One / case closure policy

DoCS has a statutory responsibility to assess the safety and wellbeing of all children reported to be at risk of harm. While DoCS' secondary risk of harm assessment policy requires that a child must be the subject of a secondary assessment if an initial assessment indicates the child may be in need of care and protection, DoCS does not have capacity to assess all reports for children who fall into this category. DoCS' Priority One case closure policy, designed to manage workload and prioritise high-risk cases, overrides the secondary risk of harm assessment policy and procedure:

> *Nothing in this policy impacts on the operation of the Priority One: Setting Priorities for Unallocated Work in the Child and Family Services Program in Community Service Centres.*[33]

Our report last year raised concerns about the effect of Priority One case closure policy. By 2004, the Priority One policy had been slightly amended by additional procedures, and by 2005 the department had commenced a trial of a new case closure policy and procedure in several CSCs. However, existing procedure still allows for a case to be closed due to lack of resources and competing priorities. The basis for closure is 'relative risk' represented by competing demands.

The department's policy aims to provide a framework for managing workload in a high demand and resource limited environment. Our reviews of deaths in 2004 identified that a large number of reports were closed without secondary assessment. Reports we reviewed that were closed under the case closure policy included reports indicative of high levels of risk.

In examining reports on the DoCS database (KiDS) for children who died in 2004, we found it difficult to identify the number of reports closed under the policy because the closure reason was not consistently recorded. However, we were able to determine which reports referred to a CSC for further assessment had secondary assessment actions and outcomes recorded in KiDS.

We examined actions and outcomes recorded on KiDS in relation to 310 reports for the 72 children who were known to DoCS and who died in 2004. Of the 310 reports, 213 reports were assessed by the Helpline to require further assessment by DoCS, and were forwarded to a CSC for a secondary risk assessment. These reports concerned 64 children.

For 135 of the 213 reports requiring further assessment (63%), no secondary risk assessment activity or action was recorded on KiDS.

Of the 135 reports that did not lead to a secondary risk assessment, 18 (13%) had been determined by the Helpline as being urgent enough to require a response within 24 hours. A further 66 reports required a response within 72 hours (49%) and 51 required a response within ten days (38%).[34] [35]

Of the 135 reports that did not lead to secondary risk assessment:

- 110 reports were closed by the CSC prior to the child's death and Priority One / case closure policy was recorded on KiDS as a closure reason for 63 of these.
- Eight reports were open and allocated for secondary risk assessment prior to the child's death but no assessment action was recorded on KiDS.
- 17 reports were unallocated and KiDS records indicated that seven of these were unallocated due to current competing priorities, in accordance with priority one / case closure policy.

For 28 children, the last risk of harm report made about them that was referred to a CSC for further assessment did not lead to any secondary assessment. Ten of these 28 children (36%) died in circumstances related to or suspicious of abuse or neglect, or the circumstances of their death was relevant to the safety and wellbeing issues last reported to DoCS:

- Two children died in circumstances related to abuse
- One child died in circumstances related to neglect
- Two children died in circumstances suspicious of abuse or neglect
- Another five children died in circumstances relevant to the issues last reported to DoCS about their wellbeing and safety.

4.2 Concerns about cases closed without assessment

Our reviews raised a number of specific concerns about cases being closed without any secondary risk assessment. In some cases, we found the closure of reports occurred despite clear indications of high risk. Some cases appeared to be closed without adequate consideration of family history.

CaseStudy11

A three-month-old baby whose death was due to SIDS was the subject of three reports to DoCS, primarily concerning the impact of domestic violence, carer drug and alcohol abuse and neglect. In the two-and-a-half years prior to his birth, ten risk of harm reports had been made to DoCS about his siblings. These reports concerned persistent and escalating domestic violence, parental drug use, physical abuse, neglect, and excessive discipline.

Six months prior to the child's birth, DoCS conducted a secondary risk of harm assessment for the family's two other children, then aged two-and-a-half and nine months. The assessment concluded that the 'probability of harm' for the children was 'highly likely' and the 'harm consequence' was 'serious'. It noted that previous reports had twice led to the case being allocated to a caseworker, and that DoCS had linked the family to numerous support services, but that further referrals would make no difference in reducing the risk of harm to these children. The assessment found there were no protective factors at home for the children. Noting that a DoCS review of the family two years earlier had recommended that any further reports of domestic violence in regard to the family should be dealt with through a legal framework, the assessment recommended that appropriate further action be discussed with management. We found no evidence on KiDS of further decisions or action being taken in relation to this matter. Four months later, there was a further report of medical neglect in relation to one of the children. In assessing the neglect report, records state that 'the last assessment …..indicates a number of services being involved as well as extended family.' Records did not indicate any change in circumstances for the children. The case was closed due to current competing priorities.

A further report about domestic violence was received three months later. The reporter noted the child was 'fine' and had been sighted by police. DoCS Helpline determined the report had no legal basis as there was no identifiable risk of harm to the child.

Less than three weeks later, another report was made about the two children, and the baby who was then aged six weeks. The baby had been born prematurely and was in hospital. The reporter raised concerns about domestic violence incidents taking place in front of the children, as well as neglect, lack of parental coping and maternal depression. Concerns were raised about the safety of the baby on discharge from the hospital. The risk was assessed by the Helpline as high, with a required response time of within 72 hours. Two days later, a further report was made in relation to similar issues. The risk was assessed as medium, with a response time of within 72 hours. Neither of the two reports was allocated to a caseworker by the CSC. Both were closed on the same day four months later—two months after the baby's death—due to 'current competing priorities'. The CSC conducted an assessment for the baby's two siblings after the death of the baby.

4.3 Trial of the draft case closure policy and procedure

Between December 2004 and June 2005 the department trialled a new case closure policy and procedure at three metropolitan CSCs. These are referred to as Enhanced Service Delivery Sites (ESD). DoCS has advised that as a result of its evaluation of the trial, the procedure has been revised and the trial is to be extended to more CSCs, as part of a staged implementation. DoCS plans to further evaluate the policy in consultation with key stakeholders prior to phased implementation across the state by June 2006.[36]

The main elements of the trial procedures are that:

- All cases (plans) must receive secondary assessment or be closed within 28 days.
- Secondary assessment stage 1 (SAS 1) must be undertaken for certain children. SAS 1 may include one or more of the following: considering any history held by DoCS; making phone calls; requesting information from other agencies; using local knowledge to inform decision making; or where relevant and approved by the manager, contacting parents or carers by telephone.
- The children for whom SAS 1 must be undertaken under the trial are:
    - All cases where initial assessment indicates a response is required within 24 hours
    - All cases where the Manager Casework determines that action is required
    - All cases where initial assessment indicates a response is required within 72 hours AND the child is under two years of age AND one or more additional factors are present. These include
        - domestic violence involving injury or use of a weapon
        - reported issues relate to neglect
        - impaired caregiver capacity due to substance misuse, unmanaged mental illness or intellectual disability
        - the child has high needs
        - the child or a sibling has been the subject of two or more reports within the past six months that have been closed without a SAS 2 (field response)
    - Any case involving children under 18 years that concerns an allegation against an authorised carer, DoCS employee or employee who works with children in a non-government or government agency.

Cases that do not fall into the above categories should only be allocated for SAS 1 if resources have not already been exhausted and they must be closed within 28 days if resources do not become available in that time to undertake the secondary assessment. Cases may be closed immediately without secondary assessment if they do not meet the criteria for SAS 1 and the manager determines that it is not possible to assess them within 28 days.

Following SAS 1, cases can be closed where the assessment has found the child to be safe and not in need of care and protection, or where *'…the child or young person is at risk of harm but the case is of lower risk relative to other cases on hand and the Manager determines that it will not be possible to conduct a Secondary Assessment Stage 2 (SAS2) with existing resource levels within 28 days…'*[37]

In our 2004 report, we recommended that the department work towards a framework for case closure that indicates a risk threshold above which cases should not be closed without protective intervention. We took the view that where a report raises issues of safety of a child, or a failure to provide adequately for a child's basic physical or emotional needs, it should not be closed until adequate steps have been taken to resolve the issues. DoCS' accepted this recommendation in principle, and referred to the trial case closure procedure as, in part, meeting this recommendation.

DoCS has advised us that in relation to the evaluation of the case closure procedure trial, which was focused on determining operational feasibility:

> *Overall the results of the focus groups and surveys indicate that the draft policy is workable, has minimum impact on current workload and meets the needs of Caseworkers for more detailed guidance about the review that must take place and be recorded on KiDS before case closure. The available data indicates that the draft policy can be implemented successfully, at least in CSCs with new resources, and on the advice of the practitioners, appears to target the right cases for further review where demand for resources exceeds supply.*[38]

DoCS advised us that field testing of the procedures is now being expanded across a range of CSCs. This would include sites that have received enhanced resources and those that have not. DoCS noted that this trial will be subject to rigorous evaluation. [39]

We remain concerned that the new case closure policy and procedure, while it provides some assurance that high risk cases will be subject to SAS 1, retains a focus on relative risk and capacity for the closure of cases without response where serious risk has been indicated. The challenge is that on one hand, current capacity within DoCS does not allow for a response to all cases, and some form of workload management is required. On the other hand, closing cases without adequately assessing the level of risk facing a child, or closing cases before a response can be made to identified risk, can leave children vulnerable to harm.

Moving towards a risk threshold that ensures a response to actual, rather than relative, risk will require considerable resources. The implementation of the reform package over the next few years will be critical to reducing the number of cases closed due to competing priorities.

4.4 Testing the case closure policy and procedure

In our work we asked whether the new case closure policy and procedure could be considered a step towards the development of a risk threshold above which cases would not be closed without intervention. We tested the new procedure against a number of cases we had reviewed.

Special report to NSW Parliament

In 2004, we released a special report to the NSW Parliament about our investigation of the death of a child and the child protection intervention prior to the child's death. The report was titled *'Improving outcomes for children at risk of harm – a case study.'* In this report, we chronicled a long history of involvement by DoCS with the child and his sister.

Over three years, DoCS received seven reports that provided evidence of chronic and serious risk of harm to the children. A number of these reports were closed under the Priority One policy. Our investigation concluded that there was a continual failure to respond adequately to reports about the risks of harm to the children, and despite the Helpline identifying the persistent nature of these risks:

> *DoCS failed to take adequate steps to protect the children from the ongoing dangers they were facing. In this office's view, this failure was unreasonable. Had appropriate action been taken, a different outcome may have resulted for the children.*[40]

DoCS' own review of the matter found that the response to reports of neglect and risk of harm was overly incident-based and responsive to individual crises, which meant that *'…every time new information was received it was responded to as if it was the first time such risks had been present for the children.'* DoCS noted the risk factors of the case had been consistent over a three-year period.

As part of our investigation, we asked DoCS to apply the new trial case closure policy principles to the facts of the case. DoCS advised us that it conducted this test, and found that the reports closed under the Priority One policy would not receive priority under the new procedure. [41] In other words, had the new case closure policy been in place at the time the children were reported, DoCS' handling of the case would have been no different.

Children who died in 2003

Last year, we reported that for 12 children who died between December 2002 and December 2003, the closure of a report was the last DoCS action before the child's death. Eight of these children died in suspicious circumstances; three children as a result of abuse; and one child in circumstances related to neglect.[42] For the three children who died as a result of abuse, the issues raised in the reports that were closed included physical abuse and domestic violence; sexual abuse, physical abuse, neglect and domestic violence; and physical abuse and carer mental health. Seven of the children died within four months of the last report. We have not included one of these children in the following analysis, as DoCS has recently advised us that some activity was undertaken by the CSC prior to the child's death, and that case closure was therefore not the last action taken by DoCS.[43]

We applied the new case closure procedure to the seven cases. In no case would the report receive priority under the new procedure. That is, had the new case closure procedure been in place at the time the last report was made about these children before they died, the report would have been closed without assessment.

The need for a case closure policy and procedure results from inadequate resources and high demand. While the $1.2 billion enhancement will result in significantly increased capacity across the department, DoCS has advised us that there is no guarantee that it will be able to move away completely from case closure on a resource-based model by the end of the rollout of the DoCS reform package in June 2008.[44]

DoCS has noted that the extra funding was based on the number of child protection reports at a point in time in 2002, but the current demand estimate is 33% growth from that time to June 2005.[45] In a response to a draft copy of this report, however, DoCS told us that recent information shows that allocation rates in CSCs that are Enhanced Service Delivery Sites:

> *…show a marked improvement. In these Enhanced Service Delivery Sites, allocation rates were 90% for 24-hour response reports, 70% for 72-hour response reports and 52% for 10-day response reports in June 2005. By comparison, the Kibble Report in 2002 reported allocation rates of 55% for level 1 (24-hour response) reports, 26% for level 2 and 12% for level 3.*[46]

We note that the department's Early Intervention Program is expected to address, through voluntary participation of carers, the 'level 3' reports, those where risk of harm is assessed as medium to low.

Regular evaluation and monitoring of the rollout of additional resources and initiatives to improve service delivery will be critical to objectively assess how DoCS' capacity is being improved. Evaluation will be particularly important in relation to monitoring the extent to which cases are closed without assessment, or are closed without intervention where risk has been identified.

5. Interagency coordination and cooperation

While DoCS has lead responsibility for child protection, the *NSW Interagency Guidelines on Child Protection Intervention* make it clear that DoCS alone cannot provide effective intervention:

> *No single agency has all the knowledge, skills or authority to safeguard a child or young person from abuse or neglect and to prosecute an alleged offender. Child protection requires the best expertise and resources available and this is only achieved by coordination.* [47]

In our 2004 reviewable deaths annual report, we raised concerns about interagency coordination and cooperation. These concerns were primarily focused on the limited use of strategies contained within the Interagency Guidelines. Specifically, we found:

- Protection Planning Meetings appeared to be seldom used where a child was assessed as being in need of child protection intervention. These meetings are designed to combine and coordinate resources to assist effective child protection intervention.
- There was little use of sections 17 and 18 of the *Children and Young Persons (Care and Protection) Act 1998.* Section 17 allows for DoCS to request another agency to provide a service to a child and their family. Section 18 requires agencies to use their best endeavours to comply with the request.
- In the matters we reviewed, DoCS referral to, and liaison with, other agencies was lacking.

Limited interagency coordination continued to be evident in deaths in 2004.

While there was evidence of interagency liaison in many cases, it generally did not lead to a comprehensive approach to protecting the children and supporting families, as envisaged by the Guidelines.

We note that the Interagency Guidelines are currently under review. The purpose of the review is to 'identify limitations in the current operation of the Guidelines and to propose refinements which will both improve practice and reflect the key pressures in this area'.[48] *At the time of writing this report, a discussion paper had been distributed for public comment. The intention is for the review to be completed and new Guidelines issued by July 2006.*

5.1 Interagency case planning meetings

Of the 72 children who were known to DoCS and who died in 2004, we found evidence that five of the children were the subject of a Protection Planning Meeting (PPM). In a number of cases, the PPM was initiated by NSW Health services. We reviewed cases where a PPM or significant liaison with relevant agencies would have been expected, but did not occur.

For example, in one case, a baby born prematurely was the subject of a secondary assessment. The baby was in hospital at the time, and concerns related to the mother's alcohol abuse and lack of bonding with the baby. DoCS identified that an early childhood nursing team would visit the mother for a period of time once the baby had been discharged. No PPM or further liaison was initiated with NSW Health. According to DoCS records, the nursing team would be involved for eight weeks, but the team ceased involvement with the family after four weeks. Although the case was open at the time of the baby's death, DoCS had no contact with the family or with the nursing team between the discharge of the baby from hospital and his death.

In another case, where a 13-year-old boy committed suicide, we found no evidence of a comprehensive planning meeting involving all relevant parties. This was despite two key agencies having very different views about what should be done to ensure the child's safety and wellbeing. This case is discussed in case study 29, on page 95.

In a response to a recommendation we made last year about ensuring compliance with the Interagency Guidelines, particularly PPMs, DoCS stated that the department *'…is committed to contact with key parties where a child or young person is assessed to be in need of care and protection'.*[49] However, DoCS also expressed concerns about the requirement to hold a PPM in these cases. The department's view is that this is *'neither possible nor necessary in every case'.* DoCS states that its preference is for involvement of *'those key parties who will provide services that are critical to achieving the outcomes of a case plan, and/or agencies involved in legal proceedings to protect a child or young person.'*

The discussion paper being used to inform the review of the Interagency Guidelines reiterates this view. The paper proposes that DoCS should have either a meeting or phone contact with 'key interagency partners' when a child or young person is in need of care and protection and the case is allocated for a full secondary assessment.

From our reviews, what is critical is early identification of the need for services for a child and/or their family, early referral to secure these services, and timely contact with the involved agency(ies) to ensure that assistance is well coordinated. Given the number of cases that DoCS is currently unable to allocate for secondary assessment, it is essential that the revised guidelines promote opportunities for interagency planning to be initiated at any point, where it is appropriate to an individual case.

We also note that within the DoCS Western region, a Complex Case Management Response Team (CCMRT) has been established. The team represents a multi-agency approach to at risk families, and allows for early exchange of information and case planning by agencies where children are identified as being at risk. Participating agencies include DoCS, NSW Police, and the Departments of Housing, Juvenile Justice and Corrective Services. The CCMRT has been reviewed by Charles Sturt University. The model has the potential to provide a timely interagency approach to dealing with problems facing children and young people, particularly where these include underlying problems such as domestic violence and drug and alcohol abuse. We have asked DoCS to advise us whether it sees the potential for the model to be extended to other areas of NSW.

An essential part of good in interagency work is exchange of relevant information. Section 248 of the *Children and Young Persons (Care and Protection) Act 1998* is critical to interagency coordination, in that it allows for information between DoCS and other agencies to be exchanged in relation to the 'safety, welfare and wellbeing' of children. Law enforcement exemptions to privacy legislation also enable disclosure or the sharing of information between police and other agencies if the disclosure is made for a law enforcement function. There are, however, gaps in the system for exchanging child protection information where agencies other than DoCS seek to exchange information with each other about child protection issues. While regulations exist to fill some of these gaps, sharing of information in this context remains a complex issue requiring further consideration by government.

5.2 Referrals to agencies

Section 17 of the *Children and Young Persons (Care and Protection) Act 1998* enables DoCS to request that other government agencies or certain non–government agencies provide services to a child or young person or their family. Section 18 of the Act requires agencies to use their 'best endeavours' to meet such a request. Our reviews identified few such requests being made by DoCS. There were cases where DoCS did not have the resources to further assess a report or to continue a case plan, and where the skills of other agencies may have provided some protective intervention.

We found referrals being made in case plans, but it was often unclear whether referrals were taken up, or whether DoCS monitored the results of referrals.

In response to our recommendation that DoCS develop strategies to ensure its staff engage effectively with other agencies, the department noted that effective use of sections 17 and 18 of the Act, and referrals in general, are critical components of good child protection practice. The department advised that consultations for the review of the Interagency Guidelines raised *'…some concerns including a lack of a shared understanding of the purpose of and place for 'best endeavours' requests, and a need for improved local relationships to facilitate the making of requests for services'.*[50] DoCS advised that the role of certain CSC managers had been changed to ensure a stronger emphasis on *'the service network'*, including facilitating effective referrals.

We note that DoCS has also indicated it will involve agencies in the closure of cases. We made a recommendation to DoCS that there should be a requirement for staff to inquire, prior to closure, about the outcomes of referrals where the case has been allocated and the child is in need of care and protection.[51] DoCS stated that; '*The draft Secondary Assessment: Risk of Harm Business Help Topic includes a requirement for caseworkers to make contact with family members and interagency partners prior to closure'.*[52]

The importance of, and issues associated with, effective interagency coordination and cooperation are further discussed in following sections of this report, particularly carer substance abuse, carer mental illness, domestic violence, adolescents, and Aboriginal children and young people.

6. Response to specific risk factors

This year, our work raised concerns about agency responses to particular risk factors that were evident in many of the deaths we reviewed. These risk factors were parental substance abuse, domestic violence, parental/carer mental illness and neglect. Our reviews of cases where there had been risk of harm reports for unborn children also raised concerns about how effectively agencies were able to help the mother and protect the child.

6.1 Parental substance abuse

Parental substance abuse has long been identified as a high risk factor for child abuse and neglect. Children living with parents who abuse alcohol or other drugs may have poor social, emotional, developmental and educational outcomes. Children exposed to maternal substance abuse prenatally and when very young are particularly vulnerable. Babies whose mothers abuse substances during pregnancy may be born with health problems and be more difficult to care for than other babies.

Research conducted by the NSW Child Death Review Team into the fatal assault of children and young people identified parent substance and/or alcohol use as a factor in 48.6% of the families of children aged 0-12 years who were fatally assaulted.[53]

The rise in substance abuse over the past few decades is attributed as one of the primary reasons for the increasing numbers of children in need of protective services.[54] DoCS identifies drug and alcohol abuse by parents as one of the main factors contributing to an increasing demand for DoCS services. [55]

DoCS funds a number of services to provide support for families affected by substance abuse under its Early Intervention and Prevention Program, including the Substance Use in Pregnancy and Parenting Service (SUPPS), the Blacktown Alcohol and Other Drugs Family Service and the Shoalhaven Drug and Alcohol in Pregnancy and Parenting Service as well as a range of services under and the Alcohol and Other Drug Program.[56]

Of the 72 children who were known to DoCS and who died in 2004, 30 (42%) were the subject of a risk of harm report where the reporter identified drug or alcohol use as an issue.

Nine of the 30 children died as a result of abuse or neglect, or in suspicious circumstances. We assessed that for 12 of the 30 children, the issues reported to DoCS were relevant to the circumstances of their death, including three of the nine children who died as a result of abuse, neglect or in suspicious circumstances. For two children, the reported issue relevant to their death was related to parental substance abuse. Both children were born with significant health issues as a consequence of maternal substance abuse during pregnancy and died from health complications within the first six months of life. For the other ten children, the reported issues relevant to their death were not about parental substance abuse but other risk factors such as physical abuse, inadequate supervision and neglect, largely reflecting the association between parental substance abuse and other risk factors.

In total, there were 167 reports about these 30 children. Seventy-five reports (45%) for these children concerned parental substance abuse, and 63 of these (84%) were referred to a CSC for secondary risk assessment. Less than half of the 63 reports (43%) referred received secondary assessment by a CSC. Thirty of the reports were closed without assessment and six were open cases at the time of the child's death. Of the 27 reports that received a secondary assessment:

- 13 reports were assessed without a field response and the assessment was based on local knowledge and/or information from other services. Several of these reports were still open months after being forwarded to the CSC.
- 14 reports received a field response, primarily involving interviewing a parent or carer and interviewing or sighting the child. This represents less than a quarter of all reports (22%) concerning parental substance abuse that were forwarded to a CSC for secondary assessment.

Following the field response, DoCS confirmed risk of harm for nine children and was still assessing another child when he died. Six of the nine were referred to other services. DoCS had closed the casework files for seven of the nine children before they died.

The adequacy of DoCS' risk assessment

The impact of substance abuse on parents' capacity to meet their children's needs and to safeguard them is a critical consideration in assessing risk of harm. Our work this year identified that, in some cases, DoCS assessment and intervention where parental drug and alcohol abuse was reported was inadequate. The DoCS risk assessment framework identifies parental substance abuse as one of many factors to consider when analysing risk. Caseworkers also receive training in working with clients with alcohol or other drug problems as part of the DoCS caseworker development course. This consists of two days training. Additional courses in alcohol and other drugs are offered to caseworkers on an ad hoc basis.

Many of the issues we identified were common to DoCS' risk of harm assessment generally and these issues are discussed in section 3 *'Assessing risk of harm'*. However, of particular concern to us was the need for improved expertise and knowledge amongst DoCS caseworkers about drug and alcohol dependency generally, and more specifically, its implications for parenting capacity and risk of harm to children. This was reflected in casework decisions that did not appear to take into account the child protection history or pattern and chronicity of parental substance abuse. We found in some cases that responses to reports about substance abuse did not seem to acknowledge the serious risk to safety and wellbeing associated with parental substance abuse.

CaseStudy12

This year we reviewed the death of a baby who died in 2003.[57] The baby was born extremely premature and died within hours of her birth.

A report was made to DoCS during the pregnancy and was recorded as a risk of harm report for the mother, then aged 17 years, and the baby's sibling, aged 13 months. Reported concerns related to chronic drug and alcohol abuse by the mother, including heavy cannabis and alcohol consumption on a daily basis, her very poor health and the poor prognosis for the baby's survival. The mother was said to be resistant to supports and involved in a relationship characterised by violence. A prenatal report was not recorded for the baby.

The Helpline referred the report to a CSC and recommended a response within 72 hours. The report was not allocated and was closed without further assessment under the Priority One case closure policy one month later.

A second risk of harm report was made four days before the baby's birth and was recorded as a prenatal report for the baby and as a report for her sibling. The report indicated that the mother was still chronically using drugs, and was in poor physical health and agitated. The Helpline referred this report to the CSC and recommended a response within 72 hours. The report was not allocated or assessed. After DoCS was advised that the baby had died, the report was downgraded to 'no response' and then closed. DoCS made no contact with the family and did not assess the safety or wellbeing of the baby's sibling.

In some cases we reviewed, risk of harm reports indicated that parental substance abuse was a chronic and recurring issue for child safety and wellbeing. We found that DoCS' response to reports about children affected by chronic parental substance abuse at times was focused on a single event, considering safety and harm at a particular point in time, without adequately considering the family's history, or the likelihood of risk continuing or recurring. In some cases, DoCS' actions were targeted at addressing the more tangible presenting issues, for example homelessness, but then failed to consider the overall risk to the child against the family's history, lifestyle and prior patterns of behaviour.

While the department's risk assessment framework promotes a holistic approach to secondary assessment and consideration of the predictability of risk in the context of the family's history and the presence of complicating factors such as substance abuse, we found cases of incident-focused practice even where the family had a long history with DoCS.

CaseStudy13

A baby boy who died during sleep at three months of age was one of four children.

There was a long history of reports to DoCS prior to the baby's birth. More than 20 risk of harm reports for his siblings had been made to DoCS over a two to three year period. The reports raised serious concerns about the safety and wellbeing of the children as a consequence of the parents' long-term drug use, their parenting capacity, ongoing domestic violence and criminality. The children were born drug-dependent and were the subjects of reports to DoCS related to chronic neglect, physical abuse, psychological harm and inadequate supervision. Historically, the family had not engaged well with support services.

Protective intervention by DoCS included removing the second born child when she was six days old. DoCS initiated care proceedings for this child and she has remained in care.

There was little evidence of positive change within the family by the time the third baby was born the following year. Nine prenatal reports about this baby were made in relation to the mother using drugs during the pregnancy and continuing domestic violence. DoCS commenced a secondary risk assessment after a further report following the baby's birth. Departmental caseworkers then met with the parents and they signed undertakings to accept the support of health services, attend a methadone clinic daily, undergo urinalysis, refrain from domestic violence and not use illicit drugs. The parents breached these undertakings within three weeks and there were further reports to DoCS concerning domestic violence and parental substance abuse. DoCS took no action in relation to the breach of undertakings.

Over the next 18 months, the parents continued to use drugs and risk of harm reports identified numerous and ongoing safety and wellbeing concerns for the two children. From time to time the children moved between the parents and relatives when the parents were in crisis or in gaol. The care arrangements for the children were made informally by the family and without DoCS intervention.

Although the case remained open, DoCS' assessment of the children's safety appears to have occurred in a disjointed way. Referrals to various services occurred from time to time but coordination of services and monitoring of the family's progress was sporadic. Our review found that DoCS assessed individual reports of risk of harm in isolation to the known history and without consideration of issues raised in other reports that had not been assessed. There appears to have been no holistic secondary assessment of the children's safety and wellbeing and, despite the ongoing involvement of DoCS and other services, by the time the fourth baby was born, no interagency planning meeting had been held in over two years.

Our work this year also highlights the challenges for DoCS caseworkers in maintaining a focus on the needs of children when parents have significant substance abuse issues. The complex needs of a parent with alcohol or other drug dependency can be so great that they may overshadow the safety and welfare issues for children. The principles of the *Children and Young Persons (Care and Protection) Act 1998* place the safety, welfare and wellbeing of the child as the paramount consideration. However, when the focus of intervention is on supporting and assisting parents, there is a significant risk that the result will be lack of attention to the needs of the child.

Interagency response to carer substance abuse

Families where parental substance abuse is an issue may be known to many agencies and each agency may have different knowledge about the family and play varying roles. It is important that agencies working with children and families where child protection concerns exist are clear about each other's roles and responsibilities and share information and expertise. Our work highlights the necessity of DoCS, as lead agency for child protection, to proactively engage other agencies in the planning and coordination of services for children where risk of harm has been identified. Some of the cases we reviewed indicated that such engagement could be improved.

Of the reports for 30 children who died in 2004 who had reports concerning parental substance abuse, three of the 75 reports were referred from the Helpline to other services – one was referred to JIRT and two were referred to police for a 'welfare check'.

Of 27 reports that received some secondary assessment, seven led to the CSC referring the family to other services. Referrals included those to the Department of Housing (one); health services, including prenatal services and community health (two); family support services (two); and two families were referred for drug and alcohol counselling. A PPM involving DoCS and other relevant agencies was held for two children. We found no evidence that the department referred any of the reports that did not receive secondary assessment to other services.

CaseStudy14

DoCS received five risk of harm reports for a newborn baby who died at eight weeks of age from undetermined causes. The first two reports, made almost one week after the baby's birth, raised concerns about the mother's drug use during pregnancy and alleged that the father had a serious drug dependency, the baby was born prematurely, had low birth weight and showed signs of drug withdrawal.

The mother had reportedly reduced her drug intake since the baby's birth and the local drug and alcohol service had made contact with the parents to offer support. The Helpline forwarded the report to the local CSC for secondary assessment but it was not allocated.

A third report a week later indicated the parents had moved and alleged that they may be avoiding contact with police and were refusing intervention from key services. The report indicated that both of the baby's parents were using drugs, the father was aggressive and the mother appeared very anxious in his presence. The Helpline telephoned the report details through to the CSC and recommended it be responded to within 24 hours. The CSC did not allocate the report, but telephoned other services to enquire about their contact with the family and requested police provide details of any criminal history for the baby's father.

Another two risk of harm reports made the following week concerned domestic violence and the mother's non-attendance at the drug and alcohol service. One reporter had grave concerns for the baby, as the mother had not kept appointments with services. The Helpline assessed that this report required a response within 24 hours and telephoned the details through to the CSC. The CSC made a plan to assess these reports by way of interview with each parent, sighting the baby and contacting other services. Over the next week, DoCS caseworkers made several visits to the parents' address but did not locate them. Shortly afterwards, the mother contacted the CSC by telephone, advising that she had left the father and that she and the baby, then four weeks old, had moved to another town. One week later, the CSC contacted the CSC in the area where the mother and baby were now residing about the case. Although this was an open DoCS case, a secondary risk assessment had not been conducted nearly two months after the report was received.

We found no record that either CSC had any further contact with the mother or other services or sighted the baby. It appears the case was still in the process of being transferred from one CSC to another when the baby died.

Our review of this child's death is incomplete, but it raises a number of issues about how DoCS and NSW Health handled child protection concerns for this baby. No prenatal reports were made for this baby despite the known chronic substance abuse of both parents prior to and during the pregnancy, during which the mother was admitted to hospital on multiple occasions. While not mandatory, prenatal reports are good practice where there is reason to believe a baby may be at risk of harm following birth and provide an opportunity for early intervention and support. Earlier reporting to DoCS by health services, either prenatally or immediately following the baby's birth, would have increased the opportunity to assess risk and coordinate services for this very vulnerable baby.

Following internal reviews of a number of child deaths, DoCS has made several recommendations focussed on the department's response to risk of harm reports where parental substance abuse is an issue. These recommendations include:

- improved availability of in-house expert drug and alcohol advice to field staff, possibly including regular case practice review discussions led by expert drug and alcohol professionals.[58]
- a Helpline quality assurance project over a two year period reviewing the adequacy of DoCS response to cases of children under one where the primary presenting problem is parental substance abuse and the priority rating level is 2 or 3.[59]
- monitoring of child deaths over a two year period where there are concerns regarding parental substance abuse, with a project around this sample group to identify common systemic and practice issues and formulate recommendations.[60]
- provision of information about parental methadone use via the department's intranet and a review of the methadone component of drug and alcohol training provided to departmental staff so that it includes contemporary research regarding risk factors.[61]

The DoCS operational consistency major project working group has identified 'drug testing' and 'dual diagnosis' as topics for inclusion on Business Help procedures. Drafting of these topics has commenced and has been allocated a high priority.[62]

Undertakings

> When a child is assessed to be in need of care and protection, a range of intervention options are available to DoCS within the *Children and Young Persons (Care and Protection) Act 1998*. All actions and decisions made under the Act must give paramount consideration to the safety, welfare and wellbeing of the child. The level of intervention should be commensurate with the level of assessed risk or harm to the child.

One strategy for protective intervention that we identified in reviewing deaths in 2004 was 'undertakings':

> *'The term "undertakings" refers to where parents and/or a child or young person agree to undertake specific actions, or agree not to take specific actions, with regard to the care and protection of a child or young person'.* [63]

The department can use undertakings given by parents in a number of ways:

- undertakings agreed upon and signed by parents as part of a case plan or unregistered care plan, that does not involve taking the matter before a Children's Court
- undertakings that are formally recorded with the Children's Court as part of a registered care plan
- a Children's Court order accepting undertakings made by the parents of a child following a finding by the Children's Court that a child or young person is in need of care. The matter may be brought back to the Court by DoCS if the undertakings are breached.

In all the above circumstances, the undertakings are reliant on the parent(s) agreeing to comply with them. Undertakings may be made in the absence of any arrangements for the department or other agencies to supervise or monitor the parent's compliance with them.

In November 2002, the department issued an internal Practice Bulletin on *Informal Undertakings* as a practice reminder to staff, advising that the department does not endorse caseworkers accepting 'informal undertakings' outside of the case planning process and that undertakings given by parents and/or a child must be included as part of a case plan.[64] The practice reminder advised caseworkers to consider:

> *'…whether parent(s) and/or a child or young person are likely to comply with agreements, and what action might be necessary to give effect to the agreements.'*

Regardless of the type of undertakings used, our reviews highlight the need for caution about relying on agreements with carers to act or not to act in certain ways as a protective measure for children, particularly where parental substance abuse is an issue. Drug dependency is a problem that is not easily resolved. Alcohol and other drug addiction is recognised as a chronic relapsing disorder, where relapse may be a common occurrence. For this reason, reliance on undertakings alone may be fraught.

We reviewed DoCS' use of undertakings as a child protection strategy for five unrelated children who died in 2004 and for the siblings of another two unrelated children who died in 2004. We found that:

- in five of the seven cases, parental substance abuse was a significant issue that the undertakings were targeting - such as attending drug and alcohol counselling, abstaining from substance use and undergoing drug screening
- in four of the five cases, the parents did not comply with the undertakings
- in at least three cases, non-compliance by parents with undertakings did not lead to a review of the child's safety or a change to the case plan.

CaseStudy15

As part of a case plan, the parents of a baby born with neo-natal abstinence syndrome agreed with undertakings that included them having regular urinalysis, attending drug and alcohol counselling and a parenting program and ensuring the baby's health was monitored by an early childhood health nurse.

Services involved with the family, including NSW Health, DoCS, non-government and private agencies, were optimistic that the parents were capable of providing a safe environment for the baby and an older child. There were numerous services involved and none identified concern for the baby during the time the undertakings were in place. It appeared the parents were compliant with the undertakings.

It was not until after the baby's death, at four months of age while co-sleeping with a parent, that services became aware that the home was in disarray, that there were serious behavioural and developmental concerns for the baby's sibling, that several services had experienced difficulty contacting the family and the parents had not kept appointments for the baby's health checks. Neither DoCS nor the early childhood health nurse had seen the baby in the month prior to the death.

Our work raised a number of concerns about the use of undertakings by DoCS even when they were agreed to as part of a signed case plan. Of particular concern to us was the use of undertakings in the absence of holistic risk assessment and/or consideration of the implications for the child's safety if the undertakings were not monitored and not complied with. In some cases we reviewed, undertakings made within a case plan were agreed to even where the history suggested they were unlikely to be complied with, or where the identified risk appeared to warrant a higher level of intervention.

CaseStudy16

We reviewed the death of a child whose 18-month-old sibling was involved in a car accident. DoCS records indicated that both parents had a history of substance abuse. The accident occurred when the child's mother was driving while affected by drugs.

In response to a risk of harm report made after the accident, the department interviewed the parents and they signed undertakings agreeing to provide urine screens twice a week for one month, not to use illicit drugs or alcohol while the child was in their care and not to drive with the child in the car. The undertakings were signed while the child was still in hospital. We found no record on KiDS that the undertakings were made as part of a case plan or that a PPM was held, or any information about how the undertakings would be monitored. DoCS records refer to the agreements made by the parents as both 'voluntary agreements' and 'official undertakings'.

A secondary risk assessment record was completed the following month and noted that the parents did not undertake urine screens as they had agreed. The DoCS caseworker substantiated risk of harm for the child and assessed that the level of risk was 'medium due to undertakings being in place around [natural parents'] drug taking and twice weekly urines however they have not completed screens as yet'.

Three weeks after risk of harm was substantiated, the child was placed in voluntary temporary care with a grandparent, at the department's request. The parents had returned 'a couple of dirty urines and are driving [the infant] in their car' but denied that they had used drugs. The parents were homeless and resided with the child during the temporary care placement. Another risk of harm report was made to DoCS while the child was in temporary care regarding parental drug use and serious safety concerns.

The child returned to her parents' care after two weeks in temporary care and following a case conference. The department supported the child's return because the parents had returned 'clean' urines during those two weeks. The parents agreed to complete random urine screens and the department agreed to close the case if these screens were clean for another six weeks. The parents were advised that the department would consider court action 'if they [the parents] returned further dirty urines without informing either DoCS or [the methadone clinic]…both parents agreed if they slipped they would inform either or both rather than it be discovered through urines.'

At this stage, the parents had already failed to comply with undertakings. DoCS decision making regarding the child's safety appears to have only taken into account the parents' behaviour over a two week period and did not adequately consider the parents' long-standing issues with substance abuse.

A secondary risk of harm assessment was completed after the case conference. DoCS determined that the child was not in need of care and protection and harm probability was 'unlikely'. 'If the parents follow the case plan and provide two urine screens a week…[the infant] will not be at risk'. However, the department remained 'concerned regarding [the infant's] long term safety if the parents do not cease their drug taking behaviour and driving whilst under the influence of drugs' and the case remained open.

KiDS records indicate that DoCS poorly monitored the agreements made at the case conference. We found no record on KiDS to confirm whether the parents did or did not comply with the agreements made at the case conference. There is no record of any casework by DoCS or any contact with the family or other agencies involved with the family until four months after the case conference. Another month later, the caseworker made enquiries and was advised that the mother had recently tested positive for amphetamine use and the father had not been tested for drug use in the past four months. By then, the family had moved to another area and DoCS eventually closed the case, without any further intervention.

In one case, we found that the level of monitoring by DoCS was inadequate when an order accepting undertakings was made in the Children's Court.

CaseStudy17

A risk of harm report for a two-year-old boy concerned serious and multiple injuries to the boy. DoCS removed the child from his immediate family and commenced care proceedings in the Children's Court.

The care application was finalised by way of an order accepting undertakings from the carers. DoCS advised the court that it considered court ordered undertakings were suitable for the child's continued protection and did not consider supervision orders to be required. The child was returned to the care of his family.

DoCS did not monitor compliance with the undertakings and had no further contact with the family. Five weeks after the order was made, and without any further contact with the family, DoCS determined that the boy was safe and closed the case.

The boy died at home in suspicious circumstances one week after DoCS closed the case. The medical cause of death was undetermined.

In DoCS' current policy, there appears to be some confusion about the meaning of the terms 'informal', 'voluntary' and 'formal' undertakings and in what circumstances it is appropriate or acceptable to use them. The terms are used interchangeably and it is unclear to us whether the department considers undertakings that are included within a signed case plan, but do not involve any action in the Children's Court, as 'informal undertakings' or 'formal undertakings'.

In a review conducted by DoCS following the death of a child in 2003, the department found that undertakings had been used on two occasions – once with the agreement of the casework manager as part of a signed case plan and once by the caseworker without management knowledge. The reviewer observed that *'undertakings were relied upon inappropriately in this case. Although practice guidelines discourage the use of undertakings, this practice still exists in the field'.*[65] In our view, the 2002 Practice Bulletin regarding informal undertakings did not discourage the use of undertakings as long as certain conditions were met. This document is still current on Business Help.

Recent information received from the department indicates that the use of 'informal' undertakings is no longer DoCS policy and that unregistered care plans are one strategy now used by DoCS to formalise agreements with parents:

> *'Informal undertakings were used to formalise agreements…without the need for court intervention… Care plans are now used to formalise agreements between DoCS and parents or carers to address the issues of concern affecting a child or young person…the type of care plan utilised will depend on the risk that exists for the child or young person and the level of agreement between the relevant parties'.*[66]

In August 2004, the department published a Business Help topic on Care Plans under the heading *Statutory and Legal Proceedings*, which states:

> *'A case plan will suffice as an Unregistered Care Plan as long as all the relevant parties are in agreement with the content and sign the case plan. The use of informal undertakings is not DoCS policy and should not be used. In these circumstances an Unregistered Care Plan is suitable'.*

Taking all this information into consideration, it appears to us that there is no difference between the use of informal undertakings as part of a case plan and agreements made within an unregistered care plan. This is particularly the case in the context that there are no requirements to monitor undertakings in either case. We believe it is essential to monitor undertakings to ensure that any commitments made by parents or carers are maintained.

In a number of reviews of child deaths, DoCS has identified the use of undertakings as an issue. Several recommendations resulting from the department's reviews focus on undertakings, including recommendations to:

- re-issue a clear policy directive across Child and Family Services that voluntary undertakings are not be be relied upon[67]
- dedicate a Practice Solutions Session to training and discussion on the appropriate use of formal and informal undertakings[68]
- update the Business Help topics on *case planning* and *order accepting undertakings* to include a statement that the use of informal undertakings is not the department's policy and should not be used. [69] DoCS has subsequently advised that this will be the case when the policies are completed by the end of November 2005.[70]

As indicated above, it is important that these initiatives provide clarity about what is meant by 'formal', 'informal' and 'voluntary' undertakings; when they should or should not be used; how they should be monitored and how non-compliance should be responded to.

6.2 Domestic Violence

Domestic violence may have long-term emotional, developmental and behavioural impacts on children. Children who are the subject of domestic violence reports are often frequently exposed to other risks, including those associated with parental drug and/or alcohol abuse, parental mental health issues, and neglect. Research over the past 20 years has identified domestic violence as a significant risk factor for unborn children, newborn babies and infants where exposure to violence can lead to failure to thrive.[71]

DoCS, NSW Police and health services all have an important role in protecting children who have witnessed or experienced domestic violence. According to DoCS' 2003/04 annual report, domestic violence was identified in 20,177 or 18.5 per cent of reports assessed by the Helpline during the year. The department's initiatives to address domestic violence include the Domestic Violence Line, participation of the department in the NSW Strategy to Reduce Violence Against Women, and piloting new ways of working jointly with NSW Police on domestic violence cases where children are affected.

Health services play an important role in identifying and responding to women who experience domestic violence. These services have a mandated responsibility under the state's care and protection legislation to recognise and report harm or risk of harm to children and young people.

Police in NSW are also mandatory reporters. In addition to this responsibility, police procedures require police officers to immediately notify DoCS when a child has been present at a domestic violence incident. Only police officers can apply for an Apprehended Domestic Violence Order (ADVO) for the protection of a child under 16 years of age. Our reviews in 2004 identified few instances of police applying for an ADVO on behalf of a child. In response to a draft copy of relevant parts of this report, NSW Police told us that in 2004, '*…roughly 7,000 children aged between 0 and 15 years were recorded in final AVO orders. While this data does not specify how many of these police applications were made on behalf of the children, anecdotal evidence would suggest more than the 'few instances' quoted within the report.*' In addition, NSW Police noted that police training is clear on this issue and highlights the need to take out ADVOs on behalf of children. [72]

Nonetheless, in the context of our findings in 2004, we believe it would be useful for NSW Police to consider how effectively ADVOs are being used in relation to children under 16 years of age.

Risk of harm reports about domestic violence

For 33 of the 72 children (46%) who were known to DoCS, the child had been the subject of a risk of harm report where domestic violence was a reported issue.[73] Thirteen (39%) of these children were Aboriginal. The 33 children were together the subject of 208 reports, 89 (43%) of which included domestic violence as a reported risk factor.

Of the 33 children, eight (24%) died as a result of abuse, neglect or in suspicious circumstances: one child died as a consequence of abuse; three as a consequence of neglect; and four in suspicious circumstances. We assessed that for 13 of the 33 children (39%), issues reported to DoCS were relevant to the circumstances of their death. This includes five of the children who died as a result of abuse or neglect, or in suspicious circumstances. However, it is notable that the relevant reported issues were not those about domestic violence. In a number of cases, for example, the relevant issues related to neglect and/or drug and alcohol abuse. This reflects the likelihood that children who are subject to domestic violence are also likely to be exposed to other risk factors.

Initial assessment

Of the 89 reports of risk of harm that included domestic violence as a risk factor, 82 were referred by the Helpline to a CSC. These reports were about 29 of the children. Few reports were assessed as requiring an urgent response.

Table 4: Response Allocated at the Helpline to reports about domestic violence

	Number of Reports
<24 hours (Level 1)	6 (7%)
<72 hours (Level 2)	32 (39%)
<10 days (Level 3)	25 (31%)
Information only (Level 4)	19 (23%)
Total	**82 (100%)**

Risk of harm reports relating to domestic violence were referred to another agency by the Helpline in only a few cases. Of the 89 reports for the 33 children, two reports were referred to police to conduct welfare checks on children. A further three reports were referred to JIRT but we found evidence that only one of these referrals was accepted.

We conducted an investigation that included issues relating to DoCS' response to risk of harm reports for two small children repeatedly exposed to domestic violence. In response to our investigation, the department told us that *'the Helpline has begun work on developing a job aid to assist in the assessment of risk in domestic violence. This will be complemented by a workshop for [Helpline] Team Leaders on the assessment of risks and indicators of escalation of violence'.*[74]

Secondary assessment

Of the 82 reports referred by the Helpline to CSCs, 63 required further assessment. However, records indicate that more than two-thirds of these reports (42 reports, 67%) did not receive secondary assessment at a CSC:

- 21 were recorded as being closed under Priority One / case closure
- 15 were closed without assessment[75]
- 6 were open at the time of the child's death (two were unallocated under the Priority One / case closure policy)

Twenty of the 63 reports received secondary assessment, and in response to seven of these reports, the children were sighted and/or interviewed.

CaseStudy18

The family of a six year old child who died from natural causes had been the subject of 15 risk of harm reports over a period of four and-a-half years. The reports related to domestic violence and parental drug and alcohol use.

Five months prior to the child's death, a secondary risk of harm assessment was completed for the child and his siblings. The assessment found that the children were vulnerable to harm continuing as domestic violence and drug and alcohol issues were long-standing and likely to continue. While the immediate safety of the children was not under threat due to the incarceration of the father, the assessment substantiated risk of harm through alcohol abuse and 'verbal domestic violence' by the father. The assessment found that protective action needed to continue, risk level was 'medium', the harm consequence for the children was 'concerning' and probability of harm was 'likely'. The plan developed to intervene with the family was closed without being implemented three-and-a-half months later due to competing priorities.

Two subsequent reports were received for the children relating to domestic violence and alcohol abuse. Despite the previous assessment outcomes, both reports were unallocated. One was subsequently closed under the Priority One policy, the other was open at the time of the child's death.

Interagency response to domestic violence

Our work this year has continued to highlight the importance of effective sharing of information between agencies that play a role in responding to domestic violence. It is important that timely information is exchanged between NSW Police and DoCS in relation to Apprehended Violence Orders, as DoCS may make risk assessment decisions based on this information. It is also important that police are aware of what action DoCS is taking in relation to the families. In regard to one investigation we conducted this year concerning a child known to DoCS and police, NSW Police told us of the difficulties experienced by police officers in protecting children when they do not know the outcome of the risk of harm reports they make to DoCS.

In response to this issue we have recommended that DoCS develop a consistent, state-wide strategy for informing mandated reporters, such as police officers, of DoCS' assessment decisions following referral of risk of harm reports from the department's Helpline to CSCs.

Our work this year has also found that while NSW Police in the main complied with their procedures for notifying DoCS when a child has been present at a domestic violence incident, there may be some confusion about their responsibility to report possible harm in domestic violence situations where the children are not physically present during the incident. As a consequence of recommendations stemming from an investigation that examined this issue, NSW Police has initiated a review of its domestic violence and child protection procedures. This investigation further identified that police officers may not be aware that under section 248 of the state's care and protection legislation, NSW Police can request certain information from DoCS to assist them determine whether a child is at risk of harm. NSW Police have advised that they are currently developing an Exchange of Information Memorandum of Understanding with DoCS and that, following completion of the memorandum, information and training will be provided to police to improve their understanding of how to access DoCS information.[76]

Through our reviews, it is clear that reports about domestic violence can often fail to provide meaningful information upon which DoCS caseworkers can effectively assess current or likely risk to a child. As noted above, NSW Police policy requires that officers must *'immediately notify the Department of Community Services when a child has been present at a domestic violence incident…'*. [77] Given the many thousands of domestic violence reports that NSW Police will make to DoCS, there is a significant onus on police officers to provide comprehensive information to the department on the child's circumstances and any risks associated with the domestic violence. In developing the MOU with DoCS, it will be critical for the document to clarify the expectations of NSW Police in reporting risk of harm related to domestic violence.

6.3 Pre-natal reports

Under section 25 of the *Children and Young Persons (Care and Protection) Act 1998*, a person who has reasonable grounds to suspect that an unborn child may be at risk of harm after his or her birth can make a report to DoCS. These are referred to as 'pre-natal' reports. Pre-natal reports, unlike risk of harm reports for children and young people, are not subject to mandatory reporting requirements.

The intention of pre-natal reporting is to provide an opportunity for early support and assistance to pregnant women, and to reduce the likelihood of the need for out-of-home care after the child is born. Pre-natal reports provide an opportunity for services to engage early with the mother to identify problems, arrange support, and where necessary, make prompt decisions to ensure the safety and protection of the newborn baby. The *NSW Interagency Guidelines for Child Protection Intervention* state that pre-natal reporting *'may be particularly helpful for pregnant women in domestic violence situations, with mental health or hazardous drug use during pregnancy because reporting can be a catalyst for assistance'.*[78]

DoCS' new early intervention program targets families expecting babies in addition to those with children less than eight years of age.

Of the 72 children who died who were known to DoCS, 11 (15%) were the subject of a report to DoCS prior to their birth. Five of these children were the subject of section 25 pre-natal reports to DoCS. A further six unborn children were the subject of reports to DoCS[79] that included their sibling(s). In one case, the unborn baby was the subject of a report with the mother, then aged 17. There were a total of 20 reports made about the 11 unborn children. The discussion below considers the response to all 11 unborn children.

In nine of the 20 reports (45%), the mother's drug and/or alcohol use was one of the concerns raised. A number of reports also raised concerns about domestic violence, neglect and lack of ante-natal care.

All 11 children died at six months of age or younger. We found reported pre-natal risks were relevant to the death of five of the children. Three of the children died as a result of complications arising from the mother's substance abuse during pregnancy. One of the children died in a bed-sharing incident where the carer was under the influence of drugs. One child died in circumstances of medical neglect.

Our reviews of children who died who were the subject of pre-natal reports indicate that these reports may not be providing the opportunity for support and early intervention envisaged by the Act.

Initial assessment of reports about unborn children

The following table shows the recommended response time given to the 20 reports by the Helpline:

Table 5: Recommended response time

	Number of reports
Level 1 (less than 24 hours)	0 (0%)
Level 2 (less than 72 hours)	12 (60%)
Level 3 (less than 10 days)	6 (30%)
Level 4 (information only)	2 (10%)
Total	**20 (100%)**

Our reviews have indicated that reports with a lower urgency rating, regardless of the assessed level of risk, are more likely to be closed without further assessment than those that are given a higher urgency rating.

The cases we considered highlighted a number of instances where a greater priority in relation to urgency and risk level may have been warranted.

CaseStudy19[80]

An unborn child was the subject of three pre-natal reports, all from mandatory reporters.

The reports raised concerns about poor ante-natal care, non-compliance with medical care and drug use, and the impact of this on the unborn child. Of the three reports, the Helpline determined that one warranted further assessment within 72 hours, one did not warrant a response and the third warranted a response within ten days. All three reports were closed without further assessment.

The baby was born with significant disabilities in part as a consequence of the mother's drug use during the pregnancy. Subsequent reports made to the Helpline concerned the baby's safety and wellbeing and the parent's capacity to care for the baby, should the baby go home with the parents. While the reports were made while the baby was in hospital, and he died before being discharged, the expectation was that he would be taken home by his parents. Concerns were also reported in relation to the safety of the baby's four-year-old sister. None of these reports resulted in a secondary risk of harm assessment.

As a consequence of our concerns about the Helpline's assessment of pre-natal reports, we recommended that DoCS review the adequacy of guidance provided to Helpline staff in relation to initial risk assessment of pre-natal reports. In response to this recommendation DoCS has advised us that the indicators of risk of harm to unborn children are the same indicators used for assessing all other risk of harm reports 'although vulnerability due to age takes an additional priority'. DoCS has told us that it will monitor how the Helpline is handling pre-natal reports.

Secondary assessment of reports about unborn children

Of the 20 reports about unborn children, 18 were transferred to a CSC for secondary risk assessment. The remaining two were referred as 'information only'. Of the 18 reports, the CSC closed 12 without any further assessment. Six received some secondary assessment, with five of these remaining open at the CSC at the time of the child's death.

Where reports were allocated for further assessment, the assessments in the main failed to take account of the risks to the unborn child. This was particularly the case where a risk of harm report was made for an unborn child and siblings concurrently. For example, one of the 18 reports transferred to a CSC related to parental drug use, the siblings' nutritional needs not being met and the filthy state of the residential home was unallocated at a CSC. The report was referred to a rostered (duty) caseworker. Secondary assessment activity involved contact with a housing provider regarding any complaints or concerns about the property. The provider indicated no concerns. No further action appears to have been taken in relation to this report.

A number of case studies below further demonstrate this issue. Refer to case study 7 on page 66 and case study 15 on page 78.

Pre-natal reports where children have been previously removed from the family

If a child has been removed from the care of a parent, and a report for an unborn child of the same parent is made suggesting that the risk factors within the family have not changed, it should be reasonable to expect that the report about the unborn child would lead to a thorough risk assessment. We found that this is not always the case. Two of the 11 children had a sibling or siblings removed prior to the pre-natal reports about them being made. For these two children, four of the five pre-natal reports made about them did not receive a secondary assessment.[81]

As noted, we observed that if a report is made about an unborn child and a sibling, DoCS' assessment focus is generally on siblings.

CaseStudy20

We reviewed the death of a baby who died from a serious treatable illness. The first pre-natal report concerning the unborn baby was made when his mother was four months pregnant. This report indicated that the same problems that had resulted in the department removing the mother's six-week-old baby 15 months earlier were still present. These problems related to the mother's drinking, her addiction to prescribed medication, her itinerancy, and the impact of these issues on the unborn child. The report was given a low priority rating by the Helpline and referred to the local DoCS office where it was closed without further assessment.

The second pre-natal report was made four days before the baby's birth. The problems identified in the first report had continued throughout the mother's pregnancy. The reporter told the Helpline that there was a 'baby alert' to hospitals in the district. The Helpline assessed that the report warranted further assessment but again gave the report a low urgency rating. Due to administrative error, the report was not forwarded to the local DoCS office until 11 weeks after the report was made. The local office closed the report without making any inquiries about the baby's circumstances.

Interagency liaison

As noted, most of the pre-natal reports for the children we reviewed were about the mother's drug abuse and failure to get appropriate ante-natal care.

Most of the reporters were health agencies. A pre-natal report in relation to a mother placing her unborn child at risk through substance abuse provides an opportunity for assessment and planning to provide supportive intervention for the mother, and to ensure the baby's wellbeing is monitored after birth. We found one of the 20 reports about the 11 unborn children resulted in a PPM of this sort. We also found little evidence of referral to appropriate support services for the mother.

In a response to a draft copy of this section, DoCS advised us that in business planning for 2005/06, DoCS identified the need for policy guidance for caseworkers on responding to pre-natal reports. DoCS stated that:

> *This work will commence soon, and will dovetail with the rollout of DoCS' Early Intervention Program and the evaluation of the Substance Use in Pregnancy and Parenting Service (SUPPS), which have a focus on pregnant mothers where there are child protection concerns. Legislative and interagency issues will be examined during the project.*[82]

This office will monitor these important developments.

6.4 Neglect

Child neglect has lasting and long-term consequences for children, but is an issue that often fails to elicit a protective response from authorities. As one researcher notes, *'Children are much more likely to die from chronic neglect than from one incident of physical abuse'*.[83]

Last year, we raised concerns about the 'neglect of neglect', and whether reports of neglect were receiving an adequate level of response from DoCS.[84] These concerns were again raised through our reviews of deaths in 2004.

Neglect is a significant issue for the department. According to DoCS' 2003/04 Annual Report, neglect related issues—basic physical needs not met or at risk; basic psychological needs not met or at risk; and necessary medical care not arranged—together accounted for 35.5 per cent of issues associated with risk of harm reports at initial assessment.[85] We found that neglect accounted for 45 per cent of the issues associated with risk of harm reports concerning the 72 children who were known to DoCS. Reports of neglect are often made in the context of substance abusing carers and domestic violence, and they may also relate to carer mental illness. Poverty can also be a significant factor in neglect. The skills and resources needed to recognise and respond appropriately to neglect can be significant.

In 2004, six children died in circumstances of neglect. Four of these children had been reported to DoCS and one was a sibling of a child reported to DoCS. Neglect featured in reports made about two of these five children prior to their deaths.

As neglect is a risk factor affecting all children in a family, we have examined reports concerning both children who died and siblings of children who died. Of the 595 reports received by DoCS, 267 (45%) included neglect related issues as a reason for the report being made. These reports related to 67 children, including 15 Aboriginal children.

Of the 310 reports made about children who died, 140 (45%) included neglect related issues as a reason for the report being made. These reports related to 48 children, including 13 Aboriginal children. The outcomes of those reports are detailed below.

Table 6: Response Allocated at the Helpline: Neglect reports

Response	Number of reports
<24 hours (Level 1)	24 (17%)
<72 hours (Level 2)	47 (34%)
<10 days (Level 3)	26 (19%)
Information only (Level 4)	43 (31%)
Total	**140 (100%)**

The Helpline referred 97 of the 140 reports to a CSC for further assessment.

We found that some form of secondary assessment activity took place in relation to 37 of the 97 reports (38%). Forty-nine reports (51%) were closed without secondary assessment and 11 were open at the time of the child's death.

In some cases, reports that indicated serious neglect were not responded to:

CaseStudy**21**

We reviewed the death of a six-month-old baby who died from natural causes. The baby was one of seven children aged under 15 years, who were the subject of 29 reports over a three year period. Twenty-three of those reports raised concerns relating to neglect, including inadequate food, clothing and bedding, inadequate supervision, failure to provide medical and dental care, the children's skin infections and lice infestations, rotting garbage and faeces in and around the home, the home lacking hot water and electricity, the children's poor hygiene and the children breaking into neighbouring properties to steal food. Other reported concerns included carer drug and alcohol use, domestic violence, emotional abuse and physical abuse.

DoCS undertook extensive casework with the family in an attempt to address the concerns reported. Casework included assessments of the family's situation, home visits, protection planning and case planning meetings, referrals to external agencies, financial assistance, funding for family day care, assistance in attending medical appointments and temporary foster care for one or more of the children at various times.

A secondary risk of harm assessment was conducted in relation to all the children following a report one month before the baby died. The report was in relation to inadequate supervision. The assessment determined that the 'risk level' was high, the 'probability of harm' was highly likely and the 'harm consequences' were extreme. Risk of harm was substantiated and a thorough family assessment, with a view to providing case direction and court action was planned. A referral for the family assessment dated two days before the baby's death notes 'intensive support has been provided to the family with little change evident'. The staff at the CSC requested assistance in preparing an affidavit for court action.

There were no suspicious circumstances in relation to the death of the baby. Further reports and casework continued after the baby's death, resulting in a further secondary risk of harm assessment. Nine months after the baby died, the children remained in their mother's care, with some of the children spending time in temporary foster care. There is no evidence in the files reviewed that the family assessment or court action proceeded.

An internal review provided to us by DoCS indicates that in 2002/03, 55 per cent of reports received at the Helpline were classified as neglect matters. [86] We note that 42 per cent of reports concerning children who died in 2004 were classified as neglect matters at the Helpline. When reports concerning the siblings of these children are included, 59 per cent of reports concerning children and siblings of children whose deaths are reviewable were classified as neglect matters at the Helpline.

In 2004, we investigated the death of a child and tabled a special report to NSW Parliament about the matter. [87] DoCS subsequently undertook a review of the case. The review has recommended a number of strategies to improve responses to neglect, including:

- the DoCS neglect policy be released with accompanying training which includes a strong emphasis on assessment of the relationship issues between the parent and the child
- development of learning strategies aimed at raising the clinical skills of casework managers in undertaking and supervising holistic assessments
- an increased focus on the integration of history in the training provided to caseworkers.

The department is also progressing the roll out of the Early Intervention Program. The program is an initiative of the $1.2 billion funding package, and is intended to reduce the need for protective action by providing services to families before risks to children escalate:

> *'Early intervention is a proactive strategy that will deliver a range of positive benefits for families, including healthier children and parents, better functioning families and reduced child abuse and neglect. It is a key element of the government's policy and an important change in the way community services are delivered in NSW'.* [88]

$186 million will be spent on early intervention and prevention in 2005/06. The program is voluntary and targeted to vulnerable families with children under eight years of age, with priority access to families with children under three years. It is envisaged that families the subject of reports of neglect that do not require an immediate safety response, and where risk is assessed as being low to medium, will be candidates for the program.

The provision of effective early support and intervention will be critical to meeting DoCS aim of reducing the rate of growth in demand for statutory intervention by the department.[89]

In November 2005, DoCS advised us that it had developed a draft policy and guidelines for caseworkers on working with neglect:

> *The documents have been informed by a review of literature on neglect conducted by DoCS' Centre for Parenting and Research, policy analysis, review of*

> *data and discussions with a range of stakeholders. The policy and guidelines have a strong child focus in assessing neglect and emphasise the need to consider relationships between the child and significant adults and parental history, and the need to consider the reporting history and the cumulation of significance from what may seem individually to be lower level risk in previous reports.*[90]

DoCS also noted that early indications from CSCs that have received additional resources through the DoCS reform package are positive, with additional caseworkers resulting in *'…an obvious increase in capacity to manage lower level cases'.* [91]

7. Response to specific groups of children at risk

This year, our work identified particular concerns about how effectively agencies were able to respond to reports of risk of harm to young people aged between 13 and 17 years; and Aboriginal children and young people.

7.1 Aboriginal children and young people

In 2004, Aboriginal children were over-represented in child deaths in NSW. While Aboriginal children comprise approximately 3.5% of all children in NSW, 32 of the 540 (6%) children who died in 2004 were Aboriginal.[92] Aboriginal children were also over-represented in reviewable deaths. Of the 32 deaths of Aboriginal children in 2004, 20 (63%) were reviewable. In comparison, of the 508 deaths of non-Aboriginal children in 2004, 84 (17%) were reviewable. Overall, 19 per cent of all reviewable deaths were Aboriginal children.

Of the 20 Aboriginal children whose deaths were reviewable, one died in circumstances related to neglect and three died in suspicious circumstances. Eighteen of the children who died were known to DoCs, and two had a sibling who was known to DoCS. For seven of the 18 children, we found the issues reported to DoCS prior to the child's death were relevant to the circumstances of their death.

Risk of harm reports for the Aboriginal children who died

A total of 70 risk of harm reports were made to DoCS about the 18 children. The most reported concern was domestic violence (25), followed by neglect (13), physical abuse (10) and carer drug and alcohol abuse (8).

The DoCS Helpline referred 52 of these reports to a CSC for secondary risk assessment. In the main, these CSCs were in regional NSW. Thirty of the reports referred to a CSC were allocated to a caseworker for the purpose of a secondary assessment. For 24 of these reports, the secondary assessment consisted of an activity such as phone contact with the reporter, phone contact with another agency, or phone contact with the parent/s. Just over one third of the 30 reports (11) resulted in the child being sighted and/or interviewed.

Last year, we raised concerns that issues of neglect, parental misuse of drugs and alcohol and domestic violence in Aboriginal communities were not being adequately addressed. We recommended that DoCS consider the issues we raised and report on any proposed strategies to address them. DoCS has advised that it has prioritised the recruitment of indigenous caseworkers, and funds indigenous organisations providing a range of services to support Aboriginal children, families and communities. The department noted that the establishment of a number of new Aboriginal Intensive Family Based Services, with a total of five eventually being in operation across the state, will potentially support 140 families annually.[93] In addition to these services, DoCS stated caseworkers are strongly encouraged to comply with the Aboriginal Placement Principles when making placement decisions for Aboriginal children assessed as being in need of care**.** DoCS also advised that it is currently developing a *'whole-of-department Aboriginal Strategic Plan to bring greater focus to its work in this regard'.*[94]

We are pleased to see these initiatives being introduced. They need to be further informed by some of the continuing concerns identified in our reviews this year. Some of the inadequacies we identified reflect the issues raised in section 3 of this report in relation to the adequacy of risk of harm assessment. Others relate to issues about the legacy of past policies of the forced removal of Aboriginal children, and the interagency response to care and protection concerns for Aboriginal children.

Challenges of intervention with Aboriginal families

The legacy of past policies of the forced removal of Aboriginal children from their families has been well documented elsewhere.[95] Research has reported on the adverse impact of these policies on the parenting skills of subsequent generations, and the trauma experienced by Aboriginal communities more generally as a consequence of the policies. Other significant factors adversely impacting on some indigenous communities have been identified as including geographical and social isolation; socio-economic disadvantage; and issues that may be associated with economic disadvantage including greater exposure to mental health problems, substance abuse and domestic violence, and increased contact with the criminal justice and child protection systems.[96]

Acknowledging this context, our work this year has highlighted that some of the Aboriginal children who died and their siblings received no, or a very limited, response by DoCS to reports that they were at risk of harm. Some of these children were the subject of multiple reports raising serious concerns for their safety. When risk assessments did occur, these often did not comply with the standards required by the department. Our reviews and investigations have identified that the risk facing some of these children warranted an application to the Children's Court for a care order. Case study 24 on page 90 is illustrative.

We are concerned that in the absence of adequate risk assessments, DoCS may be using temporary care agreements in situations where they should not be used. While these agreements may be seen as an effective strategy for minimising disruption to families and maintaining more positive working relations with them than may be possible when the Children's Court is involved, they are nevertheless voluntary. A parent can rescind the agreement and resume the care of the child at any time. If parental behaviour poses a risk to the child, then these arrangements will not protect the child from harm. Case study 24 on page 90 demonstrates these concerns.

In a response to an investigation we conducted in 2004 into the 2003 death of an Aboriginal child, DoCS indicated that the case, and similar cases, highlighted '*…the very real contextual challenges faced by DoCS staff in working with children and families in remote communities…as well as the unique circumstances and historical influences impacting upon our work with Aboriginal children in care*'.[97]

An internal departmental review conducted following the death of this child heard evidence from two DoCS managers that

> *'…a parent leaving their children with other family members whilst they went drinking was a common occurrence. Both managers asserted that if DoCS were to initiate Children's Court proceedings for all children in the…community where similar circumstances existed, virtually all children would be before the court'. The review report concludes: '…the reality of the environment in [the community] is such that regular application of Children's Court action would have a significant social impact, not all of it necessarily beneficial, Child protection assessment and intervention in the [community] is open to a high level of misapplication of solutions. In particular a predominately indigenous community needs to be treated, in child protection terms, with constant sensitivity to the historical impact of Commonwealth and state government policy that led to the "stolen generations". Wide scale removal of children in such communities is not a simple option as a child protection response.*

CaseStudy22

A baby was born with multiple congenital abnormalities and with a history of foetal alcohol syndrome. She died at four months of age as a result of complications associated with congenital heart disease. At the time of her death she was sharing a mattress with her parents and five siblings.

At the time of the baby's death the children had been reported to DoCS on 17 occasions over six years, with seven of these reports being made to DoCS in the three year period immediately prior to the baby's death. Reported concerns included domestic violence between the parents, the alleged sexual abuse of two children by a relative living with the family, wellbeing concerns for the children, inadequate supervision, and the mother's alcohol abuse. The latter included one report of the mother being at a railway station late at night asleep and intoxicated whilst caring for one of her children, who was then a toddler. Reports also included two pre-natal reports relating to the mother's drug and alcohol abuse and the effect of this on her unborn child.

Our review of the baby's death found that of the seven reports received by DoCS in the three years prior to her death, three received secondary assessment. The outcome of these secondary assessments indicated a primarily incident-based, rather than holistic, approach that failed to adequately take into consideration the harm experienced by the children as a consequence of the family's impoverished home life and significant chronic neglect.

We note that recent data confirms that application to the Children's Court in the state's Western Region is not common DoCS practice. For example, in 2003 DoCS lodged six care applications with the Children's Court for children who lived in Bourke (two), Brewarrina (nil), Cobar (two), Walgett (one), and Nyngan (one).[98]

In noting this, it is important to emphasise that a greater number of applications to the Children's Court alone would not provide a solution to risk of harm for Aboriginal children. Effective work with Aboriginal communities must include the provision of sufficient and appropriate support services for Aboriginal children and their families.

We are currently looking in more detail at issues relating to Children's Court proceedings, including the involvement of Aboriginal families and communities in these proceedings. Greater participation of Aboriginal communities in relation to the care and protection of their children, as required under chapter 2, part 2 of the *Children and Young Persons (Care and Protection) Act 1998*, is one issue that warrants closer consideration.

DoCS has acknowledged that the deaths of Aboriginal children known to the department has focused attention on *'…the importance of clear policies and procedures, effective interagency relationships and quality assessment skills in our frontline staff'.*[99] Our work this year supports this position. We will continue to monitor the work of DoCS in improving its response to this issue.

Interagency response to care and protection concerns for Aboriginal children

Our work has highlighted the need for more effective communication and coordination between agencies that play a pivotal role in the care and protection of Aboriginal children.

We are concerned that the *NSW Interagency Guidelines for Child Protection Intervention* are not being followed in matters where there is clear evidence that agencies should be sharing information and developing joint case plans to ensure Aboriginal children are kept safe. This applies equally to agencies working in metropolitan Sydney as to those working in remote areas of NSW.

The Interagency Guidelines clearly state that *'no single person or agency has all the knowledge, skills or authority to safeguard a child or young person from, or deal with the consequences of, abuse or neglect'.* This holds particularly true with children we reviewed, who were often placed at risk as a consequence of the interplay between alcohol abuse, drug addiction, poverty and family violence. These are complex social issues requiring a coordinated agency response and effective exchange of information. Our work this year has identified that DoCS should be consulting more with relevant agencies when assessing risk. Some risk of harm assessments failed to identify risks because they were not been informed by adequate consultation with other professionals working with the family.

CaseStudy23

In 2005, we completed an investigation into the conduct of five agencies who had contact with an Aboriginal teenage girl murdered by her boyfriend two years later. The girl died in late 2002. During the two years, the girl's placement, which was supervised by an Aboriginal children's service and funded by DoCS, broke down; she was reported to DoCS as a child at risk; her attendance at school was poor; she moved about between family members; and she became involved with a young man who assaulted her on a number of occasions. Because of these assaults police and health services also knew her.

Our investigation found that while the Department of Education took reasonable steps in response to the girl's poor school attendance, the other services unreasonably failed to take the necessary and appropriate steps to protect the girl. Of particular concern was the absence of a co-ordinated response between agencies to reduce risk factors for her. We found that no one took responsibility for the girl who was manifestly in need of appropriate intervention and support.

We made recommendations to four of the five agencies involved with the young person. In response to these recommendations:

- the health service involved with the girl reviewed and amended its child protection practices
- DoCS committed to improving the child protection interagency arrangements in the region where the girl resided
- our investigation report is being used to inform a review of the Aboriginal children's service involved with the girl
- NSW Police undertook to convene a meeting with all agencies involved with the girl, to look at ways to avoid such situations arising in the future.

This meeting took place in August 2005 and as a result, arrangements are now in place to improve the way agencies work together to respond to the needs of children and young people at risk of harm in western NSW.

Investigations

This year we initiated ten investigations that examined the conduct of a number of agencies following the deaths of four Aboriginal children. The children died in 2002, 2003 and 2004. These investigations have all been finalised. We are committed to ensuring the recommendations that we make are not only accepted by agencies but are also implemented. One of our investigations is reported here in some detail to highlight the at times complex interplay of the issues referred to above.

CaseStudy24

In 2004, we initiated an investigation into DoCS, NSW Police, and an Area Health Service's handling of matters concerning a five-month-old Aboriginal boy and his older sister. Our investigation took into account an internal review by DoCS of the matter.

The baby boy died in 2003. An autopsy indicated evidence of non-accidental injuries sustained over a number of occasions. He and his sister, then aged 18 months, were in the care of relatives at the time of his death. DoCS had placed the baby and his sister with relatives six weeks earlier, under a voluntary Temporary Care Agreement.

There was an extensive child protection history for the children and also their older siblings who were continuously exposed to intense and violent domestic abuse and neglect as a consequence of their parents' addictions. These risks remained unresolved at the time of the baby's birth. Six risk of harm reports for the baby, and another four for his sister, were made to DoCS in the first 14 weeks of his life. We found that DoCS' response to the first four reports was limited to a telephone call to police to establish the whereabouts of the family. Given the seriousness of the issues raised at the time of the baby's birth, it was our view that DoCS should have convened a Protection Planning Meeting with agencies involved with the family at the time. Such a meeting could have provided for the exchange of relevant information between the agencies, the development of a case plan to monitor and protect the baby, and an opportunity for the parents to discuss, and to identify ways to address, the issues of concern.

However, DoCS did not commence a secondary risk of harm assessment until the day the children were placed with their relatives. We found that, given the seriousness of the issues raised for the children's safety, this was unreasonable. We also found that the risk assessment, when it did finally occur, was inadequate.

DoCS decided that the children would remain in the care of the relatives for three months, even though the children's mother indicated that she did not want them to stay with these family members. The mother entered a drug and alcohol residential rehabilitation program the following day. DoCS did not sight the children again prior to the baby's death five weeks later.

DoCS did not assess the suitability of the relatives to act as carers for the children, nor did they assess the relative's home environment. The department did not arrange for any criminal records checks on the relatives. Had they done so, Police would have alerted the department that it would not be appropriate to place the two children with the relatives.

Support and supervision of the placement was inadequate. The children were not seen by a DoCS caseworker throughout the duration of the placement and the carers were not supervised.

We found evidence of poor casework supervision; poor documentation and file management; risk assessments that did not comply with supervisory direction; inadequate investigation of significant allegations; and case plans abandoned while identified risks clearly remained unresolved.

DoCS' internal review of the case found that the department's assessment and support of the placement was inadequate. It noted that, following the death of the baby, the relevant DoCS region completed an audit of all carers in the region to establish if relevant checks on the carers had been completed. Checks were completed for those not previously checked.

A week before the baby died, there was a domestic violence incident between the relative carers, during which the woman was injured. Police attended the incident but did not make a report to DoCS as no children had witnessed the assault. However, police knew that there were children in the home but were not aware of their status, as DoCS had not undertaken the required criminal checks prior to the temporary placement. Nevertheless, we found that police should have recognised risk of harm on this occasion and made a report to DoCS.

DoCS' internal review made no finding or recommendations in relation to the adequacy of the department's decision to pursue a temporary care agreement for the children rather than making an application to the Children's Court for a care order. We noted our concerns that, in such an environment, the needs of children can be easily overshadowed and the focus of intervention becomes something other than the paramount consideration of the safety, welfare and wellbeing of a child. We concluded that *given the extensive child protection needs for the family, and the two younger children in particular, DoCS should have dealt with the case formally through the Children's Court, rather than informally through use of a Temporary Care Agreement.*

The department's internal review also noted that discussions were underway between the department's staff development branch and the relevant region concerning the specific needs of staff working in the region. These staff often have to cover vast geographical distances, work alone, and in communities that have a history of conflict with the department. DoCS also told us that following the death of the baby, new practice guidelines were published, outlining carer assessment and approval requirements in a range of care situations.

As a result of the concerns raised by our investigation we recommended that, if it had not done so already, DoCS should review the adequacy and efficiency of the supervisory arrangements for staff working from the DoCS office in question. We also recommended that DoCS, amongst other things:

- advise us of the outcome of the discussions between its central office and the region concerning staff development needs for the staff in the region, including strategies and actions resulting from these discussions
- provide us with details on the findings of the audit of carer checks that was conducted following the baby's death
- ensure that the review of the interagency child protection guidelines scheduled for 2006 consider the adequacy of the Guidelines as they relate to the exchange of information between DoCS and other agencies
- develop a consistent, state-wide strategy for informing mandated reporters of DoCS' assessment decisions following referral of risk of harm reports from the department's Helpline to its CSCs.

DoCS has informed us that it has accepted these recommendations. We will monitor their implementation.

We also recommended that NSW Police:

- review the NSW Police Domestic Violence Standard Operating Procedures and NSW Police Child Protection Procedures to ensure that both documents provide adequate advice to police regarding:
  - the circumstances in which officers have to report risk of harm to children and young people in domestic violence situations
  - the use of section 248 of the *Children and Young Persons (Care and Protection) Act 1998* for obtaining information from DoCS for the purpose of accessing information relevant to police assessment of risk harm to children and young people.

NSW Police has informed us that it has accepted these recommendations and is taking steps to implement them.

7.2 Adolescents

Of the 104 children and young people whose deaths were reviewable, 22 (21%) were adolescents aged between 13 and 17 years. Most of these young people were either known to DoCS (16), or had a sibling(s) known to DoCS (five). In only one case was there no child protection history for the child and/or their family. In this case, the young person had significant disabilities and was living in supported disability accommodation at the time of his death.

The deaths of seven of the 22 young people resulted from an accident of some kind, including motor vehicle accidents, drowning and accidental drug overdose. In at least five of these cases, risk taking behaviour was a factor. Six of the 22 young people committed suicide, six died as a result of natural causes, and one young person died in suspicious circumstances.

For the 16 young people who were known to DoCS, there was a total of 158 risk of harm reports made about them in the three years prior to their death. Overall, the predominant concerns raised in the reports were physical abuse, followed by neglect/well-being concerns, sexual abuse and psychological abuse. Risk taking behaviours such as substance abuse, illicit drug use and running away from home were also frequently reported to DoCS. Of the 158 reports, only 28 reports in relation to eight young people resulted in secondary assessment. Five of the young people who were subject to secondary assessment were found to be at risk of harm. The department initiated care proceedings in the Children's Court in relation to only one of the young people.

Deaths involving risk taking behaviours

Nine of the 22 young people, seven of whom were known to DoCS, died in situations where risk taking behaviour was evident.

Five adolescents died in motor vehicle accidents, all of which involved excessive speeding and/or substance use. In two of the accidents, the young person was driving the vehicle at the time. In the others, the young person's peers or unrelated adults were driving. Three of these adolescents were known to DoCS, all of whom were the subject of reports in the 12 months prior to their deaths. Neglect, parental substance use, domestic violence and sexual abuse were the most commonly reported concerns for these young people.

The deaths of a further four adolescents, all of whom were known to DoCS, were linked to risk taking behaviours. One young person died of an accidental drug overdose and the other died as a result of an injury sustained while intoxicated. One young person with a history of alcohol use and non-compliance with anti-epileptic medication drowned following an epileptic seizure. One young person with a history of intoxication, running away and challenging behaviour died in circumstances suspicious of abuse where she was out alone late at night. Three of the four young people were the subject of reports to DoCS within the 12 months prior to their death, and two within the three months prior.

Risk taking behaviour is a common feature in adolescent transport fatalities in the general population.[100] In a child protection context, responding effectively to reports of risk of harm for adolescents that are related to risk taking behaviour is a particularly difficult challenge for DoCS and other agencies.

Child protection history

It is notable that ten of the 16 young people known to DoCS had been reported to the department prior to reaching adolescence. At least four of these young people had extensive child protection histories, with reports being made at regular intervals from infancy or early childhood. In these cases, it was notable that child protection responses over many years in these cases failed to resolve issues for the child.

CaseStudy25

We reviewed the accidental death of 16-year-old boy. The boy had been the subject of risk of harm reports since the age of two. At least 27 reports were made in relation to this young person and his siblings. These reports document a history of chronic neglect, carer substance use, domestic violence and inadequate supervision, culminating in reports of truancy and juvenile offending by the boy.

In the three years before he died, DoCS received 11 reports received by DoCS about him. Eight of these reports also raised concerns about his younger siblings. The reported issues included domestic violence, neglect, parental substance use, and the young person's criminal behaviour. None of the 11 reports received a response from DoCS. Eight of the reports were closed without assessment or investigation. Three reports were recorded by the Helpline as 'information only'.

We did not locate any evidence that the family was referred to external agencies in lieu of DoCS' intervention.

The boy was well known to police from the age of eight, initially as a child at risk, and in later years for offences related to drugs, property offences, arson, street crime and vehicle theft. He was charged with offences on 18 occasions and was in custody on 24 occasions. His parents were also known to police. The extent of the family's involvement with police is not reflected in the DoCS files we reviewed. We found no evidence of significant communication between DoCS, NSW Police and the Department of Juvenile Justice in relation to the boy and no interagency planning meetings were located in the files reviewed.

In a response to a draft copy of this section, NSW Police indicated that such a high risk offender should have been targeted in a more appropriate manner. NSW Police told us they have a number of options for dealing with the offending behaviour of, and welfare concerns about, young people at high risk. Options identified were reporting to DoCS; referral to Police Citizen's Youth Centre for targeted programming; inclusion in a mentoring scheme or program run by police Youth Liaison Officers; and management as a 'Suspect Target Management Plan' target in the Local Area Command. [101]

NSW Police also noted that they are limited in their response to those young people most at risk of offending behaviour by the lack of referral agencies, and that:

> *The lack of interagency coordination poses a dilemma for police where there is no clear person responsible for coordinating intervention. If this role is not prescribed to DoCS, it is difficult to understand how an individual police officer can determine the most appropriate action.* [102]

We also identified a number of cases where the parent(s) of the child who died were themselves at risk and known to the department:

CaseStudy26

We reviewed the death of a three-month-old baby who died in a sleep incident. The cause of death was noted as 'undetermined, but consistent with SIDS category II'.[103] *The baby's mother was an adolescent reported to DoCS.*

The baby was the subject of two pre-natal reports and one further report when aged three weeks old. The first report was made in the context of the baby's mother contacting DoCS to request assistance for herself and for her unborn baby. At the time the request for assistance was made, the 16-year-old mother was homeless. She informed DoCS that she had no income, no stable accommodation and no birth certificate, which she required to access Centrelink assistance. The mother was five months pregnant when she contacted DoCS. While the Helpline noted her own child protection history, no support or assistance was provided to the mother in response to her request.

Three weeks later, a report was made to the Helpline in relation to domestic violence between the mother and the baby's father. This report was not responded to until after the birth of the baby, following another report made concerning the parent's capacity to look after a new baby, the relationship between the parents and the lack of family supports in place.

CaseStudy27

We reviewed the death of a four-week-old baby, who died from undetermined causes. The mother was 17 years old and five months pregnant when she requested assistance from DoCS in relation to her lack of money and permanent accommodation. The young woman was living temporarily with a relative at the time. In assessing the request, the Helpline identified the young woman's child protection history and determined the young woman may be at risk of harm. The request for assistance was referred to a CSC as a risk of harm report, with a response time of within 10 days. The report was subsequently closed under Priority One case closure, with no record of any assistance being provided to the young woman.

In both cases, the mothers of the children who died were themselves at risk and in vulnerable situations. Neither received assistance before the birth of their babies.

Adolescent suicide and mental health issues

Six of the 22 young people committed suicide. Five of the six young people were reported to DoCS in the six months prior to their death. For three of the young people, the reports made about them in this time indicated that the young person was suicidal, or raised concerns about the young person's mental health.

The link between childhood abuse and suicidal thoughts and behaviours in adolescence has been well established.[104] A cluster of risk factors was present in the lives of these six young people, including familial histories of parental substance abuse, physical abuse and domestic violence. Four of the young people came from homes that had histories of sexual abuse and three of the young people themselves were victims of sexual abuse. Some of them had spent periods being homeless.

Four of the young people had, at one point in their lives, been removed from their families and placed in care by DoCS. At the time of their deaths two of the young people who committed suicide were the subject of Children's Court orders placing them under the parental responsibility of the Minister for Community Services, and one young person was in the process of being restored to his parents' care, having spent the previous nine months in a temporary foster care placement.

Five of the young people who committed suicide had diagnosed mental health issues, including adolescent depression, and had been treated by a psychiatrist in the 12 months prior to their deaths. Two young people had previously attempted suicide and two had threatened suicide. Most of the young people who committed suicide had contact with a number of services and agencies. In some cases we reviewed, there was limited communication or coordination between services, including between mental health services and DoCS.

CaseStudy**28**

A 16-year-old girl who committed suicide was the subject of 14 reports in the 12 months before her death. Five of these reports provided information that she was suicidal.

The objectives documented by DoCS following the first report that the girl was suicidal included 'Liaise with mental health and the school regarding suicidal ideation' and 'Conduct Secondary Risk of Harm Assessment'. This report was closed under Priority One/case closure and this action never occurred, despite a further 12 reports being made until her death. The reported issues included the girl's suicidal ideation and mental health, risk of sexual harm, physical abuse and exposure to domestic violence.

Six months prior to her death, the girl became homeless as a result of ongoing family conflict and alleged abuse. DoCS provided assistance to her in finding refuge accommodation. From this time until her death, she was also involved with a range of other services, including community health, a mental health service, a special education unit and Centrelink. Records indicate that some of these agencies made reports to DoCS on a number of occasions. At one point, she attempted suicide, resulting in hospitalisation in a psychiatric unit. Five weeks prior to her death she was discharged by the mental health service, as she had failed to make contact with the service and did not appear to be engaged with the service.

There is no evidence that DoCS contacted or interviewed the girl, nor was there any formal meeting between the range of agencies involved with her.

Our review of this matter is ongoing.

Our reviews of these cases raise concerns about the level of response provided. Twelve reports for four of these young people that contained information the young person was suicidal were closed without assessment prior to the young person's death, or were open without assessment at the time the young person died. In two of the cases we reviewed, numerous reports were made about the young person's suicide risk in the period leading up to their deaths, but reports were not recognised by DoCS as an indicator of escalating risk. In these cases, information about suicide risk was recorded by the Helpline as 'information only', as the KiDS system held similar information from a previous report.

Interagency coordination

Many of the 22 young people who died had significant periods of contact with human service agencies, including health services, mental health services, DoCS, JIRT, NSW Police, the Department of Juvenile Justice, youth refuges, foster care agencies and education services.

Protective intervention with young people poses inherent difficulties for services. Unless intervention is agreeable to, and engages, a young person, it is unlikely to be effective. DoCS has no powers of coercion under the *Children and Young Persons (Care and Protection) Act 1998,* and cannot force young people to access or engage with services. Sections 123 – 133 of the Act provide for 'compulsory assistance'. These sections have not been proclaimed. [105]

It is difficult for DoCS or any other agency to make decisions on behalf of a young person, particularly where the young person is homeless and transient and placing themselves in situations of risk. Young people over the age of 16 are able to make many decisions regarding their own welfare, medical treatment and relationships, posing a dilemma for their parents, DoCS and for other agencies offering services to this group. The principle of participation in the Act[106] is particularly relevant to young people, and requires a child or young person's views to be sought and given due weight in decisions relating to their care and protection.

In many cases we reviewed, including those where the young person's mental health issues or risk of committing suicide had been documented or well known, we saw little evidence of effective interagency coordination between the various services involved with the young person, or of application of the *NSW Interagency Guidelines for Child Protection Intervention*. Protection Planning Meetings between the young person, their family and agencies involved with the young person, such as mental health services, police, youth services and DoCS, occurred in relation to only two of the 22 young people who died. Given the difficulties of engaging effectively with young people, case meetings or protection planning meetings would appear to be an essential strategy for determining an appropriate response to the care and protection needs of young people.

The need for agency coordination and involvement of the young person is clearly illustrated in one case we reviewed. In this case, divergent views of agencies and the strongly expressed views of the young person were not effectively brought together to clearly determine action in the best interests of the child.

CaseStudy29

We reviewed the case of a 13-year-old boy who committed suicide. He had been in a temporary foster care placement for nine months prior to his death, having been removed from his family as a result of physical and psychological abuse and neglect related issues. The plan was for restoration to his family.

During the time he was in temporary care, he was the subject of seven reports to DoCS. The primary concerns reported included physical and psychological abuse while in the care of his natural family, inadequate nutrition, threatening to abscond, and threats to commit suicide if restored to his family's care. The boy had clearly and repeatedly stated his objections to family contact and to being restored to his family. Both the family contact visits and the restoration plan proceeded despite the boy's objections. On one occasion he presented to a CSC to advise DoCS that his objections to restoration were being ignored.

A mental health practitioner treating the boy in the months leading up to his death advised that the boy should be restored to his family. Another agency with a high level of involvement with the young person raised concerns about these plans and questions about the type of supports that would be in place for him. Records indicate that this agency attempted to organise a meeting with DoCS to discuss concerns, but the department was unable to attend.

He committed suicide five days before he was due to be permanently restored to his family's care.

While DoCS has no power to coerce young people into accepting assistance, in the cases we reviewed, DoCS did not appear to consistently seek to engage with the young people or to include them in making decisions affecting their safety and welfare. We saw little evidence of the application of strategies such as alternative dispute resolution, alternative parenting plans, or allocation to a caseworker to provide a consistent contact for the young person. In some cases, it was apparent that DoCS had never spoken to, assessed or sighted the young person in question.

In the cases outlined above, one young person had 16 placements and six case workers in the two year period prior to his death. Another young person had never been spoken to by DoCS, despite 14 reports in the year before her death. (refer to case study 28 on page 94). The development of positive and consistent relationships is a critical need for this group.

CaseStudy30

We reviewed the death of a 13-year-old girl who died in suspicious circumstances. The girl was the subject of reports to DoCS from the age of 10. She was the subject of 41 reports to DoCS, 28 of them in the 12 months prior to her death. Risk of harm was confirmed for the girl on six occasions.

Following a mental health assessment eight months before her death, a report was made to DoCS, informing DoCS that the girl was at 'high to extreme risk of sexual harm, drug use, criminal behaviour and early delinquency'. A number of referrals to health services were attempted, but most did not progress due to the family's reluctance to engage with services or follow up with appointments. We found no evidence that DoCS attempted to use other means to deal with this reluctance, such as alternative dispute resolution, an alternative parenting plan, development and enforcement of a care plan, or an application for a care order. Reports concerning the girl continued to be made with increasing frequency, as she began to engage in high risk behaviours such as running away from home, becoming intoxicated and placing herself in situations of risk of sexual harm. Fourteen of the reports about the girl were made in the three months leading up to her death. On a number of occasions, police found the girl wandering the streets late at night, either intoxicated or disoriented. Police regularly returned the girl home for her own safety. These incidents were reported to DoCS. While a number of the reports remained open at the time the girl died, they received little active response. There was no allocated caseworker throughout much of the time reports were made concerning the girl's safety and welfare.

The girl was admitted to hospital three times in the month before her death. Two admissions followed physical assaults and the third followed an alleged sexual and physical assault. Following the sexual assault allegation, police transported the girl to hospital and the matter was referred to JIRT. The girl was interviewed by JIRT and disclosed sexual assault. JIRT recommended that the CSC allocate a caseworker as a matter of priority, request intensive family therapy and compile a care application. An interagency planning meeting was held. Both the girl and her mother were invited to attend, but declined. It was noted during this meeting that the girl 'required containment but could not be held against her will'. Recommendations put forward at the meeting included that the girl be placed in care. However, the outcome of the meeting was that the girl was to 'remain in natural's mother's care as there is no *immediate danger' and further referrals would be made to external agencies.*

There were five further reports following the interagency meeting and the girl's death five weeks later. The reports concerned the girl running away, wandering the streets at night intoxicated, engaging in sexual activity and drug and alcohol use. A caseworker was allocated and all five reports were open at the time the child died. We found no evidence in the files we reviewed that further consideration was given to compiling a care application, despite the ongoing, extreme risks to the girl and various agencies' support for this to occur. The girl was found dead, in suspicious circumstances, five days after the last report to DoCS.

Our review of this case has not been finalised.

The circumstances of this young person's life and death illustrates the complexity of working with young people who are highly vulnerable and also capable of independent actions and decisions that can place them at risk of further harm. Working effectively to protect these young people is a continuing challenge for DoCS and the agencies with which they collaborate.

8. Recommendations

Quality assurance and compliance

1. DoCS practice improvement strategies should incorporate a systematic performance audit of each CSC in NSW. Specific areas of consideration should include:
    - efficiency of resource allocation
    - whether responses to Helpline recommendations adequately consider both recommended response time and initial assessment of risk level
    - whether secondary risk assessment practices reflect the requirement for holistic assessment
    - whether other agencies are being effectively engaged in risk assessment and response to confirmed risk of harm
    - the degree to which secondary assessments result in judgements and decisions[107]
    - the overall adequacy of secondary assessment reports and judgements and decisions
    - the overall adequacy of case plans, and their implementation, where risk of harm is substantiated
    - case closure decisions, including the basis for decisions.

    DoCS should report the results of the audits to this office.

Initial risk of harm assessment

2. DoCS should provide advice to this office about progress in achieving the stated *2005/06 DoCS Corporate Directions* priority to 'implement an improved initial assessment process'.
3. DoCS should provide advice to this office about progress in achieving the stated *2005/06 DoCS Corporate Directions* priority to 'improving accuracy of referrals to JIRTs and monitoring compliance with JIRT criteria'.

Secondary risk of harm assessment

4. DoCS should give priority for allocation for secondary assessment to reports referred to a CSC or JIRT for further assessment, where
    - a risk of harm report is made for a child living in a family where a sibling has been previously removed by an order of the Children's Court
    - a pre-natal report is made concerning an unborn baby and the baby is born into a family where a child has been previously removed by an order of the Children's Court.

The purpose of giving priority to these cases is to assess whether previously identified risk is still present.

5. In 2004, we made a number of recommendations related to the reporting of information about DoCS' work. DoCS has indicated its capacity to report certain types of information from its client information database is improving. DoCS should advise this office whether the following state-wide information is being drawn from KiDS, and if so, how the information will be reported:
    - 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
    - Risk of harm reports closed without assessment and the reason for closure
6. In 2004, we recommended that DoCS should institute a system to review decisions at a CSC to over-ride Helpline recommendations. DoCS advised us that this would be considered. DoCS

should advise this office of the outcome of its consideration to incorporate regular review of decisions at CSCs to overturn recommendations from the Helpline, as an initiative within the Practice Improvement Process.

7. In 2004, we recommended that DoCS clarify its policies about sighting children and interviewing and sighting families. DoCS has advised that guidance for sighting and interviewing children will be covered in the revised Business Help topic on secondary assessment. DoCS should provide advice to this office about changes to the Business Help topic on secondary assessment that provide guidance about the circumstances under which:
    - children should be sighted
    - children should be interviewed
    - families / carers should be interviewed.

Case closure

8. DoCS should regularly assess its capacity and provide reports to the NSW government, and to this office, on its ability to meet the objective of our 2004 recommendation that:

    A key principle in child protection intervention should be that where a report raises issues of safety of a child, or 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.

Interagency coordination

9. In the context of the current review of the *Interagency Guidelines for Child Protection Intervention*, the Child Protection Senior Officers Group should consider the issues raised in this report. The Senior Officers Group should give particular consideration to:
    - the number of cases that are currently not able to be assessed by DoCS to the point of substantiation of risk of harm, and the implications of this for determining a reasonable trigger for interagency protection planning.
    - the need to identify the types of circumstances that might warrant an interagency response at any stage of the assessment process, and the need to articulate the nature of such responses. Specific consideration should be given to timely interagency responses to reports involving:
        - substance abusing parents/carers
        - adolescents
        - unborn children (pre natal reports)
    - the need to clearly articulate in the guidelines the types of circumstances where an interagency response should be mandatory.
10. The NSW government should consider the amendment of section 248 (provision and exchange of information) of the *Children and Young Persons (Care and Protection) Act 1998* to allow for an agency that is a 'prescribed body' under the Act to furnish or request information relating to the safety, welfare and wellbeing of a child or young person, or class of children or young persons, to another prescribed body.
11. The Child Protection Senior Officers Group should ensure that the revised *NSW Interagency Guidelines on Child Protection Intervention* are released with an evaluation framework. Evaluation should focus on the assessment of agency take-up and overall effectiveness of the guidelines.
12. DoCS, in consultation with other interagency partners, should consider the outcomes of the review of the Complex Case Management Response Team operating in the DoCS Western Region and consider the potential for application of the model in other regions of NSW.

Substance abuse

13. We support recommendations made in internal departmental reviews relating to substance abuse, as described in section 6.1. DoCS should provide advice on the progress it has made in implementing these recommendations:
    - enhancement of availability of in-house expert drug and alcohol advice to field staff, possibly including regular case practice review discussions led by expert drug and alcohol professionals.
    - a Helpline quality assurance project over a two year period reviewing the adequacy of DoCS' response to cases of children under one where the primary presenting problem is parental substance abuse and the priority rating level is 2 or 3.
    - monitoring of child deaths over a two year period where there are concerns regarding parental substance abuse, with a project around this sample group to identify common systemic and practice issues and formulate recommendations.

- provision of information about parental methadone use via the department's intranet and a review of the methadone component of drug and alcohol training provided to departmental staff so that it includes contemporary research regarding risk factors.

14. DoCS should clarify and consolidate departmental policy on the use of undertakings as a protective measure. In particular, policy should clearly identify the circumstances under which undertakings may be an appropriate protective measure, and circumstances under which they may not be.
15. DoCS should require that where undertakings with parents or carers are used in case plans or unregistered care plans, the plan should include a monitoring component to review compliance with undertakings. Consequences of breaching undertakings should be agreed as part of the plan.
16. DoCS should require that a case should not be closed on the basis that undertakings have been signed. The signing of a case plan or care plan including undertakings should not be considered a protective measure for children until parents/carers have demonstrated a reasonable period of compliance.

Domestic violence

17. NSW Police should review whether ADVOs for children are being utilised effectively and whether police officers have adequate procedural guidance to determine the circumstances that warrant application for an ADVO on behalf of a child.
18. NSW Police have advised this office that they are reviewing their domestic violence and child protection standard operating procedures. In this context, NSW Police should ensure the procedures encourage full and relevant reporting to DoCS on the type and level of risk posed to children who are present at a domestic violence incident.

Pre-natal reports

19. DoCS should develop clear policy and procedural guidance for DoCS staff in relation to handling pre-natal reports and reports of risk of harm that include unborn children. Guidance should:
    - identify strategies to support and assist pregnant women and the circumstances in which such strategies should be used.
    - clarify the circumstances that would give rise to risk assessment and intervention following the birth of the child.

Neglect

20. We support recommendations made in internal DoCS reviews relating to neglect, as described in section 6.4. DoCS should provide advice as to the progress it has made in implementing these recommendations:
    - the DoCS neglect policy be released with accompanying training that includes a strong emphasis on assessment of the relationship issues between the parent and the child.
    - development of learning strategies aimed at raising the clinical skills of casework managers in undertaking and supervising holistic assessments.
    - an increased focus on the integration of history in the training provided to caseworkers.

Aboriginal children and young people

21. DoCS should consider the issues raised in this report in relation to Aboriginal children and young people, and report on proposed strategies address these issues. Particular consideration should be given to:
    - Enhancing capacity to respond to reports of risk of harm for Aboriginal children that require secondary risk assessment, particularly in regional NSW.
    - Ensuring compliance with the secondary risk of harm assessment framework in assessing reports for Aboriginal children and young people, particularly in regional NSW
    - Improving interagency coordination and collaboration in the care and protection of Aboriginal children, particularly in regional NSW.
    - Clarifying appropriate circumstances for the use of temporary care agreements as a protective measure for Aboriginal children at risk.

Adolescents

22. DoCS should consider the issues raised in this report in relation to adolescents, and report on proposed strategies to address these issues. Particular consideration should be given to:
    - Whether existing procedures and models of casework and current practice are effectively meeting the needs of adolescents at risk
    - How current responses to adolescents with mental health problems, or who have been reported to be at risk of suicide, could be enenhanced through cooperation with relevant interagency partners.

9. Monitoring recommendations

Section 43 (2) (c) of *CS (CRAMA)* requires us to provide information in our reviewable deaths annual report with respect to the implementation or otherwise of previous recommendations (as appropriate). In our 2004 reviewable deaths annual report, we made 18 recommendations to DoCS.

DoCS provided an initial response to our recommendations in February 2005, which stated that the department accepted all of our recommendations, with two being accepted 'in principle'. However, in relation to many of the recommendations, the response did not provide a sufficient level of detail to allow us to determine whether implementation was either in progress or likely to occur. Consequently, in March 2005 we wrote again to DoCS, seeking clarification and further advice in relation to recommendations 1 to 11 and 13 to 16. DoCS provided additional information in June 2005. The department also sent us a further progress report in August 2005.

Overview of progress

DoCS advice links the strategies being put in place to progress our 2004 recommendations closely to the roll-out of the NSW government's $1.2 billion DoCS reform package. A keystone of the package is the recruitment of an additional 875 caseworkers over the five years from 2003/04. A significant enhancement in 2005/06 will be the recruitment of 125 new caseworkers for child protection and early intervention services.[1]

Initiatives that DoCS has provided to evidence how the department is responding to our recommendations include:

- The *Operational consistency major project*. DoCS has a framework to develop and implement all future changes to business and casework practices. The framework incorporates development of all new policies and procedures and the identification of, and response to, inconsistent casework, managerial and administrative practices across the department. It also includes a component to improve the management of, and information contained in, case files.
- *Compliance reporting regime.* DoCS has advised that a 'compliance reporting regime' will significantly address our concerns about quality assurance in casework decision making. Advice is that the regime will consist of audits of compliance with policies and procedures through internal audit and reports from the department's client information database, the Key Information Directory System ('KiDS'); 'quality reviews' through case sampling and file reviews; and 'recommendations on remedial action'. The most recent advice to us about the components of the regime is that the department is*'….currently developing a framework outlining a standard approach to compliance monitoring and performance reporting'*.[2]
- *Review of the Interagency Guidelines for Child Protection Intervention.* The initial review of the guidelines was completed in 2005. This review provided a legislative and agency update. A more comprehensive review that will consider practice issues and changes to the guidelines is currently underway.
- *The continued roll out of the Early Intervention Program.* The program provides services for vulnerable families, with the intent of preventing families entering the child protection system or of being the subject of more serious reports, in cases where they have already been notified. The program has an initial focus on families with children up to the age of eight, and those expecting a child. The program is voluntary, with eligibility being determined by DoCS. Services include initiatives such as supported playgroups, home visiting, centre and home-based family support services and school preparation programs. Broadly, it is expected that the program will enhance the department's response to child neglect.

Generally, while these are significant initiatives to improve the State's response to children at risk of harm, it will take some time to determine their real impact in addressing those weaknesses in the child protection system that formed the basis of our recommendations.

The following table summarises the main points of DoCS' response to the 18 recommendations we made in 2004. It also provides our comments on DoCS' progress in implementing them.

Response from DoCS

Note: DoCS response is our summary of the relevant information provided by the department.

<table>
<tr><td colspan="2">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</td></tr>
<tr><td>DoCS Response</td><td>This recommendation is accepted.
DoCS' initial response indicated the recommendation was already met, as KiDS has the capacity to record information for all of the areas identified. We requested further information, as our concern was the <i>reporting</i> capacity of KiDS, rather than the <i>recording</i> capacity.
DoCS subsequently told us that it has developed the capacity to report this information. However, the release of information has been delayed due to issues arising from the introduction of KiDS and changes to the database and business practices that have required staff training. DoCS has developed an Information Quality Framework, part of which is a data remediation program.
DoCS has advised that the aim is to provide information of suitable quality for reporting by September 2005, to meet annual reporting deadlines.</td></tr>
<tr><td>Our Comments</td><td>DoCS' information system must have the capacity to provide a basis for assessment of the effectiveness of DoCS' child protection intervention and be able to report on critical aspects of its work. DoCS has not been able to effectively report on its capacity and outcomes of its work since the introduction of the secondary risk of harm assessment framework in 2002.
Progress in implementing this recommendation is pending publication of the data.</td></tr>
<tr><td colspan="2">Recommendation 2
DoCS' quarterly data publications should include numbers of reports closed and numbers of reports receiving secondary risk of harm assessment.</td></tr>
<tr><td>DoCS Response</td><td>This recommendation is accepted in principle.
DoCS resumed publication of quarterly reports in November 2004. DoCS told us that KiDS implementation issues, as described above, had limited the information available for regular reporting. DoCS said its 2004/05 annual report would contain the 'full data set'.
DoCS said it had no inherent objection to providing regular reporting of relevant data, and that the department <i>'will give consideration to further information being included in the quarterly reports on secondary risk of harm assessments and reports closed as soon as it has delivered on publication of the core data set.'</i> Later advice from DoCS clarified that quarterly reporting on secondary assessments would resume, and the accuracy and consistency of information on closed reports would be re-assessed with a view to making the information available for publication.</td></tr>
<tr><td>Our Comments</td><td>As noted above, we believe that information about secondary assessments and the outcome of protective intervention should be reported, as should indicators of inadequate capacity, particularly cases closed without assessment. Progress in implementing this recommendation is pending publication of the data.</td></tr>
<tr><td colspan="2">Recommendation 3 and recommendation 4
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
and
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".</td></tr>
</table>

DoCS Response	**Both recommendations are accepted.** As evidence of implementation of these recommendations, DoCS provided details about the review of existing, and development of additional, 'Business Help' Procedures.[3] It was noted that 12 new procedures had been published between October 2004 and February 2005, and 32 procedures were currently under development. A number of these were directly relevant to the points being recommended. DoCS noted the emphasis of KiDS training on child protection history checks; phonetic spelling and address checking; the relevance of the department's data remediation process to phonetic searching issues; and the inclusion in KiDS design of a system that reduces the creation of invalid addresses when new records are being added. A measure that went directly to quality assurance was the Helpline's 'rolling quality review process', which DoCS told us includes the escalation of risk. DoCS told us that the review process assures accuracy and compliance with relevant departmental policies and procedures: Team leaders review a sample of work completed by caseworkers on their teams against established criteria, and results are audited by the casework specialists. DoCS indicated the findings are used to improve training and supervision practice. DoCS further advised that Business Rules for history and person search will be finalised by August 2005, following which the Helpline will implement a compliance monitoring system. DoCS told us it is continuing to work with mandatory reporters to reduce the volume of duplicate reports, and is developing procedures to manage duplicate and corroborative reports more efficiently. The response also noted *'..the Operational Consistency Framework, the Practice Improvement Framework and the Compliance Reporting Regime provide the systems for quality assurance of decision making'.* In relation to operational consistency, DoCS told us the 'Operational Consistency and Continuous Improvement' *model '…involves the application of a five-step model when developing and implementing changes to systems or procedures. The five steps are: plan, develop, implement, review, and improve.'*
Our Comments	While acknowledging the critical importance of good procedure and staff training, the intent of the recommendations was for DoCS to institute quality assurance systems. The Helpline's rolling quality review process and proposed compliance monitoring system for history and person searches are clear indicators of progress in implementing the recommendations. As noted in section 3.1, the Auditor-General's Performance Audit of the Helpline also raised issues, and made recommendations about, initial assessment and the handling of reports at the Helpline.
Recommendation 5 DoCS should institute a system to document and regularly review decisions to override Required Action Plans. Reviews should focus on assessment of the appropriateness of such decisions.	
DoCS Response	**This recommendation is accepted.** DoCS advised us that the Helpline no longer develops Required Action Plans (RAPs). Instead, KiDS allows for the recording of a Required Response, Reported Issue and Risk Level in the case plan that the Helpline forwards to a CSC or JIRT. The department initially demonstrated progress on this recommendation by referring to broad service improvement strategies, such as the 'Operational Consistency Major Project'; the 'Child Protection Improvement Framework' and developments in Business Help topics. It was noted that the draft Business Help topic '*Secondary Assessment'* will provide detailed advice on review of decisions that occur within that process. In its August response, DoCS stated that the *'suggestion to introduce a system to regularly review decisions at CSCs to overturn recommendations from the Helpline will be considered as an initiative within the Practice Improvement Project*.'
Our Comments	The intent of the recommendation is for DoCS to develop a system that records and provides for review of decisions by a CSC to override the recommendations and priority level accorded to a report by the Helpline. While the Helpline no longer develops RAPs, the recommendation remains relevant in regard to the Helpline's recording of a Required Response, Reported Issue and Risk Level. DoCS has yet to make a clear decision on whether or not to implement this recommendation.

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.

DoCS Response

This recommendation is accepted.

DoCS initially stated that there is already comprehensive information and training to guide staff on this issue, noting *'…it is implicit in the Secondary Assessment phase that families or carers are interviewed'*.

However, DoCS indicated that although these actions were seen as comprehensive, it would review the guidance provided to staff.

In a later response, DoCS clarified that cases that undergo Secondary Assessment Stage 2 would involve contact with the child/young person, and the revised Business Help topic on secondary assessment will cover procedures for assessment and *'that the child/young person should be sighted /interviewed during the assessment process.'* In its August response, DoCS indicated that the draft procedure will be completed by October 2005. At this time, briefings will be provided to all relevant DoCS staff regarding new requirements.

DoCS said *'the revised topic will include a procedural requirement that children and young persons subject to Secondary Assessment Stage 2 (SAS2) must be sighted and provide practice guidance regarding appropriate observation. The new procedures will also include provisions to guide Managers Casework in prioritisation of matters for SAS2.'* In response to a draft copy of this section in November 2005, DoCS clarified that *'The Business Help topic on Secondary Assessment will state that caseworkers need to sight a child and interview where possible.'*

DoCS also told us that the Practice Improvement Framework would include the development of standards for casework practices, including assessment. This would be complemented by training, supervision and practice reviews. DoCS has identified the Compliance Reporting Regime as comprising:

- Audits of compliance with policies and procedures through internal audit and reports from KiDS,
- Quality reviews through case sampling and file reviews, and
- Recommendations on remedial action

The most recent advice to us about the components of the regime is that the department is*'….currently developing a framework outlining a standard approach to compliance monitoring and performance reporting'*.

Our Comments

The intent of the recommendation was that DoCS address a lack of clarity as to when caseworkers are required to sight a child or interview families/carers. DoCS has indicated this recommendation will be met by publication of the new secondary assessment procedure. We have not sighted the procedure and are therefore not in a position to assess the degree to which it meets the recommendation.

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.

DoCS Response

This recommendation is accepted.

Information provided by DoCS to demonstrate progress in implementing this recommendation focused on strategies already in place to address key competencies, including caseworker training, performance management and staff supervision. DoCS noted that the government's funding package included additional resources for improved staff learning and development and for the implementation of a new performance management system.

<table>
<tr><td>DoCS Response
(Continued)</td><td>Stated strategies that were already in place included:
• The minimum entry requirement for new caseworkers is a three year University degree in a relevant course.
• All new caseworkers are required to undertake the Caseworker Development Course (CDC) including 40 days of face-to-face training. DoCS has endorsed an approach to assessing the training needs of new Caseworkers prior to their being approved to undertake secondary assessment and other identified caseworker tasks, and has also implemented a graduated approach to the tasks caseworkers can undertake as they progress through the CDC.
• The CDC includes a five-day module that provides knowledge about all forms of child abuse, their indicators and effects. This module is a pre-requisite for the two-day ‘Assessing Risk of Harm’ module.
• Helpline Caseworker Entry Level Training runs for 10 weeks and covers the relevant modules of the CDC. Three days face to face training are spent on Initial Assessment theory and practice. Four days are spent on simulation of live calls. Classroom training is followed by a period of intensive supervision in the work environment.
DoCS stated the Business Help topics, ‘<i>Contact and Initial Assessment</i>’, ‘<i>Secondary Assessment</i>’ and ‘<i>Child Protection Assessment Process</i>’, once published on DoCS intranet, will provide clear direction and procedures for staff. As noted in the previous recommendation, the introduction of the revised topic will be accompanied by staff briefings. Further, DoCS is <i>‘developing a practice improvement framework for the activities of Divisional staff that focus on client casework and case management. As part of the framework, quality benchmarks for DoCS’ child protection work will be developed and areas of practice to be improved’</i>.
In response to our request for further information about strategies to monitor the effectiveness of secondary risk of harm assessment, DoCS referred us to the response to recommendation 6, specifically it’s ‘<i>multi-tiered approach to monitoring and reporting on practice improvement and compliance with policies and procedures</i>’ and ‘<i>the practice improvement project and compliance reporting</i>’. We have little information on the practice improvement project. Information provided about the Compliance Reporting Regime is outlined above in recommendation 6.</td></tr>
<tr><td>Our Comments</td><td>The intent of this recommendation is the implementation of specific strategies to ensure adequate assessment of, and response to, risk of harm. DoCS response addresses staff competencies in initial and secondary risk of harm assessment, with most strategies identified as being already in place.
However, strategies to monitor the effectiveness of secondary risk of harm assessment, and implementation of this aspect of the recommendation, is largely reliant on the implementation of the Compliance Reporting Regime. As at August 2005, this regime appears to be still in development.</td></tr>
<tr><td colspan="2">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.</td></tr>
<tr><td>DoCS Response</td><td>This recommendation is accepted.
DoCS referred us to the response to recommendations 3 and 4 above. We were also advised that there are a number of prompts in the process of secondary risk of harm assessment that lead staff to consider previous child protection history.
DoCS referred to the forthcoming Business Help topics, <i>‘Secondary Assessment’</i> and <i>‘Child Protection Assessment Process’</i> that it says will emphasise the importance of considering child protection history as part of the secondary risk assessment.
We requested DoCS provide further information as to specific strategies to provide assurance that policies regarding consideration of the child protection history of a child and their family are being adhered to in secondary risk assessment. DoCS referred us to the response to recommendation 6, specifically its ‘<i>multi-tiered approach to monitoring and reporting on practice improvement and compliance with policies and procedures</i>’ and ‘<i>the practice improvement project and compliance reporting</i>’.
Information provided about the Compliance Reporting Regime is outlined above in recommendation 6.</td></tr>
<tr><td>Our Comments</td><td>The intent of this recommendation is the implementation of specific strategies for monitoring and quality assurance in staff decision making. DoCS response to recommendation 3 and 4, referred to as relevant to this recommendation, primarily addresses training and procedural issues.
Strategies to monitor how staff adhere to policies regarding consideration of the child protection history of a child and their family, and implementation of this aspect of the recommendation, will be reliant on the implementation of the Compliance Reporting Regime. As at August 2005, this regime appears to be still in development.
We will continue to monitor DoCS’ implementation of quality assurance strategies as they apply to the monitoring of the child protection history aspect of secondary risk of harm assessment.</td></tr>
</table>

Recommendation 9

A key principle in child protection intervention should be that where a report raises issues of safety of a child, or 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.

DoCS Response

This recommendation is accepted in principle.

In February 2005, DoCS responded:

'This recommendation could be interpreted in several ways. DoCS is assuming that what is intended is that a revised framework for case closure would be developed that would require further assessment for classes or categories of cases with significant risk factors present before closure could occur. The objective would be to change their priority status should new information or assessment warrant it.'

'If the recommendation is intended to extend this to taking actual protective intervention, then it makes no sense in the context of a resource-limited system. The only reason a child protection agency would not take action in a high risk case is if it did not have the resources to deal with the case either at the time, or within a reasonable time, of the notification.'

'In this context it must be remembered that there was a 461% increase in child protection reports between 1995/96 and 2002/03 and the impact this had on DoCS' capacity to investigate cases has been placed on the public record many times. The increase in Caseworker resources to be delivered between 2002/03 and 2007/08 will improve the situation substantially. DoCS is already seeing a dramatic increase in capacity to investigate high priority cases at CSCs that have received their allocation of new Caseworkers. An equally dramatic decline in cases with significant risk factors that are closed without further assessment will inevitably follow.'

In common with all statutory child protection agencies in Australia, DoCS uses procedures to assist the agency to manage service demand when demand for assessment and casework services exceeds organisational capacity.[4] *The draft Case Closure Procedures (CCP) have been developed to meet this need and to replace Priority One'.* The criteria for the trial case closure procedure is detailed in section 4.

DoCS stated it *'is working towards a risk threshold for case closure. There is a range of criteria set down in the draft Case Closure Policy that have to be considered in order to determine risks and in order to close a case.'*

We asked DoCS whether it envisaged that a case closure policy, enabling closure of cases on the basis of lack of resources, will be required following the full roll-out of the $1.2 billion enhancement funding in 2008.

DoCS responded in June 2005. The response noted there were many factors impacting on service demand, and the capacity for DoCS to move away completely from case closure on a resource-based model by June 2008 could not be forecast with any certainty. The factors identified included the estimate for demand growth in child protection reports (33% for the period 30 June 2002 to 30 June 2005); improved efficiency within DoCS; the effect of the early intervention program (noting this would only impact after 2007/08); and evidence that Enhanced Service Delivery sites were responding to *'almost all Level 1's and a significant proportion of Level 2'* reports. DoCS said the rate of allocation of reports across all CSCs has also improved significantly since 2002.

Noting that the interaction between all of these factors cannot be predicted with certainty, DoCS advised *'A modified resource-based case closure policy will be maintained under these circumstances. However, the need for its use is expected to decline during that period as is the 'level of seriousness' of any cases closed.'*

In August 2005, DoCS advised that the Case Closure procedure had been trialled at three sites, with participation of 11 caseworkers and five managers. According to DoCS, focus groups and surveys conducted during the trial *'indicate that the draft policy is workable, has minimum impact on current workload and meets the need of Caseworkers for more detailed guidance about the review that must take place and be recorded on KiDS before case closure*.' DoCS said that practitioner's advice was that the procedure '*appears to target the right cases for further review where demand for resources exceeds supply.'*

DoCS noted the policy was to be extended to an additional number of CSCs, and the trial at the existing three sites would be extended to include children under five years of age. Following the extended trial, DoCS said a 'phased implementation' is planned to amend the policy to *'include guidance about reviewing the child protection*

Our Comments	Refer to section 4 of this report. The intent of this recommendation is for DoCS to '*work towards'* a framework that includes a risk threshold above which a case should not be closed without the department taking protective intervention. The response indicates that the department views implementation of the new case closure policy as implementation of this recommendation. However, the trial case closure policy enables closure of cases at a range of points, including where assessment has indicated a child is in need of care and protection. DoCS enhancement funding is likely to result in less cases being closed in the longer term. The possibility that the case closure policy may extend priority to children under five years, rather than the existing two years, would be a positive move, as would inclusion of a thorough review of child protection history to inform a decision to close a case. Nonetheless, the case closure policy remains based on relative priority, measured against the urgency and risk of other presenting cases. Case closure remains a significant concern.
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.
DoCS Response	**This recommendation is accepted.** DoCS referred us to the response to recommendation 9 above, and the principles of the draft case closure procedure. The new case closure procedure (draft Intake Assessment Guidelines) states: *'The child protection history of a child or young person and their family (from KiDS, CIS and/or the paper file) may provide vital information about the risks to, or vulnerability of, that particular child or young person, and any known protective factors. This information must be analysed alongside the most recent Initial Assessment, and any information obtained from further inquiries, and recorded in the SAS 1 by the caseworker.'* DoCS also noted that the draft Business Help topic *'Child Protection Assessment Process'* provides direction for cases that involve (1) subsequent reports received on a child that has been the subject of a secondary assessment or (2) siblings of a child who has died, and referred us to the response to recommendation 9, and to '*the practice improvement project and compliance reporting*' discussed in recommendations above.
Our Comments	Currently, a case can be closed at any time due to it being considered a lower priority, relative to other reports of risk of harm being considered by the CSC. The trial case closure procedure requires consideration of history to close a case.
Recommendation 11	DoCS should give priority to finalising and implementing its policy on neglect. The policy should be made public.
DoCS Response	**This recommendation is accepted.** DoCS told us that the development of a policy on neglect is a priority and the policy is due for completion and release in December 2005. The department intends to publicly release the policy through DoCS' web-site and the availability of a hard copy of the policy is being considered. In August 2005, we were advised that a literature review on neglect was nearing completion. DoCS said it was considering adapting practice guidelines from the United Kingdom specific to working with neglect, and that a case file review and statistical analysis of KiDS data on neglect was about to commence.
Our Comments	The intent of this recommendation is that departmental caseworkers and managers are able to address issues of neglect within a clear policy framework. Implementation of this recommendation is pending completion and public release of the policy on neglect in December 2005.

Recommendation 12

DoCS should provide advice to this office regarding:

(a) 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

(b) 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

(c) details of program performance indicators and the evaluation framework for the program or, if these have not been developed, plans for development

(d) details of how the department will determine "service benchmarks" and establish systems for managing demand for the program.

DoCS response

This recommendation is accepted.

(a) 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

DoCS told us in February 2005 that this was *'under development with the non-government sector and expected to be finalised by June 2005. DoCS will give consideration to consulting with other relevant stakeholders, ie NSW Health, NSW Police and DADHC regarding their respective roles and responsibilities in early intervention'*. No further response has been provided.

(b) 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

In February 2005, DoCS said that joint training would be conducted with service providers and their staff, once services are funded and established, and that a joint training strategy was under development with the External Stakeholders' Reference Group. No further response has been provided.

(c) Details of program performance indicators and the evaluation framework for the program or, if these have not been developed, plans for development

DoCS referred to the Corporate Plan 2004/05 – 2008/09. The plan indicates the result to be achieved for early intervention is *'Client children are supported so that they have age appropriate development without ongoing involvement in the child protection system.'* The Performance Measures listed in that plan are:

1. <u>Subsequent safety of EI children</u>

% (child) service recipients who were assessed as not requiring to be placed in OOHC but are later placed in OOHC.

2. <u>Development of EI children</u>

% of (child) service recipients under five who reach appropriate developmental milestones by school entry age, with particular emphasis on school readiness and physical and mental health.

3. <u>Cost of EI service delivery</u>

% of referrals not accepted by non-government service providers (NGOs) because NGO was at capacity; Case did not meet entry criteria for the program; NGO could not engage the family.

DoCS indicated the evaluation will run concurrent with program roll out and will comprise '*outcome, process and economic evaluations.*' In August 2005, DoCS advised that, in consultation with the External Stakeholders' Reference Group, the department has developed a draft evaluation framework, including performance measures, for the program. The department also indicated it was selecting a preferred consortium from proposals received through a tender process: *'The selected consortium will review the performance measures in the draft framework together with the data and reporting requirements. Depending on the contractual negotiations and the likely starting date for the consortium, a revised evaluation framework may not be available until late 2005.*

(d) Details of how the department will determine 'service benchmarks' and establish systems for managing demand for the program.

DoCS said it would *'develop service benchmarks with reference to international research and literature about early intervention, child care and family support'*. In regard to systems for demand management, DoCS stated that systems *'will be developed in consultation with stakeholders.'*

In the latest response, DoCS noted the Program was 'well underway': The EOI process Stage 1 closed on the 8 July 2005, and new services are expected to be funded from January 2006.

Our Comments

This recommendation was for DoCS to provide advice. No further action is required to demonstrate acceptance and implementation of the recommendation.

Recommendation 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:

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

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

(c) progressing and implementing processes for adequately assessing potential kin carers.

DoCS Response

This recommendation is accepted.

DoCS reported on a range of strategies, in place and planned, to address issues raised in our report. The following summarises DoCS' information:

- DoCS is committed to recruiting higher numbers of Aboriginal staff to ensure services are more culturally appropriate. The latest round of recruitment (as at February 2005) resulted in 100 Aboriginal applicants. 5.6% of DoCS staff are of ATSI descent against a benchmark of 2%.
- Some of the services funded through the early intervention program include Aboriginal playgroups and young parents groups.
- DoCS is establishing a number of new Aboriginal Intensive Family Based Services (IFBS) across the State to work intensively with Aboriginal families at risk of having their children placed into care. As at August 2005, there were four services at various levels of staffing and operational capacity. DoCS expects that the fifth service at Campbelltown will be operational by late 2005. Once all the services are fully staffed and operational, the department envisages that potentially 140 families will be supported through IFBS annually.

DoCS funds ten non-government Aboriginal foster care services. DoCS told us that more than $3.5 million in additional funding has been approved for allocation over three years. $1.29 million has been allocated to fund new Aboriginal non government organisations for authorised care services, in addition to enhancements to existing authorised care services across NSW.

The department also said it was working with Aboriginal services and communities to develop culturally appropriate services.

In relation to kinship care issues, DoCS told us all relative/kin carers (indigenous and non-indigenous) who provide out-of-home care need to be assessed and authorised in accordance with the department's policy on assessment and approval of authorised carers.

The department said it was consulting with the Aboriginal Reference Group about strategies to better meet the specific needs of Aboriginal children, young people and carers. DoCS said this included updating the *Koori Carers for Koori Kids* foster carer training package and the *Shared Stories Shared Lives* foster carer training package; and adapting the *Step by Step* assessment tool for Aboriginal carers.

DoCS said it has undertaken work to identify the support needs of relative and kinship carers, and consulted with the Partners Reference Group, to inform DoCS' policy position and service development priorities for relative and kinship care. Policy positions on these issues are expected to be finalised in 2005/06.

Our Comments

This recommendation was for DoCS to consider our report and provide information. No further action is required to demonstrate acceptance and implementation of the recommendation. Refer to section 7.1 of this report for our views on DoCS response to Aboriginal children and families.

Recommendation 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.

DoCS Response

This recommendation is accepted.

DoCS initial response to this recommendation acknowledged *'deficits in compliance with the current interagency guidelines'*, which the department linked to the increases in reports of risk of harm to DoCS since 2000. DoCS said the minor review of the *Interagency Guidelines on Child Protection Intervention* would make the guidelines more reliable in the first instance, and the major review would provide improved guidance. DoCS also noted *'the consultations and other promotional activities of the Child Protection Senior Officers Group also afford an opportunity to promote adherence to the guidelines'*, as would training and monitoring associated with the release of the Guidelines.

DoCS also indicated that the Compliance Reporting Regime would play a role in ensuring compliance with the guidelines.

We asked DoCS to provide more information about specific strategies the department would put in place to ensure that case managers comply with interagency guidelines.

DoCS told us it was *'committed to contact with key parties when a child or young person is assessed to be in need of care and protection.'*

In August 2005, DoCS further advised:

'The current Guidelines require DoCS to hold an interagency case planning meeting where a child is at risk of harm and is found to be in need of care and protection. This is neither possible nor necessary in every case. It is preferred that planning meetings will involve those key parties who will provide services that are critical to achieving the outcomes of a case plan, and/or agencies involved in legal proceedings to protect a child or young person.'

Our Comments

In progressing this recommendation, we acknowledge the importance of the review of the guidelines and associated training and monitoring strategies. However, while DoCS has accepted the recommendation, the department's view is clearly that Protection Planning Meetings are not always necessary when a child or young person is assessed to be in need of care and protection.

Refer to section 6 of this report, on interagency coordination.

Recommendation 15

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

- Ensure that caseworkers utilise sections 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 wellbeing 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 Response

This recommendation is accepted.

DoCS noted that sections 17 and 18 of the *Children and Young Persons (Care and Protection) Act 1998* and referrals in general, are a critical component of good child protection practice. DoCS stated that consultations for the review of the Guidelines have *'raised some concerns including a lack of a shared understanding of the purpose of and place for 'best endeavours' requests'*.

The main strategies identified by DoCS as progressing this recommendation were:

- Updating of the role of Managers Client Services and Managers Casework to incorporate a stronger emphasis on the importance of the service network, and in building mutual understanding between DoCS and other agencies and facilitating effective referrals.
- The inclusion of referrals in caseworker training and tools such as referral templates.

<table>
<tr><td>DoCS Response
(Continued)</td><td>• Compliance being facilitated by standards for casework practices to be developed and complemented by training, supervision and practice reviews. Reference was made to the role of the Compliance Reporting Regime in ensuring compliance.
DoCS also noted that further strategies may be included as part of the major review of the Guidelines, and that the discussion paper for the review canvasses ideas on how to better engage relevant agencies in child protection. <i>'Opportunities for shared training are seen as one avenue to foster this, and are being considered for the implementation of the new Guidelines in 2006.'</i></td></tr>
<tr><td>Our Comments</td><td>The enhanced role of DoCS managers demonstrates some progress with this recommendation. DoCS has indicated it will rely on the outcome of the review of the interagency guidelines to inform further strategies, and further implementation of this recommendation is pending this outcome.
Refer to section 5 of this report, on interagency coordination.</td></tr>
<tr><td colspan="2">Recommendation 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 <i>Care and Support: Final Report on Child Protection Services</i>, that the department establish a system for ensuring coordination through formal agreements between relevant agencies.</td></tr>
<tr><td>DoCS Response</td><td>This recommendation is accepted.
DoCS advised that:
• The workplan of the Child Protection Senior Officers Group, under the umbrella of the <i>NSW Interagency Guidelines for Child Protection Intervention</i>, includes a review / audit of local protocols. This would identify the need for, and the type of, local and/or regional protocols to improve the interagency practice.
• Memoranda of Understanding between DoCS and the Departments of Ageing, Disability and Home Care (DADHC) and Juvenile Justice (DJJ) are in place. Negotiations are underway with NSW Health (on prioritising access to health services for children and young people under the parental responsibility of the Minister) and the Department of Education and Training (DET) on mandatory reporting.</td></tr>
<tr><td>Our Comments</td><td>This recommendation was for DoCS to provide advice. No further action is required to demonstrate acceptance and implementation of the recommendation.</td></tr>
<tr><td colspan="2">Recommendation 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.</td></tr>
<tr><td>DoCS Response</td><td>This recommendation is accepted.
In August 2005, DoCS advised that the policy framework Child Deaths and Critical Reports Unit is being finalised, and provided a copy of the draft.
DoCS told us the primary focus of the child death review function within DoCS will be on <i>'organisational learning and building capacity within the system'</i>, and that <i>'the progress, outcomes and recommendations of all child death reviews conducted both centrally and locally are recorded, tracked and managed by staff of the Complaint, Assessment and Review Branch'</i>.
DoCS said the database used in this work also <i>'records recommendations made by oversighting agencies and subsequently tracks and assists with the management of responses and agreed implementation of all accepted recommendations'</i>.</td></tr>
<tr><td>Our Comments</td><td>This recommendation was for DoCS to provide advice. No further action is required to demonstrate acceptance and implementation of the recommendation.</td></tr>
</table>

Recommendation 18	
DoCS should develop strategies and provide appropriate training to ensure that departmental staff improve adherence to documentation and reporting requirements.	
DoCS Response	**This recommendation is accepted.** DoCS noted that one of the key objectives of the *Operational Consistency Project* is to improve internal administrative procedures. A major initiative – due for completion by June 2006 - has been the development and roll-out of a standard set of procedures for the creation and maintenance of paper files. Compliance auditing on this initiative has commenced. DoCS also referred to the Electronic Records and Document Management (ERDM) Program. NSW Businesslink is managing this project for DoCS and three other agencies to improve file, record and document management. The proposed outcome is new policies, procedures and a new system to assist DoCS staff meet mandatory record-keeping requirements. Draft policies and procedures for records management have been developed, and plans are for piloting the new system and staged roll-out over the next two years. Broader initiatives identified as contributing to implementation of this recommendation were caseworker training related to documenting work, and the tools used by the Helpline to examine aspects of practice and provide quality assurance.
Our Comments	DoCS' records management project and the progress of the EDRM indicate this recommendation is being progressed.

Endnotes

[1] Child or children in this report refers to children or young people under the age of 18 years.

[2] Child 'in care' is defined in s 4(1) of CS-CRAMA, and includes 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).

[3] The working definition of sibling is: *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.*

[4] While this report refers to 540 deaths, we note that the NSW Child Death Review Team *Annual Report January to December 2004* states that from January to December 2004, there were a total of 545 deaths of children and young people aged 0 – 17 years. The difference is related to legislative requirements. The CDRT legislation requires the team to consider deaths that were *registered* in NSW. The Ombudsman considers deaths that *occurred* in NSW in a given year. Deaths may not be registered in the year they occur. (see page 9 CDRT Annual Report).

[5] NSW government (2000) *Interagency Guidelines for Child Protection Intervention*, (revised 2005).

[6] NSW Ombudsman (2004) *Reviewable Deaths Annual Report 2003 – 2004*

[7] NSW Department of Community Services (2005) *NSW State Budget 2005/06.*

[8] The NSW Child Death Review Team *Annual Report January to December 2004* states that eight children and young people died as a result of fatal assault. This is due to a legislative difference. The CDRT legislation requires the team to consider deaths that were *registered* in NSW. The Ombudsman considers deaths that *occurred* in NSW in a given year. Deaths may not be registered in the year they occur.

[9] 'Unallocated' means that a report may be open at a local DoCS office (Community Service Centre) but is not allocated to a caseworker for active casework.

[10] It should be noted that 15 children known to DoCS died as a result of abuse, neglect or in suspicious circumstances. In nine of these cases, we assessed that the reported issues were not evident in the circumstances of the child's death.

[11] No reports were recorded for either the child or a sibling.

[12] Strang, H (1995); in *Australian violence: contemporary perspectives II*. Chappell, D and Egger, J (eds) Australian Institute of Criminology; Chance, T and Scannapieco, M (2002) Ecological correlates of child maltreatment: similarities and differences between child fatality and non-fatality cases, in *Child and Adolescent Social Work Journal* vol. 19, no 2 April 2002 pp 139-159.

[13] Trocme, N and Lindsey D (1996) What can child homicide rates tell us about the effectiveness of child welfare services? In *Child Abuse and Neglect* vol 20, no 3. pp 171-184.

[14] DoCS correspondence to the Ombudsman, 25 August 2005.

[15] DoCS (2005) *NSW State Budget 2005/06 – Community Services Budget*. DoCS counts each child who is mentioned in any contact to the Helpline as a separate report.

[16] A JIRT is a team of police and DoCS staff formed to conduct joint investigations of child abuse. Referrals to JIRT are generally limited to reports that indicate criminal conduct has occurred.

[17] It should be noted that 'report' here relates to the number of contacts made to DoCS, not the number of children who were mentioned in the contact(s).

[18] DoCS *Keeping Kids Safe. DoCS Child and Family Handbook.*

[19] Joint Working Party on NSW Department of Community Services. (June 2002) *Final Report. Demand for DoCS services and management of the intake and casework process*.

[20] Audit Office of NSW (2005) *Performance Audit: The Department of Community Services Helpline.*

[21] Ibid. Department of Community Services' response to the Audit Office report, p 6.

[22] DoCS *Business Help* January 2005.

[23] DoCS *Policy and Procedures for Case Plans that are rejected by JIRT*. Forwarded to the Ombudsman 25 August 2005.

[24] DoCS correspondence to the Ombudsman, 20 May 2005

[25] DoCS correspondence to the Ombudsman, 15 August 2005

[26] DoCS internal review of the death of a child. 30 June 2005.

[27] For five of the 72 children who died, it was not possible to determine whether secondary assessment involved field action.

[28] DoCS correspondence to the Ombudsman, 25 August 2005.

[29] DoCS correspondence to the Ombudsman, 7 June 2005.

[30] KBR 179 is a Business Rule for the operation of the KiDS system. The rule modifies the Priority One case closure policy, allowing closure of cases within 28 days, where cases have not been allocated.

[31] DoCS correspondence to the Ombudsman, 24 August 2005.

[32] DoCS correspondence to the Ombudsman, 2 November 2005 'Business help' us DoCS on-line policies and procedures.

[33] DoCS *Secondary Risk of Harm Assessment Policy and Principles* March 2002.

[34] Eleven of the 135 reports were also referred to a JIRT.

[35] The CSC later downgraded nine of the 135 reports. Downgrading means that a manager at the CSC has reviewed the required response timeframe determined by the Helpline and lowered it.

[36] DoCS correspondence to the Ombudsman, 25 August 2005

[37] Revised trial case closure policy (*Intake Assessment Guidelines*) August 2005

[38] DoCS correspondence to the Ombudsman, 24 August 2005

[39] DoCS correspondence to the Ombudsman, 2 November 2005.

[40] NSW Ombudsman (2004) *Improving outcomes for children at risk of harm – a case study*. A special report to Parliament under s.31 of the *Ombudsman Act 1974*. p. 22.

[41] DoCS correspondence to the Ombudsman, 7 June 2005.

[42] NSW Ombudsman (2004) *Reviewable deaths annual report 2003 – 2004*. p. 50.

[43] In response to a draft copy of this report, DoCS advised us that in this case, our assessment that closure of the report was the last DoCS action prior to the child's death was incorrect. We acknowledge that while the case was unallocated at the CSC under the Priority One system, a number of phone calls were made by the CSC in an attempt to follow up a request for information.

[44] DoCS correspondence to the Ombudsman, 7 June 2005.

[45] DoCS correspondence to the Ombudsman, 7 June 2005.

[46] DoCS correspondence to the Ombudsman, 2 November 2005.

[47] NSW Government (2000) *NSW Interagency Guidelines for Child Protection Intervention* (revised 2005).

[48] Discussion Paper Review of the *NSW Interagency Guidelines for Child Protection Intervention*. August 2005.

[49] DoCS correspondence to the Ombudsman, 24 August 2005.

[50] ibid.

[51] The recommendation was made following an investigation. The investigation was reported in a Special Report to Parliament in 2004: *Improving outcomes for children at risk of harm – a case study.* NSW Ombudsman, December 2004.

[52] DoCS correspondence to the Ombudsman, September 2005.

[53] NSW Child Death Review Team (2002) *Fatal Assault of Children and Young People*. NSW Commission for Children and Young People.

[54] Patton, N (2004) *Parental Drug Use – A Recent Phenomenon* The Mirabel Foundation.

[55] DoCS *Inside Out November/December 2003 pp2-3; DoCS website Out Services.* http://www.community.nsw.gov.au/html/about/services.htm accessed 22 September 2005.

[56] DoCS *Annual Report 2003/4*, p 33.

[57] The reviewable status of this child's death was not determined until after the tabling of our *Reviewable Deaths Annual Report 2002-03.*

[58] DoCS correspondence to the Ombudsman, 17 November 2004 (DoCS review July 2004, p 25).

[59] DoCS correspondence to the Ombudsman, 17 February 2005 (DoCS review January 2005, p 3).

[60] ibid pp 3-4.

[61] DoCS correspondence to the Ombudsman, 17 November 2004 (DoCS review July 2004, p 31).

[62] DoCS Operational Consistency Major Project Update, 5 March 2005.

[63] DoCS Practice Bulletin, *Informal Undertakings,* 15 November 2002.

[64] Ibid.

[65] DoCS correspondence to the Ombudsman, 17 November 2004 (DoCS review July 2004).

[66] DoCS correspondence to the Ombudsman, 25 August 2005 (child death review analysis pp 5-6)

[67] DoCS correspondence to the Ombudsman, 17 November 2004 (DoCS review July 2004).

[68] DoCS correspondence to the Ombudsman, 7 June 2005 (child death review).

[69] DoCS correspondence to the Ombudsman, 25 August 2005 (child death review analysis).

[70] DoCS correspondence to the Ombudsman, 2 November 2005.

[71] Callister, G, Family Violence and Child Protection, *Children Australia 2002* Vol 27, No 4, p 14.

[72] NSW Police correspondence to the Ombudsman, 1 November 2005.

[73] A further 18 children were not themselves the subject of reports about domestic violence, but had siblings who were. The siblings of these 18 children were together the subject of 87 reports that included domestic violence as a risk factor.

[74] DoCS correspondence to the Ombudsman 18 August 2005.

[75] We did not record the specific reason for closure of these reports.

[76] NSW Police correspondence to the Ombudsman 4 August 2005.

[77] NSW Police Service *Domestic Violence Policy and Standard Operating Procedures.* May 2000.

[78] NSW government (2000) *Interagency Guidelines for Child Protection Intervention*, (2000 edition, revised 2005).

[79] Two these reports were made as requests for assistance. The Helpline determined the requests to be reports of risk of harm.

[80] This case study was also reported in the NSW Ombudsman's Annual Report 2004/05.

[81] One of these reports was assessed by the Helpline as 'information only'.

[82] DoCS correspondence to the Ombudsman, 2 November 2005.

[83] Berry, M; Charlson, R; Dawson, K (2003) Promising practices in understanding and treating child neglect, in *Child and family social work* 2003, pp 13-24.

[84] NSW Ombudsman (2004) *Reviewable Deaths Annual Report 2003 - 2004* p 53.

[85] DoCS *Annual Report 2003/04* p 43. Data relates to October 2003 to June 2004.

[86] DoCS correspondence to the Ombudsman, 25 August 2005.

[87] NSW Ombudsman (2004) *Improving outcomes for children at risk of harm – a case study.* A report arising from an investigation into the Department of Community Services and NSW Police following the death of a child. A special report to Parliament under s 31 of the *Ombudsman Act 1974*.

[88] DoCS *NSW State Budget 2004/05*: Message from the Minister (the Honourable Reba Meagher) p 1.

[89] DoCS *Corporate Plan 2004/05 – 2008/09*, p 2

[90] DoCS correspondence to the Ombudsman 2 November, 2005.

[91] DoCS correspondence to the Ombudsman 2 November, 2005.

[92] Australian Bureau of Statistics (2000) *Census data 2001* No 2002.0 ABS Canberra. Information on child deaths in 2004 is from data provided by the NSW Registry of Births, Deaths and Marriages.

[93] DoCS correspondence to the Ombudsman, 24 August 2005.

[94] DoCS correspondence to the Ombudsman, 2 November 2005.

[95] Human Rights and Equal Opportunity Commission (1997), *Bringing them Home: Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families*. Commonwealth of Australia, Sydney.

[96] *Child abuse and neglect in Indigenous Australian Communities*, Child Abuse Prevention Issues, Stanley, Tomison and Pocock, Number 19 Spring 2003.

[97] DoCS correspondence to the Ombudsman, 16 May 2005. It is not known how many of the six care applications were for Aboriginal children.

[98] Director of Local Courts, Attorney General's Department - Children's Court Care Matters, Court Statistics Unit.

[99] DoCS correspondence to the Ombudsman, 16 May 2005

[100] NSW Child Death Review Team (2005) *Annual Report January – December 2004*. NSW Commission for Children and Young People. P 38.

[101] Suspect Target Management Plan is a framework for assessment, targeting and management of repeat offenders.

[102] NSW Police correspondence to the Ombudsman, 1 November 2005.

[103] SIDS Category II is defined as 'The sudden and unexplained death of an infant under one year of age, and apparently occurring during sleep, and which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history but where age range outside IA/IB (ie outside of >21 days but <9 months), where there is a history of deaths in siblings or other infants under the same caregiver, where mechanical asphyxia considered but not determined with certainty and/or where abnormal growth, or more marked pathological abnormalities are identified at autopsy.

[104] For example, Evans, E., Hawton, K., & Rodham, K. (2005) Suicidal phenomena and abuse in adolescents: a review of epidemiological studies, in *Child Abuse & Neglect, 29, 45-58.*

[105] Compulsory assistance is envisaged as a form of 'intensive care and support' to enable intervention without the young person's consent if it is necessary to protect them from suicide or other life-threatening or self-destructive behaviour.

[106] Section 9 (b) and section 10, *Children and Young Persons (Care and Protection) Act 1998*

[107] 'Judgements and decisions' is DoCS' term for decisions made following secondary assessment about whether a child is at risk and whether protective intervention is required.

[108] DoCs (2005) NSW State Budget 2005/06

[109] DoCs correspondence to the Ombudsman, 24 August 2005.

[110] DoCs 'Business Help' is the department's on-line set of policies and procedures.

[111] *'Case Closure policies in other jurisdictions have the same broad objectives ie to assist managers to make decisions when demand for services exceeds the agency's capacity to respond. The policies vary in terms of the guidance provided to staff regarding cases closed (from detailed guidance to no guidance). The policies also vary in terms of the rationale for closure. For example one state requires 'standard wording' for all case specific rationales. The draft DoCs Case Closure Procedures are at the more detailed end of the policy spectrum, and contain specific guidance regarding cases that must receive further assessment.'*

Appendices

Appendix 1

Reviewable Deaths Advisory Committees: membership

Reviewable Disability Deaths Advisory Committee

Mr Bruce Barbour: Ombudsman (chair)

Mr Steve Kinmond Deputy Ombudsman (deputy/alternate chair)

Dr Helen Beange: Clinical Lecturer, Faculty of Medicine, University of Sydney

Mr Michael Bleasdale: Director, NSW Council on Intellectual Disability; Senior Researcher, Disability Studies and Research Institute

Ms Linda Goddard: Course Coordinator, Bachelor of Nursing, Charles Sturt University

Assoc Prof Alvin Ing: Senior Staff Specialist, Respiratory Medicine, Bankstown-Lidcombe Hospital and Senior Visiting Respiratory Physician, Concord Hospital

Dr Cheryl McIntyre: General practitioner (Inverell)

Ms Anne Slater: Physiotherapist, Allowah Children's Hospital

Dr David Williams: Acting Director, Department of Neurology and Clinical Senior Lecturer in Medicine, University of Newcastle

Dr Rosemary Sheehy: Geriatrician/Endocrinologist, Central Sydney Area Health Service

Reviewable Child Deaths Advisory Committee

Mr Bruce Barbour: Ombudsman (chair)

Mr Steve Kinmond Deputy Ombudsman (deputy/alternate chair)

Dr Judy Cashmore: Associate Professor, Faculty of Law, University of Sydney and Honorary Research Associate, Social Policy Research Centre, University of New South Wales. Member of the International Society of Prevention of Child Abuse and Neglect (ISPCAN), Association of Children's Welfare Agencies, Society for Research in Child Development and American Psychological Association.

Dr Ian Cameron: CEO, NSW Rural Doctors Network

Dr. Michael Fairley:	Consultant Psychiatrist, 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, The Children's Hospital, Westmead
Dr Bronwyn Gould:	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 of Prevention of Child Abuse and Neglect (ISPCAN) and the Association of Children's Welfare Agencies
Ms Pam Greer:	Aboriginal representative, Community Worker, trainer and consultant working in Northern Territory, Queensland and New South Wales. Member of the Indigenous Women's Committee through the Women's Legal Centre
Dr Ferry Grunseit:	Consultant Paediatrician. Former Director of Emergency and Outpatient Services and Head of the Child Protection Unit at the Royal Alexandria Hospital for Children at Camperdown. Formerly, Chair NSW Child Protection Council and the NSW Child Advocate
Assoc Prof Jude Irwin:	Associate Professor, School of Social Work and Policy Studies, Faculty of Education and Social Work, University of Sydney. Deputy Chair, NSW Council on Violence Against Women, Member, Advisory Group, Australian Child Protection Research Centre
Ms Toni Single:	Senior Clinical Psychologist with the Child Protection Team at John Hunter Children's Hospital, Newcastle
Ms Tracy Sheedy:	Children's Registrar, Children's Court of NSW. Guardian and Litem Panel Co-Ordinator and editor of Children's Law News. Part-time Member of the Consumer Trader and Tenancy Tribunal

Appendix 2

Disability deaths: update of deaths that occurred in December 2002 – December 2003

Last year we reported on the primary cause of death for 90 of the total 110 reviewable disability deaths during the 2003 reporting period and noted that coronial processes were still open for the remaining 20 deaths.

At the time of writing this report the coroner had finalised 12 of the 20 outstanding 2003 matters. The remaining 8 deaths will be carried over for comment in our 2005 annual report.

The following table presents revised primary cause of death information for 2003 reviewable disability deaths.

Table A2.1: Numbers of deaths in each ICD-10-AM cause of death category*

ICD-10-AM Cause of death category	Frequency**
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.	4 (+1)
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
Mental and behavioural disorders (F00-F99) This includes disorders that affect cognitive and behavioral functioning. For example disorders attributable to the use of psychoactive substances, mental disorders due to brain damage, schizophrenia and other psychotic disorders, mood affective disorders.	1 (+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.	6 (+2)
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, haemarrhoids.	18 (+1)
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.	40 (+4)
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, zerostomia (dry mouth), oesophagitis, gastro-oesophageal reflux, haematemesis.	5 (+1)
Diseases of the skin and subcutaneous 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 the 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).	3 (+1)
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.	6 (+1)
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
Total	**102**

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

** Frequency column includes the change in the number of deaths in each cause of death category for the additional 12 matters.

The cause of death information received for the 12 outstanding 2003 matters does not alter the rest of the data reported in our 2003 Annual Report.

Appendix 3

Data: disability deaths in 2004

1. Demographic Information[1]

Age

Figure A3.1: Age at time of death for disability service residents

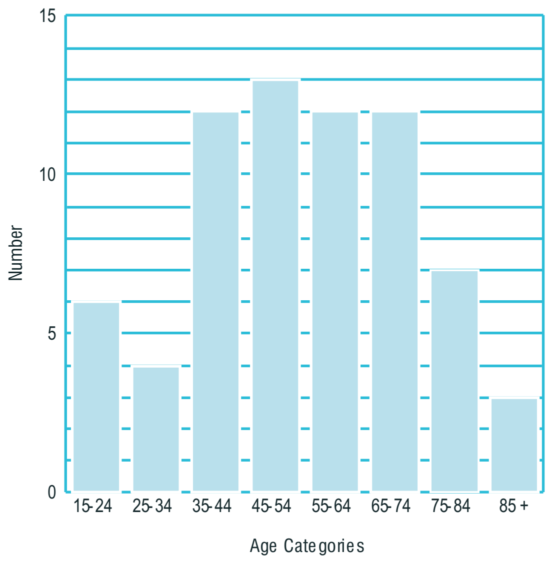
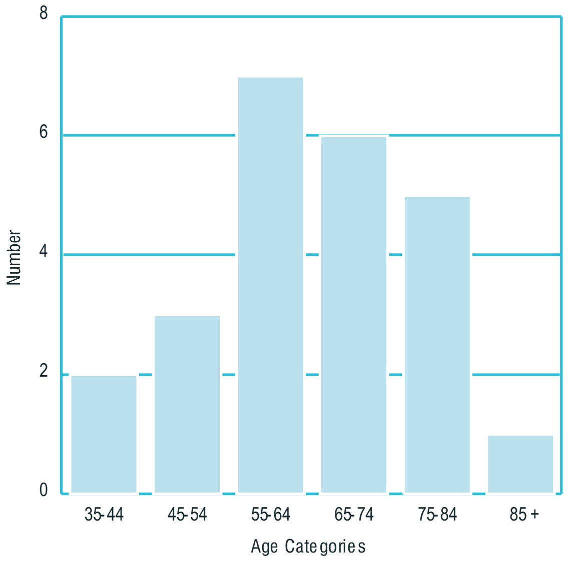


Figure A3.2: Age at time of death for boarding house residents



Gender

In regards to the reviewable disability deaths in 2004:

- The mean age at time of death for males was 59 years.
  - The mean age for males residing in disability services was 56 years.
  - The mean age for males residing in licensed boarding houses was 66 years.
- The mean age at time of death for females was 55 years.
  - The mean age for females residing in disability services was 53 years.
  - The mean age for females residing in licensed boarding houses was 64 years.

2. Service Provision

Service Type

Table A3.1: Type of residence by service provider

	DADHC Services	Funded Services	Licensed Boarding House	Total
Group Home	13	16	0	29
Large Residential Centre	21	18	0	39
Small Residential Centre	0	1	0	1
Licensed Boarding House	0	0	24	24
Total	**34**	**35**	**24**	**93**

Table A3.2: Age category by type of accommodation service

	Group Home	Large Residential	Small Residential	Licensed boarding house	Total
15-24 years	3	3	0	0	6
25-34 years	3	1	0	0	4
35-44 years	4	8	0	2	14
45-54 years	8	5	0	3	16
55-64 years	4	8	0	7	19
65-74 years	3	9	0	6	18
75-84 years	4	2	1	5	12
85+ years	0	3	0	1	4
Total	**29**	**39**	**1**	**24**	**93**

Time in residential care

Total lifetime years spent in care

Table A3.3: Total lifetime years in care by type of accommodation service

	Group Home	Large Residential	Small Residential	Licensed Boarding House	Total
Not Known	9	7	0	17	33
1-5 years	2	1	0	1	4
6-10 years	1	0	0	1	2
11-15 years	1	2	0	1	4
16-20 years	4	2	0	2	8
21+ years	12	27	1	2	42
Total	**29**	**39**	**1**	**24**	**93**

Years at most recent location

Figure A3.3: Number of years at most recent location for the disability services group

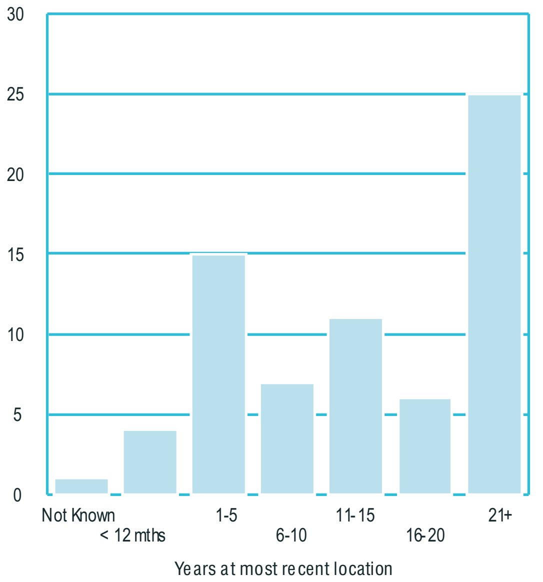


Figure A3.4: Number of years at most recent location for the boarding house group

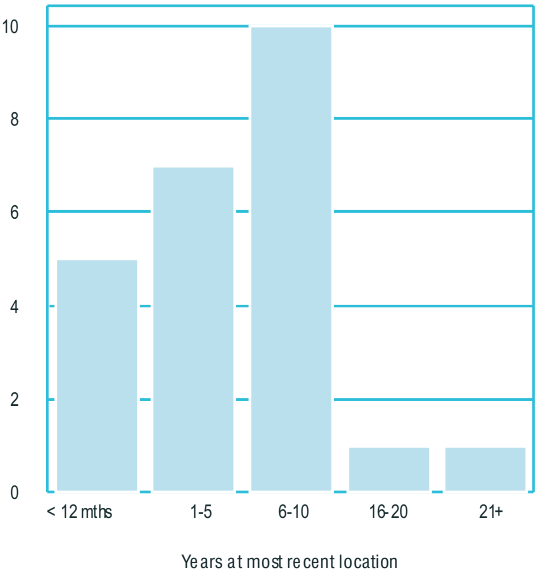


Table A3.4: Number of years at most recent location by type of accommodation service

	Group Home	Large Residential	Small Residential	Licensed Boarding House	Total
Not known	1	0	0	0	1
< 12 months	3	1	0	5	9
1-5 years	11	3	1	7	22
6-10 years	7	0	0	10	17
11-15 years	4	7	0	0	11
16-20 years	3	3	0	1	7
21 + years	0	25	0	1	26
Total	**29**	**39**	**1**	**24**	**93**

When and where people died

Figure A3.5: Season of death for the disability services group

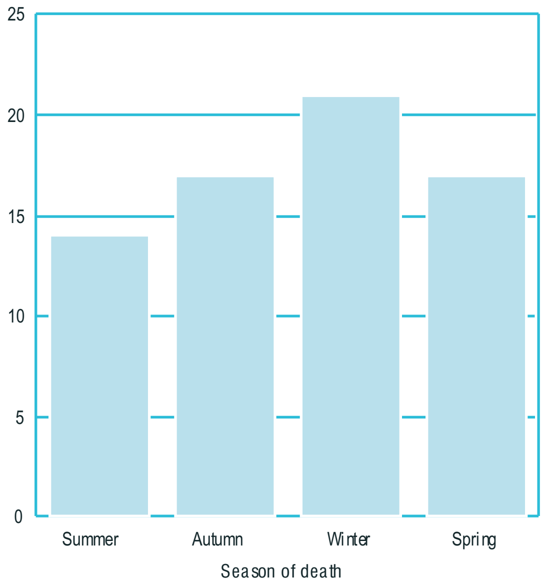


Figure A3.6: Season of death for the boarding house group

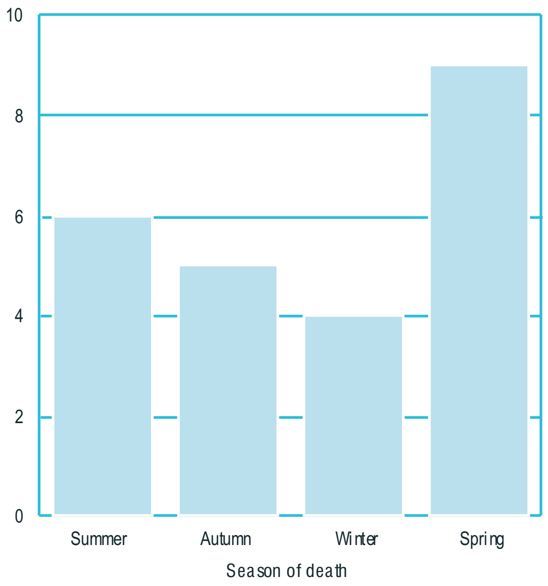


Table A3.5: Place of death

Place of Death	Disability Services Group	Boarding House Group	Total
Hospital	50	11	61
Service	16	8	24
Community	0	3	3
Palliative Care	3	0	3
Ambulance	0	2	2
Total	**69**	**24**	**93**

3. Disability, primary health conditions and support needs

Disability Data

Table A3.6: Disability Types*

	Disability Services Group(69)	Boarding House Group (24)	Total (93)
Intellectual	57	4	61
Physical	33	1	34
Sensory	30	5	35
Psychiatric	16	12	28
Neurological	7	2	9
Acquired Brain Injury	1	8	9

* Note that each person may have had one or more disabilities and so may appear in more than one category.

Table A3.7: Level of Intellectual Disability for the 61 people recorded as having had an intellectual disability

	Disability Services Group	Boarding House Group	Total
Mild	8	1	9
Moderate	13	2	15
Severe	22	0	22
Profound	10	0	10
Not known	4	1	5
Total	**57**	**4**	**61**

Figure A3.8: Total number of disabilities for the boarding house group

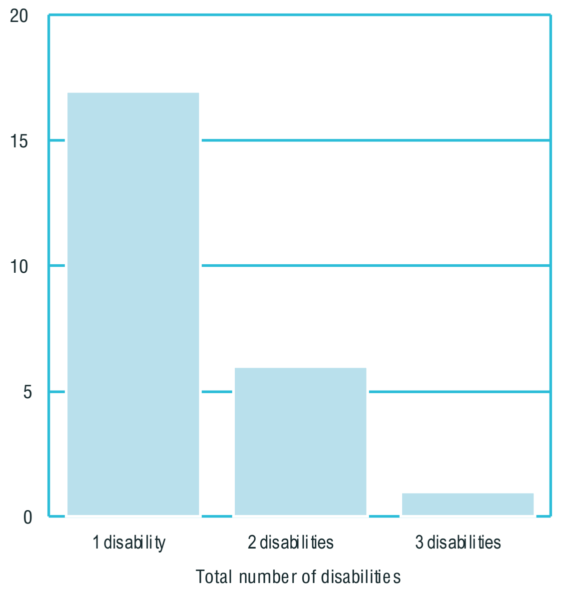


Figure A3.7: Total number of disabilities for the disability services group

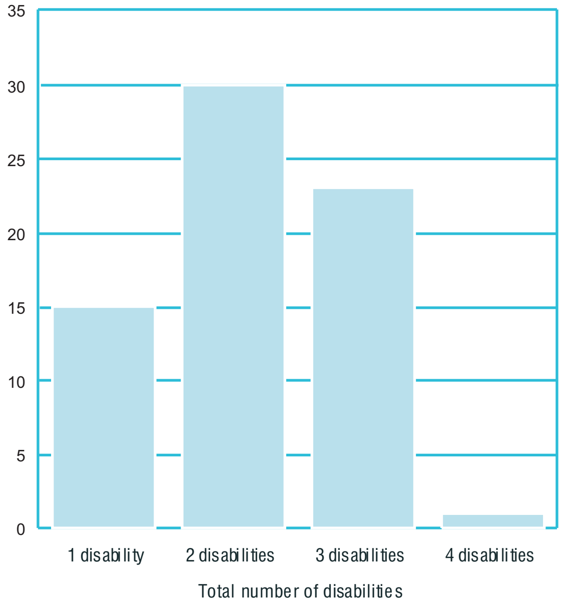


Table A3.8: Aetiology (or cause) of Intellectual Disability*

	Disability Services Group
Down syndrome	11
Acrocallosal syndrome	1
Cerebral Palsy	1
Cohen's syndrome	1
Meningitis	1
Quadriplegia	1
Fragile X syndrome	1
Noonan syndrome	1
Trisomy 18 syndrome	1
Williams syndrome	1
Total	**20**

* Note that the aetiology of intellectual disability was recorded for only 20 disability service residents and was not known for any of the people in the boarding house group.

Immunisation

Table A3.9: Immunisation status within 12 months of death

	Disability Services Group		Boarding House Group	
	Influenza	Pneumococcal	Influenza	Pneumococcal
Yes	57	21	15	3
No	3	17	1	4
Don't know	5	16	5	11
No response	4	15	3	6
Total	**69**	**69**	**24**	**24**

Weight

Table A3.10: BMI category for disability services group – 18 to 64 years[2]

	Frequency
Very underweight (<16.9 kg/m²)	6
Underweight (17 - 18.4 kg/m²)	2
Healthy weight range (18.5 – 24.9 kg/m²)	14
Overweight (25 – 29.9 kg/m²)	7
Obese (30-34.9 kg/m²)	4
Severe Obesity (>/= 35 kg/m²)	3
Total	**36**

Dentition

Table A3.11: Dentition status

	Disability Services Group	Boarding House Group	Total
All teeth	16	3	19
No teeth	20	3	23
Some teeth	22	5	27
Dental aid	10	6	16
Not known	1	7	8
Total	**69**	**24**	**93**

Consent Provider

Table A3.12: Consent provider

	Disability Services Group	Boarding House Group	Total
Person themselves	7	9	16
Person themselves + family or advocate	4	3	7
Family member	44	7	51
Public Guardian	9	1	10
No identified person – Guardianship Tribunal	3	0	3
Other	2	1	3
Not known	0	3	3
Total	**69**	**24**	**93**

4. Cause of death

Table A3.13: Numbers of deaths in each ICD-10-AM cause of death category for the disability services group

ICD-10-AM Cause of death category	No. of deaths
Certain infectious & parasitic diseases (A00-B99)	5
Neoplasms (C00-D48)	3
Diseases of the nervous system (G00-G99)	1
Diseases of the circulatory system (I00-I99)	8
Diseases of the respiratory system (J00-J99)	23
Diseases of the digestive system (K00-K99)	2
Injury, poisoning and certain other consequences of external causes (S00-T98)	4
Undetermined	23
Total	**69**

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

Table A3.14: Numbers of deaths in each ICD-10-AM cause of death category for the boarding house group

ICD-10-AM Cause of death category	No. of deaths
Certain infectious & parasitic diseases (A00-B99)	1
Neoplasms (C00-D48)	1
Diseases of the circulatory system (I00-I99)	5
Diseases of the respiratory system (J00-J99)	2
Diseases of the genitourinary system (N00-N99)	1
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	1
External causes of morbidity and mortality (V01-Y98)	1
Undetermined	12
Total	**24**

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

5. Issues arising from reviews of deaths in 2004

Audit of health conditions and plans in DADHC and funded services

Table A3.15: Service type by number of health conditions

	No. of Cases	No. of Health Conditions	Mean	Range
DADHC Large Residential	22	172	7.82	4 – 15
NGO Large Residential	17	115	6.76	3 – 13
DADHC Group Home	12	75	6.25	3 – 10
NGO Group Home	17	84	4.94	2 – 13
NGO Small Residential	1	4	4.00	-
Total	**69**	**450**		

Medications

Table A3.16: Total number of different types of medication taken in the last 12 months of life

	Disability Services	Boarding House	Total
No medications	10	5	15
1 type of medication	24	13	37
2 types of medication	25	3	28
3 types of medication	7	3	10
4 types of medication	3	0	3
Total	**69**	**24**	**93**

Communication support

TableA3.17: Communication support needs

	Disability Services Group	Boarding House Group	Total
Communication support required – type not known	13	1	14
Adjusted verbal language	2	0	2
Picture communication	2	0	2
Sign language	2	0	2
Other type of communication support	6	0	6
Communication support not required	43	22	65
Not known whether communication support was required	1	1	2
Total	**69**	**24**	**93**

6. Additional data not reported in the body of the report

Table A3.18: Tobacco use

	Disability Services Group	Boarding House Group	Total
1-10 cigarettes per day	4	4	8
11-20 cigarettes per day	1	4	5
21 + cigarettes per day	1	9	10
Occasionally	0	1	1
Non smoker	53	5	58
Ex smoker	8	1	9
No response	2	0	2
Total	**69**	**24**	**93**

Table A.19: Number of fractures sustained within 5 years of death

	Disability Services Group	Boarding House Group	Total
No fractures	51	20	71
1 fracture	13	4	17
2 fractures	2	0	2
3 fractures	2	0	2
6 fractures	1	0	1
Total	**69**	**24**	**93**

Table A3.20: Alcohol intake

	Disability Services Group	Boarding House Group	Total
Daily (1-2 drinks)	2	1	3
Weekly (1-2 drinks)	2	0	2
Weekly (3-4 drinks)	1	0	1
Weekly (> 4 drinks)	1	2	3
Occasionally (1-2 drinks)	2	4	6
Rarely (1-2 drinks)	7	1	8
Never	54	16	70
Total	**69**	**24**	**93**

Table A3.21: Mobility

	Disability Services Group	Boarding House Group	Total
Full mobility	7	18	25
Limited mobility – no information supplied about type of aid	4	0	4
Limited mobility – no aid	8	1	9
Wheelchair	42	0	42
Walking frame	5	1	6
Walking stick	1	1	2
Other aid	2	1	3
No response	0	2	2
Total	**69**	**24**	**93**

7. Coronial information for deaths in 2004

Full coronial information was not available at the time of writing for 35 of the 93 deaths in 2004. These matters will be carried over for comment in next year's annual report.

Autopsies

- An autopsy was performed in 26 of 93 cases (28%).
- Next of kin objected to an autopsy in five deaths. No autopsies were performed in relation to these five deaths.

Inquests

- No decision has been made regarding an inquest for 50 deaths.
- A coroner dispensed with an inquest in 43 deaths.

Recommendations

No coronial recommendations were made in any of the matters that have been finalised.

Appendix 4

Methodology of the health care planning review

The review was comprised of three elements:

(i) An audit of the health related plans provided with the CDN (or through the review process) in relation to all 2004 reviewable disability deaths in DADHC operated and funded services (n=69), considering the following:
  - The person's known health conditions
  - Whether the plans included adequate guidance for meeting known health needs
  - Whether the plans included adequate guidance for regular health review
  - Whether the plans included clear responsibilities for actions
  - Whether the plans included clear timeframes for actions and review

(ii) The second part of our project aimed to examine in more detail how funded services undertake health care planning. It involved a detailed file audit of 19 clients who died in 2004 drawn from 10 funded services, and considered:
  - What mechanisms (such as plans) were used by those services to plan or coordinate the general health care of the individuals who died, and their scope / content
  - Whether regular assessments or reviews of client health were undertaken, and how that information was recorded
  - Who had input into the development of health related plans
  - Whether health related plans and expert recommendations were implemented
  - Whether health related plans were reviewed
  - Whether and how services undertook monitoring of health related plans and implementation of actions / recommendations

  This part of the project also incorporated a meeting with service management to discuss our findings, clarify current practice around health care planning, and to discuss challenges experienced by the service in undertaking that work.

(iii) A telephone survey of 19 residential support workers, drawn from eight funded services. It considered:
  - The type of duties they perform
  - Their qualifications
  - Where they obtain support and information in relation to questions about client health care issues
  - How confident they feel about undertaking health care related tasks

Appendix 5

Child deaths: Update of deaths that occurred December 2002 – December 2003

Jurisdiction

In the NSW Ombudsman's (2004) *Reviewable Deaths Annual Report 2003-2004* we reported that for the period 1 December 2002 to 31 December 2003 there were 605 children and young people who died in NSW. In 2005 we received further notifications from the NSW Registry of Births, Deaths and Marriages (BDM) and information from the Coroner regarding child deaths that occurred in this period. This new information allows us to update the child deaths reported on in 2004 as follows:

For the period 1 December 2002 to 31 December 2003 there were 616 children and young people who died in NSW and 167 (27%) of these child deaths were reviewable under the Ombudsman's reviewable deaths function.[3] Table A5.1 below presents the revised number of child deaths in each group that determines a child's death as reviewable under section 35(1) of the *Community Services (Complaints, Reviews and Monitoring) Act 1993*. Note that the groupings are not mutually exclusive and that the definitions of a child death resulting from abuse or neglect or having occurred in suspicious circumstances applied here are those used in the 2004 report.

Table A5.1: Reasons for the reviewable status of child deaths by Aboriginal identity

	All Children (167)	Non-Aboriginal Children (136)	Aboriginal Children (31)
Child report <3 years prior to the child's death	100	81	19
Sibling report <3 years prior to the child's death	89	67	22
Fatal abuse	18	16	2
Fatal neglect	30	25	5
Suspicious circumstances	48	39	9
In care	11	8	3
In detention	0	0	0
In correction	0	0	0

Demographic information

Of the 616 child deaths, 49 (8%) were of Aboriginal children with 31 of these child deaths being reviewable. The deaths of 16 of these children resulted from abuse or neglect or occurred in suspicious circumstances.

More than half (54%) of the children whose deaths were reviewable were four years old and under at the time of their deaths and just over one-quarter (27%) were adolescents.

Table A5.2: Age by Aboriginal identity

	All Children	Non-Aboriginal Children	Aboriginal Children
<12 months	60	42	18
1-4 years	30	26	4
5-9 years	21	19	2
10-12 years	11	10	1
13-17 years	45	39	6
Total	**167**	**136**	**31**

Consistent with child deaths in general, slightly more male than female children's deaths were reviewable. See Table A5.3 below.

Table A5.3: Gender by Aboriginal identity

	All Children	Non-Aboriginal Children	Aboriginal Children
Male	88	72	16
Female	79	64	15
Total	**167**	**136**	**31**

Status of the Coronial Process

Previously, we reported that the coronial process had not been finalised for 50 of the 137 child deaths reported on last year. At the time of writing the coronial process remains open for 28 (17%) of the 167 reviewable child deaths.

Table A5.4: Status of the coronial process

	All Children
Open – Coronial process not finalised	28
Closed – Inquest held	17
Closed – Inquest terminated	16
Closed – Inquest dispensed	106
Total	**167**

Deaths due to abuse or neglect or that occurred in suspicious circumstances

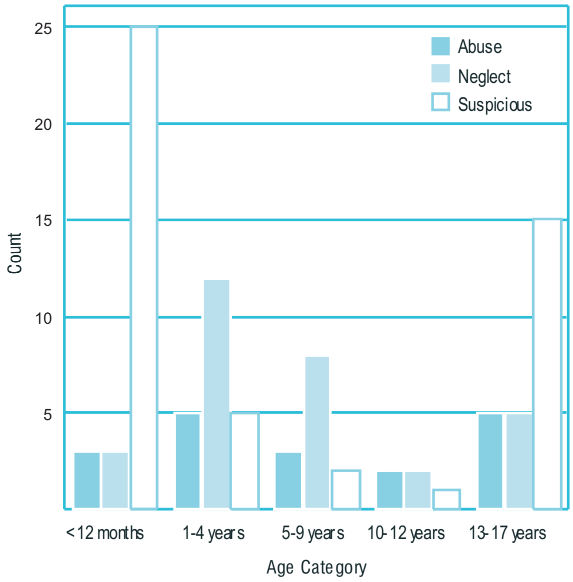
Of the 167 children whose deaths were reviewable, just over half (96 or 58%) died as a result of abuse or neglect or their deaths occurred in suspicious circumstances, using the definitions applicable in our 2004 report. Similarly with the population of all child deaths in the reporting period, slightly more male children (53%) died as a result of abuse or neglect or in suspicious circumstances than female children (47%).

Table A5.5: Abuse, neglect or suspicious child deaths by Aboriginal identity

	All Children	Non Aboriginal Children	Aboriginal Children
Abuse	18	16	2
Neglect	30	25	5
Suspicious	48	39	9
Not applicable	71	56	15
Total	**167**	**136**	**31**

While child deaths that resulted from abuse or neglect or that occurred in suspicious circumstances occurred in all age categories, the majority of suspicious deaths occurred in two of the age categories: those children that were less than 12 months old at the time of their deaths and adolescents. A large proportion of the number of deaths that resulted from neglect were concentrated in the one to nine years age groupings. The bar graph below represents the age categories of the 96 children who died as a result of abuse or neglect or whose deaths occurred in suspicious circumstances.

Figure A5.1 Age category by abuse, neglect or suspicious child deaths



Of the 96 children whose deaths resulted from abuse or neglect or that occurred in suspicious circumstances, 60 (63%) were known to DoCS. Fifty-one (53%) of the 60 children were themselves the subject of risk of harm reports to DoCS in the three years preceding their deaths and nine children had one or more siblings the subject of such reports.

Appendix 6

Data: Child deaths in 2004

Jurisdiction

For the period 1 January 2004 to 31 December 2004 BDM advised us of the deaths of 540 children and young people in NSW. The deaths of 104 (19%) of these children were reviewable under Section 35(1) of the Community Services (Complaints, Reviews and Monitoring) Act 1993 (CS-CRAMA). We were unable to determine the status of 28 (5%) deaths.[4] A child's death may be reviewable for more than one reason. Table A6.1 shows the number of children whose deaths were reviewable and why they were reviewable.

Table A6.1: Reasons for the reviewable status of child deaths

	Reviewable Child Deaths (104)
Child report <3 years prior to the child's death	72
Sibling report <3 years prior to the child's death	73
Fatal abuse	7
Fatal neglect	6
Suspicious circumstances	11
In care	8
In detention	0
In correction	0

Demographic information

Age & Gender

Table A6.2: Age category of children

	All Children
<12 months	35
1-4 years	30
5-9 years	10
10-12 years	7
13-17 years	22
Total	**104**

Table A6.3: Gender of children

	All Children
Male	55
Female	49
Total	**104**

Aboriginal and Torres Strait Islander children and young people

The deaths of 20 Aboriginal children of the 34 Aboriginal and Torres Strait Islander children who died in 2004 were determined to be reviewable.[5] Aboriginal child deaths constitute 19% of all of the reviewable deaths in NSW in 2004. Indigenous children and young people continue to be overrepresented in both the deaths of all children in NSW and in reviewable child deaths.

Table A6.4: Reasons for the reviewable status of child deaths by Aboriginal Identity

	All Reviewable Child Deaths (104)	Non-Aboriginal Reviewable Child Deaths (84)	Aboriginal Reviewable Child Deaths (20)
Child report <3 years prior to the child's death	72	54	18
Sibling report <3 years prior to the child's death	73	55	18
Fatal abuse	7	7	0
Fatal neglect	6	5	1
Suspicious circumstances	11	8	3
In care	8	7	1
In detention	0	0	0
In correction	0	0	0

Table A6.5: Age category of children by Aboriginal identity by gender

	Non-Aboriginal Children			Aboriginal Children		
	All Children	Male Children	Female Children	All Children	Male Children	Female Children
<12 months	28	15	13	7	5	2
1-4 years	23	12	11	7	3	4
5-9 years	7	4	3	3	2	1
10-12 years	7	4	3	0	0	0
13-17 years	19	9	10	3	1	2
Total	**84**	**44**	**40**	**20**	**11**	**9**

Family characteristics, living arrangements & place of death

The majority (92, 88%) of children whose deaths were reviewable usually resided with their families (89 children resided with at least one biological parent and 3 children with another family member). Four children were residing in care under the supervision of residential care workers. One young person was living independently and another was homeless at the time of their death. Six children died before discharge from hospital following birth.

Table A6.6: The place of the child's death

	All Children
Child's family home	54
Other private home	2
Residential service	1
Hospital or health facility	22
Public place	22
Not determinable	3
Total	**104**

Table A6.7: Supervision responsibility for the child at the time of the death incident

	All Children
Biological parent(s)	69
Other family member(s)	3
Residential care worker(s)	5
Non-related person(s)	6
Child/young person self-supervising	15
Child never discharged from hospital	6
Total	**104**

Circumstances of Death

Coronial Inquests

The Coronial inquest process investigates and determines the manner and cause of death of people who die in NSW. At the time of writing, the coronial process had not been finalised for 58 (56%) of child deaths that occurred in 2004.

Table A6.8: Status of the Coronial Process

	All Children
Inquest held	3
Inquest dispensed	34
Inquest terminated	9
Inquest scheduled	1
Inquest decision pending	57
Total	**104**

For the 46 children where the inquest has been finalised, the manner of death determined by the Coroner is as follows:

Table A6.9: Manner of child deaths

	All Children
Natural manner	26
Accidental manner	14
Suicidal manner	2
Homicidal manner	4
Coronial process is open	58
Total	**104**

Circumstances of Death

Although the coronial process has not been finalised for all of the child deaths that were reviewable, it was possible to determine the circumstances of death for most of the children from available records.

Table A6.10: Circumstances of child deaths

	All Children
Natural cause death	46
Passenger in traffic accident	8
Burns from fire	8
Choking/suffocation	5
Hanging	5
Drowning in bath tub	3
Pedestrian	3
Falls/jumps	2
Beating/bashing/assault	2
Driver in traffic accident	2
Bike/scooter/skateboard rider	2
Drowning in natural body of water	2
Drowning in pool	1
Drug overdose	1
Poisoning	1
Laceration	1
Undetermined/unascertained	12
Total	**104**

Children Reported to DoCS

Ninety-six children and/or their siblings had been reported to DoCS in the three years prior to their deaths. In the data below if a child was the sole subject of a risk of harm report or the child was included as being a subject of a risk of harm report that also included one or more siblings, then these reports are referred to as 'child reports.' Risk of harm reports that were made about a child's sibling(s) only are referred to as 'sibling(s) only reports.'

In total, 96 children had 595 risk of harm reports made about themselves and/or their sibling(s) in the three years prior to their deaths. Seventy-two children were the subjects of 310 child reports and another 189 reports were made about one or more of their sibling(s) only.

Number of DoCS reports

Table A6.11: Number of child reports in the 12 months & 3 years prior to death

	Reports for Children Known to DoCS
In the 12 months prior to death	172
In the 3 years prior to death	310

Table A6.12: Number of child reports by age category

	Reports for Children Known to DoCS
<12 months	51
1-4 years	62
5-9 years	33
10-12 years	6
13-17 years	158
Total	**310**

Table A6.13: Number of child reports by primary reason for the report

	Reports for Children Known to DoCS
Physical abuse/risk of physical harm	55
Domestic violence	54
Neglect/well-being concerns	48
Sexual abuse/risk of sexual harm	26
Carer drug & alcohol concerns	21
Psychological abuse/risk of psychological harm	21
Medical neglect	8
Carer/adolescent conflict/behaviour management difficulties	7
Homelessness	6
Inadequate supervision	5
Request for assistance	2
Other	57
Total	**310**

Children whose deaths resulted from abuse or neglect or that occurred in suspicious circumstances

Of the 104 reviewable child deaths, seven (7%) children died as a result of abuse, six (6%) as a result of neglect and 11 (11%) children died in suspicious circumstances (six of these eleven child deaths were suspicious of abuse and five were suspicious of neglect).

Table A6.14: Abuse, neglect or suspicious deaths by children known to DoCS

	All Children (104)	Children Known to DoCS (72)	Children with Siblings Known to DoCS (24)	Children Not Known to DoCS (8)
Abuse	7	2	0	5
Neglect	6	4	1	1
Suspicious	11	9	1	1
Total	**24**	**15**	**2**	**7**

Of the 24 children who died from abuse or neglect or whose deaths occurred in suspicious circumstances, 17 (71%) were reported to DoCS in the three years prior to their deaths (15 children were themselves the subject and two children had one or more sibling(s) the subject of such reports). One child was in care at the time of their death.

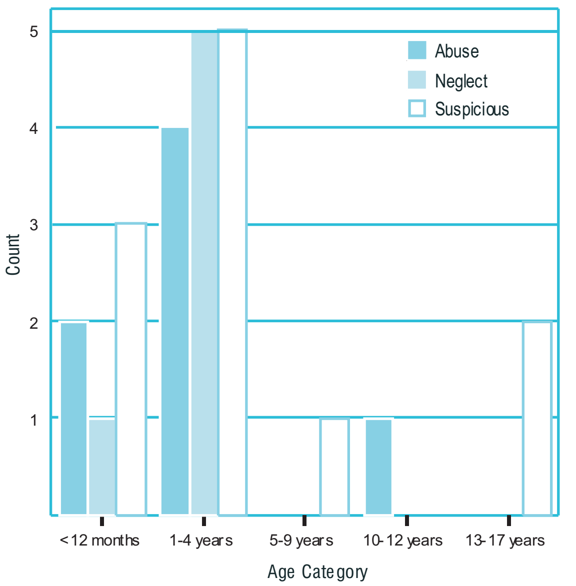
Demographic information

Of the 24 children whose deaths resulted from abuse or neglect or that occurred in suspicious circumstances, 12 (50%) were male children and 12 (50%) were female children. Four of the children identified as being Aboriginal.

Note that each person may have had one or more disabilities and so may appear in more than one category.

Note that the aetiology of intellectual disability was recorded for only 20 disability service residents and was not known for any of the people in the boarding house group.

Figure A6.1: Age category of children by abuse, neglect & suspicious deaths



Reported to DoCS

Of the group of 24 children who died as a result of abuse or neglect or whose deaths occurred in suspicious circumstances, 17 (71%) children and/or their sibling(s) had been reported to DoCS within the three years preceding their deaths. Fifteen of these children were themselves known to DoCS and two of these children had one or more of their siblings known to DoCS.

All four of the Aboriginal children and 11 (55%) of the non-Aboriginal children who died as a result of abuse or neglect or whose deaths occurred in suspicious circumstances had been reported to DoCS.

Endnotes

[1] In the NSW Ombudsman *Reviewable Deaths Annual Report 2003-2004* we reported on a total of 110 reviewable deaths that occurred during the period 1 December 2002 to 31 December 2003. Nine deaths occurred in December 2002 and have not been included in the following comparative data analyses. Any references to 2003 deaths throughout this appendix are made with regards to a total of 101 deaths that occurred in the 2003 calendar year.

[2] As noted on page 122, BMI figures are calculated differently for children and for people 65 years of age and over. Twenty-five people were not aged between 18-64 years and were therefore excluded from the table. There were a further 8 people for whom it was impossible to calculate BMI, primarily due to their height not being recorded. These people were also excluded.

[3] However, for 2 of 616 children there remains insufficient information regarding their deaths to determine if they are reviewable.

[4] In the NSW Ombudsman's Annual Report 2004-05 (p. 94) it states that the deaths of 105 children who died in 2004 were reviewable deaths and that 97 of these children were known to DoCS. These numbers have been revised and at the time writing the deaths of 104 children were reviewable and 96 of these children and/or their sibling(s) were known to DoCS in the three years prior to their deaths.

[5] Thirty-two of the children who died in 2004 were identified to be Aboriginal and 2 were identified to be Torres Strait Islander children.

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