NSW Ombudsman

Report of Reviewable Deaths in 2006

Volume 1: Deaths of people with disabilities in care

November 2007

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December 2007

The Hon Peter Primrose MLC
President
Legislative Council
Parliament House
SYDNEY NSW 2000

The Hon Richard Torbay MP
Speaker
Legislative Assembly
Parliament House
SYDNEY NSW 2000

Dear Mr President and Mr Speaker

I am pleased to present the NSW Parliament with volume one of our fourth report on reviewable deaths. This volume concerns the deaths of 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 2006; 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

Ombudsman's message

This is the fourth report of reviewable disability deaths.

It concerns the deaths in 2006 of 98 people with disabilities who lived in government and non-government disability services, and licensed boarding houses.

2007 marks five years of my office reviewing the deaths of people with disabilities in care. Thus it is timely to reflect on our work, the outcomes from our reviews and developments in the disability sector.

This year we see the continuation of critical whole-of-government and interagency planning and work in relation to people with disabilities. Of particular note, are Better Together, the NSW government's plan to ensure vital public services better meet the needs of people with a disability and their families; the progression of DADHC and NSW Health's joint work towards developing a service framework for the health care of people with an intellectual disability; and the first roll-out of Stronger Together, the NSW government's 10-year plan for the direction of disability services. We can expect to see progress in some important areas as this work continues.

I am pleased that we are increasingly able to identify examples of good practice by disability and health services. This report highlights instances of dedicated advocacy by individual services, and multidisciplinary work to improve the outcomes for people with disabilities in care.

However, considerable work remains to be done to address ongoing gaps in the delivery of services and ensure the timely progression of planned initiatives.

One example is the provision of first aid to people with disabilities living in care. This is the third consecutive report in which we have raised concerns about the provision of first aid to people with disabilities in care, such as delays in commencing CPR. The effective provision of first aid is directly relevant to the prevention of premature deaths, and yet there is currently no consistent requirement that disability accommodation providers ensure at least one staff member on each shift is qualified to render first aid.

While our past recommendations on this issue have resulted in significant improvements within DADHC-operated services, no such requirements relating to the provision of first aid exist for funded services, and similar requirements for licensed boarding houses are not able to be enforced.

It should be mandatory, regardless of the disability accommodation setting, that at least one staff member on shift is qualified to render first aid. The inconsistency across accommodation settings is unacceptable, and we will continue to pursue this issue.

This report illustrates the challenges faced by human service agencies in meeting the complex needs of people with disabilities in care. Many of the concerns we have raised are not new, and have been the subject of previous recommendations. Much of our work is about monitoring agency responses to the problems we identify and this is reflected in the recommendations made this year.

Bruce Barbour
Ombudsman

Contents

Executive Summary .... **I**

Recommendations .... **V**

1. Introduction **1**

1.1 Reviewable deaths 1

1.2 The scope of our work 1

1.3 Reviewing deaths 2

1.4 Overview of this report 3

1.5 Developments since our last report 3

2. Progress 2002–2007 .... **5**

3. Deaths of people with disabilities in care in 2006: Data **9**

3.1 Characteristics and circumstances of the people who died 10

3.2 Cause of death 10

3.3 Health conditions 15

3.4 Nutrition and swallowing 18

4. Deaths of people with disabilities in care in 2006: Our work **21**

4.1 Identification and management of risks 21

4.2 Meeting individual needs 29

4.3 Response to critical incidents 36

4.4 Discharge planning 37

4.5 End-of-life decision-making 40

4.6 Residential centres 42

5. Review of respiratory deaths in 2005 .... **47**

5.1 Background 47

5.2 Process 48

5.3 Data snapshot 48

5.4 Individual reviews 51

5.5 Systemic issues 51

6. Appendices **53**

Appendix 1 Reviewable disability deaths advisory committee — membership 53

Appendix 2 Data: Deaths of people with disabilities in care in 2006 54

Appendix 3 Report on progress with recommendations from 2006 63

Executive Summary

The purpose of the Ombudsman's reviewable deaths function is to prevent or reduce deaths, including those of people with disabilities in care.

The death of a person with a disability is reviewable if, at the time of their death, they were living in, or temporarily absent from:

- residential care authorised or funded under the *Disability Services Act 1993* ('disability services'), or
- a licensed boarding house.

Data snapshot

In 2006, we reviewed the deaths of 98 people with disabilities:

- 42 people lived in accommodation operated by the Department of Ageing, Disability and Home Care (DADHC)
- 40 people lived in accommodation services funded by DADHC
- 16 people lived in licensed boarding houses.

On average, the people who had lived in disability services were 53 years old when they died, ten years younger than licensed boarding house residents.

Men were represented more highly than women, particularly with licensed boarding house residents where only one woman died.

The people who died in 2006 who had lived in disability services had an intellectual disability as well as one or two other disabilities, typically mental illness and sensory impairment. They also tended to have co-existing health conditions that required ongoing management and regular review, such as swallowing difficulties, incontinence, and epilepsy. Their leading cause of death was respiratory illness. We have noted respiratory illness as the leading cause of death for the last four years.

We found that the licensed boarding house residents who died had generally been diagnosed with a mental illness, mainly schizophrenia. Their most common health condition was hypertension. The dominant cause of death for licensed boarding house residents was circulatory or cardiovascular disease; a trend consistent with previous years.

Key issues identified through our work

Risk management

Our reviews have found that certain deaths of people with disabilities in care may have been prevented if more effective systems were in place to identify and manage risks.

This year we found that, in many cases, risk assessments identified the risks individuals faced, but strategies were either not developed to address those risks, or provided inadequate guidance to staff about the action they needed to take. This included risk assessments that were not reviewed or updated as the person's needs changed and new risks emerged.

We highlighted particular concerns about how well services:

- responded to the risks faced by people who had falls, and
- identified and addressed the nutrition and swallowing risks faced by the people in their care, including a lack of action in response to a deterioration in a person's ability to swallow.

Our reviews also revealed the need for improvements in the management and review of medications. More than three-quarters of the people who died in 2006 were prescribed five or more medications, including 37 people who were prescribed 10 or more medications. Our reviews identified some problems with medication administration and records, as well as adverse drug interactions, and toxicity.

Meeting individual needs

Our work highlighted areas for improvement in how services coordinate and undertake planning to meet the health and other needs of people with disabilities living in care. This included instances where:

- there was no current individual plan.
- there was no current health care plan or other document to indicate the person's health needs and how they should be met.
- health-related documents contained inadequate information to guide staff, or were not updated following changes in the person's condition.

One of the areas of focus this year was people with dementia. While we noted some areas of good practice, we also identified some concerns, such as:

- inadequate assessment of the risks associated with dementia.
- lack of guidance to staff on how to support the person's increased needs.
- lack of a standard assessment process to diagnose dementia, particularly for people with Down syndrome.
- a tendency to link dementia to palliative care.

First aid

Our last three reports have consistently identified concerns about the response of services to critical incidents affecting people with disabilities in their care. This year we noted instances where:

- staff did not appear to have first aid training and were heavily reliant on the telephone instructions of the 000 operator.
- CPR was needed but was not commenced until the arrival of ambulance officers.

We consider that it should be mandatory that, regardless of the disability accommodation setting, there should always be at least one person on shift with current first aid qualifications.

However, at the moment there is inconsistency in what is required in terms of first aid qualifications in accommodation services for people with disabilities:

- residential support workers in DADHC-operated services are required to have first aid qualifications, including agency staff.
- there is currently no requirement for support workers in funded services to have current first aid qualifications.
- although there is a licence condition that requires at least one member of the licensed boarding house staff to be qualified to provide first aid, DADHC currently has no legal authority to enforce this condition.

We have consistently reported that many people with disabilities are vulnerable to critical incidents due to polypharmacy[1], significant chronic health concerns, and communication difficulties. We have also repeatedly pointed to instances where the first aid provided by services following critical incidents that ultimately resulted in deaths was inadequate. Consequently, we consider that the inconsistency in what is required in terms of first aid qualifications in accommodation services for people with disabilities is unacceptable.

Hospitalisation of people with disabilities

We noted some good examples of discharge planning for people with disabilities, including multidisciplinary involvement, clear guidance, and case conferences.

However, we had concerns about the adequacy of the assessment undertaken by hospital staff to determine the care available to the person following their discharge. There appeared to be limited consideration of whether the disability service was able to adequately meet the person's health needs, or whether it was appropriate to discharge the person back to their previous accommodation.

We also continued to identify instances where the actions of hospital staff in relation to end-of-life decision-making did not appear to be consistent with NSW Health guidelines, including limited documentation of the reasons for decisions, and lack of consultation with the person with a disability or their family.

Residential centres

This year, we had a closer look at the deaths in 2006 of 37 people who had lived in residential centres, formerly known as institutions.

We found good practice in relation to health care planning and family involvement, including examples of current, comprehensive health care plans that provided detailed guidance to staff, and proactive work on the part of staff to facilitate contact between individuals and their family.

But our work clearly highlighted the need for improvements in relation to individual planning, community access, and involvement in meaningful activities. We found that:

- some people did not have an individual plan or similar document to identify their needs and goals.
- around one-third of the people who had lived in residential centres did not appear to be involved in the individual planning process that concerned them, and, for six people, the planning process involved staff only.
- the quality of many of the individual plans was poor.
- for most of the people who had an individual plan, there was little or no evidence that staff had taken action to progress the goals.
- few residents appeared to leave the service grounds more than once a month. One person appeared to have had only one outing in his last 16 months, and three other people did not appear to have had any access to the community in at least the 12 months before their deaths. For two of these three people, it did not appear that they went outside or left the unit in which they lived.
- residents tended to receive all of their services, including employment, day activities, and community access, through their accommodation provider.

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[1] Treatment of a person with more than one medication.

Recommendations

Department of Ageing Disability and Home Care

Since our first report in 2004, we have made a range of recommendations to DADHC concerning the identification and management of risks, and meeting the individual needs of people in DADHC operated and funded accommodation services. We have also made recommendations in relation to DADHC's role in the monitoring of the licensed boarding house sector, and the provision of Boarding House Reform Program services. The department has responded to these recommendations with a number of initiatives.

Section 43(2)(c) of CS-CRAMA requires us to provide information in our annual reports to NSW Parliament about the implementation or otherwise of previous recommendations. In this context, we recommend that:

1. DADHC provide this office with progress reports in February 2008 and July 2008 in relation to:
    a. the roll out of the revised *Client Risk* policy to operated and funded services.
    b. finalising the revised *Decision-making and Consent* policy for release to operated and funded services.
    c. plans for the evaluation of the *Ensuring Good Nutrition* policy.
    d. finalising the draft Medication policy for release to operated services.
    e. outcomes of discussions with the NSW Divisions of General Practice regarding increasing GP awareness about the issues arising from polypharmacy in people with intellectual disabilities.
    f. outcomes of current work or any planned initiatives to support the implementation of the department's policy position regarding the care and support of people who are ageing.
    g. the commencement of a review of the screening tool for entry to licensed boarding houses.
    h. finalising the review of the Monitoring & Review tool associated with license condition 4 (minimum standards for record keeping) for licensed boarding houses.
    i. finalising the revised *Licensed Residential Centres Licensing, Monitoring and Closure* policy.
    j. the re-auspice of primary and secondary health care services, in relation to licensed boarding houses.

Medication administration in licensed boarding houses

This year, we identified concerns about the absence of record keeping in licensed boarding houses for medication administration. Under current licence conditions, there is no requirement for licensed boarding houses to maintain a record of the administration of residents' regular prescribed medications. Licensed boarding houses are required to record the administration of PRN medications.

2. DADHC should consider the development of specific initiatives under the primary and secondary health care program to promote good practice standards within licensed boarding houses relating to medication administration.

Community Access

This year we examined the records of people living in residential centres in terms of individual planning and community access. Overall, we found considerable variation in the quality of individual plans and levels of access to the community across both operated and funded residential centres. There were also instances where it was unclear how the community access reflected the interests of the resident.

3. In the context of the data available to the department arising from quality audits and the Integrated Monitoring Framework, DADHC should consider the issues raised in this report regarding community access.

   DADHC should advise of the outcomes of this consideration and whether it intends to take any action in relation to community access.

Response to critical incidents

In our report of reviewable deaths in 2004, we recommended that DADHC require that the services it operates, funds or licenses have at least one staff member on each shift with current first aid qualifications, and should provide assistance to funded and licensed services to achieve this requirement. In response, DADHC has advised us that in relation to operated services, extensive first aid training has been provided to disability staff in recent years. The department is also currently negotiating a requirement under the Residential Support Workers Award that all direct care staff employed by DADHC have first aid qualifications. Agency staff will also be required to have a first aid certificate.

In relation to licensed boarding houses, the department has advised that it has no legal authority to enforce the requirement under the notice of licence conditions that '*at least one staff member on each shift be qualified in first aid*'.

There is currently no requirement that support workers in funded services have current first aid qualifications. DADHC has advised us that there are no plans at this stage to provide assistance to funded services to ensure that at least one staff member on shift has current first aid qualifications.

4. DADHC should give consideration to setting a requirement that funded disability accommodation services have at least one person on shift with current first aid qualifications.
5. DADHC should report on the findings, and any actions arising from, the scoping of the status of staff with first aid qualifications in licensed boarding houses.

NSW Health

In our reports of 2005 and 2006, we made a number of recommendations to NSW Health that focused on improving the access of people with disabilities to health services, particularly in relation to their contact with the hospital system. NSW Health has responded to these recommendations through a number of initiatives.

Section 43(2)(c) of CS-CRAMA requires us to provide information in our annual reports to NSW Parliament about the implementation or otherwise of previous recommendations. In this context, we recommend that:

6. NSW Health provide this office with progress reports in February 2008 and July 2008 in relation to:
    a. actions arising from the findings of the evaluation of the *People with Disabilities: Responding to their needs during hospitalisation* policy directive.
    b. plans for the implementation and performance monitoring of the *Discharge Planning: Responsive Standards* policy at the Area level.
    c. actions arising from the evaluation of the implementation of *Advanced Care Planning and End of Life Care and decision-making* policy directives.
    d. completion and implementation of the *Discharge Planning Policy for Adult In-patient Mental Health Services.*
    e. the outcomes of the review of the Aged Care Assessment Program, relevant to the assessment processes for people with disabilities in NSW who are ageing.

Home Enteral Nutrition

This year, our reviews found that in some instances the management of enteral nutrition presented considerable challenges to disability services. In February 2007, a report by the NSW Greater Metropolitan Clinical Taskforce noted a lack of guidelines, policies and procedures for home enteral nutrition therapy across NSW health care facilities, and considered that minimum service level standards need to be developed.

7. NSW Health should advise us of any current or planned work in relation to developing guidelines, policies and procedures for home enteral nutrition therapy.

Department of Ageing Disability & Home Care and NSW Health

Last year, we made a number of recommendations to DADHC and NSW Health in relation to their joint work on a range of initiatives aiming to improve the overall framework and delivery of health and therapy services to people with disabilities, and its integration with the disability service system.

Section 43(2)(c) of CS-CRAMA requires us to provide information in our annual reports to NSW Parliament about the implementation or otherwise of recommendations made previously. In this context, we recommend that:

8. DADHC and NSW Health provide this office with progress reports in February 2008 and July 2008 in relation to:
    a. the outcome of the review of the existing arrangement with Aged Care Assessment Teams to undertake the screening of potential licensed boarding house residents using the licensed residential centre entry screening tool.
    b. finalisation of the evaluation undertaken by Health of DADHC's *Palliative Care* policy.
    c. outcomes arising from the Interdepartmental Committee on Disability addressing issues relating to the provision of therapy services, in particular:
        - the development of an interagency agreement regarding the provision of therapy services to people with disabilities in NSW,
        - strategies to enhance the recruitment, career path and staff retention for therapists and therapy assistants, and
        - the development of a procurement framework for therapy services delivered by non-government services.

d. the development of a strategic framework to improve the effectiveness of services for people with a dual diagnosis of mental illness and intellectual disability.

e. the development of a service framework to improve the health care of people with intellectual disabilities. In particular, action in relation to:

    - the development of multidisciplinary health teams across NSW, including nurse specialist positions for health care case management for people with intellectual disabilities.

    - the development of state-wide initiatives to support local specialist services, generalist primary and secondary health care services to enhance the training of health workers on health care for people with intellectual disabilities.

1. Introduction

1.1 Reviewable deaths

Part 6 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CS CRAMA) requires the Ombudsman to review the deaths of:

- a child in care.
- 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 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.

In our reviews, our focus is to identify procedural, practice and systems issues that may contribute to deaths, or that may affect the safety and wellbeing of people with disabilities in care or children at risk of harm. Our aim is to recommend relevant changes or new strategies that may ultimately help to prevent reviewable deaths.

We maintain a register of deaths that documents the characteristics and circumstances of the individuals who died. The register assists us to monitor trends and issues.

CS CRAMA also requires the Ombudsman to provide a report to Parliament each year on our reviewable deaths work. In the report, we must include data about deaths that occurred during the previous calendar year, recommendations that have arisen from the reviews, and information about the implementation of recommendations we have made in previous reports.

This fourth annual report will be released in two volumes. The first relates to the deaths in 2006 of people with disabilities in care. The second volume concerns child deaths.

In 2006, the deaths of 221 individuals were reviewable deaths. Of these, 98 deaths were of people with disabilities in care.

1.2 The scope of our work

Under CS CRAMA, the functions of the Ombudsman are to monitor and review reviewable deaths, to maintain a register of these deaths, and:

> *To formulate recommendations as to policies and practices to be implemented by government and service providers for the prevention or reduction of deaths of children in care, children at risk of death due to abuse or neglect, children in detention centres, correctional centres or lock-ups or persons in residential care (s.36 (1) (b)); and*
>
> *To undertake research or other projects for the purpose of formulating strategies to reduce or remove risk factors associated with reviewable deaths that are preventable (s.36 (1) (d)).*

Our responsibility for exploring how deaths of people with disabilities in care might be prevented or reduced can be met, in part, by considering how agencies and service providers have acted, and can act, to promote the health and wellbeing of these individuals.

Therefore, our reviews aim to identify any shortcomings in systems or practice that may have contributed to the death of a person who has lived in care, or that may expose others to risks in the future. This aspect of our work includes examining relevant records and information relating to the person who died, such as: coronial records about the person's death; government and non-government agency records about the history of their contact with the individual; and incident reports or internal reviews of the person's death. We may also request specific information from agencies to assist in our review.

In some cases, our reviews may highlight issues that warrant further inquiries about the conduct of an agency. Under the *Ombudsman Act 1974*, we can make preliminary inquiries for the purpose of deciding whether to investigate the agency, or we can move directly to investigate an agency's conduct in relation to the person that died.

CS CRAMA enables us to provide information arising from our reviews to certain agencies or service providers, and allows us to make reports to agencies about matters related to reviewable deaths, or issues that arise generally from our work.

Decisions to report to an agency on issues identified from an individual review, or to take further action under the *Ombudsman Act*, are based on a number of factors. Generally, we take these steps only where we identify concerns about practice, policy or procedure that we believe are current and warrant a response.

Particularly in relation to decisions about whether we should conduct preliminary inquiries and investigations, we consider the seriousness of the issues and whether they are systemic in nature. We also take into account any action that an agency may be taking to address the issues.

We may also delay any direct action where the matter is subject to an inquest by the NSW Coroner, or subject to internal review by the relevant agency.

1.3 Reviewing deaths

To assist in the identification of deaths that are reviewable, section 37 of CS CRAMA requires particular agencies to notify us 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 (DADHC) 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.

CS CRAMA also requires relevant government agencies and service providers to give us full and unrestricted access to the records that we need to perform our reviewable death function. This means that we are able to review all relevant documents about the characteristics and circumstances of the individuals who have died.

We have established two advisory committees to assist us in our work. The committees provide us with valuable advice on complex disability and child death matters, and on relevant policy and practice issues.

A list of the disability deaths advisory committee members is provided at Appendix 1. The committee assisted in the preparation of this report.

1.4 Overview of this report

This report concerns the deaths in 2006 of 98 people with disabilities who had lived in care, our work in relation to these deaths, and research and other work consistent with our functions.

Section 2 of the report, Progress 2002–2007, provides an overview of the issues that we have identified during our five years of carrying out this work, and commentary on agency progress in responding to these issues.

Section 3 of the report provides information about the characteristics and circumstances of the people with disabilities in care who died in 2006. Where relevant, we have compared information about deaths in 2006 with previous years (2003–2005).

In section 4, we discuss service practice and systemic issues arising from our reviews of the deaths of the people who died in 2006. These include the identification and management of health risks, as well as other matters relating to the response by agencies to meeting the health, behaviour, and social needs of the people who died. In this section we also consider some of the trends and themes that emerge from the 98 deaths, including specific issues associated with the deaths of people with dementia, and the need for risk management strategies to minimise the risk of people falling and injuring themselves.

Section 4 provides further comment on developments in the disability and health fields in response to our previous recommendations. Detailed commentary on the progress of all of our recommendations can be found at Appendix 3.

The outcome of the medical and service delivery review of the deaths of 27 people from respiratory illness in 2005 is reported in section 5.

We use case studies throughout this report — however, we do not identify any individual who has died.

1.5 Developments since our last report

Since our last report, there have been four key developments relating to services for people with disabilities in care.

- In May 2006, the NSW Government released a 10 year plan for disability services titled *Stronger Together*, and committed $1.3 billion of additional funds over 5 years to improve the capacity of the services to respond to the needs of people with disabilities. *Stronger Together* includes plans to improve and/or expand on services in areas such as day programs, therapy, accommodation, ageing, and health care.

  This year has seen the implementation of the plan and the roll out of the first $154 million in additional funding. In terms of therapy services, for example, implementation of *Stronger Together* has created 600 new therapy places, and established partnerships with providers of therapy services to improve recruitment, training, professional practice, and service delivery.

- In February 2007, the NSW Government released an interagency policy and service delivery framework for disability services in NSW: *Better Together — A new direction to make NSW Government services work better for people with a disability and their families 2007–2011.*

  Better Together resulted from a review of services across 12 NSW Government departments, which identified a number of areas in which improvements could be made to the way services are delivered to people with a disability and their carers. Eight priority areas for work were identified, including therapy and early intervention.

- In January 2007, NSW Health and DADHC released a discussion paper on the development of a service framework to improve the health care of people with intellectual disabilities.

  The paper proposes a service framework that aims to improve the health care provided to people with intellectual disabilities across a range of areas, including community health, acute health care, and specialist health services.

  The discussion paper canvasses a number of options for the key elements of the service framework, including intellectual disability health clinics, networks of specialist Clinical Nurse Consultants, and creation of a statewide specialist centre for support and clinical leadership.

- The other notable development since our last report is the Commonwealth Government's decision to add to the Medicare Benefits Schedule an item allowing for an annual comprehensive health assessment for people with intellectual disabilities. The new assessment item, which provides a structured clinical framework for GPs to assess the individual's overall health and plan for their long-term care, commenced on 1 July 2007.

DADHC and NSW Health have undertaken other specific work in the past year that is relevant to people with disabilities in care. Information regarding this work is outlined in Appendix 3.

2. Progress 2002–2007

From November 1998 until December 2002, the Community Services Commission reviewed the deaths of people with disabilities who had lived in care. While this was not a legislated function, it proved to be valuable in identifying service and systems deficiencies, and for providing a catalyst for service improvement.

In 2002, new community services legislation conferred responsibility on the Ombudsman for reviewing the deaths of people with disabilities in care. With this responsibility came significant powers.

This new legislation required the deaths of people with disabilities in care to be notified to both the Coroner and the Ombudsman. The jurisdiction of reviewable deaths also extended to those who, at the time of their deaths, were living in licensed boarding houses.

The amendments also enabled the Ombudsman and Coroner to transfer information about deaths, and ensured that the Ombudsman had unrestricted access to the records held by the Coroner and service providers.

We are one of very few agencies in the world with the function of reviewing the deaths of people with disabilities in care, and our role is unique in terms of its scope and the breadth of our legislative powers.

In reviewing service policy, practice, and systems, our aim is to identify gaps in service delivery, and make recommendations aimed at helping to prevent or reduce the premature deaths of people with disabilities in care.

We bring areas requiring improvement to the attention of the relevant services or agencies, and monitor their response.

One of the strengths of our work is that, by drawing together information from a range of agencies about people whose deaths we review, we are well placed to gain a holistic perspective on the services delivered and to identify areas for service improvement.

Over the past five years we have identified a number of issues of concern. These have included deficiencies in service practice in relation to the assessment and management of the risks for individuals in care; service coordination in response to often challenging health conditions; and the need to ensure appropriate responses to critical incidents.

We have also identified broader systems issues that can present tremendous challenges to people with disabilities and the services supporting them, such as: the availability of, and access to, important health services like therapy and mental health services; and the provision of services to people with disabilities who are ageing.

In response to many of the issues we have raised, there has been considerable work undertaken by agencies to improve the service delivery to, and the outcomes for, people with disabilities in care.

Some important areas of progress are:

- The development and implementation of minimum requirements for identifying and addressing the nutrition and swallowing risks faced by people with disabilities living in DADHC-operated and funded accommodation services.

  The *Ensuring Good Nutrition* policy provides clear guidance to these services, and provides for staff to be accountable in meeting residents' swallowing and nutrition needs.

- The development of key policies by NSW Health to guide service provision to people with disabilities during hospitalisation. These policies provide guidance to the staff of health services around three key areas: discharge planning, end-of-life decision-making, and the provision of care to people with disabilities in hospital.

  The NSW Health directives outline specific requirements in relation to meeting the needs of people with disabilities in hospital, and provide the means for addressing many of the concerns that we have raised in our four previous annual reports, including the need for adequate:

  - assessment of risks,
  - consultation with people with disabilities and their families, and
  - support and referral on discharge.

- An increased focus on identifying and meeting the health needs of licensed boarding house residents. DADHC has developed specific service requirements, key performance indicators, and a means of monitoring the delivery of primary and secondary health care services under the Boarding House Reform Program. This has strengthened the accountability and quality assurance requirements of those services.

  DADHC has also funded additional caseworkers to support licensed boarding house residents, and commenced a review of the health needs of residents in the inner-west area of Sydney.

Over the five years in which we have been carrying out our review work, there has been considerable change in the disability sector, with a greater focus on interagency and whole-of-government work to meet the needs of, and improve the outcomes for, people with disabilities.

As noted previously, in May 2006, the NSW government committed $1.3 billion of additional funds to improve the capacity of services to respond to the needs of people with disabilities, and 12 government departments have made plans to improve their services across eight priority areas focused on meeting the needs of people with disabilities and their carers.

In addition, NSW Health and DADHC have commenced work on developing a service framework to better meet the health care needs of people with intellectual disabilities. This work brings together many of the recommendations we have made, and has the potential to progress longstanding concerns in the coordination and delivery of health related services to people with intellectual disabilities in NSW.

Recently, we sought DADHC and NSW Health's views on our work in reviewing the deaths of people with disabilities. In particular, we wanted to know their views on whether our work has contributed to improvements in the agencies' capacity to respond effectively to the needs of people with disabilities living in care.

NSW Health told us that our work has had a positive impact on the provision of quality care and support to people with disabilities, and pointed to three key initiatives that had indirectly or directly resulted from our recommendations:

- An independent evaluation on the implementation of the *People with Disabilities: Responding to their needs during hospitalisation* policy directive across Area Health Services.
- The development of the NSW Health and DADHC discussion paper on the development of a service framework to improve health care for people with intellectual disabilities, including a strong focus on developing training of health care workers on the health care of people with disabilities.
- Progress in relation to the Interagency Standing Committee on Disability's work on access to health services for people with disabilities. This includes the development of the whole-of-government strategy *Better Together* — involving improved coordination, planning and delivery of services for people with disabilities and their families, and improvements to the whole service system.

DADHC told us that the recommendations in the reviewable disability deaths annual reports have often complemented the department's own identified priorities for improvements to systems, policy review and service delivery practice, and advised that the department has developed a robust system for examining its own business.

DADHC indicated that it had implemented a range of initiatives in response to our recommendations, including first aid training and a standardised record keeping system for client information in DADHC services, and noted that the reviewable disability death function has provided a useful function in its oversight of licensed boarding houses.

DADHC also highlighted examples of where our reviewable disability death function has had a positive impact on its practice and policy, including:

- reviews of the *Epilepsy, Health Care, Abuse and Neglect, Client Risks, Medication*, and *Decision Making and Consent* policies,
- external evaluation of the *Ensuring Good Nutrition* and *Palliative Care* policies, and
- implementation of the Inclusive Communication and Behaviour Support (ICABS) project.

However, DADHC also noted that '*the recommendations — and subsequent reporting requirements — resulting from the reviewable disability death function's reports can at times impinge on strategies for improvement in areas the Department itself has identified as priorities*'.

DADHC further advised that, while it had addressed any critical issues arising from the deaths of individuals in a timely fashion, '*our experience is that there is often a significant length of time from an individual's death and the commencement of a review by your Office*'.

We acknowledge the importance of timely reviews and action in response to the deaths of people with disabilities in care. Issues of timeliness, and our consequent ability to inform service practice are considerations in our reviews and the action we determine to take as a result. There are a number of factors that impact on the timeliness of our reviews, including Coronial processes, and the need for reviews to incorporate external medical review.

3. Deaths of people with disabilities in care in 2006: Data

In 2006, the deaths of 98 people with disabilities in care in NSW were reviewable. Of the 98 people who died:

- 42 people lived in DADHC-operated accommodation,
- 40 people lived in DADHC funded accommodation[2] operated by 27 funded services, and
- 16 people lived in 10 licensed boarding houses.

Where relevant, we have separated the data relating to the deaths of people in DADHC-operated or funded services (referred to in this report as 'disability services') from the data relating to the deaths of people in licensed boarding houses.

Table 1: Number of deaths and number of people accommodated by residence type

Type of residence	No. of people accommodated	No. of deaths in 2006	Percentage of population who died in 2006	Percentage of reviewable deaths in 2006
Group home (funded)	2111	30	1.4	30.6
Group home (DADHC)	1355	14	1.0	14.3
Residential centre (funded)[3]	559	10	1.8	10.2
Residential centre (DADHC)[4]	1153	28	2.4	28.6
Licensed boarding house	855	16	1.9	16.3

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[2] One young person who lived in DADHC funded accommodation was under the care of the Minister of Community Services, and the Department of Community Services funded his placement.

[3] Includes large residential centres, small residential centres, and hostels.

[4] Includes large and small residential centres.

The separation of these two groups reflects the differences in the legislation and service provision framework.

3.1 Characteristics and circumstances of the people who died

In this report, we have compared the characteristics and circumstances of those who died in 2006 with the information from the previous three years.

The profile relating to a considerable amount of this information has been very consistent over the past four years.

On average, the people who died in 2006 who had lived in disability services:

- Were 53 years old, slightly higher than last year's average of 49 years.
- Were more likely to be men, but women died at an earlier age.
- Had lived in care for 30 years and had not moved recently.
- Had an intellectual disability as well as one or two other disabilities, typically mental illness and sensory impairment.
- Had co-existing health conditions that required ongoing management and regular review, and were receiving five or more medications.
- Required support with the activities of daily living, including mobility and eating and drinking, and required another person to make decisions and/or provide consent to medical and dental treatment.

As in the previous three years, respiratory illness was the leading cause of death for people in the care of disability services.

On average, the people who died in 2006 who had lived in the care of licensed boarding houses:

- Were 63 years old, unchanged from 2005.
- Were much more likely to be men; only one female boarding house resident died in 2006.
- Had lived in care for 14 years and had not moved recently.
- Had been diagnosed with a mental illness, mainly schizophrenia, and were smokers.
- Provided their own consent to medical and dental treatment, and were receiving five or more medications.

As with the previous three years, the leading cause of death for boarding house residents was cardiovascular disease.

A more detailed description of the characteristics of the people who died is in Appendix 2.

3.2 Cause of death

The following tables identify the primary cause of death for 68 of the 98 people who died in 2006, categorised according to ICD-10-AM codes.[5] At the time of writing, the Coroner had not made a cause of death determination for the other 30 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).

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

Table 2: Number of deaths in each ICD-10-AM cause of death category

Primary cause of death for disability services residents

Diseases of the respiratory system (J00-J98) Includes diseases of the combination of organs and tissues needed for breathing. For example, influenza, pneumonia, bronchitis, asthma, pneumonitis, pulmonary oedema.	**22**
Diseases of the circulatory system (I00-I99) Includes diseases 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, cardiac arrest.	**10**
Neoplasms (C00-D48) A new and abnormal growth, any benign or malignant tumour, often referred to as cancer.	**9**
Diseases of the nervous system (G00-G98) Includes diseases that can cause a decrease in body activity by affecting the nerves and their function. For example, cerebral palsy, meningitis, encephalitis, Parkinson's disease, Alzheimer's disease, epilepsy, hydrocephalus.	**4**
Injury, poisoning and certain other consequences of external causes (S00-T98) Includes injuries such as fractures, traumatic amputation and burns, poisoning by overdose or the wrong substance taken in error, toxic effects of non-medicinal substances, effects of deprivation, and complications of surgical and medical care.	**3**
Certain infectious and other parasitic diseases (A00-B99) Diseases generally recognized as communicable or transmittable. For example, tuberculosis, tetanus, meningococcal, septicemia, influenza, and other acute respiratory infections.	**2**
Endocrine, nutritional and metabolic causes (E00-E89) Diseases that can affect the production of hormones, breakdown of substances that can in turn affect the growth and functioning of the body. For example, hypothyroidism, diabetes mellitus, malnutrition, testicular dysfunction, obesity.	**2**
Diseases of the genitourinary system (N00-N99) Diseases that affect the reproductive system and also the urinary system. For example, renal failure, cystitis, and urethritis.	**2**
Diseases of the digestive system (K00-K92) Includes diseases that affect the breakdown of food for absorption by tissue in the body. For example, gingivitis and periodontal disease, oesophagitis, gastro-oesophageal reflux, haematemesis.	**1**
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99) Includes signs and symptoms, abnormal results of clinical or other investigative procedures, and other conditions not classifiable elsewhere. For example, dyspnoea, asphyxia, sudden death, dysphagia, senility.	**1**
Not yet determined	**26**
Total	**82**

Number of deaths in each ICD-10-AM cause of death category

Disability services

The NSW Coroner has provided the cause of death for 56 of the 82 people who had lived in disability services (70%). The cause of death has not yet been determined for 26 people.

As has consistently been the case over the last four years, the foremost cause of death of disability services residents, was diseases of the respiratory system. Including antecedent information, the deaths of 26 disability services residents were related to respiratory illness.

The second most dominant cause of death among disability services residents was diseases of the circulatory system, including coronary artery atherosclerosis,[6] intracerebral

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[6] Atherosclerosis is an accumulation of fatty materials on the inner lining of the arteries. The resulting blockage restricts blood flow to the heart.

haemorrhage,[7] and cardiomegaly.[8] Including antecedent information, the deaths of 11 disability services residents were related to circulatory disease.

Table 3: Primary cause of death for licenses boarding house residents

Diseases of the circulatory system (I00-I99) Includes diseases 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, cardiac arrest.	**7**
Diseases of the digestive system (K00-K92) Includes diseases that affect the breakdown of food for absorption by tissue in the body. For example, gingivitis and periodontal disease, oesophagitis, gastro-oesophageal reflux, haematemesis.	**2**
Neoplasms (C00-D48) A new and abnormal growth, any benign or malignant tumour, often referred to as cancer.	**1**
Diseases of the nervous system (G00-G98) 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**
Injury, poisoning and certain other consequences of external causes (S00-T98) Includes injuries such as fractures, traumatic amputation and burns, poisoning by overdose or the wrong substance taken in error, toxic effects of non-medicinal substances, effects of deprivation, and complications of surgical and medical care.	**1**
Not yet determined	**4**
Total	**16**

The deaths of nine people were related to cancer, including three people who had lung cancer.

Licensed boarding houses

The NSW Coroner has provided the cause of death for 12 of the 16 people who had lived in licensed boarding houses.

Of these 12 people, the leading cause of death was circulatory disease, including heart failure due to an enlarged heart, cardiomyopathy,[9] and myocardial infarction.[10] Including antecedent information, the deaths of eight licensed boarding house residents were related to circulatory disease.

Over the past four years, circulatory system disease has consistently been a key feature in the deaths of licensed boarding house residents.

The deaths of two residents were due to diseases of the digestive system — one resident died as a result of a bowel obstruction caused by volvulus,[11] and the other person died from acute gastric haemorrhage due to stomach lesions.

The deaths of the remaining three people were due to Sudden Death in Epilepsy (SUDEP), suicide by hanging, and end stage adenocarcinoma.

Deaths related to respiratory illness

As noted above, the dominant cause of death for people with disabilities in care in NSW has consistently been related to respiratory illness. In 2006, respiratory illness was either the primary or antecedent cause of death for 26 of the 69 people for whom we have cause of death information.

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[7] Intracerebral haemorrhage is a cause of some strokes, in which vessels within the brain begin bleeding.
[8] Cardiomegaly is enlargement of the heart.
[9] Cardiomyopathy is a type of heart disease in which the heart muscle is abnormally enlarged, thickened, and/or stiffened.
[10] Myocardial infarction is also known as heart attack.
[11] Volvulus is an abnormal twisting of the intestine causing obstruction.

However, for five of these 26 individuals, death due to respiratory illness came at the end of palliative treatment. Our further consideration of deaths related to respiratory illness has therefore focused on the remaining 21 people.

All of the 21 people lived in the care of disability services, including 14 people who had lived in residential centres. Four of the people whose deaths were related to respiratory illness had Down syndrome.

Of the 21 people whose deaths were related to respiratory illness:

- Pneumonia or bronchopneumonia was the primary or antecedent cause of death for eight people.
- Aspiration pneumonia was the primary or antecedent cause of death for seven people.
- One person died from acute respiratory failure as a result of steroid dependent asthma.
- Preliminary coronial information indicates that one person choked on food.
- Chronic obstructive airways disease was the antecedent cause of death for one person, and a significant condition possibly contributing to the deaths of two other individuals.
- Cerebral palsy, quadriplegia, spastic quadriplegia, and/or multiple sclerosis was the antecedent cause of death for three people who died from respiratory illness, and a significant condition possibly contributing to the respiratory deaths of another three people.

Research indicates that there are a number of risk factors associated with the development of respiratory illness. These factors include swallowing difficulties (dysphagia), requiring assistance with meals, enteral feeding, limited mobility, being under or over weight, smoking, requiring assistance with oral care, and receiving multiple medications.[12]

Conversely, influenza and pneumonia vaccinations have been shown to reduce morbidity.[13]

Most of the 21 people whose deaths were related to respiratory illness:

- Had swallowing difficulties and required assistance with eating and drinking (17 people).
- Had limited mobility (20 people), including 15 people who were reliant on a wheelchair for mobility.
- Had only some or no teeth (14 people). Only nine of the 21 people whose deaths were related to respiratory illness were recorded as having had a dental review.
- Had recurrent respiratory infections (13 people). Less than half of these 13 people had seen a respiratory specialist (five people).
- Had received the influenza vaccination in the 12 months prior to their death (15 people). However, only one-third of the people whose deaths were related to respiratory illness had received the pneumococcal vaccination.
- Were taking more than 10 medications.
- Of the 15 people for whom weight and height information was available, most were within the healthy weight range. Five people were recorded as being overweight or obese, and one person was underweight.

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[12] Bohmer, Klinkenberg-knol, Niezen-de Boer, Meuwissen and Meuwissen (1997) “Dental Erosions and GORD in Institutionalised Intellectually Disabled Individuals” in *Oral Diseases*, 3: 272-275, Langmore, Terpenning, Schork, Chen, Murray, Lopatin and Loesch (1998) “Predictors of Aspiration Pneumonia? How Important is Dysphagia” in *Dysphagia*, 13: 69-81 and Limeback (1998) “Implications of Oral Infections on Systemic Diseases in Institutionalised Elderly with a Special Focus on Pneumonia” in *Annals of Periodontology*, v.3, no. 1, July 1998.

[13] Centre for Research and Clinical Policy (2000), *Current Situational Analysis: Respiratory Disease*, NSW Health Department.

Seven people were reliant on enteral nutrition, and just over one-third of the people whose deaths were related to respiratory illness were reported to have gastro-oesophageal reflux disease (GORD — eight people). GORD is discussed further in section 3.3.

We discuss respiratory deaths further in section 5, in our review of deaths in 2005 from respiratory illness.

Deaths due to aspiration[14]

The deaths of nine people in 2006 were related to aspiration[15], and all lived in the care of disability services.

Eight of the nine people had swallowing difficulties and required assistance with their meals, and two individuals relied exclusively on enteral nutrition.

Eight people had a current nutrition and swallowing checklist, but the checklists for two people did not include an action plan despite identified risks. Eight of the nine people had an eating and drinking plan or equivalent guiding document.

Two-thirds had seen a speech pathologist, and most had been reviewed in the 12 months prior to their deaths.

As reported last year, GORD is also associated with death due to aspiration pneumonia. Four of the nine people whose deaths were related to aspiration pneumonia had GORD, two of who were receiving medication for the condition. All four people were recorded as having gastroenterology and speech pathology reviews.

Deaths due to cardiovascular disease

Cardiovascular 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.[16]

Deaths due to cardiovascular (or circulatory) disease have consistently remained the second most dominant cause of death among disability services and the leading cause of death for licensed boarding house residents.

In 2006, cardiovascular disease was the primary or antecedent cause of death for 14 of the 68 people for whom we have received cause of death information.[17] Cardiovascular disease was also identified as a significant condition possibly contributing to the death of one person.

In our *Report of Reviewable Deaths in 2004*, we identified major preventable risk factors for cardiovascular disease such as tobacco smoking, high blood pressure, high blood cholesterol, insufficient physical activity, overweight and obesity, poor nutrition and diabetes.[18]

Licensed boarding house residents

Just over half of the 15 people whose deaths in 2006 were related to cardiovascular disease had lived in licensed boarding houses. Of these eight people, four had been diagnosed with heart problems, such as ischaemic heart disease, and all of these four people were taking medication for the condition. Two of the licensed boarding house residents with known cardiac problems had cardiology reviews.

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[14] Aspiration refers to the entry of material (food, liquid, or saliva) into the airway. 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.

[15] Aspiration was the primary or antecedent cause of death for 11 people, but two people were excluded from consideration in this section as they died at the end of palliative treatment. Members of our Advisory Committee have advised that it is likely that more of the respiratory deaths are associated with aspiration and / or reflux than this figure suggest as chronic aspiration is often under-reported.

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

[17] The deaths of another three people were related to circulatory disease, but were excluded from this discussion as the cardiovascular event was the end-point of another illness. For example, the death of one person was excluded as their cardiac arrest was related to a bone marrow operation.

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

Of the eight boarding house residents whose deaths were related to cardiovascular disease, all but one person smoked and over one-third had high blood pressure. Three of the five residents whose weight and height information was available were overweight or obese.

Disability services residents

Of the seven disability services residents whose deaths were related to cardiovascular disease, three had been diagnosed with cardiac problems, and all three were receiving medications for the condition. Two of the disability services residents with known heart problems had cardiology reviews.

Almost three-quarters of the disability services residents whose deaths were related to cardiovascular disease were overweight or obese. Over half had high blood pressure, and three people had limited mobility. Only two of the disability services residents smoked.

3.3 Health conditions

Many of the people who died in 2006 had a number of co-existing health conditions, indicating the importance of a coordinated approach to supporting the health needs of people with disabilities in care. The following tables identify the most commonly reported health conditions for disability services and licensed boarding house residents.

Epilepsy

Half (41) of the 82 disability services residents who died in 2006 were reported to have epilepsy. Two licensed boarding house residents were also recorded as having epilepsy.

Last year we noted a number of people for whom epilepsy was a feature in their death, including five people whose deaths were due to Sudden and Unexpected Death in Epilepsy (SUDEP).

Table 4: Health conditions most commonly reported for disability services residents

Condition	Percentage
Dysphagia	61
Double incontinence	55
Epilepsy	50
Constipation	46
Recurrent respiratory illness	41
GORD	38
Osteoporosis	23
Cancer	19
Asthma	16
Hypertension	16
Diabetes	16
Hypothyroidism	15
Arthritis	15

Table 5: Health conditions most commonly reported for licensed boarding house residents

Condition	Percentage
Hypertension	50
GORD	19
Asthma	12
Dysphagia	12
Cancer	12
Epilepsy	12
Recurrent respiratory illness	12

This year, epilepsy was the primary or antecedent cause of death for six people, and a significant condition possibly contributing to death for another seven individuals.

Of the six people where epilepsy was recorded as the primary or antecedent cause of death, one person died from SUDEP, and one person died from status epilepticus.[19] Two people died from aspiration as a result of epileptic seizures. Epilepsy was a long-standing condition for each of the six individuals.

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[19] Status epilepticus is a state of continuous seizure activity.

The majority of people for whom epilepsy was recorded as a significant condition possibly contributing to their deaths died from respiratory illness.

Medical practitioner review

Management of epilepsy typically involves the use of anticonvulsant medication and should also include regular review by a medical practitioner.

As we reported last year, the Epilepsy Association of Australia recommends annual review by a neurologist for all people with a diagnosis of epilepsy.

At the time the deaths occurred, DADHC's *Managing Client Health* and *Support of Clients with Epilepsy* policies required that an epilepsy management plan be completed for all residents of DADHC-operated accommodation and respite services, and that a neurologist needed to sign the plan. The policy indicated that the plan was only to be signed by a GP if the person was unable to access a neurologist (such as people accessing rural and remote services).

Of the 41 disability services residents who had epilepsy, 13 did not appear to have been reviewed at any point by a neurologist. Eight of these 13 people lived in DADHC funded services. Of the two boarding house residents who had epilepsy, one had not seen a neurologist.

All of the people whose deaths were directly related to their epilepsy had seen a neurologist.

In May 2007, DADHC released the revised *Epilepsy* policy and procedures for DADHC-operated and funded accommodation services. This new policy requires that the epilepsy management plan must be developed in consultation with the person's doctor/s, and that it must be signed by the person's GP or neurologist.

Risk assessment and epilepsy management plans

Effective management of epilepsy is reliant on an assessment of the individual, the risks associated with that person's epilepsy, and control of those risks.

In 2006, the key guiding documents in relation to epilepsy management were the *Support of Clients with Epilepsy* and *Managing Client Health* policies. These policies required DADHC-operated accommodation services to develop epilepsy management plans for all residents with epilepsy.

Of the 41 disability services residents who had epilepsy, over two-thirds (28) had an epilepsy management plan or similar guiding document.

Of the 13 people who did not have an epilepsy management plan, four people lived in DADHC-operated accommodation, and nine lived in the care of funded services. There was no notable difference between group homes and residential centres.

Neither of the two boarding house residents had an epilepsy management plan or similar guiding document.

As noted above, DADHC has released a revised *Epilepsy* policy. It is a minimum requirement of the policy that all clients with epilepsy have an epilepsy management plan, and that practice and risk management systems for clients with epilepsy are audited every six months.

Osteoporosis

Since 2003, the number of people in disability services who died and who were recorded as having osteoporosis has continued to increase in small increments, from 14% in 2003 to 23% in 2006.

In 2006, 19 people had osteoporosis, and all had lived in the care of disability services. Almost all of these people (17) had limited mobility, including eight people who required a wheelchair.

Five of the 19 people with osteoporosis experienced recurrent falls. Four people with osteoporosis had at least one fracture in the five years before their deaths, including two people who experienced falls.

Almost two-thirds of the people (12) with osteoporosis were receiving medication for that condition. Three people who were reported to have osteoporosis were also reported to have vitamin D deficiency.[20]

Gastro-oesophageal reflux disease

Gastro-oesophageal reflux disease (GORD) is a condition in which food travels backwards from the stomach to the oesophagus. This can cause symptoms such as heartburn, regurgitation, vomiting, sore throat, coughing, and difficulty swallowing.

In 2006, over one-third (31) of the disability services residents were reported to have GORD — an increase in the number of people reported with this condition in previous years.

The deaths of eight people who had GORD were related to respiratory illness.[21]

Risk factors associated with GORD include alcohol and tobacco use, enteral feeding, immobility and constipation.[22] When we considered these risk factors against the 31 disability services residents with GORD, we found that:

- Over three-quarters (24) had limited mobility, including 16 people who relied on a wheelchair for mobility.
- Over half (18) were recorded as having constipation.
- Below one-third (9) were recorded as consuming alcohol, and only three disability services residents were recorded as being current smokers.
- Seven people received enteral feeding. This represents two-thirds of all of the people who died in 2006 who received enteral nutrition.

We have previously reported that positive management of suspected or diagnosed GORD includes referral for a review by a gastroenterologist, prescription of GORD medication, and review of eating and drinking by a speech pathologist.

- Just over a third (12) of the 31 disability services residents with GORD had seen a gastroenterologist, and most of these individuals were reviewed in the 12 months prior to their deaths.
- Nineteen people with GORD had seen a speech pathologist, and most of these individuals were reviewed in the 12 months prior to their deaths.
- Most of the 31 people (26) were receiving medication to treat GORD.

Three licensed boarding house residents were reported to have GORD. The only risk factors for GORD that were present for these three people were smoking (one person), and limited mobility (one person).

Each of the three boarding house residents with GORD was receiving medication for the condition, but none were reported to have seen a gastroenterologist.

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[20] Vitamin D is important to form strong bones and teeth, and prevent rickets and osteoporosis. It is produced by the skin through access to sunlight, and found in certain foods, such as milk, fish and eggs.

[21] The deaths of 11 people who had GORD were related to respiratory illness. However, we did not include the deaths of three people with GORD as respiratory deaths, as their death from respiratory illness was at the end of palliative care.

[22] Developmental Disabilities Digest www.ddhealthinfo.org and Bohmer, Klinkenberg-Knol, Niezen-de Boer and Meuwissen (2000) 'Gastroesophageal Reflux Disease in Intellectually Disabled Individuals, How Often, How Serious, How Manageable?' in *The American Journal of Gastroenterology*, v.95, i. 8.

Hypothyroidism

In 2006, hypothyroidism was reported as a health condition for 12 people. Hypothyroidism is caused by an under-active thyroid gland failing to secrete enough hormones into the bloodstream.

People with Down syndrome are prone to developing thyroid problems, including hypothyroidism. Of the 12 people in disability services who were reported to have hypothyroidism, just under half (5) had Down syndrome.

Symptoms of hypothyroidism can include unexplained weight gain, depression, intolerance to cold temperatures, slow heart rate, fatigue and low energy levels, and constipation.

Weight and height information was available for 11 of the 12 disability services residents with hypothyroidism, and six of these individuals were overweight or obese. Five people with hypothyroidism experienced chronic constipation, and a quarter had been diagnosed with depression.

Hypothyroidism is typically treated with lifelong hormone replacement. Of the 12 people reported to have hypothyroidism, eight people received medication for that condition.

The CHAP tool provides a prompt to staff to record the date of the last thyroid function test for people with Down syndrome, for the information of the GP during the annual health assessment.[23]

3.4 Nutrition and swallowing

Nutrition and swallowing issues are significant for many of the people whose deaths we review.

Dentition

In previous reports we have highlighted the connection between poor oral health and the development of chronic respiratory disease. We reported that poor oral/ dental status has been identified as a major risk factor for the development of aspiration pneumonia.

Almost three-quarters (59) of disability services residents who died in 2006 had all or some of their teeth. Half (8) of the boarding house residents who died in 2006 had all or some of their teeth, and one-third (5) had a dental aid, such as dentures.

In 2006, the key document guiding staff practice around dental reviews was DADHC's *Managing Client Health* policy, which only applied to DADHC-operated accommodation services. This policy required that people in the care of DADHC-operated services had a dental review every six months.

Just over half of the people who had lived in the care of disability services did not appear to have received any form of dental review in the 12 months prior to their death. Of the 45 people who had not had a dental review, 32 people lived in the care of funded services, and 13 people lived in DADHC-operated accommodation.

Over one-third (35) of the people who had lived in the care of disability services had seen a dentist in the 12 months prior to their death. The proportion of people who had seen a dentist within the 12 months prior to their death (42%) has increased in comparison to previous years when approximately 26% of disability services residents saw a dentist in the 12 months prior to their death.

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[23] The Comprehensive Health Assessment Program (CHAP) is a tool that is used by the person's Keyworker and GP to identify and assess their health needs on an annual basis.

Only two licensed boarding house residents appeared to have seen a dentist, and only one of these individuals had seen a dentist in the 12 months prior to their death. Over the previous three years the number of licensed boarding house residents accessing dental services has been constant, with only one person in 2004 and one person in 2005 seeing a dentist.

In March 2007, DADHC released the revised *Health Care* policy, which applies to DADHC-operated and funded accommodation services. This policy requires that clients in DADHC-operated accommodation receive an annual dental review. Minimum requirements in relation to dental reviews for residents of funded accommodation are not outlined in the policy.

Enteral nutrition

Eleven people who died in 2006 received enteral nutrition. All had lived in the care of disability services, including six people who had lived in residential centres.

The proportion of people reliant on enteral nutrition has remained largely unchanged over the four years of data, averaging 12% of the people who died each year.

Of the 11 people who died in 2006 who received enteral nutrition:

- Nine people had a percutaneous endoscopic gastrostomy (PEG) tube, One person also received food orally as well as via a feeding tube.[24]
- One person had a percutaneous endoscopic jejunostomy (PEJ) tube.
- One person had both PEG and PEJ tubes.

Height and weight information was available for 10 of the 11 people who were receiving enteral nutrition. Most of the people (7) were in the healthy weight range.

Two people were underweight, including the person who also received food orally. The person who had both PEG and PEJ tubes was very underweight.

Only one of the people receiving enteral nutrition had not seen a dietician in the 12 months before their death. That person was in the healthy weight range, had a PEG, and lived in a funded group home.

The majority of the people (9) who were reliant on enteral nutrition did not appear to have had a dental review at any point. Of the two people who had received a dental review, one person had not seen a dentist for over two years.

The Coroner has issued the cause of death in relation to 10 of the 11 people who had received enteral nutrition. All were respiratory-related, including five people whose deaths were due to aspiration pneumonia.[25]

Malnutrition was referred to in the cause of death information for two people. For one person it was the primary cause of death as a result of a malfunctioning PEG feed delivery system,[26] and for the other person it was identified as a significant condition that possibly contributed to the death from recurrent pneumonia.

Enteral nutrition is discussed further in section 4.2.

Swallowing difficulties

Fifty of the 82 people in disability services had swallowing difficulties, as did two licensed boarding house residents. In total, just over half of all people with disabilities in care in NSW who died in 2006 had swallowing difficulties.

In previous years, the number of people with dysphagia has been fairly constant, averaging around half of the people who died each year.

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[24] A PEG tube feeds directly into the stomach, whereas a PEJ tube feeds into the jejunum (part of the small intestine).

[25] The insertion of a feeding tube does not eliminate aspiration risks — the person may still aspirate from saliva and/or reflux.

[26] No post-mortem was conducted following this person's death.

Risk identification and management (nutrition and swallowing checklist)

The *Ensuring Good Nutrition* policy requires DADHC-operated and funded disability accommodation services to identify and address individual risks related to food intake, nutrition, and nutrition support needs by using an appropriate checklist, such as the nutrition and swallowing checklist.

The policy recommends that the checklist be completed annually in tandem with the individual planning process.

Of the 50 disability services residents with swallowing difficulties, most (41) had a current nutrition and swallowing checklist. The nine people without a current nutrition and swallowing checklist lived in funded accommodation, and most lived in group homes.

As we did last year, we considered the quality of the nutrition and swallowing checklists for people with swallowing difficulties who had lived in the care of disability services. We assessed:

- whether the checklist recorded all of the swallowing and nutrition risks of the individual; and
- where risks were identified, whether steps were taken to address those risks (such as completion of the action plan at the end of the checklist).

We found that over half (58%) of the completed nutrition and swallowing checklists recorded all of the known risks for the individuals and addressed them in the action plan. This represents a slight increase on 2005, where the nutrition and swallowing risks had been comprehensively assessed for 50% of the disability services residents who died.

In six of the 41 nutrition and swallowing checklists, the action plan did not address all of the risks that had been identified. Most of these people (5) lived in DADHC-operated accommodation.

For just under one-quarter (9) of the people with a nutrition and swallowing checklist, there was no indication that action was taken in response to the identified risks, including no action plan. Almost all (7) of these people lived in funded services.

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 and consistencies, and suggested food items and quantities.[27] The information in the plan needs to be updated regularly, according to the needs of the person.

All except two of the 50 people in disability services who had swallowing difficulties had an eating and drinking plan, or equivalent guiding document. The two people who did not have such a document on file about how to support the person with eating and drinking had lived in a funded group home and a funded large residential centre.

Fifty-four people in disability services required assistance with meals. Of these people, three-quarters (41) had an eating and drinking plan or similar document. Of the 13 people who required assistance with meals and did not have an eating and drinking plan, most (10) had lived in funded services.

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

4. Deaths of people with disabilities in care in 2006: Our work

In this section, we report on our observations arising from our reviews of the deaths of 98 people who died in 2006. In the main, these observations concern:

- Identifying and managing risks commonly faced by people with disabilities in care, such as falls and swallowing difficulties.
- Meeting the needs of individuals through effective health care and individual planning.
- Responding to critical incidents when they occur.
- Providing services to people with disabilities during hospitalisation, including discharge planning.
- Making end-of-life decisions for people with disabilities in care, including consultation with the person and their family, and documentation of the decisions.

Some of the practice we have reviewed has been exemplary, while some has been concerning or, more generally, has raised questions about the adequacy of service practice and policy guidance.

Where relevant, the following discussion about these matters includes consideration of agencies' progress toward implementing recommendations arising from our earlier reviews of the deaths of people with disabilities in care.

4.1 Identification and management of risks

Our reviews have found that certain deaths of people with disabilities in care may be prevented if more effective systems were in place to identify the risks people face, and to ensure that these risk factors are appropriately managed.

Last year we reported specific concerns about identifying and managing swallowing and nutrition risks, and risks associated with boarding house residents smoking cigarettes.

This year we found that in many cases, risk assessments identified the risks individuals faced, but strategies were either not developed to address those risks, or provided inadequate guidance to staff on what action they needed to take.

It is concerning that where risks assessments had been conducted it was often difficult for us to see how the assessment informed service practice.

Examples of this included:

- risk assessments that were not reviewed or updated as the person's needs changed and new risks emerged;
- assessments that did not appear to be linked to any other support documents; and

- service records that indicated that risk management strategies were not implemented in practice.

We also identified concerns about assessing and addressing risks in the following specific areas:

- Falls
- Pressure ulcers
- Medications
- Nutrition and swallowing

Falls

Twenty-one of the 98 people who died in 2006 had either experienced falls or had been identified as being at risk of falls. Falls resulted in hospital admissions for 10 people, and a number of these people had multiple admissions as a result of falls. Many of the falls had serious consequences for the individuals concerned, including bruising, cuts, fractures, and head injury occasioning death.

There are many factors that may place a person at risk of falls, including limited mobility or gait, multiple medications, medications that can cause ataxia or dizziness, sensory impairment, and health conditions such as osteoporosis, low blood pressure, incontinence, and dementia.

Conversely, there are a number of environmental and individual strategies that can reduce the risk of falls, such as the reduction of slip and trip hazards, and the maintenance of a person's overall balance, gait, vision, muscle, and bone strength[28].

In reviewing the deaths of people who experienced falls, we considered the adequacy of the action taken by services to identify and address the falls risks for those individuals.

We found that some services had developed plans to address the mobility and falls risks of the individuals in their care. These included examples of clear links between the client's risk assessments (for example, the Client Risk Profile) and the resulting management plans, such as a mobility management plan.

We also noted efforts by services to minimise falls risks for individuals, including moving a person to a unit with more intensive support, and organising for assistance from allied health services such as physiotherapy and occupational therapy.

However, we had concerns about the risk identification and management undertaken by services in relation to some of the people who experienced falls. Our concerns stemmed from instances where:

- Falls were not identified as a risk in risk assessments or health-related plans, despite the fact that the progress notes or incident reports recorded more than one fall.
- Falls were recognised as a risk for individuals, but there was little or no evidence to indicate what action was taken to address or minimise the risks.
- Risk assessments were not reviewed and incident reports were not completed in response to a person who experienced repeated falls over a short period of time.

Pressure ulcers

Pressure ulcers can occur when a person stays in one position for long periods of time, such as in bed or in a chair. They usually occur when a bony part of the body presses on the skin for an extended period of time, and can progress from a reddened area, to a sore, to an ulcer affecting tissue and muscle, leading to infection and necrosis (death of tissue).

People with an impaired ability to change position are most at risk of developing pressure areas. Other risk factors include acute or chronic illness, weight loss, poor nutritional status, incontinence and compromised skin integrity.

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[28] *Preventing injuries from falls in older people* NSW Health 2001.

CaseStudy1

An elderly man who lived in a large residential centre received palliative treatment for cancer in hospital. On discharge, the service's nursing staff assessed him as having a Grade 2 pressure area.

Over the following two weeks, the service ensured that the man had the input and follow-up of his GP and an occupational therapist. Pressure relieving methods were implemented, including an air mattress and a bolster, antibiotics were commenced, and the type of dressing used was changed.

When the pressure areas continued to deteriorate, staff involved a rehabilitation clinical nurse consultant, who made recommendations that were quickly implemented.

Despite the active management and review by service staff, and the regular involvement of medical and allied health practitioners, the man's pressure ulcers continued to deteriorate, and he was readmitted to hospital three weeks after being discharged.

At the time of his readmission, the man's right foot was believed to be gangrenous, and vascular surgeons found that the only option was an above knee amputation. While the man was in hospital, and in consultation with his family, a decision was made that he should receive palliative care, including debridement of his pressure ulcers and amputation of two toes, but no amputation of his leg. The man subsequently developed pneumonia while in hospital, and died two days later.

Following the man's death, the service advised that all residents returning to their care from an acute health setting with pressure areas would have photographs taken of these areas to provide a pictorial record to monitor the healing process. The service also advised that referrals would be required to the rehabilitation clinical nurse consultant to review the pressure area and provide advice on management.

Pressure ulcers can develop very quickly, and can have a significant impact on the individual's health and quality of life, including restricting or preventing access to the community. The case study above illustrates the rapid progression of pressure ulcers that can occur, and their considerable impact on health.

People with mobility difficulties are particularly at risk of developing pressure ulcers. Just under two-thirds (63) of the 98 people who died in 2006 were identified as having limited mobility, requiring the use of a walking aid, wheelchair, or staff assistance with mobility.

In general, we found that the people who were particularly at risk of developing pressure ulcers, including people with paraplegia or profound physical disabilities, tended to live in services where they were supported by nursing staff, such as large residential centres.

In many of these services we noted good practice in the identification and management of risks relating to the development of pressure ulcers. For example, the use of risk assessment tools such as the Braden tool, regular inspections of skin integrity, the introduction of methods for pressure relief, and the development of clear procedures for managing the risks, including repositioning / turning.

However, a small number of our reviews this year concerned people with pressure ulcers who were supported by non-nursing residential support workers. The level of support provided to these individuals varied, and included one person who received drop-in support only.

In the main, it did not appear that these services were aware that the individuals in their care could develop pressure ulcers, and there did not appear to be any consistent means of assessing pressure ulcer risks.

In some cases the disability services' management of pressure ulcer risks did not appear to be assisted by the discharge planning of hospitals. We noted instances where pressure ulcers were noted by hospital staff on the discharge documents, but no guidance appeared to be provided to the disability service staff as to what steps they needed to take to manage the pressure areas.

Existing guidelines around pressure ulcer prevention and management, including those developed by NSW Health and the Australian Wound Management Association, indicate that any person with a mobility deficit or a change in their mobility status should undergo a risk assessment in relation to pressure ulcers.[29]

The guidelines state that people at risk of developing pressure ulcers and their carers should be educated and supported about:

- risk factors for the person in relation to developing pressure ulcers,
- sites that are the greatest risk for them,
- how to inspect the person's skin and recognise skin changes,
- how to care for the person's skin,
- methods for pressure relief, and
- where the person and their carers can seek further advice and assistance.

The demands on residential support workers, particularly in relation to identifying and managing the health needs of the people in their care, are considerable. It is unreasonable to expect that non-nursing staff would be cognisant of all potential health risks faced by individuals in care, and what needs to be done to address those risks.

As a result, it is critical that disability service staff seek the advice and involvement of the person's GP in managing their health needs. Where the person has mobility problems, this advice should include how to identify and manage the risks associated with pressure ulcers.

For some people with pressure ulcers who are supported by residential support workers, the assistance of community nurses may be required, and the GP is typically the point of referral for this service.

Medications

In our *Report of Reviewable Deaths in 2004*, we highlighted the vulnerability of people with disabilities in care to adverse events as a result of medication, and pointed to the deaths of three people as a result of drug toxicity or overdose.

Polypharmacy can increase the risk of side effects, drug interactions, toxicity and adverse events such as falls, confusion, and functional decline. As we highlighted in 2005, people with disabilities in care tend to possess many of the factors associated with medication related adverse events.

These factors include taking five or more regular medications, taking more than 12 doses of medication per day, significant changes made to the medication treatment regimen in the last three months, medications requiring therapeutic monitoring, patients attending a number of different doctors, and discharge from hospital within the last four weeks.[30]

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[29] NSW Health (2005) *Clinical Practices — Pressure Ulcer Prevention* policy directive; NSW Health (2003) *Prevention of pressure ulcers — transport of a patient* and *Prevention of pressure ulcers — community care settings* guidelines; and Australian Wound Management Association (2001) *Clinical Practice Guidelines for the Prediction and Prevention of Pressure Ulcers*.

[30] Department of Health and Ageing (2001) *Domiciliary Medication Management — Home Medicines Review.*

CaseStudy2

A woman with a severe intellectual disability had been seen by her GP over several months for weight loss and increased behavioural disturbance. In response to her behavioural symptoms, several adjustments were made to her medication regime that included antipsychotic, antidepressant, and anti-anxiety treatments.

Several new medications were also introduced in response to her deteriorating presentation, including sedative medication for sleep disturbance and an analgesic for pain relief. Concurrent medical investigations revealed evidence of possible abnormalities, and arrangements were put in place for surgery.

Prior to her scheduled admission to hospital for surgery, she was admitted to hospital with lethargy, pain, cognitive decline, and behavioural disturbance. She was assessed as having a urinary tract infection and experiencing side effects from her medication. She was discharged later that day following some adjustments to her medication regime.

The following day, the woman was readmitted to hospital with further cognitive decline, pain, loss of mobility, and bruising to her legs. During this admission, it was determined that the woman's symptoms were the result of adverse drug interactions associated with polypharmacy. As a result, changes were made to her medication regime to reduce any further risk of medication-related adverse events.

There was no indication from the records that a medication review was conducted prior to the woman's hospital admissions.

More than three-quarters (82) of the people who died in 2006 were prescribed five or more medications, including 37 people who were prescribed 10 or more medications. More than two-thirds of the people who died were prescribed one or more psychotropic medications.[31]

Our reviews this year identified some concerns regarding medication administration, and again emphasised the vulnerability of people with disabilities in care to adverse events relating to medication:

- Coronial toxicology results indicated that two people had medications in their blood that they had not been prescribed. A woman who had lived in a funded large residential centre had traces of an anticonvulsant medication that she had not been prescribed. A man who had lived in a licensed boarding house was found to have traces of two antipsychotic medications that were different to those prescribed to him.
- The preliminary coronial information in relation to the death of a DADHC group home resident indicates that the woman died of '*probable Olanzapine toxicity*'.
- A woman who had lived in a DADHC large residential centre had an episode of Lithium toxicity, and a psychiatrist raised concerns that Lithium administered to a licensed boarding house resident was not being monitored according to well-established guidelines.

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[31] Psychotropic medication is treatment that has an effect on a person's mental state, and includes antipsychotic, anti-anxiety, antidepressant, hypnotic, and sedative drugs.

- A neurologist identified possible Epilim toxicity in relation a resident of a funded group home.

We identified blank spaces in the medication administration records for a number of people who died in 2006, which raised questions as to whether the medications were administered as prescribed.

In addition, the internal reviews by some services following the deaths of individuals in their care also identified some problems with medication administration, including medications given but not signed for, and agency staff not following medication administration protocols.

We also noted problems with drug interactions for a small number of people. Of particular note was the impact of certain medications on the seizure activity of some people with epilepsy.

As an example, the death of a licensed boarding house resident was found to be as a result of sudden death due to epilepsy (SUDEP). The Coroner reported that the man was receiving a 'markedly sub-therapeutic' dose of his anti-convulsant medication, and noted that his antipsychotic medication, Clozapine, is known to lower the threshold for seizures.

Thirteen people were receiving antipsychotic medication but were not recorded as having a mental illness. Five of these individuals did not appear to demonstrate any behaviour that could be considered 'challenging', and there were no records to indicate that a psychiatrist had reviewed their need for the psychotropic medication. These five individuals lived in a licensed boarding house, small residential centre, and group homes.

Medications and record keeping in licensed boarding houses

Our reviews of the deaths of licensed boarding house residents raise concerns about the adequacy of the protocols in place for the administration of regular medications.

Licensed boarding houses are required to maintain a recording system for the administration of PRN medication, including the name and dosage of the drug, and the date and time of administration. In response to a draft copy of this report, DADHC noted that the current licence conditions do not authorise DADHC to impose a requirement for record keeping related to regular prescribed medications.

The lack of guidelines relating to the administration and recording of regular medications in licensed boarding houses raises questions about the accountability of staff practice and the adequacy of steps to minimise harm to residents.

This gap in medication records for people with disabilities in care is particular to licensed boarding houses. Requirements and standards apply to the administration of medication in accommodation that is operated and funded by NSW Health or DADHC. These include NSW Health's *Guidelines for the Handling of Medication in Community-Based Health Services and Residential Facilities in NSW*, DADHC's *Medication* policy, and the *Standards in Action* manual.

Given that many of the people who live in licensed boarding houses are prescribed regular psychotropic medication, we consider that there is a need for similar guidance and requirements relating to medication administration and record keeping in this accommodation setting.

Nutrition and swallowing

This year, we continued to identify instances | in DADHC-operated and funded services where risks were identified through the nutrition and swallowing checklist or similar assessment, but strategies were not developed to address those risks.

This is of concern for many reasons, including the fact that the checklist has been available to DADHC-operated and funded services since at least mid-2004, provides prompts to staff about how to address the risks, and the consequences of failing to address swallowing and/or nutrition risks can be considerable.

We identified many instances where emerging nutrition or swallowing risks were recorded in the service progress notes, but this did not lead to a risk assessment, or actions to address the risks.

Similarly, we found examples where deterioration in the person's swallowing function, or adverse changes in the person's nutritional status, failed to result in the checklist or other assessment document being revisited, or steps being taken to address the new risks.

We were also concerned that in a number of instances, while risks were identified and strategies developed to address those risks, the service did not appear to implement the strategies. In some cases, this included where professionals had made recommendations about the steps staff needed to take to control or address the swallowing or nutrition risks, but those recommendations were not followed.

Examples include:

- A resident of a regional DADHC large residential centre had a PEG tube inserted three years before her death from pneumonia. One year later, a gastroenterologist reviewed the woman and recommended a speech pathology review to determine whether long-term enteral feeding remained appropriate. There was no indication on the woman's records that the speech pathology review occurred at any point during the following two years until her death.
- A dietician reviewed a resident of a funded large residential centre two years before his death, noted that the man was underweight, and found that the man did not like the way the food was cooked. The dietician noted that a new menu was about to be introduced, and recommended that the man have a further dietetic review once the menu changes were made. There was no indication that the follow-up dietetic review occurred. On admission to hospital two weeks before his death from bronchopneumonia and lung cancer, the man was assessed as having severe malnutrition.
- A nutrition and swallowing checklist conducted six months before the death of a funded group home resident identified that he was underweight, and a plan for increasing his weight was subsequently developed. The dietary plan stated that the man was to be referred to a dietician if he did not put on weight, or if he lost weight for two consecutive months. There was no indication in the service records that the man's weight was regularly monitored.

  When the service weighed the man two weeks before his death, he had lost over 15kg and was very underweight. He was taken to the GP who conducted a range of tests and found that the man had advanced cancer.
- A speech pathologist assessed a DADHC group home resident seven years before her death, and found that she was at acute risk of choking due to mild oral dysphagia exacerbated by rapid eating behaviour, and she required annual speech pathology and nutrition reviews. There was no indication that any speech pathology reviews occurred after this assessment. Preliminary coronial information regarding the woman's death indicates that she choked on food.

Our previous recommendations on identification and management of risks

We have made recommendations in relation to the identification and management of risks for people with disabilities in care in each of our reports. The recommendations have been wide-ranging, and have included:

- Review of existing risk assessment tools including the Hunter region's chest care checklist, and the current application of the screening tool for entry to licensed boarding houses.

DADHC has reported that it has completed its review of the chest care checklist. In response to a draft copy of this report, DADHC advised that it does not intend to implement the chest care checklist. The Comprehensive health assessment program (CHAP) will be used as the key health assessment tool for the *Health Care* policy.

- Provision of guidance to funded services and licensed boarding houses about risk assessments, including release of the *Managing Client Risk* policy.

  In May 2007, DADHC released a draft of the renamed *Client Risk* policy and procedures for consultation, with implementation planned for the end of September 2007.

- Monitoring the implementation and evaluating the effectiveness of key policies on risk identification and management, including *Ensuring Good Nutrition* and *Managing Client Risk*.

  DADHC has advised us that it has developed a specification for evaluating the *Ensuring Good Nutrition* policy, and will liaise with the Centre for Developmental Disability Studies (CDDS) to conduct the evaluation. DADHC's Health Care Review Team has developed an audit tool to monitor the implementation of the *Ensuring Good Nutrition* policy in DADHC-operated services, and intends to evaluate the tool prior to implementation.

- Promotion of medication reviews, including the use of Domiciliary Medication Management Reviews, with disability accommodation services and GPs.

  DADHC has indicated that it is revising its *Medication* policy to include reference to Domiciliary Medication Management Reviews and some of the criteria that can trigger a medication review. DADHC also reported that it would meet with the NSW Divisions of General Practice in August 2007 to identify ways of increasing GP awareness about the issues arising from polypharmacy in people with intellectual disabilities.

While there has been some progress, significant work still needs to be done to address our concerns in this area.

Guidance to funded services in relation to risk identification and management is not on par to that provided to DADHC-operated services. Key departmental policies that may provide some necessary direction to funded services, including *Client Risk* policy, are yet to be released to those services.

The lack of information and guidance provided to licensed boarding houses in relation to risk identification and management continues to be a concern. The review of the screening tool for entry to licensed boarding houses may provide a means to improve the entry process so that only people with low support needs are accepted as residents. However, the review recommended by this office in 2005, is yet to commence.

Further work needs to be done to ensure that all current residents of licensed boarding houses with high support needs are transferred to more appropriate accommodation, and that the risks faced by the remaining residents are identified and adequately managed.

In addition, an evaluation of the *Ensuring Good Nutrition* policy and its implementation is yet to be undertaken. The evaluation is necessary to determine whether the policy and associated tools and resources are effective in identifying and minimising the nutrition and swallowing risks for people with disabilities in care, and what work, if any, remains to be done to improve its effectiveness in this regard.

4.2 Meeting individual needs

We have consistently raised issues related to planning and coordination of health care for people with disabilities in care. Many of the concerns that we identified in our *Report of Reviewable Deaths in 2005* were also a feature of our reviews of deaths in 2006.

This included instances where:

- there was no evidence of a current individual plan to outline the person's needs, goals, and wishes, and identify how goals would be achieved. Individual planning is discussed further in section 4.6 in relation to people in residential centres.
- there was no evidence of a current health care plan or other document to record the person's existing health issues, or indicate how staff should meet their needs.
- the health care plan or other guiding document did not record all of the significant health issues for the person, or contained inadequate information to guide staff.
- health related documents were not updated or reviewed following changes in the person's condition, such as the commencement of seizures or increasing falls.

In some cases, we found that the health needs of individuals were unknown to the service, despite the fact that the person had been a long-term client, as exemplified by the case study below. We also found a number of annual health assessments that appeared to be inadequate, inaccurate, or cursory.

CaseStudy3

A man who lived in a group home died as a result of lung cancer.

The answers to many of the questions in the service provider section of the CHAP tool were recorded as 'don't know', including the man's immunisation history, cardiac issues, muscle and joint pain, bowel issues, mental health, and vision. This is despite the fact that the man had been a resident of the service for 12 years.

The man's health care plan appeared to contain inadequate information, listing only his medications and the names of involved medical practitioners. The plan did not identify the man's health issues, which included epilepsy and recurrent respiratory infections, or outline health intervention strategies.

A neurologist regularly reviewed the man's epilepsy, but seizure charts did not appear to be consistently maintained.

The man's eating and drinking plan did not appear to be updated to reflect the deterioration in his swallowing function due to the cancer progression.

While there were minutes from an Individual Planning meeting on file, there was no Individual Plan. There were also insufficient documents on file to indicate the man's activities, such as day program involvement, vocational placement, and community access.

Information on the man's file indicated that he demonstrated inappropriate sexual behaviour and aggressive behaviour towards other residents. While there were many incident reports on file, it was not clear what action was taken in response to prevent recurrence. There was no behaviour intervention and support plan.

Numerous documents including his client risk profile indicated that the man was at risk of falls. However, there was no document on file that indicated how those risks would be managed, or how staff should support the man with his mobility.

We also found exmples of good practice in health care planning and coordination by services:

- A resident of a licensed boarding house had schizophrenia, an acquired brain injury, and epilepsy. We found good liaison and coordination between the manager of the licensed boarding house, the GP, the Boarding House Project Officer, and the local mental health team. It was clear that these services consulted with the man and liaised with each other to try to meet his multifaceted health needs.
- The complex health needs of a resident of a DADHC large residential centre appeared to have been well coordinated by the service. In addition to profound intellectual and physical disabilities, the man had multiple significant health concerns, including epilepsy, chronic aspiration pneumonia, and GORD.

  The service developed clear plans that provided detailed guidance to staff on how to meet the man's health needs, reviewed the plans regularly, coordinated the regular involvement of relevant allied health and specialist services, and held a multidisciplinary meeting to confirm appropriate support arrangements as his condition worsened.

Enteral nutrition / complex health needs

Many of the people who died in 2006 had complex health needs that presented challenges for themselves, service providers, and health practitioners. This included 11 people who received enteral nutrition.

Enteral nutrition - the delivery of liquid nutritional formula via a tube - is provided to patients who are either unable to take their nutritional requirements orally, or for whom oral intake is unsafe.

The methods of enteral nutrition used by people with disabilities in care tend to be either a percutaneous endoscopic gastrostomy (PEG), where the tube feeds directly into the stomach, or a percutaneous endoscopic jejunostomy (PEJ), where the tube feeds into the jejunum (part of the small intestine).

Of the 11 people who died in 2006 and relied on enteral nutrition, only one also received food orally. The remainder relied exclusively on their PEG or PEJ tubes for their nutritional requirements.

The individuals who received enteral nutrition typically had significant intellectual and physical disabilities in addition to multiple and complex health concerns, including swallowing difficulties and recurrent respiratory infections.

We noted good practice by services in managing the complex health needs of many of these individuals, including clear and detailed guidance for staff on nutrition and stoma management, enteral feeding regimes, regular GP and allied health reviews, regular review of health related plans, and consistent weight monitoring.

However, we noted that enteral nutrition care and management presented considerable challenges to both the individuals in care and the disability services — often requiring hospital intervention and assistance.

Tube feeding can present complications, including tube dislodgement and deterioration. At least five of the 11 people who relied on enteral nutrition encountered difficulties associated with tube feeding, including tubes that became blocked, dislodged, leaked, and split. There were also issues around the stoma site, including infections, weeping, bleeding, and development of pressure sores.

Many of the above issues resulted in numerous hospital presentations. This is also the case for people receiving enteral nutrition in the broader community. A NSW Greater Metropolitan Clinical Taskforce report on home enteral nutrition in February 2007 noted that, in 2004–05, there were approximately 700 presentations to emergency departments for gastrostomy care or gastrostomy feeding tube blockage.

We noted that the people who lived in or near metropolitan areas appeared to have access to nutrition support nurses and regular tube replacements in hospital.

However, we found that the people who lived in regional areas tended to have some difficulty in getting feeding tubes replaced in hospital, and the overall guidance and support provided to service staff about enteral nutrition, and how best to support the people in their care, appeared to be minimal.

The Greater Metropolitan Clinical Taskforce noted in its report that there is currently a lack of guidelines, policies and procedures for home enteral nutrition therapy in place in NSW healthcare facilities. It considered that '*minimum service level standards need to be applied across NSW in order to ensure patient safety, clinical risk management and clinical governance*'.

This is particularly important for people with complex health needs living in regional group homes supported by non-nursing staff, as illustrated in the following case study.

CaseStudy4

Two residents who lived together in a regional group home died in 2006. One man died from malnutrition and failure to thrive as a result of a malfunctioning PEG tube delivery system due to mechanical obstruction. The other man's death was due to abdominal and chest sepsis.

Both men had very high medical and overall support needs, possessing profound intellectual and physical disabilities and chronic, complex health issues. Both residents relied on enteral nutrition, and experienced significant complications associated with their tube feeding. Both men presented to hospital 13 times in the 12 months before they died.

In the year prior to his death, one of the men had recurrent bouts of aspiration pneumonia and respiratory tract infections, chronic MRSA infections of the PEG and PEJ tube sites, weeping from the stoma site, leakage and splitting of the tubes, and bile discharging into the tubing.

The other man had a considerable history of gastrointestinal complaints, with significant issues during the last 12–18 months of his life. He experienced complications associated with PEG feeding, including blocked or deteriorated tubing, and instances of gagging, vomiting, or discharges from the PEG tube occurring on a daily to weekly basis.

Our reviews of the deaths of both men raised questions about the adequacy of the care and support provided by staff of both the group home and the regional hospital, including:

- The extent of the input and review from specialists outside of hospital, such as a stoma nurse.
- The amount of interagency work, such as case conferences or multidisciplinary meetings between the disability service and hospital staff.
- The extent of the communication with, and guidance to, group home staff, and referrals for post-discharge care by the hospital in the discharge planning process.

This office has commenced an investigation into the adequacy of the response by the disability service and the Area Health Service to the critical health issues of both men, and the adequacy of the interagency work undertaken by both agencies to meet their health needs.

Dementia

At least 15 of the people who died in 2006 were reported to have dementia.[32] Eleven of the 15 people with dementia also had Down syndrome.

The onset and progression of dementia for the people who died in 2006 tended to have a considerable impact on their health and support needs. This included increasing confusion, dysphagia, drowsiness, wandering, and weight loss, as well as declining mobility and speech. Over half of the people with dementia experienced falls in the 12 months before their deaths.

We noted that almost three-quarters (11) of the 15 people with dementia had epilepsy, including nine people who developed epilepsy subsequent to their dementia diagnosis.

We found that some disability and health service providers were responsive to the increasing support needs associated with dementia, including the involvement of allied health services such as occupational therapy and community nursing, and specialist reviews such as neurology, geriatric medicine, and ACAT assessments.

In one matter we reviewed, the increasing needs of a 60-year-old man with Down syndrome and Alzheimer's disease appeared to be actively managed by staff at the regional group home in which he lived.

The service organised for the man to receive case management and additional direct care support through the Disability Aged Care Pilot, provided support to the man during his hospital admissions, and actively advocated on the man's behalf for access to ACAT and geriatric assessments and the provision of additional support on discharge from hospital.

In addition, group home staff received pharmacy training on the man's medication regime, including advice about possible side effects and drug interactions.

However, we found that there were gaps in the service provision and planning to meet the increased needs of some of the people who developed dementia. This included:

- Management of dementia symptoms through acute hospital admissions rather than comprehensive assessment and management by primary care physicians.
- Lack of, or inadequate, assessment of the risks associated with the person's dementia.
- Lack of plans or guiding documents outlining the actions staff needed to take to support the person's increased needs.

We found considerable variation in the assessment process used to identify or confirm a diagnosis of dementia, particularly in relation to people with Down syndrome.

In some cases, the person's diagnosis of dementia was made following examination by a geriatrician or neurologist combined with neuropsychological testing. In other cases, a diagnosis of dementia appeared to be made on the basis of the person's declining functional skills and the existence of Down syndrome, with no specific assessment conducted.

Best practice in the dementia diagnosis and assessment process for people with Down syndrome involves a range of tests and assessments to rule out any reversible conditions that may be causing the changes and impairments to the person's health, memory, or behaviours.

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[32] Dementia is a general term used to describe problems with memory and thinking. There are different forms of dementia and each has its own causes, with Alzheimer's disease being the most common (Alzheimer's Australia).

The establishment of baseline information regarding the person's usual level of functioning and detailed medical history is important, as is a psychiatric assessment to identify any treatable disorders and to manage symptoms that can occur with the onset of dementia, such as depression, anxiety and delusions[33].

Of particular concern to us in our reviews of the deaths of people with dementia in 2006 was the propensity to link dementia to palliative care. This is discussed in section 4.5: End-of-life decision-making.

Communication

In our *Report of Reviewable Deaths in 2004*, we highlighted the importance of communication for people with disabilities in care, and noted that being unable to communicate effectively '*has significant implications for client health, as it can affect identification of illness, pain, and recognition of adverse effects of medications*'.

This year we have again noted the impact of communication difficulties on the health of people with disabilities in care. The impact can be considerable — from being unable to voice or indicate specific needs to being excluded from end-of-life decision-making.

Our reviews of deaths in 2006 have pointed to the impact of communication difficulties, and the lack of communication supports, on the diagnosis and treatment of mental and physical health needs.

One example was a licensed boarding house resident who died in hospital from a bowel obstruction secondary to volvulus and hernia. The woman was admitted to hospital for hypotension, chest pain and confusion. The hospital records indicate that communicating with the woman was difficult. This resulted in a vague patient history being obtained. The following day, the woman was confused and disoriented, became unresponsive after vomiting, and was unable to be resuscitated. One of the findings in NSW Health's root cause analysis following her death, was that '*due to the patient's difficulties with communication as a result of her chronic mental health conditions, treating staff...were unable to elicit symptoms or signs suggestive of bowel obstruction or volvulus*'.

We are continuing to review the death of another licensed boarding house resident, whose communication difficulties presented challenges to the management of his mental illness.

This man had schizophrenia, and was prescribed a complex medication regime involving multiple medications. While his country of origin was documented as Croatia, the services and practitioners involved with him variously recorded his language of choice as Swedish, Hungarian, Polish, Czech, and Dutch.

The services involved with the man, including his GP and psychiatrist, recorded that it was difficult to communicate with him, difficult to obtain a history from him, and difficult to establish whether he was experiencing psychosis.

There was no indication that any of parties involved with the man attempted to access interpreter support to clarify his language, or to obtain assistance in communicating with him.

While most of the people who died had significant cognitive and/or physical impairments, we noted that few were reported to receive any communication support, such as adjusted verbal communication or picture communication.

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[33] Alzheimer's Australia 2005.

This raises questions about the adequacy of the actions undertaken by services to determine the communication needs of the individuals in their care, such as organising a communication assessment, and to implement strategies to meet those needs. It was difficult to see how many of the individuals with communication difficulties were able to have input into decisions that affected them.

Our previous recommendation in relation to communication was that DADHC should ensure that the revised *Health Care* policy provides adequate guidance on the importance of considering resident communication issues in relation to health care needs, and when referral for a communication assessment is required.

While the revised policy does include information for staff about the importance of communication in meeting the health needs of people with disabilities in care, it does not clearly indicate when referral for a communication assessment may be required.

Consent

In our reviews of deaths in 2006, we identified some concerns around consent to medical treatment.

We found that for at least two people in separate licensed boarding houses, the boarding house manager was listed as the person responsible for providing consent to medical treatment. Under the *Guardianship Act 1987*, paid carers cannot act as the persons responsible for providing consent to medical treatment. As both of these people were also recorded as providing their own consent to medical treatment, it was not clear who was providing consent in practice.

While most of the licensed boarding house residents were recorded as providing their own consent to medical treatment, there were also instances, including the man identified in the previous example, where it was not clear how this occurred in practice. For example, in relation to this man, records indicated that there were questions on the part of his medical practitioners about his ability to understand English, yet there did not appear to be any query about the implications of this on his capacity to provide informed consent.

Our review of the death of a man who lived in a regional funded group home highlights the potential consequences of failing to clarify consent arrangements.

CaseStudy5

The man was admitted to his local hospital with fluid on the lung, shortness of breath, and back pain. He had some cognitive impairment, but was generally considered able to provide informed consent to his own medical treatment. The man did not have a guardian or other person consenting to medical treatment on his behalf.

The man was diagnosed with a pleural effusion, and two unsuccessful attempts were made to drain the fluid from his lung. Hospital medical staff then recommended that a video-assisted thoroscopy (VAT) be conducted under general anaesthetic, which required the man to be transferred to a larger hospital, located in another State with different legislative requirements in relation to the provision of substitute consent.

A medical officer at the out-of-State hospital advised a medical officer at the NSW hospital that there was a need to explain the VAT procedure to the man's guardian, they would forward paperwork that day, and the guardian would need to accompany the man to the out-of-State hospital for informed consent.

The NSW medical officer then contacted the team leader at the disability service who apparently indicated that he was 'unsure whether he is the legal guardian or not. Will find out'.

It is not clear why it was considered that the man required a substitute decision-maker for this procedure when he had been providing his own consent to treatment both before and during his current admission to hospital. There was no indication that NSW hospital staff assessed the man as lacking the capacity to provide informed consent to the VAT procedure, or advised the out-of-State hospital medical officer that this was the case.

The man was transferred to the out-of-State hospital for the VAT procedure 17 days after agreement was reached between staff of the two hospitals that he would be put on the waiting list for a bed.

However, the out-of-State hospital transferred the man back to the NSW hospital the following day without the VAT being done, due to not having a valid consent for the procedure.

As we have no access to records outside of NSW, it is unclear whether staff in the out-of-State hospital assessed the man's capacity to provide informed consent before transferring him back to NSW. The NSW hospital records provide no evidence to indicate that this occurred.

On return from the out-of-State hospital, the man was breathless and distressed. His condition continued to deteriorate, and he died the following day.

We are continuing to review this man's death.

Our previous recommendations on meeting individual needs

Our main recommendations in this area have been directed at DADHC, and have focused on:

- The need to review and release key health care policies to funded services, including the *Managing Client Health, Epilepsy,* and *Decision-making and Consent* policies.

  The *Epilepsy* and renamed *Health Care* policies have been released to DADHC-operated and funded services in the last year, and training will be provided on both policies by the end of 2007. The revised Health Care policy includes some basic guidance to staff about facilitating communication with the individuals in their care.

  The release of DADHC's *Decision-making and Consent* policy has been delayed following feedback received during consultation on the policy in 2006. It is expected to be re-issued for further consultation in September 2007.

- Provision of an improved model for coordinating the health needs of people with disabilities in care, including review of the Clinical Nurse Specialist (CNS) model of health care coordination and consideration of its broader application.

  The review of the CNS model was completed in 2006, and recommended the establishment of specific CNS positions attached to DADHC Community Support Teams and local Area Health Service Rehabilitation Teams. DADHC has advised us that while it supports the concept of the CNS model in principle, it needs to be considered within the context of competing demand for resources. We were also advised that a decision will be made about this issue following the consultation on the NSW Health / DADHC discussion paper on the development of a service framework to improve the health care of people with intellectual disabilities.

- Improving the health care management of licensed boarding house residents, including provision of key health care information, and delivery and monitoring of primary and secondary health services under the Boarding House Reform Program (BHRP).

  DADHC has reported that it is re-auspicing the primary and secondary health services with revised service type descriptions, and will monitor service delivery in this area via its Integrated Monitoring Framework. DADHC has also commenced a review of the health needs of licensed boarding house residents in the inner-west area of Sydney. The review is due to be completed by 30 September 2007.

- Improving records management in all services, including a review of record-keeping practices in licensed boarding houses, and the development of strategies to ensure the maintenance of reliable and accurate records for service users in DADHC-operated and funded services.

  DADHC has reported that it has completed a review of record-keeping practices in licensed boarding houses and is now reviewing the tool used to monitor practice in this area. DADHC has also advised that it has implemented a standard client record-keeping system in all DADHC-operated group homes, has started to roll out a similar system in large residential centres, and is undertaking work in relation to record-keeping in respite units.

In the main, progress in relation to meeting individual needs has been patchy and slow.

It has taken a considerable period of time for DADHC to review key policies and release them to DADHC-operated and funded services. The amended *Epilepsy* policy was reviewed for over two years before its release, and it took four years for the *Health Care* policy to be revised and released. The *Decision-Making and Consent* policy has been under review since 2005.

The review of the CNS model of health care coordination was undertaken in 2005, but a decision regarding the broader application of this model has yet to be made.

The development and introduction of performance indicators to ensure the accountability of the primary and secondary health care program only occurred in July 2006, eight years after the commencement of the program.

While we recognise the need for review processes to be thorough, lack of contemporary and appropriate guidance for staff can be an impediment to the delivery of quality care to people with disabilities.

There has also been little progress towards providing health care information to licensed boarding houses, with DADHC's work on updating its *Licensing, Monitoring and Closures* policy manual in progress since early 2006. In addition, the department's review of the *Youth and Community Services Act 1973* to resolve existing issues about the enforceability of licence conditions has been in train since 2003, with no outcome to date.

4.3 Response to critical incidents

The effective provision of first aid is directly relevant to the prevention of premature deaths.

We have consistently raised concerns about the response of services to critical incidents affecting people with disabilities in their care, including instances where first aid did not appear to be provided, or was inconsistent with best practice, or there were delays in calling for an ambulance.

This year our reviews have again identified concerns regarding the adequacy of the first aid response by some disability services in response to critical incidents.

In a number of cases, staff did not appear to have first aid training, or lacked confidence in applying their skills in this area, and were heavily reliant on the telephone instructions of the 000 operator. We also noted instances where necessary CPR was not commenced until the arrival of ambulance officers.

In one matter, it appeared that the capacity of the staff member to follow the operator's instructions was impeded due to the use of a landline phone located in a different room to where the incident occurred. We have since been advised by the service that a cordless phone has been installed to improve the capacity of the service to respond to medical emergencies.

Our previous recommendations regarding response to critical incidents

In our view, we consider that it should be mandatory — regardless of the disability accommodation setting — that there should always be at least one person on shift with current first aid qualifications. This view is reflected in the recommendation we have previously made to DADHC about this issue.

DADHC has advised that it has no legal authority to enforce the requirement under the notice of licence conditions for boarding houses, regulated by the *Youth and Community Services Act* 1973, that *'at least one staff member on each shift be qualified in first aid'*. The department is undertaking a project to assess the extent of first aid qualifications in these facilities in order to have a better understanding of current practice.

In relation to DADHC staff, the department has employment selection criteria that encompasses first aid training, and has recently signed contracts with suppliers of agency staff to ensure that all agency residential support workers or nursing staff contracted by DADHC have current first aid qualifications.

There is currently no requirement that support workers in funded services have current first aid qualifications. DADHC has also advised us that there are no plans at this stage to provide assistance to funded services to ensure that at least one staff member on shift has current first aid qualifications.

We have consistently reported that many people with disabilities are vulnerable to critical incidents due to polypharmacy, significant chronic health concerns, and communication difficulties. We have also repeatedly pointed to instances where the first aid provided by services in response to the critical incidents that resulted in deaths was inadequate.

Given the direct relevance to the prevention of premature death, illness or injury, we consider that inconsistencies in requirements for first aid qualifications in accommodation services for people with disabilities are unacceptable.

4.4 Discharge planning

In our last two reports, we have raised concerns about discharge planning following the hospitalisation of people with disabilities in care. Our concerns have included failures to apply the screening tool for entry to licensed boarding houses at the time of discharge, and the adequacy of discharge planning for people who were readmitted to hospital shortly after being discharged.

This year we noted some examples of good practice in discharge planning, including:

- Coordinated and planned hospital discharge following the involvement of the discharge planner, social worker, ACAT, and occupational therapist, including assessments of the person and their home environment.
- Multidisciplinary involvement during the hospital stay and clear agreement of continued

support following discharge, including training for group home staff, assistance with implementing care plans, review of alternative care options, supply of relevant clinical equipment and ongoing oversight of the individual's respiratory health.

- Organisation of a case conference regarding long-term care and feeding options, with subsequent ACAT and social worker assessments.

However, we also continued to identify some concerns about the risk assessments and discharge planning undertaken by hospital staff in relation to people with disabilities in care.

Discharge planning and risk assessments

Our concerns about discharge planning primarily relate to individuals who had complex health needs, declining health, and/or increasing health support needs. In our reviews of deaths in 2006, we noted that there were a number of people who had repeated contact with hospitals and who faced increasing risks related to their health conditions.

When we looked at the steps taken by hospital staff to assess these risks, or to consider the adequacy of the support provided by the disability service, we found that there were some gaps.

We generally found that the hospital records contained some form of discharge risk screening document, such as the 'ED Risk Screening' section of the Emergency Department Clinical Record, or a 'Discharge Risk Screen' form.

These documents provide the means for hospital staff to identify patients who have particular risks that need to be taken into account in discharge planning, and direct attention to questions such as whether the person has a history of frequent admissions, has decreased mobility, and is likely to have problems in managing self care on discharge.

A 'Yes' response to any of the questions in these assessments requires action to be taken by hospital staff, such as a referral to a service that may assist in reducing the risks, such as community nursing.

However, we found that the assessment was often not completed. On the occasions where the assessment had been completed, the documentation did not indicate any specific action, such as referral to an Integrated Care Program, or any other appropriate referral.

On one occasion, a line was drawn through the Discharge Risk Screen form, and above the line was written 'D. D. Home', suggesting that the assessment was not relevant for the individual because she resided in a disability group home.

We also noted that each of the individuals we reviewed should have scored at least one 'yes' response to the risk screening questions, thereby requiring action to be taken to consider the supports the person may require upon discharge.

The importance of completing the risk screening assessment would be of less significance if there were other triggers that prompt hospital staff to consider the adequacy of the care available to the person following their discharge. However, in the records we reviewed, there appeared to be limited consideration of whether the disability service was able to adequately meet the person's health needs, or whether it was appropriate to discharge the person back to their previous accommodation. This was despite people presenting and re-presenting to hospital with complex needs, progressive decline in their health, and/or increasing risks. This included:

- A woman who had four admissions to hospital in one month, with readmissions occurring one to five days after the previous discharge.
- An older woman who had three presentations to the emergency department in one month due to recurring falls that

resulted in a significant injury to her head and body.

- A young man who presented to hospital 13 times in the last 12 months of his life with recurring respiratory concerns, enteral feeding problems, and infections.

This year we also noted an increased number of instances of disability services raising concerns to hospital staff about their ability to continue to meet the health needs of the person admitted to hospital.

In the main, we found that where the service had raised these concerns, hospital staff took steps to determine the person's support needs, and to establish whether additional supports or alternative accommodation would be required prior to discharge. This was particularly the case where the disability service indicated that they could not continue to accommodate the person.

Discharge planning and palliative care

For a number of people whose deaths we reviewed, the decision to treat their health conditions palliatively was made while they were in hospital.

Despite this change in treatment, and the implications for both the person and the service supporting them, we found that this decision did not necessarily provide a trigger to hospital staff to consider whether the person's support needs could be met by the disability service, or whether referrals for additional support should be made.

CaseStudy6

An older man who lived in a group home developed pneumonia while in hospital for insertion of a PEG. A decision was made between the treating physician and the man's relative that the pneumonia would not be treated, and he would receive palliative care.

The hospital dietician developed a feeding regimen for the man's PEG six days prior to his discharge from hospital, however this regimen did not appear to reflect the situation at the time of discharge, or provide all of the necessary information.

For example, in the hospital progress notes, the dietician recorded that the man was to be elevated >45°, but this information was not included in the feeding regimen for the service to follow.

Furthermore, although the quantity of water to be flushed through the PEG tube was reduced by the dietician the day before the man's discharge from hospital, this reduction was not recorded on the feeding regimen.

The service manager requested that a palliative care plan be developed prior to the man being discharged from hospital. The treating physician reportedly advised that a palliative care plan was not necessary, although agreed that the man would die soon. The man was discharged from hospital, and the GP subsequently made a referral to the local palliative care team.

The day prior to the man's discharge, he required suctioning, and it was recorded that very thick, white secretions were suctioned. There did not appear to be any assessment by hospital staff to determine whether the disability service had access to suctioning equipment or had the capacity to provide this level of care prior to discharging him.

The discharge summary did not indicate any referrals, such as to a palliative care team, and only recommended follow-up with his doctor. The Nursing Transfer Summary indicated that the man had a pressure sore on his buttock and a comfeel dressing was in situ, but provided no guidance to service staff on how to appropriately manage the pressure area.

A physiotherapist saw the man after he had been discharged from hospital, and advised that he needed suction. The service manager then made inquiries about hiring a suction machine for this purpose.

The man was readmitted to hospital with continual seizure activity three days after being discharged. At that point the service manager raised concerns that the service did not have appropriate resources to support the man's current health needs.

Nevertheless, once the seizure activity was addressed through anticonvulsant drug treatment, hospital staff contacted the service manager and indicated that he would be discharged back to the disability service.

The service manager found that there was no discharge plan, and refused to accept the man back to the service unless appropriate plans were put in place, explaining that the group home could provide only minimal medical support.

Two days later the man was transferred to another hospital for palliative care. From the records available, it does not appear that the disability service was informed of the man's transfer.

We are continuing to review this man's death.

Our previous recommendations on discharge planning

Our recommendations in this area have largely centred on monitoring the progress of NSW Health in releasing, implementing, and evaluating its policy directives on *People with Disabilities: Responding to their needs during hospitalisation*, and *Discharge Planning: Responsive Standards*.

The *Discharge Planning: Responsive Standards* make specific reference to discharge planning for people with disabilities, and, in response to our recommendations, now incorporate the screening tool for entry to licensed boarding houses.

4.5 End-of-life decision-making

Concerns about end-of-life decision-making for people with disabilities in care have been raised in each of our reports. This year, we noted two particular areas of concern:

- Compliance with NSW Health policy.
- End-of-life decision-making for people with dementia.

Compliance with NSW Health policy

NSW Health released its *Guidelines for end-of-life decision-making* in March 2005. Despite the release, we continue to identify instances where the actions of hospital staff in relation to end-of-life decision-making do not appear to be consistent with the guidelines. This includes instances where:

- Decisions to limit treatment, commence palliative care, or not perform CPR, appear to be made by medical staff without the involvement of the person's family.
- Documented reasons for end-of-life decisions were either absent or limited. For example, in one case, '*family wishes*' was the only reason documented for making a no-CPR decision.

- In some cases, there was no indication that hospital staff attempted to contact the person's family to discuss treatment limitation and/or no-CPR decisions either before or after the decision had been made.

End-of-life decision-making for people with dementia

As noted earlier, at least 15 of the people who died in 2006 had dementia, including 11 people who had Down syndrome. On average, the people with Down syndrome and dementia were 57 years old when they died.

While we identified some areas of good practice in relation to supporting people with dementia, an area of concern for us was the apparent propensity to link dementia with palliative care.

As would be expected in people with dementia generally, we found that many of the people with dementia whose deaths we reviewed showed a decline in their functioning over time. This included increased confusion and decreased mobility, coordination and balance.

What was concerning to us was that, for a number of the people who had dementia, a decision was made by their GP or by hospital staff that they should be treated palliatively, and no reasons were provided to indicate why the palliative care decisions were made.

In some cases, the decision to commence palliative treatment appears to have been made prematurely. For example, a 51-year-old man with Down syndrome, who had been assessed by a geriatrician as having dementia, experienced a decline in his mobility and level of functioning in the 12 months prior to his death. Following a further deterioration in his mobility, he was assessed by his GP as being in the end stages of his dementia and a decision was made for palliative care.

However, the records provided have raised questions about whether the man had late stage dementia at the time the palliative care decision was made. Expert medical advice obtained by us indicates that the man's interactions with staff, at that time, were not suggestive of late stage dementia.

The impact of the palliative care decision was particularly significant for some of the individuals concerned, as it involved the withdrawal of treatment. This included the cessation of medications used to treat the person's co-existing health concerns, such as epilepsy and diabetes.

In a small number of cases it also included the cessation of food and the provision of minimal fluids. For some, it meant that the pneumonia that they subsequently developed was not treated, while pain medications were simultaneously introduced that further affected their respiratory function.

What is also concerning to us is that palliative care teams seem to have been involved with only a few of these individuals. It appears that the treating medical practitioners, whether hospital staff or GPs, did not consider that a palliative care referral was warranted.

This is of particular concern where the person was supported by non-medical group home staff. It appears that, for at least one person, the disability service had difficulty meeting the person's increasing palliative care needs. Responding to these needs places an unfair burden on residential support workers, especially where no specialist palliative care support is involved.

Our previous recommendations on end-of-life decision-making

Our recommendations in this area have focused on the need for NSW Health to evaluate the implementation of the guidelines in its Area Health Services. In addition to the evaluation of this policy, NSW Health has advised that it is currently developing an adjunct policy on 'No Cardio Pulmonary Resuscitation (CPR) orders', in consultation with stakeholders and the NSW Health Clinical Ethics Advisory Panel.

NSW Health has developed a Role Delineation Framework for palliative care services to provide a single system of referral and case management of patients, and to facilitate a collaborative relationship with primary care workers and specialist palliative care teams. NSW Health has employed clinical and project officers to implement the Role Delineation Framework, and has commenced a mapping exercise of palliative care services to monitor the implementation.

DADHC released a *Palliative Care* policy in 2006 that applies to both DADHC-operated and funded services. DADHC has reported that NSW Health has agreed to conduct an evaluation of the *Palliative Care* policy and its effectiveness in facilitating palliative care for DADHC clients. It is estimated that the evaluation will be completed within the 2007/08 period.

4.6 Residential centres

From the deaths in 2006, over one-third (37) of people with disabilities we reviewed involved people who had been living in residential centres, sometimes referred to as institutions. One person had been living in a small residential centre (7–20 people), and 36 people had lived in large residential centres (>20 people). Most of the people had lived in residential centres operated by DADHC (28 people).

This year we took a closer look at these 37 people. In doing so, we considered different aspects of the service they received, including health care management, assessment of risk, medication and consent, and meeting their individual needs.

The majority of the people who died from this group were over 54 years of age, and had lived at the same residential centre for over 21 years.

Health care management

In our *Report of Reviewable Deaths in 2004*, we reported that people living in large residential centres tend to have high health support needs. We noted that the people who died in 2004 who had resided in large residential centres tended to have the highest number of health conditions overall, averaging seven health conditions per person.

Similarly, most of the people who had lived in residential centres who died in 2006, had high support needs, including multiple significant recurrent or chronic health issues. Their health conditions included respiratory illnesses, dysphagia, enteral feeding, GORD, and epilepsy requiring regular review, consistent management, and multidisciplinary intervention.

In the main, we found that the people whose deaths we reviewed this year had a history of regular involvement with relevant medical practitioners, specialists, and allied health providers. It appears that, for most of the residents, allied health services were highly responsive to requests for assistance.

We also found good examples of health care planning, particularly in some DADHC-operated residential centres. We noted current, comprehensive health care plans that provided detailed guidance to staff, and good links to health support plans (such as an epilepsy management plan). We also identified some good examples of strong links between risk assessments and health care planning.

However, there were some gaps in the health care management of some individuals from residential centres. Some residents of the DADHC-operated centres had annual health assessments that appeared to be cursory at best, and inaccurate at worst. The immunisation status of some appeared to be unknown, despite the person's long residence at the same centre.

In relation to swallowing and nutrition, we noted some differences between practice in DADHC-operated and funded residential centres.

In the main, we noted sound identification and management of swallowing and nutrition risks in DADHC-operated centres, including close and comprehensive monitoring over extended periods of time, involvement of relevant allied health services, and detailed mealtime management guidance for staff.

However, few of the people who died in funded residential centres had any form of nutrition or swallowing risk assessment, or, where an assessment was conducted, there was little indication of what staff needed to do to address the identified risks. This was despite some of the individuals demonstrating significant nutrition and/or swallowing risks.

Generally, we saw appropriate action on the part of both DADHC-operated and funded centres in response to people who were overweight or obese, including the provision of weight reduction diets, and oversight of these residents by dieticians. However, where the recommendations for weight loss included exercise, it was difficult to see implementation.

Individual planning

Individual planning is a critical part of service delivery to people with disabilities in care. It is the means by which disability services ensure that the services they provide meet the current and future individual needs and goals of the individuals in their care. For DADHC-operated services, risk assessments and health care reviews and planning are all incorporated into the individual planning process.

When we considered the individual planning undertaken in relation to the people who had lived in residential centres, we identified some concerns.

While we found that most of the residents in funded residential centres had current individual plans or a similar planning document, four people did not appear to have any documented plan. It was not evident what input those individuals had into their service provision, or how their wishes, needs or goals were identified.

In the main, where individual plans were in place, the individual planning process appeared to involve the person, their family and/or other representative[34], and staff. However, we noted that 12 residents did not appear to be involved in the planning process concerning them. For six of these residents, the planning process involved their family or other representative and staff. For the remaining six people, the planning involved staff only.

In relation to the quality of the individual plans, we noted that the plan for one resident of a funded centre contained goals that were clearly linked to her wishes, the goals were broken down into steps for staff to follow, and progress notes kept in relation to each goal.

However, we identified concerns about the quality of many of the individual plans of the people who died, including:

- Many of the goals or proposed actions to be taken lacked specificity and were open to interpretation, including ‘*look at way to provide comfort*’, and ‘*investigate other leisure activity*’.
- It was difficult to see how many of the recorded actions could be considered to be goals for the person to achieve. Some appeared to be instructions for staff, such as ‘*monitor epilepsy*’ and ‘*encourage to attend day program*’, while others appeared to be statements, including ‘*may not wish to participate in any outings*’.
- Some plans appeared to outline a continuation of the person’s current routine rather than goals, such as ‘*continue to offer opportunity to participate in preferred activities*’.
- A number of the plans featured goals that appeared for three consecutive years with

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[34] These representatives include staff from the Office of the Public Guardian, advocates, and friends.

little indication of review or active steps to progress implementation.

- The format of some of the individual planning documents did not seem to encourage staff action. Few of the plans contained a summary of the agreed goals/needs, indicated who or what position would be responsible for assisting the person to achieve that goal, or set out what actions staff needed to take to meet the person's needs.

For most of the individuals who had an individual plan, we found little or no evidence that staff had taken action to try to progress the goals. The ill health of some of the residents may have affected the implementation of some of their goals, but we did not see evidence that the individual plans were revisited in light of this.

Community access and involvement in activities

Last year, we raised concerns that some people in residential centres did not appear to have much involvement in activities in the community, noting that, in some cases, it seemed that the individuals very rarely left the unit in which they lived.

We commented that the benefits of community access extend beyond a person's sense of involvement and integration in the community, to include important health benefits.

The individual plans of many of the residents who died in 2006, including the majority of those who lived in DADHC-operated centres, included goals of increasing or maintaining community access. However, in many cases there was little evidence on file to suggest that these goals had been achieved or were in the process of being implemented, or to indicate that strategies were in place to promote achievement of the goals.

We found several examples where the amount of community access the person experienced did not match the goal in their plan — with reasons including 'staffing issues' as well as the person's poor health.

Quantity

We noted that a few of the residents of funded residential centres whose deaths we reviewed were either able to access the community independently, or it was clear that they had regular community access and involvement in activities.

However, in the main, few residents appeared to leave the service grounds more than once a month. Many residents had significantly less community access than once a month, and some did not appear to leave the centre, or their unit, for at least a year before they died.

For the majority of the residents of funded centres, there were either no records to indicate what community access they had experienced (two people), or the records indicated that they had very little or no community access (five people).

One person appeared to have had only one outing in his last 16 months, and three other people did not appear to have had any community access in at least the 12 months before their deaths. For two of these three people, it did not appear that they went outside or left the unit.

We noted that nine of the people who had lived in residential centres received Vitamin D supplements.

Quality

We noted that the quality of the community access varied. While community access for some individuals appeared to reflect their interests, it was more difficult to see this in the outings of other people, such as monthly trips to the chemist.

There were instances of 1:1 outings, but these were much more seldom than group or bus outings. One DADHC residential centre appeared to link some residents into group outings with a tour company, but this did not appear to be replicated in other regions or centres. Two residents worked, and one resident attended school. For the remainder of the residents, it appeared that their key activity was attendance at a day program on site. Very few residents had any involvement with services outside of their accommodation provider.

In the main, the residents received all of their services, including employment, day activities, and community access, through their accommodation provider.

Family involvement

We found that the staff of the residential centres actively encouraged and tried to facilitate contact between the individuals and their family. In this area, staff demonstrated initiative, resourcefulness, and persistence.

We found examples of staff providing transport to the person or their family members to facilitate physical contact, making regular telephone calls to keep families updated and involved in the person's life, and negotiating with families to coordinate holidays and trips.

It appeared that staff efforts to facilitate and maintain family contact did not falter even where the family member did not reciprocate contact.

5. Review of respiratory deaths in 2005

5.1 Background

Last year we reported that we were conducting a clinical and service delivery review of deaths related to respiratory illness. We included deaths where respiratory illness was identified by the Coroner as a primary or contributing factor in the cause of death. The deaths of 27 people were included in our review.[35]

The 27 deaths relating to respiratory illness accounted for 40% of all 2005 reviewable disability deaths. The dominance of respiratory illness as a cause of death for people with disabilities has been reported consistently for many years.

This is not the first time that we have looked more closely at deaths due to respiratory illness. In our first reviewable deaths annual report in 2004, we examined the deaths of 33 people whose deaths were related to respiratory illness, and highlighted a number of risk factors for these deaths, including high dependency needs, a history of recurrent respiratory illness, underweight, a diagnosis of GORD, and swallowing difficulties.

The recommendations that resulted from our previous review of deaths due to respiratory illness focused on the following areas:

- Strengthening the guidance to staff of disability services on immunisation recommendations.
- Monitoring implementation of the *Ensuring Good Nutrition* policy, including completion of nutrition and swallowing risk assessments, development of eating and drinking and oral care plans, and maintenance of weight charts and immunisation records.
- Review of the Illawarra region's clinical nurse specialist model of health care case management, and consideration of its potential for wider application in DADHC-operated and funded services.
- Review of the Hunter region's chest care checklist for identifying clients who require regular chest care.

Our aim in revisiting this particular cause of death was to determine whether there were any systemic service or clinical practice issues we needed to report, and what further recommendations, if any, we should make to reduce the number of preventable deaths due to respiratory illness.

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[35] Our review originally included the deaths of 31 people. However, subsequent information provided by the Coroner indicated that the deaths of three individuals were unrelated to respiratory illness, and they were excluded. We also excluded one person on the basis that the person's death from bronchopneumonia was the end point of palliative treatment of cancer.

We found that many of characteristics of the people who died from respiratory illness in 2005 were consistent with those outlined in our first report.

5.2 Process

The reviewable disability deaths team and a consultant respiratory physician reviewed each death, with consideration and assessment of both the quality of care provided by the disability service and the clinical care provided by the health system.

Following the reviews, we compiled and analysed the information, and then met with the respiratory sub-committee of the Reviewable Disability Deaths Advisory Committee to discuss the 27 deaths and determine whether there were any systemic issues that needed to be highlighted.

5.3 Data snapshot

The core data from the people whose deaths in 2005 were respiratory-related did not show a marked difference to the data from our previous review, or to what is commonly known — namely, that people who die from respiratory illness typically have a high degree of cognitive impairment, epilepsy, poor mobility, and require assistance with eating and drinking.

Age and gender

Most of the people whose deaths were respiratory-related were male (16 people).

On average:

- DADHC group home residents died youngest, at 30 years of age, and licensed boarding house residents were the oldest at 61 years.
- disability services residents died at 43 years of age.
- group home residents died at a younger age (36 years) than the people who lived in large residential centres (47 years).

Table 6: Number of people in each age band by gender

		Gender		Total
		Male	**Female**	
Age bands	15–24	2	2	4
	25–34	2	2	4
	35–44	5	1	6
	45–54	2	1	3
	55–64	3	4	7
	65–74	1	0	1
	75–84	1	1	2
Total		**16**	**11**	**27**

Accommodation

Most of the 27 people who died had lived in large residential centres (14 people), including eight people who had lived in DADHC-operated centres, and six people who had lived in funded centres. Nine people had lived in group home accommodation (7 NGO, 2 DADHC), and four people had lived in licensed boarding houses.

Table 7: Number of people in each accommodation type

	Frequency	Percentage
Group Home	9	33.3
Large Residential	14	51.9
Licensed Boarding House	4	14.8
Total	**27**	**100.0**

Disability, health, and support

Support needs

In our 2004 review of respiratory deaths, we noted that a high degree of dependency on support for daily living activities is associated with increased risk of the development of respiratory infections.

This was reflected in the review of respiratory deaths in 2005 where, out of the 27 people who died:

- 21 had an intellectual disability, including 14 people who had a severe to profound level of cognitive impairment.
- most had multiple co-existing health issues, such as osteoporosis, diabetes, asthma, and incontinence.
- 20 people required some form of assistance with meals but only eight people had any document outlining what assistance they required, such as an eating and drinking (or mealtime management) plan.
- 17 had swallowing difficulties. Six of these had not had a swallowing review for over 12 months when they died.
- 22 had mobility difficulties, including 17 people who relied on a wheelchair to mobilise.

Of the 27 people whose deaths in 2005 were related to respiratory illness, nine people had cerebral palsy, two people had significant physical disabilities such as spastic quadriplegia, and one person had muscular dystrophy.

Epilepsy

In 2004, we noted that both epilepsy and anti-convulsant medications are known to increase the risk of respiratory problems, and aspiration pneumonia can result from people aspirating during a seizure.

Most of the people who died from respiratory illness in 2005 also had epilepsy (19 people).

Recurrent respiratory infections

In 2004, we reported that it would be best practice for a GP to make a referral to a respiratory specialist if a person:

- has asthma that is not controlled by medication, or oral steroids are needed;
- has a 'peak flow' (the rate at which a person can expel air from the lungs) of less than 60%;
- has a diagnosis of chronic obstructive pulmonary disease (COPD) to enable assessment and determination if respiratory damage is reversible; or
- has a disability and an occurrence of pneumonia.

Just over one-third of the 27 people who died in 2005 had recurrent respiratory infections. This represents a much lower proportion compared to those reported in 2004, when almost two-thirds had a history of recurrent respiratory infections.

Of the 10 people with recurrent respiratory infections who died in 2005, two had seen a respiratory specialist.

GORD

As reported in 2004, GORD is commonly associated with respiratory complications including chronic cough and chronic lung disease due to recurrent aspiration. GORD is also associated with death due to aspiration pneumonia.

Positive management of suspected or diagnosed GORD includes:

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

GORD was recorded as a health concern for 12 of the 27 people who died in 2005, and 15 people were receiving medications for reflux. This is a lower proportion than reported in 2004, when almost three-quarters had a diagnosis of GORD or were on GORD medications.

A quarter of the people with GORD who died from respiratory illness in 2005, had seen a gastroenterologist, and just over half had seen a speech pathologist in the 12 months before their death.

Weight

In 2004, we noted that underweight people are at greater risk of contracting pneumonia due to their susceptibility to infection as a result of an impaired immune status.

The weight and height was known for 23 of the 27 people whose deaths in 2005 were respiratory-related. Most of the 23 people (17) were outside of the healthy weight range.

Five people were very underweight, four people were overweight, and four people were obese or severely obese.

Just over half of the 17 people (9) who were outside the healthy weight range had seen a dietitian.

(See table 8 below.)

Immunisation

The major modes of pneumonia prevention include immunisation against influenza and pneumococcus.[36] The Australian Immunisation Handbook 8th Edition (2003) indicates that people with disabilities in care should receive an annual influenza vaccination, and that people with chronic illness should also receive pneumococcal vaccination.

Of the 27 people whose deaths in 2005 were related to respiratory illness, most (19) had received the influenza vaccination. The proportion of people who were immunised against influenza (70%) was the same as the proportion reported in 2004.

Of the people who had not received the influenza vaccination, one person had recurrent respiratory infections, and one person was very underweight.

Only seven people had received the pneumococcal vaccination. The pneumococcal vaccination status of 12 people was either unknown or not recorded, including nine people who had lived in the care of disability services.

Cause of death

The dominant cause of death was pneumonia, including eight people whose deaths were due to aspiration pneumonia. Deaths due to pneumonia, bronchopneumonia or aspiration pneumonia accounted for over three-quarters of the 27 deaths (21 people).

Table 8: Number of people in each weight range by service type

		Service Type			Total
		DADHC	FUNDED	Lic. BH	
Weight range	Very underweight	1	4	0	5
	Healthy weight range	6	3	0	9
	Overweight	3	2	0	5
	Obese	0	2	0	2
	Severe obesity	0	1	1	2
	Not recorded	0	1	3	4
Total		**10**	**13**	**4**	**27**

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[36] Salive, M.E., Satterfield, S., Ostfield, A.M., Wallace, R.B., & Havlik, R.J. ‘Disability and cognitive impairment are risk factors for pneumonia-related mortality in older adults’ in *Public Health Reports*, Vol 108, No 3, May-June 1993, pp314-322.

The Coroner identified a number of significant conditions that were relevant, and sometimes the antecedent, to the deaths of many of these individuals. These included cerebral palsy, Down syndrome, muscular dystrophy, schizophrenia, epilepsy, dementia, chronic obstructive pulmonary disease, and heart conditions such as congestive cardiac failure and ischaemic heart disease.

The group included two people who died after choking on food, and two people who made the informed decision to eat and drink at consistencies that were unsafe for them. These individuals, and the circumstances of their deaths, were discussed in last year's report.

As we have reported previously, many of the people whose deaths are related to respiratory illness are medically frail with multiple and complex health needs. For some of the people who died from aspiration pneumonia, it is uncertain whether anything further could have been done to prevent or minimise aspiration. For this reason, we queried the preventability of many of these deaths.

5.4 Individual reviews

In relation to the support provided to particular people, we identified some examples of good practice, including carefully constructed management or care plans, timely implementation of allied health and practitioner recommendations, active treatment of presenting respiratory issues, and specialist respiratory and gastroenterology reviews.

However, we also noted some gaps in the provision of health and medical services to some individuals whose deaths were respiratory-related. The following examples are illustrative:

- There were missed opportunities by hospital staff to correctly diagnose pneumonia, including delays in performing a chest x-ray.
- The service documented an increase in the number of seizures, but had no clear plan for further action.
- A woman with recurrent episodes of pneumonia was not referred to a respiratory physician, there was a delay in prescribing antibiotic treatment for pneumonia due to a query about the diagnosis, and a clear adverse change in her clinical condition did not result in a referral to hospital for treatment.
- There was no indication that smoking cessation strategies were actively employed for a woman who had chronic obstructive pulmonary disease and smoked 80 cigarettes a day. It appeared that the woman's medical practitioners acted in isolation and missed opportunities to share information or work together.
- There appeared to be a delay in hospital staff detecting the dislodgement of a woman's tracheostomy and diagnosing a blood clot in her arm.

5.5 Systemic issues

We found that there were only a few systemic issues that stood out across most of the 27 deaths. However, there were significant issues relating to the involvement of respiratory physicians, provision of first aid, and end-of-life decision-making.

Involvement of respiratory physicians

While over a third of the people who died from respiratory illness had experienced recurrent respiratory infections, only two of these individuals had seen a respiratory physician.

In 2004, we reported that referrals to respiratory specialists should be made for individuals who experience recurrent episodes of respiratory illness. People with evident aspiration should also receive respiratory specialist advice.

It is not clear why people with disabilities in care who have recurrent respiratory issues are not typically being referred to respiratory specialists.

Consultation with a respiratory specialist requires referral by a treating medical physician. The respiratory physicians on our expert committee note that their referrals always come through hospital admissions — community-based referrals do not tend to occur. They also commented that the triggers that would indicate that the person should be referred for specialist advice might not be clear for GPs.

We consider that there needs to be additional work in this area to determine:

- How general practitioners manage respiratory illness in people with disabilities.
- When general practitioners would refer a person to a respiratory specialist.
- What factors may affect the decision of general practitioners to refer a person to a respiratory specialist.

First aid

There were gaps in the provision of first aid on two levels.

Firstly, we identified gaps in the provision of first aid in response to critical incidents. Our concerns in this area have been raised in each of our reports, including this year, and we will continue to monitor agency progress towards meeting our recommendations on this issue.

Secondly, we noted some gaps in the ability of staff to recognise deterioration in the person's health and take action, such as responding to an increase in the number of seizures experienced. While these instances were not common, a failure to respond to deteriorating health can have very significant consequences.

End-of-life decision-making

Last year, we raised concerns about end-of-life decisions that were made in relation to some of the people who died in 2005, including a lack of documentation of the reasons for those decisions.

End-of-life decision-making was one of the key issues that emerged from the review of the 27 deaths in 2005 that were respiratory-related. This included no-CPR decisions that appeared to have been made prematurely, treatment limitation and no-CPR decisions that were not revisited when the person's condition improved, and end-of-life decisions that appeared to be based on reasons other than the person's clinical diagnosis and prognosis. These issues were discussed at length in our *Report of Reviewable Deaths in 2005*.

As highlighted in section 6.5, end-of-life decision-making has been identified as a concern again this year, and we are continuing to monitor NSW Health's progress towards implementing our recommendations in this area.

Summary

In the main, our review of respiratory-related deaths in 2005 was consistent with the findings of our first review of this issue, which we reported in 2004.

The key risk factors for respiratory illness highlighted in 2004, including high support needs and swallowing difficulties, were largely evident for the people who died in 2005.

This review has identified some areas for further inquiry, including the issue of GP referrals to respiratory specialists for people with disabilities in care. It has also confirmed the importance of many of the areas that continue to be a focus of our attention, including the provision of first aid.

Many of the recommendations we previously made in relation to respiratory illness are still in train, including the review of the clinical nurse specialist model of health care case management, and monitoring of the implementation of the *Ensuring Good Nutrition* policy.

We will continue to monitor the work of key agencies in relation to our recommendations and consider the need for possible further work in this area. Given the ongoing dominance of respiratory illness as a cause of death for people in the care of disability services, we will revisit a review of such deaths in the near future.

6. Appendices

Appendix 1

Reviewable disability deaths advisory committee — membership

Mr Bruce Barbour:	Ombudsman (chair)
Mr Steve Kinmond:	Deputy Ombudsman and Community and Disability Services Commissioner
Ms Margaret Bail:	Human services consultant
Dr Helen Beange:	Clinical Professor, Faculty of Medicine, University of Sydney
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)
Dr Ted O'Loughlin:	Paediatric Gastroenterologist, The Children's Hospital at Westmead
Dr Rosemary Sheehy:	Geriatrician/Endocrinologist, South West Sydney Area Health Service
Ms Anne Slater:	Physiotherapist, Allowah Children's Hospital
Assoc Prof Ernest Somerville:	Prince of Wales Clinical School, Neurology
Dr Julian Troller:	Senior Research Fellow University of NSW and Senior Staff Specialist, Neuropsychiatric Institute, Euroa Centre, Prince of Wales Hospital

Appendix 2

Data: Deaths of people with disabilities in care in 2006

1. Demographic Information

Age

The ages of people with disabilities who died in care in NSW in 2006 ranged from 14 to 94 years.

- The average age at death for group home residents was 49 years. Just under two-thirds of the people living in group homes in NSW are younger than 44 years of age.[37]
- The average age at death for people who had lived in residential centres was 57 years. Just under two-thirds of the people living in residential centres in NSW are 44 years of age and older.[38]
- The average age at death for licensed boarding house residents was 63 years. Of the 606 people in the broader licensed boarding house population in NSW whose ages have been identified, most are older than 52 years of age.[39]

Table 9: Age at time of death — disability services residents

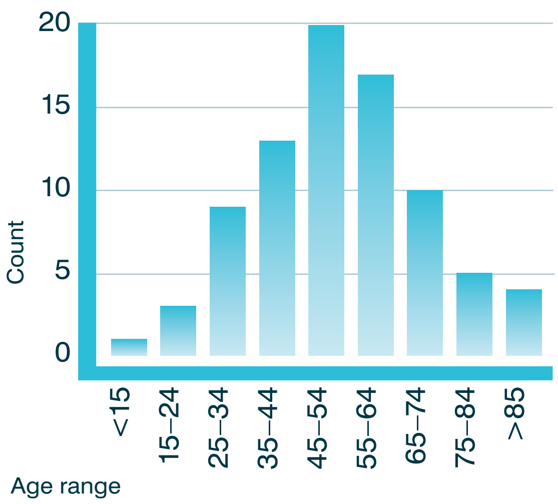
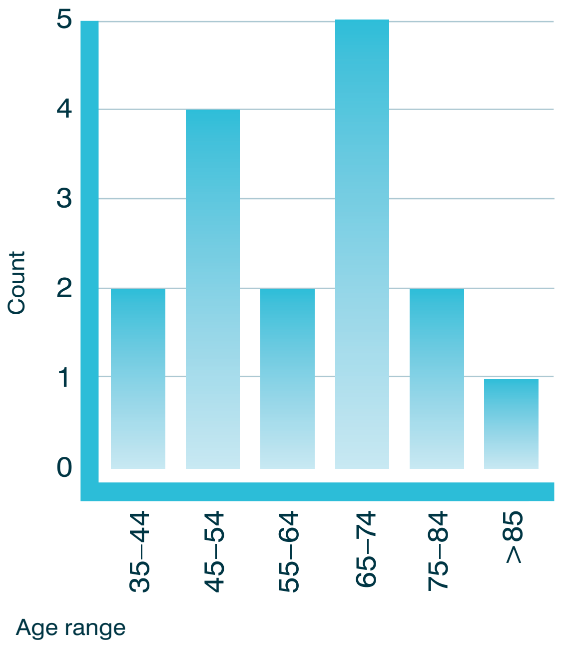


Table 10: Age at time of death — licensed boarding house residents



Gender

As with previous years, in 2006 the deaths of males outnumbered the deaths of females in both disability services and licensed boarding houses, reflecting the trend in the wider community.

- 52 of the 82 people who had lived in disability services were male.
- 15 the 16 people who had lived in licensed boarding houses were male.

For both disability services and licensed boarding houses, the average age at death was lower for males than for females, which differs from what is reported for the general community. In NSW, men can expect to live 78.9 years and women can expect to live 83.7 years.[40]

- In relation to disability services residents, males died at 54 years, and females died at 51 years.

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[37] Data source: DADHC Client Information System and the Minimum Data Set 2005-06.
[38] Data source: DADHC Client Information System and the Minimum Data Set 2005-06.
[39] Data source: DADHC records as at 9 August 2007.
[40] Report of the NSW Chief Health Officer, December 2006.

- In relation to licensed boarding house residents, males died at 63 years and the one female died at 71 years.

Cultural Background

Three people were identified as being Aboriginal or Torres Strait Islander, and all had lived in the care of disability services. No licensed boarding house residents were identified as being of Aboriginal or Torres Strait Islander background.

Four disability services residents were born outside Australia. Two people were born in England, one person was born in the Czech Republic, and one person was born in Hungary. All spoke English as their first language.

Two of the 16 licensed boarding house residents had been born overseas. One person was born in Malta and spoke English, and the other person was born in Croatia and spoke Croatian.[41] One other person from a non-English speaking background, who was born in Australia, spoke Finnish.

2. Service Provision

Time in residential care

Disability services residents had spent from one to 70 years in care. The average length of time that disability services residents had lived in care was 29 years. On average this group had lived at their most recent location for 17 years.

On average, residents in DADHC-operated services had lived at their most recent location (23 years) for longer than residents of funded services (11 years), and people who had lived in residential centres had lived at their most recent location (29 years) for a lot longer than group home residents (7 years).

For licensed boarding house residents, the length of time in care and the most recent location was known for 14 people, and they had lived in care for 14 years. On average, licensed boarding house residents had lived at their most recent location for 12 years.

Table 11: Total lifetime in care by service provider

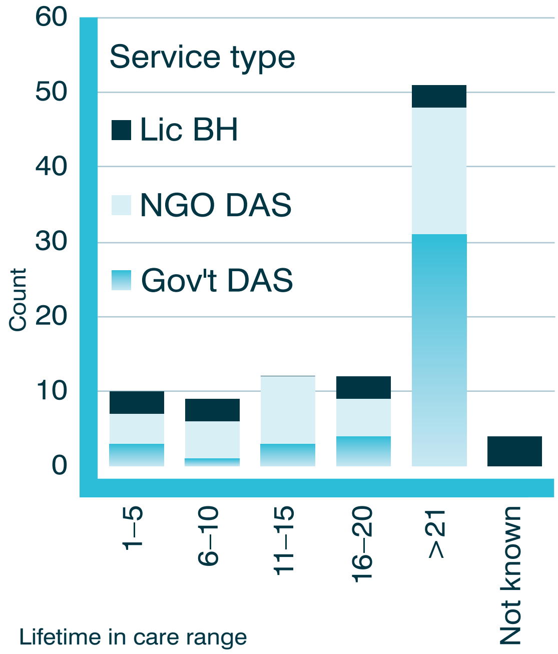
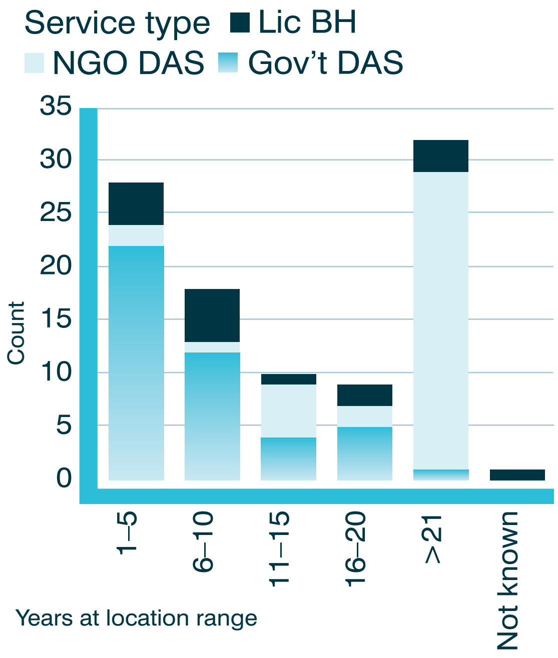


Table 12: Number of years at most recent location by accommodation type



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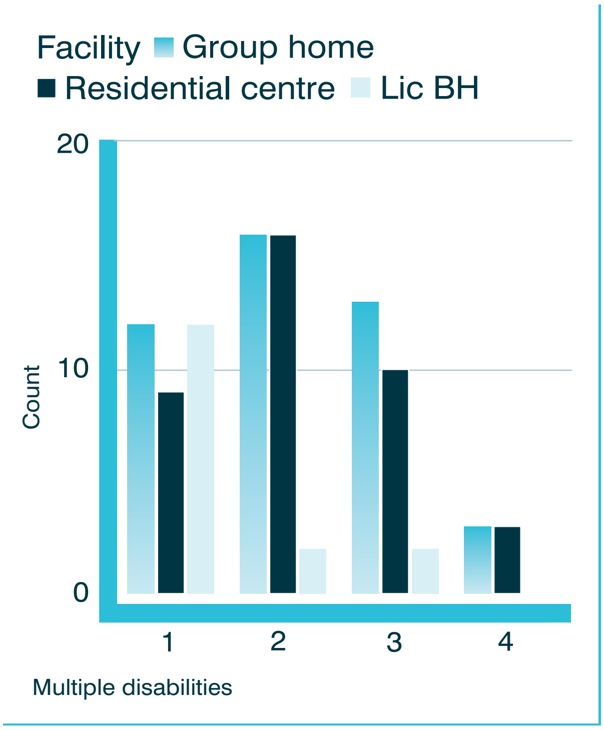
[41] As indicated in section 4.2, while the man's country of origin was documented as Croatia, the services involved with him variously recorded his language of choice as Swedish, Hungarian, Polish, Czech, and Dutch.

3. Disability, health and support needs

Disability

Three-quarters (61) of the people who had lived in disability services had two or more disabilities. The large majority of boarding house residents (12) had one disability.

Table 13: Multiple disabilities by accommodation type

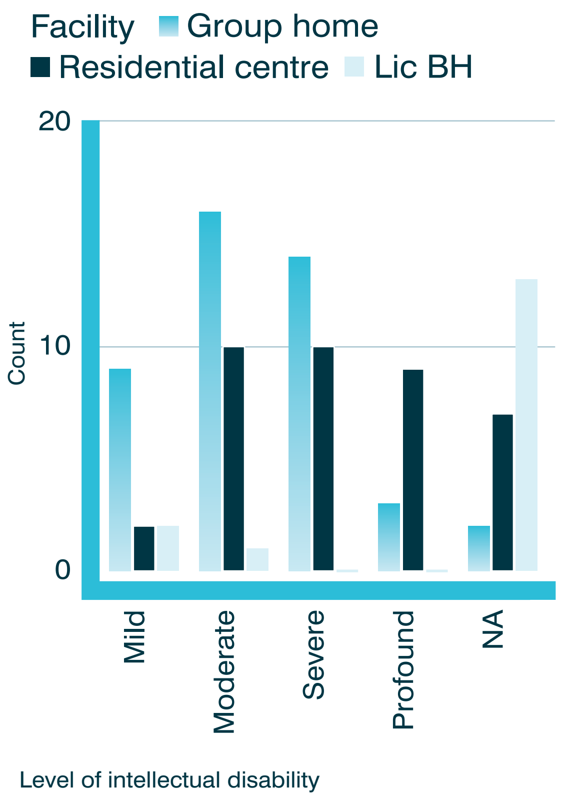


As has consistently been the case, the most commonly reported disability for disability services residents was intellectual disability (73 people).

Residents of DADHC-operated services were more often reported to have had a severe or profound level of cognitive impairment (27 people) than the people who lived in the care of funded services (nine people).

Eight of the nine disability services residents who did not have an intellectual disability lived in funded services.

Table 14: Level of intellectual disability by accommodation type



Among licensed boarding house residents, psychiatric disability was the most commonly reported disability (12 people). This is consistent with previous years. The number of licensed boarding house residents reported as having had a psychiatric disability has increased steadily since 2004, with 59% in 2003, 50% in 2004, 69% in 2005 and 75% in 2006.

Table 15: Number of people with psychiatric disability by accommodation type

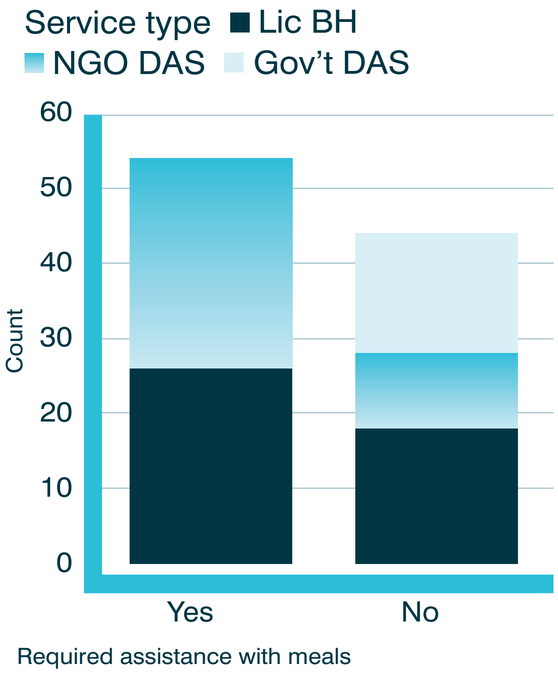
		Facility			Total
		Group home	Residential centre	Lic BH	
Psychiatric disability	Yes	12	12	12	36
	No	32	26	4	62
Total		**44**	**38**	**16**	**98**

Assistance with meals

Two-thirds (54) of the people who had lived in the care of disability services required assistance with meals (either to chop food or to use utensils). Unlike 2005, when most people in residential centres required assistance and most group home residents did not, the number of people requiring assistance with meals in 2006 was fairly evenly divided between residential centres (28) and group homes (26).

None of the licensed boarding house residents required assistance with meals.

Table 16: Required assistance with meals by accommodation type



Weight

It was possible to calculate the Body Mass Index (BMI) for 72 of the 82 disability services residents. Of these 72 people, 27 were within the healthy weight range.

The weight of 32 disability services residents was above the healthy weight range, and half of these individuals had seen a dietician in the 12 months prior to their death.

Thirteen people who had lived in the care of disability services were below the healthy weight range, and eight of these individuals had seen a dietician in the 12 months before their death. Of the eight people who were very underweight, three people had not seen a dietician.

BMI information was available for half of the 16 boarding house residents. Most of these individuals (6) were above the healthy weight range, including one person with severe obesity, but none of these individuals had seen a dietician. The other two people were in the healthy weight range.

Table 17: Weight range by accommodation type

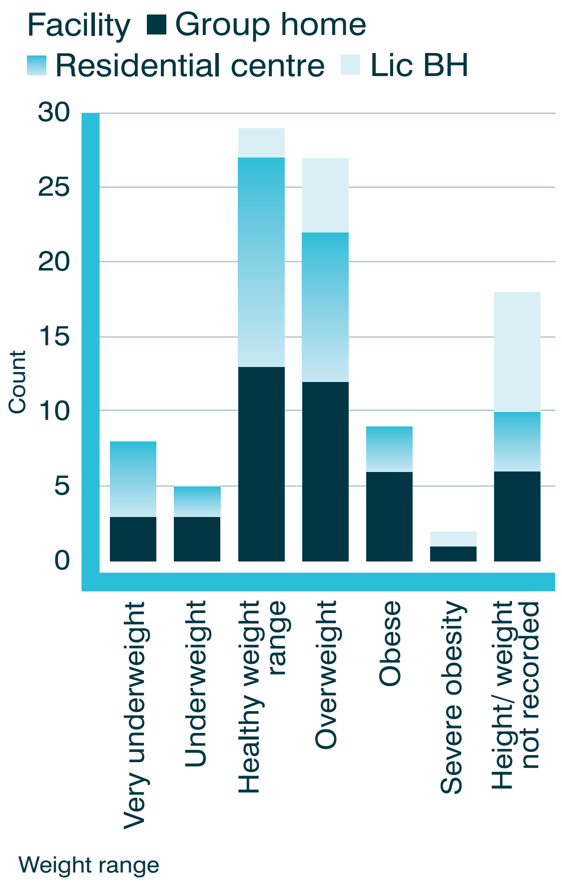
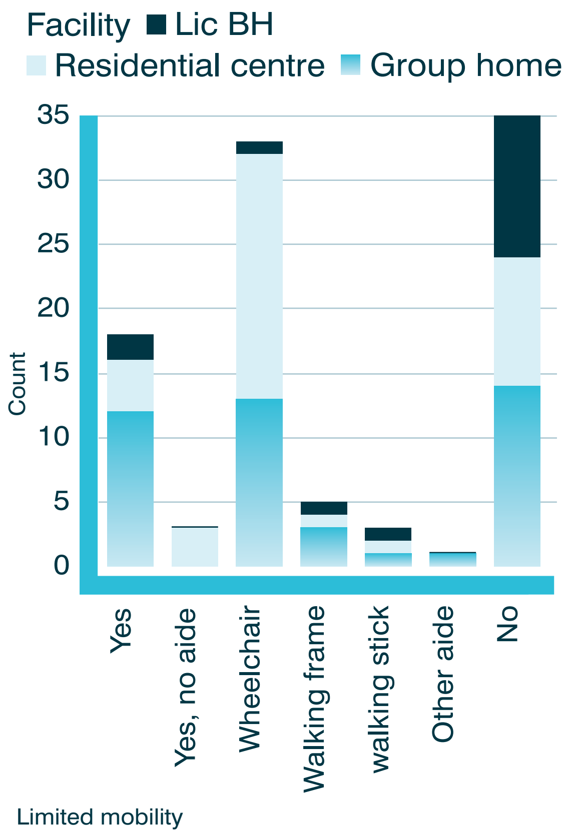


Table 18: Mobility by accommodation type



Mobility

The majority of the people who had lived in disability services (58) had some form of limited mobility, including 32 people who required wheelchair support. This is consistent with the broader in-care community, where most of the people living in the care of disability services require mobility support.[42]

Among the licensed boarding house residents, five people had limited mobility, including one person who required a wheelchair. This is consistent with the broader licensed boarding house population, where the majority do not require mobility assistance.[43]

Communication

Almost three-quarters (61) of disability services residents required communication support, including five people who communicated via pictures, and three people who used sign language. This is consistent with the broader disability services in-care population, where the majority require communication support.[44]

Three licensed boarding house residents were reported to have required communication support, but the method of communication was not specified. The majority of people in the licensed boarding house population in NSW do not require communication support.[45]

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[42] Data source: DADHC Client Information System and the Minimum Data Set 2005-06.

[43] Data source: DADHC records as at 9 August 2007.

[44] Data source: DADHC Client Information System and the Minimum Data Set 2005-06.

[45] Data source: DADHC records as at 9 August 2007.

Table 19: Communication support by accommodation

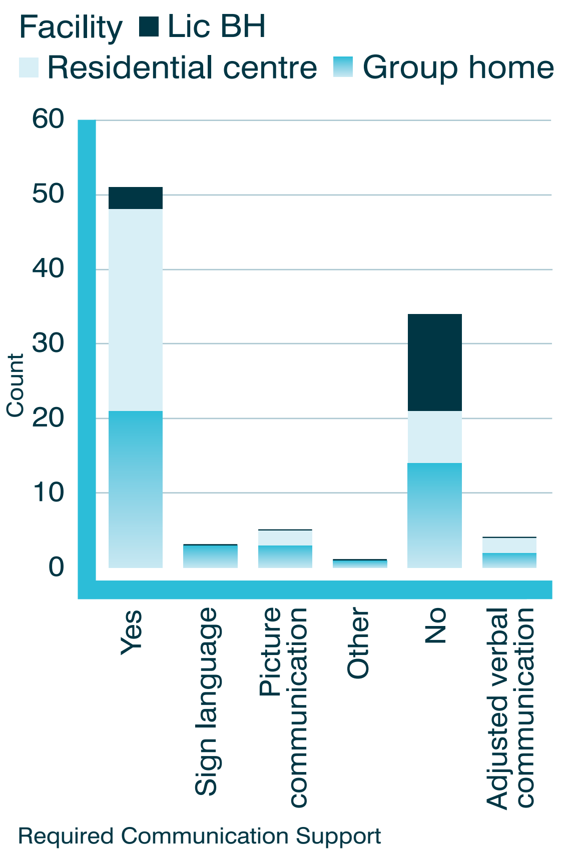
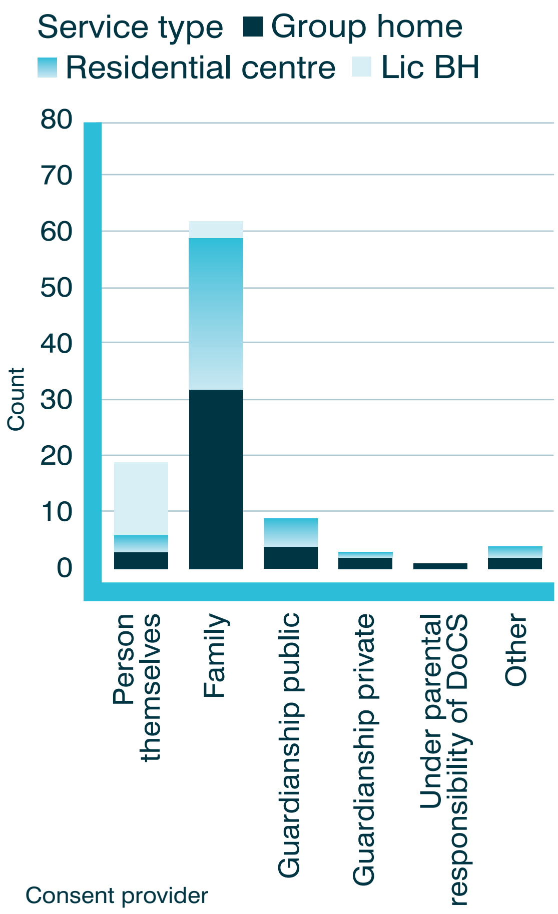


Table 20: Consent provider by accommodation type



Consent provider

Almost all of the people who had lived in disability services (76) were reported as having a ‘person responsible’ for providing consent to medical and dental treatment. As has consistently been the case, family members were the main people involved in consent decisions for disability services residents.

The number of people who lived in disability services who provided their own consent has continued to decrease — from 15% in 2003, 12% in 2004, 11% in 2005, and 7% in 2006. All of the six people who lived in disability services who provided their own consent had lived in funded services.

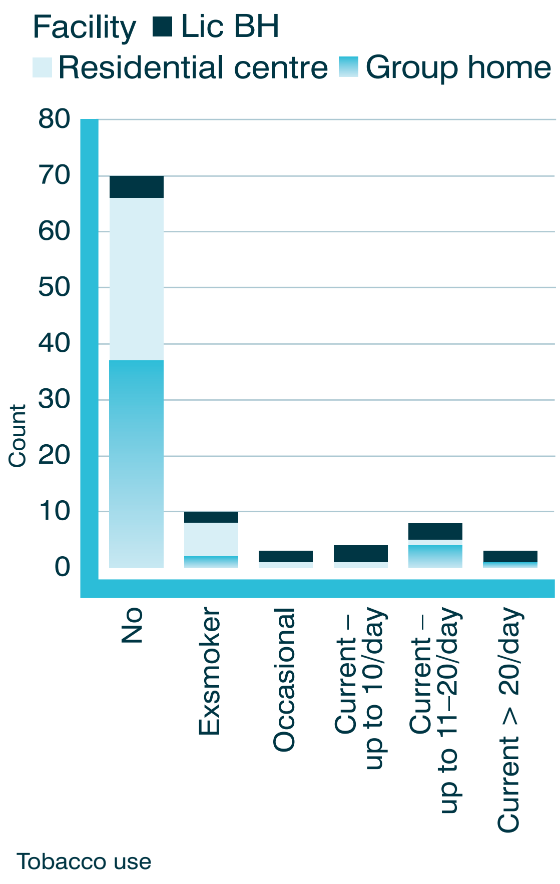
Of the licensed boarding house residents, 13 people provided their own consent to medical and dental treatment, and three people had family members recorded as ‘person responsible’.

Smoking

The majority of disability services residents (66) did not smoke. Eight people were current smokers, ranging from occasional cigarettes (one person) to more than 20 per day (one person). Three-quarters of the people who were current smokers at the time of their deaths lived in funded services.

Ten licensed boarding house residents were current smokers, ranging from occasional cigarettes (two people) to more than 20 per day (two people). Four people did not smoke, and two people were ex-smokers.

Table 21: Tobacco use by accommodation type



Immunisation

The Australian Immunisation Handbook indicates that people with disabilities in care should receive annual influenza vaccination, and that people with chronic illness should also receive pneumococcal vaccination.

Just below three-quarters of disability services residents (58), and over half of licensed boarding house residents (9 people) had been vaccinated against influenza. These figures are unchanged from 2005. (See table 23.)

Medication

Over one-third of disability services residents (31 people) were receiving antipsychotic medication. This is a considerable increase on the number recorded in previous years — 27% in 2004, 20% in 2005, and 38% in 2006. Six of the 31 disability services residents receiving antipsychotic medication had not seen a psychiatrist.

Eleven disability services residents who received antipsychotic medication did not have a psychiatric disability. Of these eleven people, five had not seen a psychiatrist.

Thirteen licensed boarding house residents received antipsychotic medication. Six of these individuals had not seen a psychiatrist. In comparison with 2005 (30%), an increased proportion of licensed boarding house residents who received antipsychotic medication had seen a psychiatrist (54%).

Two of the 13 licensed boarding house residents who received antipsychotic medication did not have a psychiatric disability, and one of these individuals had not seen a psychiatrist. (See table 24.)

Table 22: Influenza vaccination by accommodation type

		Facility			Total
		Group home	**Residential centre**	**Lic BH**	
Flu vaccination	Yes	27	31	9	67
	No	3	1	0	4
	Not recorded	14	6	7	27
Total		**44**	**38**	**16**	**98**

Table 23: Pneumococcal vaccination by accommodation type

		Facility			Total
		Group home	Residential centre	Lic BH	
Pneumococcal	Yes	17	14	4	35
	No	4	16	1	21
	Not recorded	23	8	11	42
Total		**44**	**38**	**16**	**98**

Table 24: Number of people with a psychiatric disability and/ or receiving antipsychotic medication by accommodation type

Psychiatric disability			Facility			Total
			Group home	Residential centre	Lic BH	
Yes	Anti-Psychotic Medication	Yes	11	9	11	31
		No	1	3	1	5
	Total		12	12	12	36
No	Anti-Psychotic Medication	Yes	7	4	2	13
		No	25	22	2	49
Total			**32**	**26**	**4**	**62**

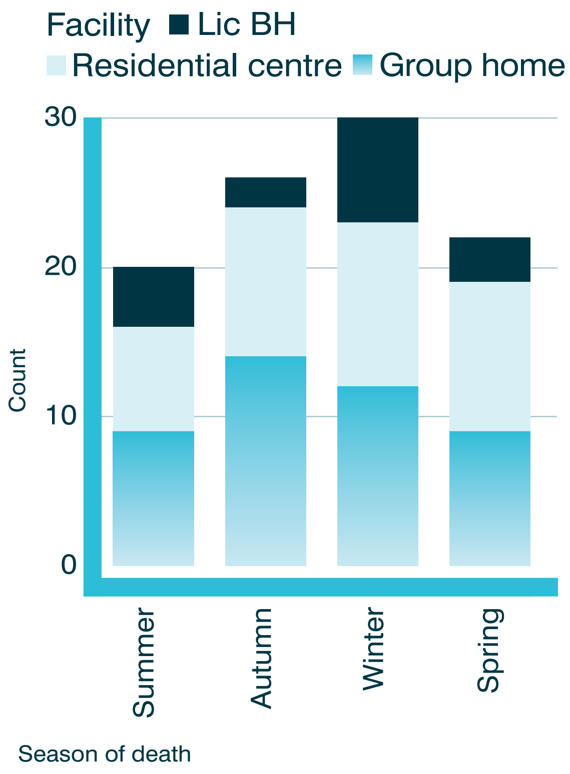
4. When and where people died

Season of death

Most of the disability services residents died in autumn (24 people), although there was very little difference to winter. Winter was the most common season in which licensed boarding house residents died (seven people).

(See table 25.)

Table 25: Season of death by accommodation type

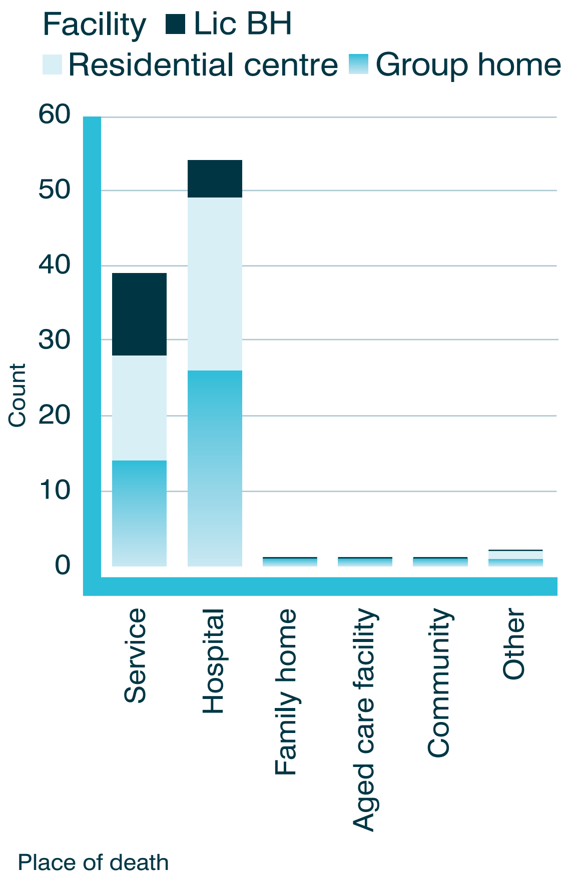


Place of death

Over half of the disability services residents (49) died while in hospital.

Most of the licensed boarding house residents (11) died at home. In 2006 there was a notable increase in the number of deaths of licensed boarding house residents that occurred at the service — from approximately 39% over 2003 - 2005, to 62% in 2006. This is matched by a decrease in the number of deaths of licensed boarding house residents in the community — from approximately 16% over 2003 - 2005, to none in 2006.

Table 26: Place of death by accommodation type



Autopsy

Autopsies were conducted in relation to 27 people, including one person in which there was an objection by the person's family.

Table 27: Autopsy

		Autopsy objection			**Total**
		Yes	No	Not recorded	
Autopsy	Yes	1	21	5	27
	No	10	17	2	29
	Not yet received	0	11	31	42
Total		**11**	**49**	**38**	**98**