



NSW Ombudsman



Report of Reviewable Deaths in 2007

**Volume 1: Deaths of people with
disabilities in care**

December 2008



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Our logo has two visual graphic elements; the 'blurry square' and the 'magnifying glass' which represents our objectives. As we look at the facts with a magnifying glass, the blurry square becomes sharply defined, and a new colour of clarity is created.

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December 2008

The Hon Peter Primrose MLC
President
Legislative Council
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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 fifth 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 s.43 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 2007; 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
NSW Ombudsman

Ombudsman's message

My office is one of very few agencies in the world with the function of reviewing the deaths of people with disabilities in care.

Our work in reviewing individual deaths is important: it highlights gaps in service practice, policy and systems, and drives service improvement from a grassroots level.

It is through considering the deaths of people with disabilities in care more broadly, identifying trends, risk factors and systems issues, that we aim to minimise preventable deaths in this vulnerable community. Our annual report provides the means for us to consider the deaths of people with disabilities in care in the context of the larger service system, and to effect change across government and non-government agencies, and across disability, health, and other sectors.

The main way in which we seek to bring about change through our annual reports is by making recommendations to government and service providers, and monitoring the implementation of those recommendations until we are confident that progress has been made. One of the strengths of our reviewable deaths work has been the breadth of issues we have highlighted for agency action. The recommendations we have made and monitored over the past five years illustrate this breadth of focus, including those aimed at effecting change for all people with disabilities living in care, such as first aid, and those targeted at improving outcomes for specific groups, such as people with dual diagnosis, and ageing people with disabilities.

I am pleased that, in our fifth report on reviewable deaths, we are able to detail important progress by agencies regarding areas of concern that have consistently been a focus of our recommendations. This includes reviews of the effectiveness of key policies and risk assessments, such as the *Ensuring Good Nutrition* policy and the Screening Tool for Entry to Licensed Boarding Houses, and interagency work regarding access to therapy services, and support for people with dual diagnosis.

However, progress in other significant areas the subject of our recommendations has been slow. Of particular note is agency progress towards ensuring consistent first aid requirements across accommodation services for people with disabilities, progress towards completing the review of the *Youth and Community Services Act 1973*, and progress towards implementing a service framework to improve the health care of people with intellectual disabilities. These areas will continue to be a focus of our work over the next year.

We also seek to drive service improvement and reduce preventable deaths through our annual report by highlighting the issues we identify through individual reviews, and providing clear case studies to illustrate gaps and/or good practice. In this regard, we recognise that the people who are in the best position to improve outcomes for people with disabilities in care are the support workers who provide direct care, and their managers.



Bruce Barbour
NSW Ombudsman

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Executive summary

The purpose of the Ombudsman’s reviewable deaths function with regard to people with disabilities is to prevent or reduce the premature deaths of people living in, or temporarily absent from:

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

About the people who died in 2007

In 2007, the deaths of 98 people with disabilities were reviewable:

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

On average, the people who had lived in disability services were 54 years old when they died — six years younger than licensed boarding house residents — and around 25 years younger than the general population.

The profile of the people with disabilities whose deaths we have reviewed has been consistent during the five years in which we have held this function.

The disability services residents who have died have typically had cognitive and additional impairments, as well as significant and ongoing health concerns such as swallowing difficulties and epilepsy. The leading cause of death of people in the care of disability services is respiratory illness, including pneumonia, aspiration pneumonia, and bronchopneumonia. Disability services residents are vulnerable to respiratory illness due to the existence of many risk factors, such as swallowing difficulties, need for help with meals and oral care, limited mobility, and taking multiple medications.

The licensed boarding house residents who have died have typically had a mental illness and several risk factors for cardiovascular disease, such as hypertension and heavy smoking. Diseases of the circulatory system, such as ischaemic heart disease, are the leading cause of death of people who live in licensed boarding houses.

Key issues identified through our work

Meeting complex needs

Some of the people whose deaths we review had complex needs, including complex health, behaviour, and/or support needs. While we identified examples of good practice in health care planning, we also noted some areas for improvement in meeting the complex health and other needs of some of the people who died in 2007. This included instances where:

- nutrition and swallowing risks were not identified and/or addressed,
- inadequate action was taken to address emerging health concerns, such as pressure ulcers,
- inadequate guidance was provided to staff as to how to meet the needs of some individuals, such as positioning for meals, behaviour support, and responses to threats of self-harm,
- there was a lack of effective interagency work to provide coordinated and comprehensive support.

First aid

The effective provision of first aid is directly relevant to the prevention of premature deaths. However, for the past four years, we have repeatedly identified instances where first aid has not been provided, first aid has been ineffectively provided, or there have been delays in seeking medical assistance. We had concerns about the first aid provided in relation to at least five people who died in 2007.

We have consistently stated that 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. Our concern is that, while first aid qualifications are mandatory for DADHC staff, this is not the case for staff in funded services or licensed boarding houses.

We note that, of the five people who died in 2007 who appeared to receive inadequate first aid, four lived in the care of funded services, and one lived in a licensed boarding house.

It is critical that people with disabilities in care are supported by staff who have had first aid training, particularly given their vulnerability to critical incidents related to medication toxicity or overdose, choking, falls, and serious health concerns.

Advance care directives

Our reviews this year alerted us to ‘advance care directives’ on the files of a small number of people who did not appear, at the time the directives were developed, to have the capacity to make informed decisions.

An advance care directive is a document that describes a person’s future preferences and wishes for medical treatment in anticipation of a time when they will no longer be able to state those preferences because of illness or injury.

People who lack the capacity to make informed decisions regarding their own health care are not able to make advance care directives, and nor can it be done on their behalf.

We consider that it is important that:

- advance care directives are only developed by people who are able to make informed health care decisions;
- the development of advance care directives is optional for these individuals; and
- individuals and services refer to NSW Health’s *Using Advance Care Directives (NSW)* policy when considering these directives.

Down syndrome and dementia

Given the prevalence of dementia in people with Down syndrome whose deaths we review, this year we took a closer look at these individuals and current research in this area. Of the 63 people with Down syndrome who lived in care who died between 2003 and 2007, 29 were diagnosed with dementia. Of the 34 people who did not show signs that they had dementia while they were alive, five were noted at post-mortem to have changes in the brain consistent with Alzheimer’s disease.

Key findings

- In comparison with the general population, dementia occurs at a much younger age for people with Down syndrome, and occurs in a higher percentage of people.
- Alzheimer’s disease is the most common form of dementia for the general population as well as people with Down syndrome. There is a strong link between Down syndrome and Alzheimer’s disease, thought to be associated with the extra copy of chromosome 21.

- In our review, the main cause of death for people with Down syndrome and dementia was respiratory illness.
- There are two features of dementia in people with Down syndrome that are not typical of Alzheimer's disease: the development of seizures, and serious swallowing difficulties associated with weight loss and aspiration pneumonia. The onset of seizures in older adults with Down syndrome is often one of the first signs of Alzheimer's disease.
- In the main, services and health professionals appeared to be responsive to the changing or increasing needs of people with and without dementia in our review, including the involvement of allied health practitioners and specialists.
- Diagnosing dementia can be difficult when a person has Down syndrome because the usual skill tests used for diagnosis do not take into account existing cognitive and other impairments, and communication difficulties can affect the assessment. In addition, people with Down syndrome are more susceptible to reversible conditions that can be mistaken for dementia, including depression, medication side-effects, and vitamin deficiencies.
- It is important that people with an intellectual disability have a comprehensive assessment of memory, other cognitive functions and behaviours at least once in early adulthood to obtain a baseline of their level of functioning. Having a baseline makes it easier to identify changes in the person's functioning, and can be important in diagnosing dementia.
- For people with Down syndrome, best practice in diagnosing dementia includes assessment to determine any decline in the person's functioning, medical tests to work out if decline is due to physical illness, psychiatric assessment to work out if decline is due to mental illness, and multidisciplinary assessments, including allied health involvement. Any reversible causes of decline need to be treated before a diagnosis of dementia can be made.
- The focus of caring for a person with dementia should be on flexibility and meeting individual needs. In our review, we found evidence of good practice by some of the services that supported people with Down syndrome and dementia, including changing personal care times and mealtimes, and adjusting routines to minimise distress, adapting the physical environment to ensure safety, and ensuring that support was provided by familiar staff.

Overall, our review indicated that disability services endeavour to meet the increasing needs of people with Down syndrome and dementia within existing resources, and with the involvement of relevant health and ageing practitioners. However, we are concerned that:

- As the number of older people with disabilities increases, the ability of services to meet the greater support needs of people with disabilities related to dementia and/or ageing with their existing resources will be challenging, particularly for smaller organisations.
- Disability services staff generally do not have expertise in dementia and aged care, and they are unlikely to receive the necessary training and support through the involvement of practitioners in the diagnostic process alone.
- Access of people with disabilities in care who have dementia to community-based aged care supports, such as Community Aged Care Packages, is hampered by the program, funding and policy separation between the disability (state) and aged care (Federal) sectors.

Recommendations

First aid

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. Currently, this is a requirement only in DADHC operated services. Funded services are not required to ensure that staff are trained in first aid. In our view, this is unreasonable given the risks faced by people with disabilities in care.

For the past three years we have made recommendations regarding the need for consistent first aid requirements. While there has been some progress towards ascertaining the gap in first aid training in funded services, a consistent requirement remains outstanding.

Our reviews of deaths in 2007 identified at least five people in funded or licensed services for whom first aid did not appear to be provided, or was ineffectively applied.

1. DADHC should make it a requirement that, in the services it funds, at least one person on each shift has current first aid qualifications. In making this requirement, DADHC should:
 - a) amend funding agreements to reflect the requirement; and
 - b) ensure that the requirement is included in the Integrated Monitoring Framework documents, including the service provider self-assessment and the Service Review Instrument.

Swallowing and nutrition

DADHC's *Ensuring Good Nutrition* policy, incorporating the nutrition and swallowing risk checklist, was rolled out to DADHC operated and funded disability accommodation services in 2004. Our recommendations in relation to nutrition and swallowing risks have focused on the need to effectively monitor the implementation of the policy, to evaluate the policy once implemented, and to consider links to a chest care checklist to identify respiratory risks.

In 2006, DADHC advised that the chest care checklist would be linked to the respiratory related questions in the nutrition and swallowing risk checklist. However, the nutrition and swallowing risk checklist has not yet been amended to include that link.

During the past year, an independent evaluation of the policy has commenced.

2. DADHC should report on the outcome of the evaluation of the *Ensuring Good Nutrition* policy, including advice as to how the chest care checklist will be incorporated.

Licensed boarding houses

Screening tool for entry

The purpose of the Screening Tool for Entry to Licensed Boarding Houses is to prevent the inappropriate placement of people with high support needs into boarding house

accommodation. Our reviews of deaths from 2004 onwards have raised questions about the application of the screening tool, including the accuracy and consistency of assessments, and identification of additional services to minimise risks.

Since 2005, we have recommended that DADHC undertake a review of the current application of the screening tool. This year, an independent review of the screening tool has commenced.

3. DADHC should advise what action, if any, the department intends to take in relation to the findings and recommendations of the review of the Screening Tool for Entry to Licensed Boarding Houses.

Identifying and addressing health needs and risks

In 2007, DADHC contracted NSW Health to conduct a review of the health needs of licensed boarding house residents in the inner west area of Sydney. The review highlighted significant gaps in the assessment and provision of health care to licensed boarding house residents in that region, and made seven recommendations to DADHC to improve the health outcomes of people living in licensed boarding houses across NSW.

4. DADHC should provide advice about any action it intends to take in relation to the findings and recommendations of the 2007 review of the health needs of licensed boarding house residents in the inner west area of Sydney.

Administration of regular prescribed medication

In our report last year, we raised concerns about the adequacy of the protocols in place for the administration of regular medications in licensed boarding houses. While licensed boarding houses are required to maintain a recording system for PRN medication, there is no such requirement for record keeping related to regular prescribed medications.

This year, DADHC advised that it consulted with the Boarding House Expert Advisory Group regarding this issue, and conducted a survey of 33 licensed boarding houses, which indicated good practice. The department advised that it would consider this recommendation further after consulting with NSW Health and primary and secondary health care providers.

5. 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 administration of regular medication.

Record keeping and guidance

In 2005 and 2006 we raised concerns about:

- compliance of licensed boarding house operators with record-keeping requirements, and
- access of licensed boarding house staff to information about good practice in health care, including access to relevant departmental policies.

In response, DADHC advised in 2006 that it was reviewing and updating its *Licensing, Monitoring and Closures* policy manual and incorporating information on good practice in supporting the health needs of people with disabilities that DADHC officers could use to assist licensed boarding house operators.

In relation to record keeping, DADHC reviewed record keeping practices in licensed boarding houses in 2006 and identified actions that it would take to strengthen the compliance by proprietors with Licence Condition 4 and encourage better practice. Licence Condition 4 sets out the record keeping responsibilities of boarding house licensees and licensed managers, including requirements to maintain a register of key resident information, record the administration of PRN medication, and record efforts to facilitate the integration of residents into community activities. The actions DADHC identified to strengthen compliance with this licence condition included reviewing the Monitoring and Review Tool, setting good practice benchmarks, and developing a resource to support the sector to improve compliance and practice in this area.

Last year, DADHC advised that its licensed boarding house reference group had commenced a review of the Monitoring and Review Tool. This year, the department has indicated that the Monitoring and Review Tool will be an appendix to the revised *Licensing, Monitoring and Closures* policy.

6. DADHC should report on progress towards:

- a) setting good practice benchmarks for Licence Condition 4; and
- b) developing a resource to support the sector to improve compliance and practice in regard to Licence Condition 4.

Review of the *Youth and Community Services Act 1973*

In 2002, DADHC commenced a review of the *Youth and Community Services Act 1973* (YACS Act). DADHC's review was initiated for a number of reasons, including questions about the enforceability of the legislation. Legal advice provided to the department in 1999 indicated that many of the licence conditions may be *ultra vires*; that is, beyond the power of the department to enforce.

These licence conditions include the administration and supervision of medication and access to health care, staffing suitability, and requirements to minimise financial exploitation, abuse, mistreatment and neglect of residents.

In 2005, we conducted an inquiry into DADHC's monitoring of licensed boarding houses. The inquiry found that uncertainty over the enforceability of certain licensing conditions adversely affects DADHC's capacity to effectively monitor and enforce licence conditions. In response to the inquiry report, DADHC told us in May 2006 that it would soon complete the review of the Act and was 'currently providing advice to the Government on directions for the Act'.

In October 2008, DADHC advised that an Inter-departmental Committee (IDC) on Reform of the Private Residential Service Sector has been formed to progress a whole-of-government approach to reform, and the review of the YACS Act will now come under the ambit of the IDC.

The IDC is creating a working party to formulate a work plan to progress reforms, but at this stage no timeframe for the reform process has been set.

The continuing issue regarding the enforceability of licence conditions has a significant impact on the ability of DADHC to implement recommendations we make regarding licensed boarding houses, including:

- first aid requirements,
- record keeping,
- medication administration.

7. DADHC should provide detailed advice regarding action taken by the Inter-departmental Committee on Reform of the Private Residential Service Sector to:
 - a) develop a work plan to progress the reforms;
 - b) progress the review of the *Youth and Community Services Act 1973*; and
 - c) develop a policy framework.

Palliative care

Over the past three years, we have raised some concerns about the provision and coordination of palliative care to people with disabilities, including the involvement of the person with a disability in decision-making, and the adequacy of discharge planning for people receiving palliative care.

In 2006, DADHC released a *Palliative Care* policy to DADHC operated and funded services. In the past year, an independent evaluation of the policy has commenced, which is considering the extent to which the policy has improved the coordination, planning and delivery of palliative care services for people living in DADHC operated and funded accommodation services.

8. DADHC should report on the outcome of the evaluation of the *Palliative Care* policy, and provide advice regarding any action the department intends to take in relation to the findings and recommendations.

Implementation of DADHC's *Health Care* policy

DADHC released its revised *Health Care* policy to DADHC operated and funded accommodation services in July 2007. Given that the policy was a new requirement for funded services, we considered that it would be important for DADHC to evaluate its implementation in those services.

In 2006, DADHC advised that it had contracted the Centre for Developmental Disability Studies (CDDS) to establish baseline data to measure the impact of the policy in funded accommodation services. Last year, DADHC told us that CDDS had submitted its report, and it would be provided to the Ombudsman's office once endorsed by the department. DADHC advised that it would consider the report's application to future monitoring and evaluation strategies after the revised policy was rolled out to DADHC operated and funded services.

To date, DADHC has not provided a copy of the CDDS report.

9. DADHC should provide advice as to any plans the department has for evaluating the *Health Care* policy and its implementation in DADHC operated and funded accommodation services.

People with disabilities who are ageing

In 2006, we undertook consultations across NSW on people with disabilities in care and their interaction with the health system. In these forums, staff from disability accommodation services raised concerns about the lack of policy guidance from DADHC on 'ageing in place' for people with disabilities in care, and argued that this tended to result in inconsistent practice across disability services. At that time, DADHC had advised that it was developing a policy for the care and support of people with an intellectual disability who are ageing.

Last year, DADHC advised that its policy position is that:

- DADHC will continue to provide disability services to clients with a disability as they age; and
- People with a disability, including DADHC clients, should have the same access to aged care services as people without a disability.

DADHC also advised that its work would progressively lead to the development of models that have an improved integration of both the disability and aged care perspective. The department told us that it would provide further clarity on these issues for the funded sector by early 2008.

Our project this year on people with Down syndrome and dementia identified continued concerns about the support available for people with disabilities in care as they age, and the impact of the continued barriers between the disability and aged care sectors, including inability to access community-based aged care services.

While we note DADHC's work in this area, including the younger people with disabilities in aged care facilities program, we consider that there is a need for greater clarity about the department's position on ageing in place, and long-term vision regarding the care and support of people with disabilities as they age.

10. DADHC should develop a policy that clearly articulates and documents the directions, strategies and actions that the department will take to support people with disabilities as they age. The department should also consider developing a policy for DADHC operated and funded services to guide decision-making and the delivery of services when working with ageing people with disabilities.

Access to health services for people with dual diagnosis

In 2006, we undertook widespread consultations across NSW on people with disabilities in care and their interaction with the health system. Access to services for people with dual diagnoses of intellectual disability and mental illness was raised as a significant issue by consultation participants. Of particular concern was the perceived lack of clarity about the responsibilities of DADHC and NSW Health in supporting people with dual diagnosis.

This year, our reviews have also raised concerns about the provision of mental health services to people with a cognitive impairment.

In December 2007, an Intellectual Disability Mental Health Working Party was formed to develop a strategic framework to improve the effectiveness of services for people with dual diagnoses of mental illness and intellectual disability. Key initiatives of the reference group include creating a University Chair and an Advanced Psychiatric Fellowship program in Disability Mental Health, and the updating of interagency roles and responsibilities in relation to supporting people with a mental illness and intellectual disability.

11. NSW Health should report on progress towards improving the effectiveness of services for people with dual diagnosis. In providing this advice, NSW Health should:

- a) advise of progress towards filling the University Chair position and the Advanced Psychiatric Fellowships in Disability Mental Health; and
- b) provide a copy of the updated interagency roles and responsibilities document regarding supporting people with a mental illness and intellectual disability.

Health service framework for people with an intellectual disability

Our consultations with the disability sector in 2006 raised widespread concerns about the interaction of people with disabilities in care with the NSW health system. Significant concerns were raised about access to health services, and the quality of the service provided to people with disabilities across a wide range of areas, including allied health, mental health, hospitals, and aged care. The consultations demonstrated the need to improve the adequacy and quality of health services for people with disabilities.

In 2007, NSW Health consulted with key stakeholders about a discussion paper it had developed with DADHC and the Council for Intellectual Disability on a service framework to improve health care for people with an intellectual disability. The discussion paper outlined possible options for developing local area specialist health resources and a statewide specialist centre to provide clinical leadership.

This year, NSW Health advised that the (then) Minister for Health had endorsed the proposed service framework in principle, and had approved the department to develop a more detailed business case to implement it.

Previous NSW Health and DADHC advice indicated that the service framework would pick up on many of the recommendations we have made, including:

- Training for health workers on health care for people with an intellectual disability;
- The potential for broader application of multidisciplinary health teams across NSW for people with an intellectual disability; and
- The potential for wider application of the clinical nurse specialist model of health care case management for people with an intellectual disability.

In our view, the development and implementation of the health service framework is critical to improve the health services delivered to people with disabilities and the health outcomes for this vulnerable community.

12. In relation to the service framework to improve health care for people with an intellectual disability, NSW Health should provide detailed advice regarding:

- a) the anticipated framework;
- b) progress towards implementing the framework; and
- c) the timeframe for implementation.

Part 1: Deaths of people with disabilities in 2007



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 fifth annual report will be released in two volumes. The first relates to the deaths in 2007 of people with disabilities in care. The second volume concerns child deaths.

In 2007, the deaths of 264 individuals were reviewable deaths. Of these, 98 deaths were of people with disabilities in care. One of these deaths was that of a child. The review of this child's death is therefore included in both volumes of this report.

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:

- (a) 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.
- (b) 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.
- (c) 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 deaths 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 advisory committee members for the deaths of people with disabilities in care is provided in Appendix 2.

1.4 Developments since our last report

Many of the key developments since our last report have resulted from the continued roll out of the NSW Government's 10-year plan for disability services: *Stronger Together*. Of particular relevance to our work in reviewing the deaths of people with disabilities in care has been:

- increased funding for therapy places, including occupational therapy, speech pathology and physiotherapy — at the end of the second year of the roll out of *Stronger Together*, 1,800 new therapy places have been allocated,
- increased funding to prevent young people entering aged care facilities,
- the creation of a Chair in Disability Mental Health at the University of NSW (UNSW) to enhance workforce capacity in the provision of mental health services to people with an intellectual disability,
- funding for nine Advanced Psychiatric Fellowships in Disability Mental Health over three years through the NSW Institute of Psychiatry.

In the past year, there have been key developments in relation to areas that have been the subject of recommendations in our previous reports, including:

- commencement of reviews of the screening tool for entry to licensed boarding houses and DADHC's *Ensuring Good Nutrition* policy,
- commencement of an evaluation of DADHC's *Palliative Care* policy to consider the extent to which the policy has improved the coordination, planning and delivery of palliative care services for people living in DADHC operated and funded services.

Further information about the progress of DADHC and NSW Health towards meeting our recommendations is outlined in Part 3 of this report.

2. Reviews of the deaths of people with disabilities in 2007

2.1 About the people who died

In 2007, the deaths of 98 people with disabilities in care in NSW were reviewable. Of the 98 people who died:

- 31 people lived in DADHC operated accommodation,
- 52 people lived in DADHC funded accommodation operated by 33 funded services,
- 15 people lived in 11 licensed boarding houses.

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

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

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

Type of residence	No. of people accommodated	No. of deaths in 2007	Percentage of population who died in 2007	Percentage of reviewable deaths in 2007
Group home (funded)	2,227	37	1.7	37.8
Group home (DADHC)	1,365	6	0.4	6.1
Residential centre (funded) ¹	514	15	2.9	15.3
Residential centre (DADHC) ²	1,215	25	2.1	25.5
Licensed boarding house	830	15	1.8	15.3

Included in the people who died in 2007 was a man who died while receiving respite in a funded service, and a man who was living with a group of 20 people in the care of a funded service following the closure of a licensed boarding house.

¹ Includes large residential centres, small residential centres, and hostels.

² Includes large and small residential centres.

Since 2005, a greater proportion of people who lived in group homes operated by funded services have died in comparison with people who lived in DADHC operated group homes. In addition, the proportion has been increasing since that time; the difference has been 0.3% in 2005, 0.4% in 2006; and 1.3% in 2007.

In relation to people who lived in residential centres, for four out of the last five years, a greater proportion of people who lived in funded residential centres have died in comparison with people who lived in DADHC operated residential centres. In 2006, the percentage of people who died in DADHC residential centres (2.4%) was greater than those who died in funded residential centres (1.8%).

Disability services

Of the 83 people who had lived in the care of disability services, the youngest was four years old and the eldest was 94 years of age.

On average, the people who died in 2007 who had lived in disability services:

- were 54 years old,
- were more likely to be men,
- had lived in care for 30 years, and had lived at the same place for the last 16 years,
- had a moderate to severe level of cognitive impairment,
- required support with daily living activities, including mobility, communication, and eating and drinking,
- had significant health concerns that required ongoing management and regular review,
- required family members to make decisions and/or provide consent to medical treatment on their behalf.

This profile of disability services residents who have died has been consistent over the past five years.

It is important to note that many of the common characteristics of the people who have died reflect the broader population of people with disabilities in care.

Licensed boarding houses

Of the 15 people who had lived in licensed boarding houses, the youngest was 42 years old and the eldest was 85 years of age.

On average, the people who died in 2007 who had lived in licensed boarding houses:

- were 61 years old,
- were twice as likely to be men,
- had lived in care for nine years and had lived at the same residence for the last eight years,
- had been diagnosed with a mental illness, mainly schizophrenia,
- were heavy smokers,
- provided their own consent to medical treatment.

The profile of the licensed boarding house residents who have died over the past five years has been consistent, and generally reflect the broader licensed boarding house population.

A more detailed description of the characteristics of the people who died is in Appendix 1.

2.2 Cause of death

The following tables identify the primary cause of death for 89 of the 98 people who died in 2007, categorised according to ICD-10-AM codes.³ At the time of writing, the Coroner had not issued a final cause of death for the other nine people.

The NSW Coroner provides three possible fields of information in relation to cause of death:

- (a) The 'direct cause' — the disease or condition directly leading to death (eg: sepsis),
- (b) The 'antecedent cause' — the morbid condition(s), if any, giving rise to the direct cause (eg: bronchopneumonia that led to sepsis),
- (c) 'Other significant conditions' — conditions possibly contributing to the death, but not relating to the disease or condition causing it (eg: cerebral palsy).

Table 2: Primary cause of death for disability services residents

Description	Number
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.	19
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.	15
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.	11
Neoplasms (C00-D48) A new and abnormal growth, any benign or malignant tumour, often referred to as cancer.	8
Diseases of the digestive system (K00-K92) Includes diseases that affect the breakdown of food for absorption by tissue in the body. For example, oesophagitis, gastro-oesophageal reflux, bowel obstruction, pancreatitis, and peritonitis.	6
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, hanging, toxic effects of non-medicinal substances, effects of deprivation, and complications of surgical and medical care.	5
Certain infectious and other parasitic diseases (A00-B99) Includes diseases generally recognized as communicable or transmittable. For example, tuberculosis, tetanus, meningococcal, septicaemia, influenza, and other acute respiratory infections.	3

³ Nationally and internationally, morbidity and mortality data are coded and tabulated according to the International Statistical Classification of Diseases and Related Health Problems (ICD) system. The ICD is the international standard health classification published by World Health Organisation (WHO) for coding diseases for statistical aggregation and reporting purposes. The ICD-10-AM is the tenth revision, with Australian Modification.

Table 2: Primary cause of death for disability services residents cont'd

Description	Number
Diseases of the genitourinary system (N00-N99) Includes diseases that affect the reproductive system and also the urinary system. For example, renal failure, cystitis, and urethritis.	3
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99) Includes congenital conditions such as congenital heart problems, and conditions related to chromosomal differences such as Down syndrome.	3
Endocrine, nutritional and metabolic causes (E00-E89) Includes 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.	1
External causes of morbidity and mortality (V01-Y98) Includes instances where environmental events and circumstances have caused injury, poisoning and other side effects. For example, fatal blood levels of medication, pedestrian injured in collision with vehicle.	1
Undetermined at time of writing report	8

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

Description	Number
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.	8
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, hanging, toxic effects of non-medicinal substances, effects of deprivation, and complications of surgical and medical care.	2
Mental and behavioural disorders (F00-F99) Includes schizophrenia, dementia, anorexia nervosa, and mood disorders.	1
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.	1
Diseases of the digestive system (K00-K92) Includes diseases that affect the breakdown of food for absorption by tissue in the body. For example, oesophagitis, gastro-oesophageal reflux, bowel obstruction, pancreatitis, and peritonitis.	1

Table 3: Primary cause of death for licensed boarding house residents cont'd

Description	Number
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, asphyxia, sudden death, dysphagia, senility.	1
Undetermined at time of writing report	1

2.2.1 Respiratory illness

The leading cause of death for disability services residents in NSW is respiratory disease. This has consistently been the case each year.

In 2007, respiratory illness was the direct or antecedent cause of death for 25 people who lived in disability services, and a significant condition contributing to the deaths of another three people. Pneumonia, bronchopneumonia and aspiration pneumonia were the main causes of the deaths related to respiratory disease.

Last year, our report included a summary of our clinical and service delivery review of deaths in 2005 related to respiratory illness. Our review noted gaps in the involvement of respiratory specialists, provision of first aid, and recognition of changes or decline in an individual's health status.

We are continuing to monitor the work of key agencies in relation to our recommendations in this area.

2.2.2 Diseases of the circulatory system

Deaths due to diseases of the circulatory system featured highly in 2007 for residents of disability services and licensed boarding houses. This included deaths from ischaemic heart disease,⁴ congestive cardiac failure,⁵ and heart block.⁶

Disability services residents

In 2007, disease of the circulatory system was the direct or antecedent cause of death for 20 people who lived in disability services, and a significant condition contributing to the deaths of another five people.

Of the disability services residents whose deaths were related to heart problems or cardiovascular disease:

- Most had known heart problems, such as congestive cardiac failure, enlarged heart, and atrial fibrillation. Four of these individuals had Down syndrome — including two people who had pace makers. Many of the people with known heart problems had contact with cardiac specialists.
- Nine people did not have known heart problems. Of these nine people, most had limited mobility, and four had hypertension.

⁴ Also known as coronary heart disease — it is characterised by insufficient blood supply to the heart.

⁵ Congestive cardiac failure is where the heart is unable to pump enough blood to keep pace with the demands of the body.

⁶ Heart block refers to a delay in the normal flow of electrical impulses that cause the heart to beat.

Licensed boarding house residents

Cardiovascular disease has consistently been a dominant cause of death for licensed boarding house residents. In 2007, it was the direct or antecedent cause of death for nine people who lived in licensed boarding houses, and a significant condition contributing to the death of another person.

Some of the licensed boarding house residents whose deaths were related to cardiovascular disease had several risk factors:

- seven were heavy smokers,
- six were overweight (for half of these people, obesity was listed by the Coroner as a significant condition contributing to their deaths),
- four had limited mobility or were otherwise identified as doing minimal physical activity,
- four had hypertension,
- three had type II diabetes,
- two had high cholesterol.

The high cardiovascular risks for at least two licensed boarding house residents were well known by the individuals and their treating health practitioners. The two people, aged 47 and 53 years, had multiple risk factors for cardiovascular disease, and their general practitioners (GPs) and other health practitioners raised concerns about this.

The treating GPs spoke with the residents on many occasions to effect change, and both had contact with relevant specialists. However, both individuals refused to modify their practice with regard to diet, activity, or smoking — severely affecting their treatment options and chance of improvement.

2.2.3 Choking

Deaths from choking on food are largely preventable. This is particularly the case where swallowing risks have been assessed, and strategies have been put in place to address the risks.

In 2007, the deaths of four people were due to choking on food.

A 68-year-old man who lived in a licensed boarding house died after choking on a sandwich. According to boarding house staff, the man did not have swallowing difficulties but choked after eating the sandwich too fast.

An 82-year-old woman who lived in a DADHC group home asphyxiated on her dinner, which had been cut into very small pieces in line with speech pathologist recommendations. The service had identified and taken steps to address the woman's swallowing risks, including speech pathology review, providing supervision with prompts for the woman to slow down when eating, and the use of a visual prompt card for mealtime management.

The other two people lived in the care of funded services and had previously been identified as having swallowing difficulties. It appears that both of the individuals died after choking on food that they were not supposed to have, and had not been given by staff.

A 62-year-old woman choked on an orange that she had taken from a fruit bowl. Due to her swallowing difficulties, the woman needed all food to be cut up and prompting to pause between mouthfuls.

Following the woman's death, the service conducted a root cause analysis and took action to try to prevent such deaths recurring. The service told us that it would conduct risk assessments on all residents' access to food; create a 'dining room scanner' position to watch for people having swallowing problems; increase training for staff in choking management; and train staff in the use of suctioning equipment.

The other person's death is the subject of the following case study.

Case study 1

A 67-year-old man collected his special cut-up dinner and his girlfriend's meal at the same time. Shortly afterwards, he choked on some meat. It is possible that the man ate from his girlfriend's plate rather than the one specifically prepared for him. Staff responded quickly to the emergency, sought an ambulance, attempted to remove the blockage through suction, and provided CPR.

The man had significant swallowing risks and had two previous instances of gagging on food. While the man's GP reviewed his dietary and health needs, there did not appear to be referral to a speech pathologist for a swallowing assessment.

The man was usually actively supervised during meals, as he was known to be at risk of choking, had specific dietary requirements for diabetes, and reportedly would continually eat unless supervised. However, on this occasion he was unsupervised at the time that he collected the meals and when he choked, as staff had been called to attend another situation.

Following the man's death, the service told us that the event had prompted a full review of service practices to ensure compliance with the *Ensuring Good Nutrition* policy.

In addition, the service told us that it has focused on staff training, with a significant number of employees completing Certificate III or Certificate IV in Disability Work.

2.2.4 Epilepsy

Epilepsy was the primary or antecedent cause of death for 10 people who died in 2007, and was listed by the Coroner as a significant condition for another seven people. All lived in the care of disability services.

The 10 people for whom epilepsy was determined to be the primary or antecedent cause of death included two people who died following continuous seizure activity (status epilepticus), two people who died following falls caused by a seizure, and two people who died from respiratory illness linked to epilepsy.

In the main, we noted good practice in epilepsy management, including regular neurology reviews, current epilepsy management plans to guide staff, actions by staff to minimise risks, and recording of seizure activity.

While most of the 10 people had regular seizure activity, three did not. Two women who died reportedly did not have seizures for at least 12 years before their deaths, and one man had his first seizure one month before he died.

In the main, we found that services had appropriate strategies in place to manage risks associated with the person's condition. For example:

- A man who died from aspiration due to epilepsy was known to be at high risk of aspiration. When his anticonvulsant medication was increased nine months before his death, staff noted that he was at increased risk of aspiration due to the sedative effects. A speech pathologist recommended the insertion of a PEG tube,⁷ but a surgeon recommended against this action due to the man's high anaesthetic risks. Staff took all appropriate actions to minimise the risks of aspiration, such as mealtime positioning and regular health reviews, including neurology.

⁷ A percutaneous endoscopic gastrostomy (PEG) tube feeds directly into the stomach.

- The service supporting a man who died following a fall at home due to a seizure had comprehensive strategies in place to minimise his risks due to epilepsy. This included six-monthly neurology reviews, current guidance for staff on seizure management, and the use of a helmet except when eating, showering or seated. While the man was not wearing his helmet during this fall, the opinion of medical staff who subsequently treated the man in hospital was that he would have sustained severe and irreversible brain damage in any case.

2.2.5 Causes of death 2003–2007

We have engaged the National Centre for Classification in Health, based at Queensland University of Technology, to analyse underlying causes of death for the 458 people with disabilities who died between 2003 and 2007 and whose deaths were reviewable by this office.

Specifically, we have sought:

- an analysis of causes of death and contributory causes of death for all deaths of people with disabilities in care in NSW,
- a comparison between the leading causes of deaths of people with disabilities in care and deaths in the general population,
- a systematic literature review relating to risk factors that may contribute to these causes of death.

The main reason we have sought this analysis is to gain a better understanding of the range of factors that may contribute to particular causes of death, in order for us to be aware of areas that may warrant detailed focus in the course of our reviews.

The National Centre for Classification in Health's work will be reported in next year's annual report.

2.3 Our work in reviewing deaths that occurred in 2007

Where our reviews highlight issues that warrant further inquiries about the conduct of an agency, there are a number of options available to us.

Under the Ombudsman Act, 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 who 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.

A number of the deaths that we reviewed this year highlighted issues that warranted further action:

- We investigated agency conduct in relation to the deaths of two men. One investigation concerned DADHC (see case study 5), and the other investigation involved DADHC, a funded service, and two Area Health Services (see case study 4). Both investigations have been finalised.
- As a result of our review of the death of one man, we conducted inquiries with DADHC for the purpose of deciding whether to investigate the department's conduct (see case study 3). As at October 2008, our work in relation to this man's death is continuing.
- We raised concerns or questions about practice and sought a response from two Area Health Services and five funded services in relation to nine people who died in 2007.

- These concerns related to:
 - behaviour support and health care management for a man with epilepsy, diabetes, obesity and obsessive compulsive disorder who consumed excessive quantities of diet soft drink,
 - assessment and management of swallowing and nutrition risks and guidance for staff in relation to a man who choked on some meat, and a man who died from aspiration,
 - assessment of the use of bed rails for a man who died after his head became trapped between the rails,
 - hospital discharge planning for a licensed boarding house resident with high support needs,
 - hospital action in response to abnormal pathology results for a man who died from a perforated duodenal ulcer and acute peritonitis,
 - the use of advance care directives in relation to three women at the same service,
 - the progress of a service towards implementing the actions it identified in an internal review following the death of a man with epilepsy who appeared to drown in a bath.
- Further action can also include provision of information to agencies. This year, we provided information to DADHC in relation to the death of a licensed boarding house resident as certain records suggested that he may have been the victim of a physical assault.

In addition to this work, we sought advice from members of our reviewable disability deaths advisory committee, official community visitors, or other experts in relation to the deaths of 29 people.

2.4 Issues arising from our work

In this section, we report our observations from our reviews of the deaths of 98 people who died in 2007.

In many of our reviews this year, we found examples of good practice by services and agencies supporting people with disabilities. This includes areas we have raised concerns about in our previous reports, including hospital discharge planning and palliative care.

However, we also found some gaps in service practice, particularly in relation to first aid and meeting complex support needs.

Where relevant, this section includes reference to the progress agencies have made towards implementing our previous recommendations in these areas.

2.4.1 Meeting complex needs

Health care planning

We saw examples of good practice in health care planning, particularly for people with complex health needs, including:

- good coordination of complex health needs by multidisciplinary teams,
- regular involvement of appropriate health professionals, including GPs and allied health practitioners,
- involvement of the person and their family in health care decisions.

The following case study provides an example of good health care practice demonstrated by a funded service.

Case study 2

A 24-year-old man who lived in a funded group home died from aspiration pneumonia due to the combined effects of muscular dystrophy and epilepsy.

He had a profound degree of intellectual and physical impairment, as well as significant health concerns, including gastro-oesophageal reflux disease, recurrent respiratory infections, swallowing difficulties, and osteoporosis. He relied on a PEG tube for his food and medication.

The service documented clear strategies for staff to follow to appropriately support the man's complex health needs. Health care planning and reviews were regular and included relevant allied health and medical specialists, including a respiratory specialist, gastroenterologist, and consultation with a developmental disability clinic.

The service's Health Care Planner played a key role in liaising with the man's father, GP, specialists, and service staff. The service sought to resolve emerging concerns, such as whether to introduce enteral feeding, through case conferences and discussion.

During the man's hospital admissions, carers from the disability service provided support and the Health Care Planner liaised with the hospital regarding his condition.

However, there were gaps in health care planning to meet the needs of some of the people who died in 2007.

In some cases, this centred on actions to effectively identify and meet nutrition and swallowing risks, such as a lack of guidance to staff regarding positioning; a lack of, or inadequate, assessment of nutrition and swallowing risks; and no apparent referral for appropriate assistance when risks were identified.

For some of the people who died, we had broader concerns about the adequacy of health care planning provided by the service, including the man in the following case study:

Case study 3

A 61-year-old man who lived in a DADHC group home had a moderate to severe level of cognitive impairment, was largely reliant on a wheelchair for mobility, and had significant health concerns such as epilepsy, recurrent respiratory infections, psoriasis and fragile skin.

Our review of the man's death raised questions about the adequacy of the support provided by DADHC in response to his emerging health risks. There appeared to be gaps in the service's health care planning for the man, including no current health care plan, no recent comprehensive health assessment, and inconsistent and incomplete recording of his seizure activity.

It also appeared that there were gaps in the service's response to recommendations made by allied health practitioners, including the need for monthly weight charts in light of the man's underweight status; and a pressure mattress and pressure cushion to manage the man's pressure area risks.

Case study 3 cont'd

Two weeks before the man's death from septicaemia, he was admitted to hospital after a 10cm pressure sore on his buttock had failed to heal. Group home staff advised hospital staff that they were no longer able to meet the man's care needs.

There was no record on file of how staff had managed the man's pressure sore, aside from reference to one visit to the GP six days before his admission to hospital. There was insufficient information to indicate what action staff took when the pressure sore did not improve between the GP visit and hospital admission.

In response to our inquiries, DADHC told us that a physiotherapist reviewed his positioning for meals six months before he died. Staff also made a referral for the man to be reviewed by a physiotherapist in relation to his pressure area risks, but he died before this could occur.

DADHC also told us that the need to weigh the man was overlooked as staff did not seek assistance when they were unsure where to take him. As a result, DADHC advised that it had started undertaking a review of the region to identify locations for weighing residents who are reliant on wheelchairs.

Following DADHC's advice, we met with the department to discuss our concerns. DADHC advised that it would set up a small review team to examine the man's death and consider broader implications for DADHC practice. The department also told us that it had implemented a better system for managing requests for allied health services.

As at October 2008, our work in relation to this man's death is continuing.

Mental health and behaviour support

In 2006, we reported concerns about the support provided to people with a dual diagnosis of mental illness and intellectual disability, including a lack of cooperative work between health and disability services, and gaps in discharge planning from inpatient mental health units.

This year, our investigation into the conduct of four agencies in relation to a young man who committed suicide in 2007 identified gaps in the provision of planning and support by health and disability services to meet his complex mental health and behaviour needs.

Case study 4

A 24-year-old man who lived in the care of a funded service committed suicide. He had a traumatic brain injury, cognitive impairment, and antisocial personality disorder with psychosis.

The man had complex support needs and a history of drug use, suicidal ideation, significant challenging behaviours, and contact with the criminal justice system.

Our review of the man's death raised questions about whether he received adequate and appropriate support for his behavioural and mental health needs.

We therefore decided to investigate the conduct of four agencies: the non-government service, two area health services, and DADHC.

Case study 4 cont'd

Our specific concerns included:

- The funded disability service did not appear to have the skills or training to adequately support people with disabilities, particularly those with complex needs.
- The service did not appear to provide adequate guidance to staff regarding how to appropriately and consistently support the man's complex behaviour needs. He demonstrated significant challenging behaviour, including self-injury, risk-taking, aggression, and arson, but the service did not take steps to develop behaviour intervention strategies to address the risks, and used restrictive practices without authorisation.
- The man was discharged from an extended stay in an inpatient mental health hospital without referral by hospital staff to appropriate ongoing mental health support.
- The disability service did not appear to provide adequate support to meet the man's mental health needs, including inadequate coordination of psychiatric reviews, and inconsistent responses to his threats of self-harm.
- The man was discharged from an in-patient mental health hospital without a suicide risk assessment or referral for outpatient mental health support despite being admitted the previous day due to a suicide attempt.

In response to our notices of investigation, we were advised of relevant changes that had occurred since the man's death. Of note, we were told that the disability service is no longer funded by DADHC and does not currently support any people with disabilities, and both area health services have made changes to improve inpatient discharge planning processes.

In addition, one of the area health services has commissioned an acute care service to provide assertive short-term follow-up on recently discharged patients, with self-harm and suicide attempts a high priority.

As a result of this advice, we discontinued our investigation.

Our previous recommendations regarding meeting complex needs

Over the past five years we have made many recommendations relating to support for people with complex needs. Of particular relevance to the concerns we have raised in this report are the recommendations we have made on the need for:

- clear policy guidance in key areas such as meeting health care needs, supporting people with enteral nutrition, and supporting people with epilepsy,
- monitoring of current practice and evaluation of current policies and risk assessments in relation to nutrition and swallowing,
- improved access to therapy services across the disability and health sectors,
- improved access to mental health services for people with dual diagnoses of intellectual and psychiatric disabilities.

There has been considerable progress in many of these areas over the past five years, and some key advances in the last 12 months.

During the past year, an independent evaluation of the *Ensuring Good Nutrition* policy has commenced, and DADHC, NSW Health, and the Greater Metropolitan Clinical Taskforce

have started discussions on improving support for people living in group homes who receive enteral nutrition.

In relation to therapy services, work is underway between DADHC, NSW Health, the Department of Education and Training, and the Department of Community Services to develop an interagency disability therapy roles and responsibilities agreement to improve the coordination of disability therapy services.

In addition, key agencies are undertaking work on therapy workforce development, and DADHC has started to reform the allocation of funding to the non-government sector for the provision of therapy and other services.

In mental health, progress has included the development of a DADHC/NSW Health reference group, establishment of a Chair in Disability and Mental Health at UNSW, and creation of an Advanced Psychiatric Fellowship program in Disability Mental Health. Work is also underway to update the relevant interagency roles and responsibilities agreement between DADHC and NSW Health.

In the past year, NSW Health has also released a *Discharge Planning for Adult Mental Health Inpatient Services* policy, which includes special care considerations in the discharge planning process for people with an intellectual disability.

2.4.2 Response to critical incidents

We have consistently raised concerns about the response of staff to critical incidents affecting people with disabilities in their care, including gaps in the provision of first aid and delays in seeking medical assistance.

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

First aid

Our reviews of deaths in 2007 identified at least five people for whom first aid did not appear to be provided, or was ceased prior to paramedic involvement. Four of the five people lived in the care of funded services, and one man lived in a licensed boarding house.

- A 68-year-old man died after choking on a sandwich. Residents alerted the staff member on shift when the man collapsed, who called for an ambulance. Ambulance records suggest that the staff member did not appear to commence CPR despite identifying that the man did not have a pulse. Paramedics declared the man deceased when they arrived 20 minutes after he began choking.
- There was no evidence that CPR was given by staff to two men when they collapsed.
- While a staff member initially provided CPR to a 42-year-old man who was found with his head trapped in his bed rails, this was ceased prior to the arrival of paramedics.
- Staff relied on the instructions of the 000 operator regarding first aid for a 41-year-old woman who fell and lost consciousness. Staff were also unclear about whether there were prior end-of-life instructions in place that would affect the provision of CPR.

Identifying and responding to critical health incidents

Our investigation into DADHC's conduct in relation to one man who died in 2007 highlighted the importance of identifying critical health incidents and taking appropriate and timely action.

Case study 5

A 36-year-old man who lived in a group home was found deceased in his bed after a short illness. Preliminary coronial information indicates that the man's death was related to adrenocortical insufficiency and pneumonia.

Group home staff took the man to see his GP on the first day that he showed signs of illness, including shivering and not eating. He saw the GP again early the following day, and was prescribed antibiotics. That afternoon and the following day the man generally lay on the lounge, received fluids, but ate very little.

At approximately 2am on the fourth day since becoming unwell, a group home staff member checked on the man and found him to be hot and breathing heavily. When the staff member checked on him again at approximately 6am, he was deceased.

Our investigation found that the actions of group home staff in response to the man's presenting illness on the first three days were reasonable. Staff ensured that he was reviewed by his doctor as required, administered medications as prescribed, encouraged food and hydration, allowed him to rest, and ensured that a staff member was in the group home at all times.

However, the man's condition had changed by the time he was checked on the morning of his death. Despite the change in condition, the staff member did not take further action at that time.

As part of our review of the man's death, we sought advice from a medical practitioner on our Advisory Committee in relation to his presentation on the morning of his death. They advised that the man's condition was serious at the point at which he was noted to be hot and that urgent assistance was required and should have been sought at that time.

In accordance with the department's *Managing Client Health* policy, in place at the time of the man's death, best practice would have been for the staff member to have checked the man's temperature to ascertain whether immediate medical assistance was required.

That the staff member did not take such action in response to the change in condition raised a question about whether the staff member was aware of the policy requirements.

We found that DADHC's response to the man's presenting health condition at that time was inadequate.

Our recommendations included that DADHC should review current practice at that group home to ensure that staff have a comprehensive understanding of the department's practice requirements as they relate to client health needs.

We are continuing to monitor the department's implementation of our recommendations.

Our previous recommendations regarding responses to critical incidents

For the past three years we have made consistent recommendations regarding first aid and the response of services to critical incidents involving people with disabilities in their care.

We have clearly stated that 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 issue has been resolved in DADHC operated services, with first aid training a prerequisite for employment.

However, progress towards meeting our recommendation in funded and licensed disability accommodation services has been slow.

In relation to licensed boarding houses, there is a licence condition that requires a member of the staff to be qualified to render first aid in the case of an accident or sudden illness. However, DADHC believes that it has no legal authority to enforce a requirement that at least one staff member on each shift in licensed boarding houses is qualified in first aid.

An Inter-departmental Committee (IDC) on Reform of the Private Residential Service Sector has been formed to progress a whole-of-government approach to reform, including DADHC, Housing NSW, NSW Health, Treasury, Office of Fair Trading, and Departments of Local Government, Planning, and Premier and Cabinet. The review of the *Youth and Community Services Act 1973*, which has been underway for six years, will now come under the ambit of the IDC.

The IDC is establishing a working party to formulate a work plan to progress reforms, but at this stage no timeframe for the reform process has been set.

In relation to funded services, there is currently no requirement for staff to have first aid qualifications. DADHC has taken steps, in conjunction with National Disability Services NSW, to obtain an accurate picture of current practice in funded services with regard to first aid requirements. DADHC has indicated that this information will then inform the department's further action in this area.

In our view, ensuring service capacity to appropriately respond to life-threatening incidents is a critical strategy for preventing deaths. Given the risks we have repeatedly and publicly reported, we consider that it is unreasonable for people with disabilities in care to continue to be supported by staff who have not had first aid training.

2.4.3 End-of-life decision-making

Advance care directives

Many decisions regarding end-of-life care for people with disabilities are made in hospital when the person is seriously ill, and typically involve medical practitioners and family members.

However, there are advantages to discussing future treatment and end-of-life care before that critical point. This is particularly the case for people who have a life-limiting illness, have the capacity to make informed decisions, or are elderly.

Advance care planning — where people prepare for likely scenarios near the end of life — provides the means for the person and key people in their life to discuss options for future care and treatment.

However, there are critical differences between undertaking 'advance care planning' and developing an 'advance care directive'.

An advance care directive is a document that describes a person's future preferences and wishes for medical treatment 'in anticipation of a time when one is unable to express those preferences because of illness or injury'.⁸

There are important points to note in relation to advance care directives:

- an advance care directive that complies with NSW Health policy requirements is legally binding in NSW; and

⁸ NSW Health (2004) Using Advance Care Directives (NSW), p1.

- a person must be ‘competent’ to make their own health care decisions when the advance directive is drafted. That is, they must be able to understand, retain, and weigh up the relevant information and then make a choice.

People who lack the capacity to make informed decisions are not able to make advance care directives, and nor can it be done on their behalf.

Nevertheless, our reviews this year alerted us to advance care directives on the files of a small number of people who did not appear to have the capacity to make informed decisions. In these cases, a family member consented to the directive on the person’s behalf.

It is important that advance care directives are only developed by people who, at the time that the directive is drafted, have the capacity to make informed decisions about their health care. It is also critical that the development of an advance care directive is optional for these individuals, and is not developed as a matter of course.

NSW Health’s policy directive *Using Advance Care Directives (NSW)* provides clear guidance about both advance care planning and the use of advance care directives.

In relation to instances of the use of advance care directives for people without decision-making capacity who died in 2007, we are continuing to look at this issue.

Palliative care planning

We have previously raised concerns about the palliative care provided to some people with disabilities. Our concerns have included a lack of involvement of the person with a disability in the palliative care planning, and a lack of coordination of palliative care to licensed boarding house residents.

This year, we noted good practice in relation to palliative care planning by disability services for a number of people who died in 2007. Typically, this practice included:

- multidisciplinary palliative care meetings, including the person’s family,
- development of a comprehensive palliative care plan,
- regular review of the plan,
- involvement of local palliative care teams.

The following case study provides an example of good palliative care planning and service support.

Case study 6

A 54-year-old man who lived in a funded large residential centre died as a result of prostate cancer.

Five months before the man’s death, the disability service developed a palliative care plan as his cancer was no longer responding to active treatment. The plan was developed during a palliative care meeting involving the man’s family, a palliative care clinical nurse consultant, and the service’s health care coordinator and accommodation manager.

The palliative care plan was reviewed the following month due to a decline in the man’s condition, including breakthrough pain and episodes of nausea. Following this review, a wheelchair and a new bed were purchased.

The service sought and obtained funds through a disability aged care pilot to provide an additional four to five hours staffing support to the man each day. The

Case study 6 cont'd

service also organised for the man to visit his sister at her home. The palliative care team local to his sister's house provided support while the man visited, including the provision of lifting equipment and bedding.

The service reviewed the man's palliative care plan monthly, and his GP saw him twice weekly for pain management. Two months before the man's death, the service was advised that the disability aged care pilot funds were no longer available. The costs of additional staffing were then covered by the disability service.

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

In relation to advance care planning, our recommendations have focused on the need for NSW Health to evaluate the implementation of its *Using Advance Care Directives (NSW)* policy directive in Area Health Services.

In the past year, there has been considerable progress in this area, including funding Area Health Services for 12-month project officer positions to implement the policy directive, and providing staff training.

NSW Health is targeting residential aged care facilities in stage one of the implementation, including a survey to ascertain the level of advance care planning knowledge and activity, and provision of a train the trainer workshop.

In relation to palliative care, our recommendations have focused on the release of DADHC's *Palliative Care* policy, and the need for joint work between DADHC and NSW Health on the coordination of palliative care for people with disabilities in care.

There has also been significant progress in this area over the past 12 months. NSW Health's Statewide Centre for the Improvement of Palliative Care is project managing an evaluation of DADHC's *Palliative Care* policy, and has contracted Mercury Consulting to conduct the evaluation. The work is scheduled for completion by the end of 2008.

2.4.4 Discharge planning

We have consistently raised concerns about hospital discharge planning, including gaps in conducting risk assessments prior to discharge, inconsistent application of the screening tool before discharging licensed boarding house residents, and inadequate discharge plans.

Our reviews of deaths in 2007 identified a number of examples of good practice in relation to discharge planning, including:

- the provision of a comprehensive hospital discharge plan for a young woman who had been admitted to hospital with respiratory distress. The document included thorough care instructions for disability service staff to follow, including required bed angle, pre- and post-feeding routines, instructions regarding procedures for readmission to hospital, and referral to a community nursing service for intravenous medication administration.
- assessment prior to discharge from hospital for a woman who had been admitted with hip pain following a fall at a licensed boarding house. During admission, the manager of the boarding house attended a physiotherapy session in which the woman's suitability to return to the boarding house was assessed. Planning for the woman's discharge back to the boarding house continued as her mobility increased.

However, the discharge planning in relation to one licensed boarding house resident did not appear to be sufficient to meet his needs, and did not seem to comply with NSW Health

policy. Case study 7 underscores the importance of coordinated discharge planning for licensed boarding house residents whose needs increase during hospitalisation.

Case study 7

A 61-year-old man who lived in a licensed boarding house died from a coronary artery atheroma.⁹

Three months before the man's death he was discharged from hospital following a three-week admission for treatment of pneumonia. Shortly after the man arrived back home, the boarding house manager sent him back to hospital due to concerns that his care needs were too high to be supported in that setting.

The concerns included that the man now required full assistance with eating and drinking, had incontinence, and required increased supervision when taking medication. The boarding house manager also raised concerns about the absence of a coordinated post-hospital discharge plan.

The hospital discharged the man back to the boarding house the following day, in the company of a community nurse who conducted a home visit to discuss the management of his post-discharge care needs.

The boarding house manager remained concerned about the capacity of the boarding house to meet the man's support needs, and contacted DADHC with her concerns. DADHC project officers conducted a home visit that day, and developed a seven-day support plan following consultation with the boarding house manager and community nurse.

The management plan included the involvement of Home Care for personal care and supervision of medication, and visits from a respiratory nurse in relation to the man's emphysema.

The following week, the respiratory nurse raised concerns about the suitability of the man's placement in a boarding house, and recommended an Aged Care Assessment Team (ACAT) review. Four days later, the community health team contacted ACAT to request an assessment.

ACAT advised that the man did not meet their criteria and should be referred back to DADHC in relation to his accommodation issues.

There was no indication that the screening tool for entry to a licensed boarding house was conducted in relation to this man either before he was discharged from hospital, or at the time that he was referred to ACAT by the community health team.

Our review in relation to this man's death is continuing.

Our previous recommendations regarding discharge planning

Our recommendations in this area have focused on the need for clear guidance for health services regarding discharge planning for people with disabilities. There has been significant progress in this area over the past five years, including the implementation and evaluation of the *People with Disabilities: Responding to their needs during hospitalisation* policy directive, and release of the *Discharge Planning: Responsive Standards* policy directive.

Of particular relevance to the issues raised in this report are our previous recommendations regarding discharge planning for licensed boarding house residents.

⁹ An atheroma is the fatty, fibrous deposit that develops on the artery lining. In atherosclerosis, the fat deposits on the wall of the artery block the flow of blood.

Our recommendations in this area have centred on the use of the screening tool for entry to licensed boarding houses, and the need for the tool to be reviewed.

In the past year, there has been progress. DADHC has contracted an independent consultant to review the screening tool. The review includes consultations with key stakeholders, such as Aged Care Assessment Teams, DADHC staff, licensees and boarding house managers, and licensed boarding house residents. The review is scheduled for completion by the end of 2008.

2.4.5 Duty of care and dignity of risk

Twenty of the 98 people who died in 2007 provided their own consent to treatment. At least half of these people made informed decisions regarding their lifestyle and/or health care that placed them at risk and presented considerable challenges to the services and practitioners supporting them.

These included decisions to continue smoking, continue drinking alcohol, refuse medical treatment, and refuse food.

In many cases, we identified some links between the decisions made by these individuals and their deaths. Given our focus on preventable deaths, we were particularly interested in the support provided to these people.

In the main, we found that the services and practitioners supporting the people who made decisions that compromised their health raised concerns with the individuals about their decisions, and provided opportunities for them to improve their health and reduce the risks they faced.

This included discussions about quit-smoking strategies, support to access detoxification units, and involvement of multidisciplinary health practitioners.

We noted that attempting to meet the health needs and minimise the significant risks faced by the ten people was difficult for the services involved. The deaths of two people who lived in licensed boarding houses illustrate this challenge:

- A 47-year-old woman had high cardiovascular risks, and died from coronary artery disease. While the local Boarding House Team supported the woman to access appropriate health services, it was difficult to address her cardiovascular risks as she refused to attend some appointments, cease smoking, or exercise.
- A 43-year-old man died from alcohol toxicity. He had a long history of alcohol abuse from the age of 12, and his entry to the boarding house followed years of living on the streets interspersed with periods of alcohol rehabilitation. The man was repeatedly taken to emergency departments by ambulance or police after being found collapsed in the community due to inebriation. The year before his death, arrangements were made for him to attend a detoxification unit in hospital, but he refused attendance, and denied that he was drinking. The detoxification unit was unable to accept him unless he was a voluntary patient.

Three women who lived in the care of funded services made decisions regarding refusal or limited intake of food that posed considerable risks to their health, including two women whose refusal of food appeared to be linked to depression and one woman who had a 26-year history of anorexia nervosa.

We noted good practice on the part of the services involved, including involvement of specialist psychological assistance for assessment of decision-making capacity and ongoing support, clear documentation of decisions and guidance to staff regarding supporting the individuals, as well as multidisciplinary meetings to determine appropriate means of support.

The following case study highlights good practice in balancing duty of care with dignity of risk for a person whose informed decisions adversely affected her health.

Case study 8

A 70-year-old woman who lived in a funded group home had cerebral palsy and significant health concerns, but no cognitive impairment.

Five months before the woman's death from atherosclerosis, her GP referred her to an Aged Care Psychiatry Team for treatment of depression and assessment of her mental capacity to make informed decisions about her health.

The woman had stated to staff a number of times that she wanted to die, and considered refusing medications and food/drink the way to do it.

A psychologist assessed the woman and reported that she was aware of the decisions she was making and fully understood the consequences of the decisions. A hospital social worker also assessed the woman and felt that she was not acutely depressed and did not need guardianship.

The woman was due to have a home visit from the Aged Care Psychiatry Team four months before her death, but she refused. Records indicate that the woman often refused interventions, including temperature checks, health appointments (such as dental checks), and medications.

Group home staff maintained excellent records regarding the woman's refusal of treatment and services, including individual planning.

Staff explained to the woman the proposed interventions, the likely consequences of not having the interventions, and encouraged her to discuss the issues with her family before making a final decision, but she generally still refused.

It was evident that the woman directed her care and the services she received: she advised staff that she wanted more intellectually-stimulating activities and outings, negotiated with an occupational therapist about the best type of seating support for her, and outlined the support she wanted during end-of-life care.

Our previous recommendations regarding identification and management of risks

Over the last five years, we have made many recommendations aimed at improving how services identify and manage the risks faced by the people with disabilities in their care. In relation to specific known risks, including nutrition and swallowing, medication, and respiratory illness, our recommendations have focused on the need for review of existing risk assessment tools, evaluation of relevant policies, and promotion of existing risk management supports, such as Domiciliary Medication Management Reviews.

Our recommendations have also emphasised the need for DADHC to provide improved guidance to funded and licensed disability accommodation services on identifying and managing risks. DADHC has told us that it will roll out a revised *Client Risk* policy to DADHC operated and funded services in 2008.

2.4.6 HIV testing

We noted evidence of HIV tests on the files of a small number of people this year. All were residents of licensed boarding houses, and the results of the tests were kept on their file at the boarding house — and therefore open to the inspection of staff and certain visitors.

Current Australia-wide policy regarding HIV testing highlights the importance of ‘confidential voluntary testing with informed consent’.¹⁰ NSW Health policy regarding HIV confidentiality states that disclosure of HIV status may only occur when there is written consent of the person concerned.¹¹

There are many legitimate reasons for HIV testing some individuals with disabilities who live in care. At this stage, we have insufficient information to raise specific concerns about the testing of the individuals whose deaths we reviewed.

However, given the potential impact of HIV testing for the individuals concerned, we will maintain an active interest in this area, and monitor the frequency and circumstances of such testing through future reviews. In particular, the questions that we will be seeking to resolve are:

- whether HIV testing is being conducted as a matter of course in some services,
- the reason(s) why testing was conducted,
- whether confidentiality and disclosure requirements are met,
- whether testing is conducted only with the informed written consent of the person.

¹⁰ Department of Health and Ageing (2006) *National HIV Testing Policy 2006*, p3.

¹¹ NSW Health (2005) *HIV Confidentiality: A Guide to Legal Requirements*.

Part 2: Down syndrome and dementia



1. Introduction

Dementia is the general term for more than 70 conditions that cause progressive deterioration in memory, thinking, and everyday activities. It commonly affects behaviour, emotion and personality.¹² Alzheimer's disease is the most common form of dementia, and accounts for 50 to 70 per cent of all cases. By 2016, dementia is predicted to be the major cause of disability for Australians, overtaking cardiovascular disease, cancer and depression.¹³

In our reviews of the deaths of people with disabilities who have lived in care, many of the people who were identified or suspected of having dementia also had Down syndrome. Our *Report on Reviewable Deaths in 2006* noted that at least 15 of the people who died in 2006 had dementia, and almost three-quarters of these individuals (11 people) had Down syndrome.

Given the prevalence of dementia in people with Down syndrome whose deaths we review, we took a closer look at these people and current research in this area.

In considering people with Down syndrome and dementia, our aims were to:

- (a) consider current research and findings in this area,
- (b) consider the deaths of people with Down syndrome against these findings,
- (c) identify risk factors associated with the deaths of people with Down syndrome and dementia,
- (d) identify potential strategies to reduce or remove risk factors associated with the deaths of people with Down syndrome and dementia that are preventable.

The project comprised two parts:

1. We contracted the Centre for Developmental Disability Studies (CDDS) to conduct a literature review of current research on dementia and people with Down syndrome.
2. We conducted a file review of the people with Down syndrome and dementia who died in 2003–2007 inclusive, drawing on the above research findings.

Of the 63 people with Down syndrome who died between 2003 and 2007:

- 29 people were either diagnosed with dementia or showed signs that they had dementia while they were alive.
- Five people were noted only at post-mortem to have changes in the brain consistent with Alzheimer's disease.
- 29 people have not been identified through reviews or Coronial information as having had dementia.

We reviewed the files of the 29 people who had dementia, and the five people who were diagnosed with dementia after death. In addition, preliminary research told us that many people with Down syndrome in their forties and older have changes in the brain associated with Alzheimer's disease.¹⁴ As a result, we also reviewed the files of 18¹⁵ people with Down syndrome aged 40 years and older who were not recorded as having dementia.

We have separated the three groups for reporting purposes.

¹² Australian Health Ministers' Conference (2006) *National Framework for Action on Dementia 2006–2010*; and Alzheimer's Australia (April 2008) *Understanding Younger Onset Dementia*.

¹³ Australian Health Ministers' Conference (2006) *National Framework for Action on Dementia 2006–2010*.

¹⁴ AIHW (2006) *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: final report*, citing Bittles, A.H., & Glasson, E.J. (2004) Clinical, social and ethical implications of changing life expectancy in Down syndrome, in *Developmental Medicine and Child Neurology*, 46(4):282–7.

¹⁵ Nineteen people with Down syndrome aged 40 and over were identified, however we did not have file information for one man who died in 2003.

2. Dementia and Down syndrome: research and review findings

2.1 Prevalence

In the general community, the number of people with dementia is estimated to increase from over 175,000 in 2003 and 190,000 in 2006, to almost 465,000 in 2031.¹⁶

Age

The prevalence of dementia is related to older age and increases rapidly with very old age, as indicated in the following table.

Table 4: Prevalence of dementia in the general population¹⁷

Age	Percentage of age group with dementia
60–64	0.3
65–69	0.5
70–74	1.7
75–79	3.2
80–84	6.8
85+	21.9

For people with Down syndrome, there is also sharply increased prevalence with age. However, in comparison to the general population, dementia occurs at a much younger age, and in a higher percentage of people.¹⁸

Changes in the brain associated with Alzheimer’s disease are believed to develop in most people with Down syndrome by the age of 40 years, and initial symptoms tend to be recognised in the mid-50s.¹⁹ In our review, it was possible to ascertain the age at diagnosis for 19 people. Of these 19 people, more than half were diagnosed with dementia when they were between 55 and 64 years of age.

However, physical changes in the brain that are typical of Alzheimer’s disease do not necessarily produce symptoms of dementia in people with Down syndrome. A significant number of people with Down syndrome are older than 40 and show no symptoms of having the disease. It is not known why this is the case.²⁰ In our review, five people who were found during autopsy to have changes in the brain typical of Alzheimer’s disease had not previously shown symptoms of dementia.

¹⁶ AIHW (2004) *The impact of dementia on the health and aged care systems*.

¹⁷ *Ibid*, p8.

¹⁸ Holland, A.J., Hon, J., Huppert, F.A., Stevens, F., & Watson, P. (1998) Population-based study of the prevalence and presentation of dementia in adults with Down syndrome, in *British Journal of Psychiatry*, 172: 493–498; Prasher, V.P. (1995) End-stage dementia in adults with Down’s syndrome, in *International Journal of Geriatric Psychiatry*, 10(2):1067–69; and Visser, F.E., Aldenkamp, A.P., van Huffelen, A.C., Kuilman, M., Overweg, J., & van Wijk, J. (1997) Prospective study of the prevalence of Alzheimer-type dementia in institutionalised individuals with Down syndrome, in *American Journal of Mental Retardation*, 101(4):400–412.

¹⁹ AIHW (2006) *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: final report*, citing Bittles, A.H., & Glasson, E.J. (2004) Clinical, social and ethical implications of changing life expectancy in Down syndrome, in *Developmental Medicine and Child Neurology*, 46(4):282–7.

²⁰ Alzheimer’s Australia (2005) *Down syndrome and Alzheimer’s disease help sheet*.

Type of dementia

Alzheimer's disease is the most common form of dementia for the general population as well as people with Down syndrome.

There is a strong link between Down syndrome and Alzheimer's disease, thought to be associated with a gene found on chromosome 21. People with Down syndrome have an extra copy of chromosome 21 (three copies instead of two).²¹

While most adults with Down syndrome who develop dementia have Alzheimer's disease, some may develop other forms of dementia in the same way as the general population.²²

Other common forms of dementia reported in Australia are vascular dementia — which results from problems with blood circulation in the brain, such as a number of 'mini-strokes'; dementia with Lewy bodies — which involves degeneration and death of nerve cells in the brain; frontotemporal dementia; and mixed dementia.²³

In our review, of the 29 people with Down syndrome who had been identified as having dementia, 15 (52%) had Alzheimer's disease, and one man had been diagnosed with Lewy bodies dementia. The type of dementia was not specified for the remaining 14 people.

Gender

Approximately two-thirds of the general population diagnosed with Alzheimer's disease are women.²⁴ Even when life expectancy is taken into account, Alzheimer's disease still seems to be more prevalent in women.

Studies that have looked at the early onset of Alzheimer's disease in people with Down syndrome have had conflicting results with gender comparisons. However, more recent biological studies have provided some support for the finding of higher risk of Alzheimer's disease among women with Down syndrome.²⁵

In our review, 21 of the 29 people (72%) with Down syndrome and dementia who died were men. However, it is important to note that there are more men than women with disabilities in care in NSW, and this is reflected in the numbers of deaths of men and women each year.

2.2 Life expectancy

Life expectancy in Australia is 77.8 years for men, and 82.8 years for women.²⁶ The Australian Institute of Health and Welfare (AIHW) reports that the ageing and greater longevity of the population is leading to more people, particularly at older ages, having a disability.²⁷

The life expectancy of people with Down syndrome has increased dramatically over the last 50 years. In 1947, the average life expectancy was between 12 and 15 years; today about 80 per cent of people with Down syndrome can be expected to live to over 50 years of age.²⁸

In our review:

- The age at death of the 29 people who had Down syndrome and dementia ranged from 41 to 79 years. The average age at death was 56 years.

21 Department of Health and Ageing (2007) *Australian government dementia health priority initiative — Dementia Research Mapping Project*; and Holland, A.J. (2000) Aging and learning disability, in *The British Journal of Psychiatry*, 176:22–31.

22 Down's Syndrome Scotland (2002) *It's Your Move — Down's Syndrome and Dementia* fact sheet.

23 Stancliffe, R.J., & Harman, A.D. (2007) *Evidence-based literature review on dementia and people with intellectual disability*, Centre for Developmental Disability Studies.

24 Prasher, V.P., Percy, M., Jozsvai, E., Lovering, J.S., & Verg, J.M. (2007) Implications of Alzheimer's disease for people with Down syndrome and other intellectual disabilities, in Brown, I., & Percy, M. (Eds) *A comprehensive guide to intellectual and developmental disabilities*.

25 Prasher, V.P., Visvanathan, J., & Holder, R. (2002) Down syndrome, dementia and macrocytosis, in *Irish Journal of Psychological Medicine*, 19:115–20; and Volpato, S., Guralnick, J.M., Fried, L.P. et al. (2002) Serum thyroxine level and cognitive decline in euthyroid older women, in *Neurology*, 58:1055–61.

26 AIHW (2006) *Report on Life Expectancy and Disability*.

27 Ibid.

28 Prasher, V.P. (2005) *Alzheimer's disease and dementia in Down syndrome and intellectual disabilities*.

- The age at death of the five people who had Down syndrome and were found at autopsy to have changes in the brain consistent with Alzheimer's disease ranged from 35 to 74 years. The average age at death was 47 years.
- The age at death of the 29 people who had Down syndrome without dementia ranged from 21 to 74 years. The average age at death was 47 years.

On average, people with dementia in the general population will survive four and a half years after diagnosis, with age, gender, and any existing disability all having an influence on life expectancy.²⁹ However, it is widely considered that difficulties and reluctance in screening for dementia is known to cause delays in diagnosis.³⁰

Of the 19 people for whom it was possible to ascertain the date of diagnosis, most (13 people; 68%) died less than three years after diagnosis.

Three people lived for more than five years after diagnosis. These people were at a younger age when diagnosed (average age 49.3 years) when compared to those who lived for less than a year after diagnosis (average age 60.3 years).

2.3 Cause of death

Studies have found that the main causes of death for people with Down syndrome are congenital heart problems, respiratory diseases, and diseases of the circulatory system (other than congenital).³¹

In our review, the main cause of death for people with Down syndrome and dementia was respiratory illness, including pneumonia, bronchopneumonia, and aspiration pneumonia. Although dementia is a life-shortening illness, another condition or illness may be the cause of death. The person's ability to cope with infections and other physical problems is likely to be impaired due to the progress of the disease.³²

People whose general health is compromised by the physical effects of dementia may be less resistant to ailments that might otherwise not result in death. In general, causes of death positively associated with dementia largely reflect the physical deterioration it confers on the individual.³³

The strong, consistent association of dementia with bronchopneumonia, pneumonia and influenza has been observed,³⁴ and may reflect the opportunistic nature of these illnesses.

2.4 Symptoms of dementia/changes

Common features of dementia (for people with and without Down syndrome) include:³⁵

- memory loss,
- disorientation,
- changes in mood, behaviour or personality,
- disturbed sleep,

29 Xie, J., Brayne, C., & Matthews, F E (2008) Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up, in *British Medical Journal*, 10:1136.

30 Verbal advice from Alzheimer's Australia, 9 October 2008.

31 Baird, P.A., & Sadovnick, A D (1988) Causes of death to age 30 in Down syndrome, in *American Journal of Human Genetics*, 43:239–48; and Day, S M., Strauss, D J., Shavelle, R M., & Reynolds R M (2005) Mortality and causes of death in persons with Down syndrome in California, in *Developmental Medicine & Child Neurology*, 47:171–176.

32 Alzheimer's Society (2003) The later stages of dementia (electronic version), www.alzheimers.org.uk.

33 Wilkins, K., Parsons, G F., Gentleman, J F., & Forbes, W F (2000) Deaths due to dementia: an analysis of multiple cause of death data, in *Chronic Diseases in Canada*, 20(3).

34 Mölsä, P K., Marttila, R J., & Rinne, U K (1986) Survival and cause of death in Alzheimer's disease and multi-infarct dementia, in *Acta Neurol Scand*, 74:103–107.

35 Prasher, V P (2005) *Alzheimer's disease and dementia in Down syndrome and intellectual disabilities*; and Down's Syndrome Scotland (2002) *It's Your Move — Down's Syndrome and Dementia*.

- language difficulties,
- hallucinations or delusions,
- wandering behaviours,
- impaired ability to coordinate movements or manipulate objects,
- impaired ability to recognise common objects, persons or sounds,
- incontinence,
- seizures.

There are two features of dementia in people with Down syndrome that are not typical of Alzheimer’s disease: the development of seizures, and serious swallowing difficulties associated with weight loss and aspiration pneumonia.³⁶

While seizures may occur in up to 80 per cent of people with Down syndrome and dementia, the prevalence rate in the general population with Alzheimer’s disease is approximately 10 per cent.³⁷ It has been suggested that the onset of seizures in older adults with Down syndrome is often one of the first signs of Alzheimer’s disease.³⁸

In our review, epilepsy was much more common in people who had dementia — 23 of the 29 people with dementia had epilepsy. For at least nine of the 23 people, the onset of seizures occurred with dementia. While three of the five people who were diagnosed with dementia after death had epilepsy, only three of the 18 people without dementia aged 40 years and older had seizure activity.

People with dementia

The following table outlines the most common changes in health or functioning experienced by the 29 people diagnosed with dementia in our file review.

Table 5: Most common changes experienced by people with Down syndrome and dementia

Change	Number of people
Decline in mobility Nine people who had a decline in their mobility experienced falls, including four people whose falls resulted in fractures.	27
Decline in living skills For many people the decline in living skills, such as dressing and eating, progressed to a point at which they required full assistance from staff.	21
Change in behaviour The changes in behaviour included individuals becoming more socially withdrawn, calling out at night, being aggressive to others, having increased irritability, refusing to put clothes on, taking other people’s belongings, having increased lethargy/sleeping, experiencing hallucinations, and developing depression.	18

36 Singh, I., & Dickinson, M J (2006) Down syndrome, dementia and superoxide dismutase, in Prasher, V P (Ed.) *Down syndrome and Alzheimer’s disease*, pp79–85.

37 Ibid.

38 Van Buggenhout, G J C M., Trommelen, J C M., Schoenmaker, A., De Bal, C., Verbeek, J J M C., & Smeets, D F C M (1999) Down syndrome in a population of elderly mentally retarded patients: genetic-diagnostic survey and implications for medical care, in *American Journal of Medical Genetics*, 85(4):376–84.

Table 5: Most common changes experienced by people with Down syndrome and dementia cont'd

Change	Number of people
Decline in ability to eat/drink This included some people who had existing swallowing difficulties, but whose ability to eat/drink declined with the onset and progression of dementia.	18
Onset of epilepsy or increase in seizures Twelve people developed epilepsy with the onset of dementia. Six people who already had epilepsy experienced increased seizure activity with the progression of dementia.	18
Increased incontinence This included some people who had existing continence problems, but whose incontinence increased with the onset and progression of dementia.	10
Confusion This included one person who tried to walk through a mirror.	9
Increased delay in response This included people who were noted to be slower to respond to tasks, questions, and instructions.	9
Disorientation This included a woman who had difficulties navigating her way to the bathroom and her bedroom.	9
Wandering This included people who began wandering away from their accommodation or day activity for no apparent reason or purpose.	9
Memory loss This included people who forgot they were holding an object, or no longer recognised familiar objects.	7
Decline in interest This included people who were noted to be less/no longer interested in activities they previously enjoyed.	6
Weight loss This included three people who lost a significant amount of weight in a short period of time, such as one woman who lost 20kg in six months. It did not include people who had planned weight loss.	6
Decline in attention/increased difficulty understanding/ decline in cognitive function This included people who spent increasing amounts of time staring into space, and had increasing difficulty understanding instructions.	6
Decline in ability to communicate This included a reduction in the person's vocabulary, or loss of their verbal communication skills.	4
Decline in social skills This included a woman who no longer paid attention to people she used to speak to.	4

People diagnosed with dementia after death

The five people who were only diagnosed with dementia after death appeared to experience few of the changes/decline in functioning experienced by the people who were diagnosed before death.

The only changes noted were onset of seizures (2 people), change in behaviour (2), weight loss (1), mobility decline (1), and attention decline (1). For one of the five people, the change in behaviour and decline in attention was noted to be related to her mental illness.

People 40 years and older without dementia

The 18 people who were aged 40 years and older who did not have dementia experienced some similar changes to the people who had dementia — but they were much less common.

The changes noted to occur most frequently in the people without dementia were:

- decline in mobility (seven people), which included one person who experienced numerous falls and some fractures,
- change in behaviour (six people),
- decline in living skills, which included decline in work performance, and need for increased prompting with daily activities,
- increased incontinence (four people).

Seven of the 18 people without dementia aged 40 years and older experienced a decline in their health and functioning that had some characteristics similar to dementia. This included:

- A 59-year-old man who died from pneumonia. In the one to two years before his death, he experienced some decline in work performance, ability to do some self-care tasks, mobility (from mobilising independently to being unable to stand without assistance), increased incontinence, and change in behaviour (refusing to go to bed, calling out). While the man experienced decline in these key areas, he was not noted to have a decline in his cognitive functioning.
- A 67-year-old woman who died from aspiration pneumonia. In the 12 months before her death, she needed prompting with her daily activities, was increasingly disoriented, had numerous falls with fractures, dramatic weight loss, decline in swallowing function, was more lethargic with increasing amounts of time spent in bed, and change in her sleep patterns. The woman had vision and hearing impairments and had schizophrenia. A CT scan shortly before her death did not find any indication of dementia.

Action taken in response to changes/decline

In the main, services and health professionals appeared to be responsive to the changing or increasing needs of people with and without dementia. This included:

- involvement of allied health practitioners for assessment and review — including speech pathologists, occupational therapists, physiotherapists, and psychologists,
- involvement of appropriate specialists — particularly neurologists for assessment and review of seizure activity, psychiatrists for behaviour changes, and geriatricians/gerontologists for consideration of ageing and dementia needs,
- regular review by general practitioners.

For three people, the increase in their support needs prompted referral to Disability Aged Care Pilot services for additional assistance.³⁹ Two of the three people had dementia.

However, we noted gaps in the response to changes in mobility and behaviour for some people.

It was not clear what action was taken in response to the increasing mobility problems of six people, such as occupational therapy or physiotherapy involvement. This included instances where the decline in mobility had a significant impact on the person, such as falls or no longer being able to weight bear.

For at least six people with dementia, a change in their behaviour — such as increased aggression, distress, disturbed sleep, or self-injurious behaviour — did not appear to prompt consideration of behaviour intervention strategies. For three people, the response appeared to focus on medication only.

2.5 Diagnosis

Diagnosing dementia can be difficult in the general population, and particularly for people with Down syndrome, because:

- people with Down syndrome are more susceptible to reversible conditions that can be mistaken for dementia,
- the usual skill tests used for diagnosis (such as the Mini-Mental State Examination — MMSE) do not take into account existing cognitive and other impairments,
- communication difficulties, experienced by some people with Down syndrome, can affect the assessment.⁴⁰

Conditions that can mimic dementia

Making the diagnosis of dementia in a person with Down syndrome is usually based on excluding other possible causes of symptoms.⁴¹ People with Down syndrome are more susceptible to some of the treatable conditions that can be confused with dementia, including:

- vision or hearing impairment/loss,
- hypothyroidism,
- constipation,
- depression,
- medication side-effects,
- sleep apnoea/lack of sleep,
- menopause,
- recent bereavement or significant change,
- cardiac abnormalities,
- compulsive disorders,
- osteoporosis,
- delirium,
- urinary tract infections,
- diabetes,

³⁹ In 2003/04, the Commonwealth Department of Health and Ageing initiated a Disability Aged Care Pilot program to explore the provision of community-based aged care services for ageing residents in group homes. The funding enabled eligible people with disabilities in group homes to receive additional services to meet their ageing-related needs, and allowed disability service staff to receive relevant training.

⁴⁰ Alzheimer's Australia (2005) *Down syndrome and Alzheimer's disease* help sheet.

⁴¹ Ibid.

- spine disturbance/changes in knee or hip joints,
- vitamin deficiencies, including vitamin B₁₂, folic acid and niacin.

The physical, mental, and/or behavioural effect of these conditions can be similar to symptoms of dementia. For example, hypothyroidism can present with mental impairment, dulling of personality, apathy and slowing down, together with a number of physical symptoms.⁴² Similarly, the following case study illustrates the impact of vitamin B₁₂ deficiency on mental, physical and behavioural functioning.

Case study 9

A man with Down syndrome who lived in a funded group home died from an intracerebral bleed at 60 years of age. In the six months before his death, he had a decline in his health and functioning that had characteristics similar to dementia.

He experienced increased confusion, problems with attention at work, increased slowness in his responses, a decline in living skills and mobility, and a change in behaviour.

The man's GP referred him to a neurologist who conducted a number of tests, including a CT scan and blood tests. The CT scan showed that a number of small blood clots were forming in his brain, and the blood tests indicated vitamin B₁₂ deficiency. The B₁₂ deficiency meant that his red blood corpuscles were not carrying sufficient oxygen to his brain.

The service reported that the man had a decrease in confusion and improved functioning as a result of treatment with vitamin B₁₂ injections. He did not develop dementia.

Because the effect of these conditions can be similar to symptoms of dementia, a key part of diagnosing dementia involves testing for, and treating, these conditions.

Getting a baseline

A fundamental part of diagnosis is being able to determine a change in a person's level of functioning.⁴³ In order to do this effectively for people with an intellectual disability, it is important that they are routinely screened to establish important baseline information.

A 'baseline' assessment records the person's usual level of functioning — such as memory, cognitive function, and skills.

If a person's baseline level of functioning is known, it becomes much easier to clearly identify any changes.

Having a baseline to consider in a dementia screening assessment makes it easier to work out whether a person's current level of memory and other functioning is related to their intellectual disability, or indicates potential dementia-related decline.

International agencies have recommended that all adults with an intellectual disability should have a comprehensive assessment of memory, other cognitive functions and behaviours at least once in early adulthood, to obtain the baseline level of functioning.⁴⁴

The Centre for Developmental Disability Studies (CDDS) has advised that many of the instruments used to test functioning in a range of areas to obtain the baseline information

⁴² Percy, M., & Prasher, V P (2006) Thyroid disorders, dementia and Down syndrome, in Prasher, V P (Ed.) *Down syndrome and Alzheimer's disease: Biological correlates*. Oxford: Radcliffe Publishing, 99-139.

⁴³ Alzheimer's Australia (2001) *Diagnosing Dementia* reference paper.

⁴⁴ International Association for the Scientific Study of Intellectual Disability, and the American Association of Mental Retardation.

require administration by a psychologist trained in the area of intellectual disability. If this is not available, staff or families need to keep records of observed behaviours.

Case study 10

A 45-year-old man who lived in a group home had a severe level of cognitive impairment but did not have dementia.

Six years before his death, group home staff noted that the man was reluctant to participate in his usual day program activities. Staff assessed the man using the Minda Broadscreen Checklist of Observed Behaviours in order to gather data to enable future assessments for dementia.

Two years later, a psychologist reassessed the man using the same checklist after it was noted that he was becoming increasingly irritable and was experiencing mood swings. Comparison of the results of the assessments indicated some cognitive decline, and arrangements were then made for the man to see a Geriatric Team at the local hospital. The hospital team made a differential diagnosis of dementia or depression, and recommended a psychiatric review.

At the same time, the man was reviewed by a developmental disability clinician who indicated that he may have obsessive compulsive disorder. A psychiatrist confirmed this diagnosis and depression.

The diagnosis process

Diagnosis requires expert clinical assessment based on information gathered from all sources, including a range of detailed diagnostic investigations.⁴⁵

For people with Down syndrome, research indicates that best practice in diagnosing dementia includes:

1. Expert clinical assessment. This includes:
 - a) assessment to determine any decline in the person's functioning, such as cognitive decline.

A number of assessments have been developed for people with an intellectual disability who are suspected of having dementia. The following table outlines some of the tools used in assessing dementia in the general population and specifically in people with an intellectual disability.

Table 6: Tools for assessing dementia⁴⁶

General population	ID population
Global assessment	
CDR (Clinical Dementia Rating)	DMR (Dementia Questionnaire for Mentally Retarded Persons)
BPRS (Brief Psychiatric Rating Scale)	CAMDEX-DS

⁴⁵ Stancliffe, R.J., & Harman, A.D. (2007) *Evidence-based literature review on dementia and people with intellectual disability*, Centre for Developmental Disability Studies.

⁴⁶ Source: Centre for Developmental Disability Studies (2008).

Table 6: Tools for assessing dementia cont'd

General population	ID population
CAMDEX (Cambridge Mental Disorders of the Elderly Examination)	AADS (Assessment for Adults with Developmental Disabilities)
Neuropsychological assessment	
MMSE (Mini Mental State Examination)	DSDS (Dementia Scale for Down Syndrome)
AMTS (Abbreviated Mental Test Score)	TSI (Test for Severe Impairment)
ADAS (Alzheimer's Disease Assessment Scale)	Early Signs of Dementia Checklist
Clock-Drawing Test	Prudhoe Cognitive Functioning Test
	BPT (Brief Praxis Test)
Neuropsychiatric assessment	
BEHAVE-AD (Behavioural Symptoms in Alzheimer's Disease)	DSMSE (Down Syndrome Mental State Examination)
NPI (Neuropsychiatric Inventory)	PRIMA (Psychopathology Instrument for Mentally Retarded Adults)
MOUSEPAD (Manchester and Oxford Universities Scale for the Psychopathological Assessment of Dementia)	
RAGE (Rating Scale for Aggressive Behaviour in the Elderly)	
Activities of daily living	
ADL (Activities of Daily Living Index)	Vineland Adaptive Behaviour Scales
FAQ (Functional Activities Questionnaire)	AAMD-ABS Part I and II (AAMD — Adaptive Behaviour Scale I and II)
	ABC (Aberrant Behaviour Checklist)
	ABDQ (Adaptive Behaviour Dementia Questionnaire)
Caregiver assessment	
Burden Interview	DSQIID (Dementia Screening Questionnaire for Individuals with Intellectual Disabilities)
Marital Intimacy Scale	
Cornel Scale for Depression in Dementia	

- b) medical tests to determine if a decline is due to physical illness including blood tests, hearing and vision assessments and brain scans.
- c) psychiatric assessment to determine if a decline is due to psychiatric illness, such as depression or delirium.
- d) multidisciplinary assessments, including allied health involvement.

2. Any reversible causes of a decline, including physical and psychiatric illness, are treated.
3. Information is reviewed and diagnosis (where possible) is made.

Given the complexity of the assessment process, it is advantageous to have the involvement of a specialist familiar with the area of intellectual disability.

Generally, there is a view that, wherever possible, the assessments should be conducted in the person's own home to minimise any environmental impact and enable the involvement of a range of carers. For people with disabilities who live in care, it is important that staff members who know the person well are involved in the assessment process.

In our review, we found that:

- Excluding the five people who were diagnosed with dementia after they died, a diagnosis of dementia had been recorded for 25 people. A formal diagnosis had not been made for four people:
 - For two people, clinicians considered it likely that they had dementia, and a diagnostic process was underway when they died.
 - An informal diagnosis for two people appeared to be made by staff or the GP based on presenting symptoms such as 'loss of utilities' or onset of seizures.
- We found evidence of a diagnostic process for dementia involving expert clinical assessment in relation to 14 people — two of whom were found to not have dementia. For these 14 people, we noted the involvement of a range of clinicians, including geriatricians, neurologists, psychiatrists, psychologists, and developmental disability practitioners. The most common tests involved blood tests and CT scans. For the other people with dementia, there was insufficient file information to indicate the diagnostic process.
- In some instances, we found evidence that particular consideration had been given in the assessment process to the impact of the person's impairment. This included an assessment which noted that the person's hearing impairment may have had an impact on the results; and an assessment for a man with Lewy body dementia that took into consideration his communication difficulties.

Case study 11

A neurologist and neuropsychologist diagnosed a woman, who lived in a funded group home, with dementia two years before her death at the age of 49 years. The neurologist noted that the woman had become increasingly disoriented, had lost weight, and had developed an unsteady gait in the previous 18 months.

The neurologist also recorded that the woman had new short-term memory loss, a general decline in skills, and had started collecting photos, magazines and other people's belongings and stuffing them in her handbag. A CT scan showed some generalised cortical atrophy.

The neurologist recommended that the woman's home environment be modified and her routines made more predictable. The service developed a number of strategies for staff to minimise the woman's confusion.

Nine months before her death, the woman was assessed by a developmental disability clinician who confirmed the diagnosis of dementia. Tests conducted by the clinician included the Adaptive Behaviour Dementia Questionnaire, blood tests to rule out hypothyroidism, and tests for Coeliac's disease. The clinician also provided

Case study 11 cont'd

an assessment form to the staff supporting the woman in order to screen for mental health issues such as depression.

The Adaptive Behaviour Dementia Questionnaire results suggested that the woman did not have dementia. However, the developmental disability clinician considered that the result may have been affected by the fact that the functional decline and behaviours had been present for a number of years.

2.6 After diagnosis

Treatment

At present, there is no cure for Alzheimer's disease. However, some medications and alternative treatments have been found to reduce the primary symptoms of dementia, including memory loss.

Cholinesterase inhibitors such as donepezil (Aricept), rivastigmine (Exelon), and galantamine (Reminyl) can be helpful for some people.⁴⁷ On average, one-third of people with dementia who take these medications note some improvement, one-third stabilise, and one-third have no response.⁴⁸

The effectiveness of these medications for people with Down syndrome has not been systematically studied.⁴⁹ In addition, to obtain these drugs at reduced cost through the Pharmaceutical Benefits Scheme (PBS), the person with Down syndrome and dementia:

- needs a specialist diagnosis of mild to moderately severe Alzheimer's disease;
- has to have a Mini Mental State Examination (MMSE) or Standardised MMSE score of nine or less and be assessed using the Clinicians Interview Based Impression of Severity (CIBIS) scale; and
- needs to show definite improvement in function to continue with the medication through the PBS. The person must be reassessed with the Clinicians Interview Based Impression of Change (CIBIC) scale by the clinician who initiated the treatment and achieve a rating of 'very much improved' or 'much improved'.

In our review, dementia-specific medications were considered in relation to seven of the 29 people who were noted to have dementia before they died. Four people were trialled on Aricept or Exelon (one person was trialled with both), and one man was trialled on Reminyl. Trials of Aricept and Exelon were considered for another two people, but were deemed inappropriate.

Medications are also used to treat some of the secondary symptoms of dementia, including agitation, aggression, depression, hallucinations, and sleep disturbance. These medications include antidepressants, antipsychotics, and mood stabilisers.⁵⁰ These medications can have significant side effects and can affect already compromised functioning, such as mobility and alertness.

Trials involving aromatherapy with essential oils of lemon balm and lavender to treat secondary symptoms have reportedly shown significant beneficial effect on agitation.⁵¹

47 Alzheimer's Australia (2005) *Down syndrome and Alzheimer's disease* help sheet.

48 Dr Susan Kurrle (2005) *Dementia Drugs — Mainstream and Alternative Medicines*, Alzheimer's Australia conference paper, www.alzheimers.org.au/upload/DementiaDrugsKurrle.ppt.

49 Alzheimer's Australia (2005) *Down syndrome and Alzheimer's disease* help sheet.

50 Ibid.

51 Ibid.

Good practice in supporting people with disabilities and dementia

While there is no one model of dementia care, the focus of caring for a person with dementia should be on flexibility and meeting individual needs.⁵²

It has been suggested that good practice in supporting people with dementia in the care of disability services involves:⁵³

1. Early screening and diagnosis — including the collection of information on the person's baseline level of functioning.
2. Clinical supports — use of experienced clinicians and trained staff for diagnosis and intervention.
3. Environmental modifications — may involve simple changes or major redesigns of living spaces.
4. Program adaptations — involves re-thinking how daily activities are planned and managed in order to provide appropriate support to the person with dementia and help them retain existing skills.
5. Specialised care — staff adaptation to changes in needs according to the dementia stages. Later stages of dementia require increasingly structured care and supervision.

In our review, we found evidence of good practice by some of the services that supported people with Down syndrome and dementia. This included evidence of health care and support planning that incorporated dementia, such as the development of strategies to help minimise confusion for the person; development of comprehensive dementia support plans that were updated as the person's needs changed; and review and amendment of other support plans, such as mobility management plans, to reflect changes due to dementia.

Some services demonstrated good practice in responding in a flexible way to meet the individual needs of people with dementia, such as:

- using 'non-drug' strategies to support a man who began waking through the night, including providing a night-light in his room, and ensuring that he had his comfort item with him;
- changing personal care times and mealtimes, and adjusting routines to minimise distress and meet the needs of the person with dementia;
- adapting the physical environment to ensure a man's safety when mobilising; and
- ensuring that support was provided by familiar staff.

While there were some people whose involvement in regular activities or outings was restricted following their dementia diagnosis, this was not the case for most people, including continued involvement in day program activities and access to the community.

In our *Report on Reviewable Deaths in 2006*, we considered the deaths of all people with dementia in 2006 and raised concerns about what appeared to be a link between a diagnosis of dementia and a decision to commence palliative care. However, this review did not identify the same issue for people with Down syndrome and dementia.

- Sixteen people diagnosed with dementia before death received palliative care, but for 10 people the decision was made when the person was critically ill, for example with pneumonia, typically while the person was in hospital.
- There was a link between a dementia diagnosis and a decision to commence palliative care for one person. However, the man had been diagnosed with dementia five years

⁵² Alzheimer's Australia (2007) *Quality Dementia Care Standards*.

⁵³ AIHW (2006) *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: final report*, citing Wilkinson, H., Kerr, D., & Cunningham, C (2005) Equipping staff to support people with an intellectual disability and dementia in care home settings, in *Dementia*, 4(3):387–400.

previously, and palliative care was commenced when a reassessment indicated that he had late stage dementia.

- Seven of the 16 people had Palliative Care Team involvement.
- In the main, illnesses that emerged after a diagnosis of dementia appeared to be actively treated.

For some people, we noted reassessment of their cognitive functioning and/or review of dementia after diagnosis. Thirteen people had some form of reassessment or review, such as review by a geriatrician or neurologist, or reassessment of functioning by a psychologist or developmental disability practitioner.

For the people with dementia and the services supporting them, these reviews and reassessments provided access to expert advice about dementia and recommendations about how to meet the person's changing needs.

Aged Care Assessment Teams had contact with 11 of the people with dementia; all of whom were under 65 years of age. The contact included assessment for home modifications, assessment for entry to residential aged care, and geriatrician reviews.

Ageing in place for people with Down syndrome and dementia

Current research indicates that:

- people with an intellectual disability living in care with dementia place higher demands on staff than residents who do not have dementia; and
- disability services are generally meeting the changing needs of people with dementia and/or who are ageing within their existing resources, with no increase in funding to take account of the increase in the support needs.⁵⁴

For the people with Down syndrome and dementia whose deaths we reviewed, it was evident that services supported them at home for as long as possible. While many of the people had pre-existing health concerns that required ongoing support, it was clear that dementia — and the progress of the disease — meant an increase in the support needs of the people concerned and greater investment of resources for the services supporting them.

Some services took steps to try to resolve the tension between increased support needs and existing resource constraints by seeking increased funding, obtaining support from external services, or redistributing their resources:

- One funded service sought additional funding from DADHC to provide support to a man with dementia as his needs increased.
- Two people received additional support through a Disability Aged Care Pilot, which included increased direct care and funding to train staff.
- DADHC moved two people to alternative accommodation in its service that offered greater supervision and medical support.

Case study 12

A 60-year-old man who lived in a funded group home in regional NSW died from bronchopneumonia. He was diagnosed with Alzheimer's disease at least three years before his death.

The man experienced decline due to the progression of Alzheimer's disease —

⁵⁴ Bigby, C (2008) Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability, in *Journal of Intellectual & Developmental Disability*, 33(1):76–86.

Case study 12 cont'd

he developed swallowing problems, was losing the ability to feed himself, was increasingly unable to support his neck, had increasing drowsiness, developed significant mobility problems, developed seizure activity, and experienced disorientation, confusion, delusions, agitation, and night wandering.

The service provided active management and coordination of the man's declining health, including links to appropriate specialists such as a gerontologist, neurologist, ACAT, continence specialist, and allied health providers.

The service also linked the man in with a Disability Aged Care Pilot (DACP), which provided him with additional support for four hours each day from an external service, and enabled group home staff to have relevant training.

Through the DACP, funding was also provided for the man to have physiotherapy input regarding his gross motor movement.

The DACP coordinator liaised with the disability service, the man's GP, and hospital staff to ensure comprehensive support as his health declined and his needs increased.

We noted that services generally involved expert practitioners, including specialists and allied health clinicians, but ultimately it was the responsibility of direct care staff to meet the increasing support needs of the people with dementia in their care.

In the main, staff in supported accommodation services do not have clinical or medical expertise, and do not necessarily have knowledge about supporting people who are ageing or who have dementia. It is important that staff supporting people with dementia receive appropriate training and support, but this is unlikely to be achieved through contact with the practitioners conducting assessments and reviews.

DADHC funds 29 Dementia Advisory Services across NSW to provide dementia information, education and support, and to link people to assessment and support services. There are no restrictions to people with disabilities in care accessing these services. Alzheimer's Australia also provides support, information, education and counselling for people affected by dementia, including assistance for disability services to understand and support the changes associated with dementia.

As the number of older people with disabilities increases, the ability of services to meet the greater support needs of people with disabilities related to dementia and/or ageing with their existing resources will be challenging. This is particularly the case for smaller organisations with less capacity to absorb the increasing costs.

Currently, people with Down syndrome and dementia who live in supported accommodation are unable to access some of the support services available to people in the general population with dementia. Of note, people with disabilities in care are unable to access community-based aged care supports such as Community Aged Care Packages. The barrier to accessing these services is the program, funding and policy separation between the disability and aged care sectors.⁵⁵

In 2003/04, the Commonwealth Department of Health and Ageing initiated a Disability Aged Care Pilot program to explore the provision of community-based aged care services for ageing residents in group homes.

⁵⁵ Bigby, C (2008) Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability, in *Journal of Intellectual & Developmental Disability*, 33(1):76–86.

In its evaluation of the pilot program, the AIHW found that the provision of additional services with an aged care focus had ‘significantly improved the quality of life of care recipients’, and enabled an exchange of knowledge and skills between aged care and disability services staff. The AIHW reported that one of the key strengths of the pilot was access to gero-psychology services and close attention to the needs of people with dementia.⁵⁶

At the end of the pilot, the Department of Health and Ageing agreed to continue to fund people already in the pilots, but not to admit new entrants or to expand the pilots into a program.

2.7 Current work relevant to people with Down syndrome and dementia

Dementia plans

There are two current state and federal government plans relating to people with dementia that may result in improved access to dementia services and support for people with an intellectual disability.

One of the aims of the *National Framework for Action on Dementia 2006–2010* is to achieve a ‘more coordinated and seamless transition for people with dementia between the various government services and programs’.⁵⁷

The national framework involves work to develop an evidence base of best practice in care and support, and to develop national quality standards to benchmark services, performance and outcomes. Of particular relevance to people with dementia who have an intellectual disability is the planned work to identify specific barriers to the access of care and support, including people with dementia and another cognitive impairment or dual diagnosis.

The *NSW Dementia Action Plan 2007–2009* links in with the national framework, and outlines key strategies to be implemented by NSW Health and DADHC. The strategies include:

- development of programs involving joint assessment of older people with intellectual disability who are showing a change in behaviour that suggests possible dementia,
- identification of a Home and Community Care (HACC) service model(s) to meet the needs of people with a younger onset of dementia,
- development of a Dementia Services Planning Framework, with consideration of service mix and staffing levels, recognition of the importance of multidisciplinary diagnostic and assessment services, and development of performance indicators.

An evaluation strategy is being developed that will include the development of performance indicators, and linkage to a proposed evaluation of the national framework.

Disability and ageing work

The need to resolve the access barriers for people with disabilities in care and improve the linkages between the disability and ageing sectors has been reported in at least two recent Senate inquiries.⁵⁸ This issue was also the subject of election commitments in 2007 by the current Commonwealth Government to ‘allow people living in disability group homes to access community aged care under a blended payment system’.⁵⁹

56 AIHW (2006) *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: final report*, p18.

57 Australian Health Ministers’ Conference (2006) *National Framework for Action on Dementia 2006–2010*, p17.

58 Senate Community Affairs Reference Committee (2005) *Access and Equity in Aged Care*; and Senate Community Affairs Reference Committee (2007) *The Funding of the Commonwealth States/Territories Disability Agreement*.

59 Australian Labor Party (2007) Disability and carers election fact sheet, p6, downloaded from www.kevin07.com.au, July 2008.

In 2007, the Council of Australian Governments (COAG) agreed on key reform directions relevant to ageing people with disabilities. These included the need for greater levels of community-based care, opportunities for more seamless delivery, and the intersection between aged care, HACC and disability funding.

At the COAG meeting in July 2008, it was agreed that fixing the intersection of aged care and disability services and clarifying roles and responsibilities would be a major reform priority. The COAG Health and Ageing working group is to further develop service delivery improvements and reforms for consideration at the next scheduled meeting in October 2008.

3. Conclusion

In comparison with the general population, people with Down syndrome develop dementia at a much younger age, and in a higher percentage of people. Diagnosing dementia in this population can be difficult, as it is often affected by the pre-existing cognitive impairment, the presence of conditions that mimic dementia, and communication difficulties.

As a result, it is important that at-risk populations, like people with Down syndrome, are routinely screened for dementia, and that the diagnostic process is thorough — involving appropriate clinicians, assessments to exclude other health conditions, and consideration of information about the person's baseline level of functioning.

Supporting people with Down syndrome and dementia requires flexible service provision that is focused on the person's needs. The support needs of this population increase markedly as the disease progresses, impacting on the health and independence of the individual and presenting significant challenges to the disability service that supports them.

Overall, our review indicated that disability services endeavour to meet the increasing needs of people with Down syndrome and dementia within existing resources, and with the involvement of relevant health and ageing practitioners.

However, disability services staff generally do not have expertise in dementia and aged care, and they are unlikely to receive the necessary training and support through the involvement of practitioners in the diagnostic process.

Given the link between Down syndrome and dementia, the increasing prevalence of dementia in the general population, and the ageing of people with disabilities in care, it is important that disability services have a clear plan in place for responding to emerging dementia.

While we would not expect disability services staff to be experts in this area, we consider that providing effective support to people with dementia necessitates an understanding of the disease and its impact. In particular, we consider that services should be aware of:

- what dementia is likely to involve for the person concerned
- the risks associated with dementia for that person (such as falls and swallowing risks) and how to minimise those risks
- how to appropriately support the individual; including maintaining skills/independence
- how to obtain advice and assistance for staff and the person with dementia.

Strategies to improve access for people with Down syndrome to dementia and community-based aged care supports available to the general population may result in greater support for people with dementia in residential care and enable those individuals to continue living safely at home for as long as possible. Current work underway by Commonwealth and state governments on the intersection of the aged and disability sectors may provide the means to resolve the existing access barriers.

In addition, current national and NSW dementia policy frameworks include consideration of the needs of people with an intellectual disability. Of particular benefit to people with Down syndrome and dementia is likely to be the consideration of assessment and diagnosis for people with pre-existing cognitive impairment. Importantly, the strategies outlined in these policies include a focus on best practice and quality improvement.

Part 3: Monitoring recommendations



Section 43(2)(c) of CS-CRAMA requires us to provide information in our reviewable deaths annual report with respect to the implementation or otherwise of previous recommendations.

In our *Report of Reviewable Deaths in 2006*, we made eight recommendations. We directed five recommendations to DADHC, two recommendations to NSW Health, and one recommendation jointly to both agencies.

The following section outlines our recommendations and agency progress since the last report.

Department of Ageing, Disability and Home Care

Recommendation 1

DADHC should 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,

DADHC response

DADHC told us that briefing kits for DADHC regional staff are being developed for release of both policies, and will be provided to DADHC operated and funded services. By the end of August 2008, DADHC expects that the *Client Risk* policy will be released, and the *Decision-making and Consent* policy will be approved for release.

Our comments

DADHC has made progress towards releasing these key policies to both DADHC operated and funded services. We will monitor the implementation of these policies in relation to people with disabilities in care through our reviews.

- c) plans for the evaluation of the *Ensuring Good Nutrition* policy,

DADHC response

DADHC advised that CDDS is evaluating the policy, and has commenced consultations with DADHC operated and funded services and external stakeholders. The project is due to be completed by December 2008.

Our comments

Evaluation of the *Ensuring Good Nutrition* policy has been a focus of our recommendations for the past two years, and stemmed from concerns we had identified through our reviews about the adequacy of actions taken by services to identify and address nutrition and swallowing risks.

DADHC has made considerable progress on evaluating the policy. Given the importance of nutrition and swallowing risk management in preventing the premature deaths of people with disabilities in care, we will seek advice on the outcomes of this work.

- 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,

DADHC response

DADHC told us that it will release the revised *Medication* policy by the end of October 2008. The policy will be mandatory for all services operated by DADHC that are occupied or otherwise accessed by people with a disability who require support to self-medicate or who have medications administered by a member of staff.

In relation to discussions with the NSW Divisions of General Practice, DADHC told us that a number of changes have occurred since this recommendation was made, including:

- the Australian Government has introduced two items to the Medicare Benefits Schedule. The items enable GPs to conduct annual health assessments of people with an intellectual disability, including an assessment of their medications and their need for a formal medication review; and
- DADHC is about to finalise its revised *Medication* policy, which includes reference to Domiciliary Medication Management Reviews.

In addition, DADHC met with representatives of the NSW Alliance of the Divisions of General Practice in August 2007 to discuss increasing GP awareness about the issues arising from polypharmacy in people with intellectual disabilities. However, because of competing work priorities, the department does not intend to take further action on this matter at this time.

Our comments

We have raised concerns in several of our reports about the vulnerability of people with disabilities in care to adverse events as a result of medication, such as drug toxicity. In response, we highlighted Domiciliary Medication Management Reviews as a potential safeguard, and asked DADHC to consider ways in which these reviews may be promoted for use with people with disabilities in care.

DADHC's revision of its *Medication* policy to include reference to Domiciliary Medication Management Reviews may provide a means for promoting this option within its own accommodation services.

The addition to the Medicare Benefits Schedule of an item for an annual health assessment for people with an intellectual disability is positive, and includes consideration of medications. The health assessment must include (as relevant to the patient) assessment of medications, including non-prescription medicines taken by the patient, prescriptions from other doctors, medications prescribed but not taken, interactions, side effects and review of indications. As part of this assessment, GPs must advise carers of the common side effects and interactions, and consider the need for a formal medication review.

This addition to the Medicare Benefits Schedule came into effect on 1 July 2007. The introduction of this assessment item may provide a means of reducing the risks faced by people with an intellectual disability in relation to polypharmacy. We will monitor the impact of this development on people with disabilities in care through our reviews.

- 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,

DADHC response

DADHC told us that it is continuing to explore appropriate and effective models of care for people with a disability as they age, both in the community and residential care. The department is undertaking this work through:

- case management and liaison with aged care providers around the needs of individual clients whose functional needs are changing as they age;
- development of specific accommodation models for people with a disability as they age; and
- discussions in the context of Commonwealth/State policy and funding negotiations.

Our comments

This recommendation came as a result of our consultations with disability accommodation providers in 2006 on the interaction of people with disabilities with the health system. In these forums, services raised concerns about the lack of policy guidance from DADHC on 'ageing in place' for people with disabilities in care, and argued that this tended to result in inconsistent practice across disability services. At that time, DADHC had advised that it was developing a policy for the care and support of people with an intellectual disability who are ageing.

One of the stated roles of DADHC is to provide strategic leadership and policy advice on ageing and disability issues. On the issue of care and support to people with disabilities who are ageing, we consider that there is currently a lack of clear vision and related policy direction.

Our project this year on people with Down syndrome and dementia identified continued concerns about the support available for people with disabilities as they age, and the impact of the continued barriers between the disability and aged care sectors. While we note DADHC's work in this area, including the younger people with disabilities in aged care facilities program, we consider that there is a need for greater clarity about the department's position on ageing in place, and long-term vision regarding the care and support of people with disabilities as they age.

Support for people with disabilities as they age is a continuing area of focus in our work in reviewing deaths. As a result, we will continue to monitor the department's work in this area.

- g) the commencement of a review of the screening tool for entry to licensed boarding houses,

DADHC response

DADHC advised that it has engaged an independent consultant to review the screening tool for entry to licensed boarding houses with the aim to develop a new or revised screening tool consistent with contemporary best practice, with operational guidelines to support its application.

The review includes consultations throughout July 2008 with stakeholders, including a workshop with screening agencies such as Aged Care Assessment Teams (ACATs), meetings with DADHC staff, licensees and boarding house managers, and referral staff, and meetings with some licensed boarding house residents who have been screened during the last year.

The review is expected to be completed in December 2008.

Our comments

This recommendation has featured in our last three reports. In the past year, there has been significant progress towards meeting this recommendation.

Our reviews continue to identify concerns about the implementation of the screening tool to prevent people with high support needs from entering licensed boarding houses. As the review is still underway, we will continue to monitor the department's work in this area.

- h) finalising the review of the Monitoring and Review Tool associated with licence condition 4 (minimum standards for record keeping) for licensed boarding houses,
- i) finalising the revised *Licensed Residential Centres Licensing, Monitoring and Closures* policy,

DADHC response

DADHC told us that it is currently progressing the drafting of the *Licensed Residential Centres Licensing, Monitoring and Closures* policy, and anticipates its completion in December 2008. The Monitoring and Review tool is an appendix to this policy.

Our comments

In 2005 and 2006 we raised concerns about:

- compliance of licensed boarding house operators with record-keeping requirements, and
- access of licensed boarding house staff to information about good practice in health care, including access to relevant departmental policies.

In response, DADHC advised in 2006 that it was reviewing and updating the *Licensing, Monitoring and Closures* policy manual and incorporating information on good practice in supporting the health needs of people with disabilities that DADHC officers could use to assist licensed boarding house operators.

In relation to record keeping, DADHC reviewed record keeping practices in licensed boarding houses in 2006 and identified actions that it would take to strengthen the compliance by licensed boarding house proprietors with the relevant licence condition and encourage better practice. The actions included reviewing the Monitoring and Review Tool, setting good practice benchmarks, and developing a resource to support the sector to improve compliance and practice in this area.

Last year, DADHC advised that its licensed boarding house reference group had commenced a review of the Monitoring and Review Tool.

Progress in relation to these recommendations has been slow, and the policy has not yet been completed. As a result, we will continue to monitor the department's work in this area.

- j) the re-auspice of primary and secondary health care services, in relation to licensed boarding houses.

DADHC response

DADHC told us that primary and secondary health care services continue to offer case management and brokerage services to licensed boarding house residents under the new auspice arrangements. Funding for these services has been extended until 30 June 2009.

DADHC also advised that an evaluation of the primary and secondary health care service for licensed boarding house residents is expected to be completed by March 2009. The recommendations from the review of the health needs of licensed boarding house residents in the inner west area of Sydney will be considered within the scope of this evaluation.

Our comments

In 2005, we raised concerns about the inconsistent access of licensed boarding house residents to primary and secondary health care services. Since then, DADHC has developed new auspice and service model arrangements for primary and secondary health care services, and contracted a review of the health needs of licensed boarding house residents in the inner west area of Sydney.

We are pleased that the recommendations from the inner west health review will be considered within the scope of the evaluation of primary and secondary health care services. The review identified significant gaps in the assessment and provision of health care to licensed boarding house residents in that region, and made seven recommendations to DADHC to improve the health outcomes of licensed boarding house residents across NSW.

Given the significance of primary and secondary health care for licensed boarding house residents, we will continue to monitor the department's work in this area.

Medication administration in licensed boarding houses

Recommendation 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.

DADHC response

DADHC advised that it has consulted the Boarding House Expert Advisory Group in relation to this issue. As part of these consultations, the department surveyed 44 licensed boarding houses regarding compliance with licence conditions and good practice in relation to medication administration. The data indicated:

- a high level of compliance with licence conditions relating to the safe storage and record keeping requirements of prescribed medication; and
- a number of good practice activities, including the use of medication organisers such as Dosette boxes, in all surveyed premises.

DADHC advised that it will consider this recommendation further after consultation with NSW Health and primary and secondary health care providers.

Our comments

We made this recommendation in response to concerns raised through our reviews last year about the adequacy of the protocols in place for the administration of regular medications in licensed boarding houses. While licensed boarding houses are required to maintain a recording system for PRN medication, current licence conditions do not authorise DADHC to impose a requirement for record keeping related to regular prescribed medications.

We note DADHC's advice about the positive survey results and continued consideration of this recommendation. We will continue to monitor the department's work in this area.

Community Access

Recommendation 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.

DADHC response

DADHC told us that it is using the information it gathers from the Integrated Monitoring Framework to manage the performance of individual funded services in relation to issues of client access to the community. Broader monitoring of performance will identify systemic issues to be addressed and relevant actions for service improvement.

DADHC told us that, in relation to specific regions:

- Community access is a priority in DADHC's Hunter Residences, and is monitored for all clients:
 - Quarterly reports are provided to the Disability Practice Review Group, including data on 1:1 outings, small group purposeful outings, small group diversional outings, and holidays.
 - The Nurse Manager, Accommodation and Nursing Service, from each centre reports on continuous improvement strategies and outcomes.
 - Each Residential Unit Nursing Manager is expected to develop strategies that will facilitate and enable individual 1:1 outings for each person on a regular basis, and address any barriers impacting on an individual's community participation opportunities.
 - Clients of Hunter Residences access the services of a non-government organisation, Newcastle and Hunter Community Access, on a fee-for-service basis to increase their opportunities to access community participation and integration activities.
- DADHC's Metro Residences has started improving the quality of individual plans, and is keeping a database on all community access with the aim of increasing

the quantity and quality of community access for residents. There has been an improvement in community access since 2006, and Metro Residences will focus on this area in 2008.

Our comments

While DADHC has provided considerable information on this recommendation in relation to Hunter Residences and Metro Residences, no information has been provided for the other residential centres.

The Ombudsman's office is currently undertaking a review of individual planning and the meeting of individual needs in DADHC residential centres, which includes considering access to the community. We will pursue this issue through the review.

Response to critical incidents

Recommendation 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.

DADHC response

The department advised that it agrees in principle with this requirement, but needs to ascertain the potential implications for DADHC and its funded service providers. As a result, DADHC will:

- determine the extent to which first aid is already a requirement for employment in funded disability services. DADHC has contracted National Disability Services NSW to meet with the Accommodation Policy and Development Branch to discuss this issue,
- determine how the gap (if any) in first aid knowledge may be bridged in the funded sector,
- establish a way of ensuring that first aid skills are maintained in the long-term,
- decide on DADHC's approach to making this recommendation a requirement of its funded services,
- the Accommodation Policy and Development Branch will develop a paper outlining an approach that is acceptable to all parties.

DADHC has advised that the strategy will be in place by the end of 2008.

In August 2008, DADHC told us that National Disability Services has conducted a survey of its members, seeking information on the type and status of staff, extent of current first aid qualifications and the frequency of shifts that are covered by a qualified first aid staff member. The results are currently being analysed and will be used to assist DADHC in establishing a suitable approach for addressing this recommendation by the end of 2008.

Our comments

There has been progress in relation to this recommendation. We will continue to monitor the department's work in this area.

Recommendation 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.

DADHC response

DADHC advised that data on staffing practice found that 88 per cent of licensed boarding houses were compliant with Licence Condition 9.1.1: *'...at least one member of the staff of the residential centre for persons with disabilities shall, in the case of an accident or sudden illness, be qualified in the opinion of the Director-General, to render first aid pending the arrival of medical aid'*.

In addition, approximately 50 per cent of licensed boarding houses had more than one staff member qualified in either nursing or first aid.

DADHC told us that, through regular monitoring procedures, it follows up licensed boarding houses that are identified as non-compliant with this licence condition.

DADHC also advised that it believes that it has no legal authority to enforce our original recommendation that at least one staff member on each shift be qualified in first aid in licensed boarding houses. DADHC told us that staffing suitability continues to be one of the issues considered as part of the review of the *Youth and Community Services Act 1974* (YACS Act).

In relation to the review of the YACS Act, DADHC told us that an Inter-departmental Committee (IDC) on Reform of the Private Residential Service Sector has been formed to progress a whole-of-government approach to reform, including DADHC, Housing NSW, NSW Health, Treasury, Office of Fair Trading, and Departments of Local Government, Planning, and Premier and Cabinet. The review of the YACS Act will now come under the ambit of the IDC.

As at October 2008, two IDC meetings have taken place, with discussions focusing on scoping:

- the roles and responsibilities of agencies in relation to boarding houses;
- issues faced by agencies relating to boarding houses; and
- the development of a policy framework to progress the reforms.

The IDC is establishing a working party to formulate a work plan to progress reforms, but at this stage no timeframe for the reform process has been set.

Our comments

While DADHC advises that most licensed boarding houses are compliant with the current licence condition regarding first aid, we note that the department's interpretation of this licence condition is that one staff member at each boarding house needs to be qualified in first aid — not one staff member on each shift. Given this reading, it is concerning that 12 per cent of licensed boarding houses do not have any staff members qualified in first aid. In our view, all licensed boarding houses should be compliant with this licence condition as a minimum requirement.

Further, given that our reviews continue to identify gaps in the provision of first aid to residents of licensed boarding houses, we consider that at least one staff member on each shift should have current first aid qualifications.

Leaving aside DADHC's interpretation of the current licence condition, the situation highlights the need for an enforceable condition that provides for the provision of first aid in licensed boarding houses on a 24-hour basis.

In our view, the review of the YACS Act, which has been underway for six years, needs to be completed as a priority, and requirements regarding the provision of first aid in licensed boarding houses should be clarified in any proposed amendments to the legislation.

Given the impact of this issue on current licensed boarding house residents, and its broader significance for the provision of care and support to vulnerable people in NSW, we will continue to monitor DADHC's work in relation to the review of the YACS Act.

NSW Health

Recommendation 6

NSW Health should 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,

NSW Health response

NSW Health told us that it re-issued the revised policy directive on *People with Disabilities: Responding to their needs during hospitalisation* in February 2008 following evaluation of the policy and extensive consultations within NSW Health. Amendments to the policy include:

- greater emphasis on local protocols/agreement between hospitals and disability service providers and the engagement of consumers and advocates,
- communication with people with cognitive impairments,
- clarification of patient consent and information about enduring guardianship,
- explicit links to NSW Health's Disability Action Plan requirements for monitoring and reviewing the policy directive.

Our comments

NSW Health has undertaken considerable work to improve the guidance available to health services on supporting people with disabilities in hospital. We will monitor implementation of the policy in relation to people with disabilities in care through our review work.

- b) plans for the implementation and performance monitoring of the *Discharge Planning: Responsive Standards* policy at the Area level,

NSW Health response

NSW Health advised that it monitors the efficiency of discharge planning processes through quarterly reviews of the Relative Stay Index, and consideration of data on unplanned admission rates. Over the last couple of years, there has been a downward trend of the Relative Stay Index and no rise in the readmission rates in the NSW Health system.

NSW Health updated the discharge planning policy in November 2007 to strengthen the discharge checklist, with the explicit inclusion of a requirement to follow up all diagnostic and laboratory tests.

In addition, NSW Health told us that implementation of the *Discharge Planning Responsive Standards* forms a key part of the broader Patient Flow and Access Program being undertaken.

Our comments

The importance of planned and coordinated hospital discharge planning has featured in our last four reports. We note the work NSW Health has done to provide clear guidance to health services on this issue, and will monitor implementation of the policy in relation to people with disabilities in care through our review work.

c) actions arising from the evaluation of the implementation of the *Advance Care Planning and Guidelines for end-of-life decision-making* policy directives,

NSW Health response

NSW Health told us that it has commenced a project to roll out the *Advance Care Planning* (ACP) policy in the Area Health Services. To support the project, Area Health Services have been funded for 0.6 project officer for 12 months, and training has been provided.

In addition, NSW Health's Health Service Performance Improvement Branch (HSPiB) is supporting the Area Health Services ACP project teams throughout the project, through means such as fortnightly teleconferences with project teams and an online discussion group.

NSW Health advised that during July — October 2008, Area Health Services will survey residential aged care facilities to gain an understanding of the level of ACP knowledge and activity. HSPiB will finalise the training package and conduct an ACP Train the Trainer workshop in late August.

In addition, the ACP model of care document has been updated and is hosted on the Australian Research Centre for Hospital Innovation (ARCHI) website.

Our comments

There has been progress in this area. We will continue to monitor the implementation of the *Guidelines for end-of-life decision-making* and *Advance Care Planning* policy directives through our review work.

d) completion and implementation of the *Discharge Planning Policy for Adult In-patient Mental Health Services*,

NSW Health response

NSW Health told us that it released the *Discharge Planning for Adult Mental Health Inpatient Services* policy to Area Health Services and other relevant agencies in early January 2008. The department consulted with DADHC during the policy's development, and the final policy identifies special care considerations in the discharge planning process for people with an intellectual disability.

NSW Health advised that implementation of the policy directive has been identified as a policy priority for Mental Health in the Area Chief Executives 2008–09 Agreements.

Implementation by Area Health Services will include review and modification of existing local protocols, staff education, performance management, and monitoring of the discharge planning process and outcomes for consumers.

Area Mental Health Service's implementation of the policy will be monitored through:

- local and mandatory state wide performance indicators
- structured reviews of serious clinical events (Root Cause Analyses)
- other formal review and improvement processes.

NSW Health also told us that it is developing a state wide *Discharge and Transition Policy for Child and Adolescent Mental Health Services* to complement the adult policy directive. The policy will provide guidelines for discharge and care transition planning for services providing treatment for children and adolescents with mental health problems. It will be applicable across a range of settings including inpatient, community, custody and out-of-home care.

Our comments

NSW Health has undertaken key work to improve discharge planning for people who are admitted to mental health services. We will monitor implementation of the policy in relation to people with disabilities in care through our review work.

- 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.

NSW Health response

NSW Health advised that NSW ACATs undertake assessments of people with disabilities who are ageing in accordance with the national Aged Care Assessment Program (ACAP) guidelines. While there are no age restrictions on eligibility for aged care assessment, an ACAT assessment is undertaken for a younger person only where all other appropriate services have been explored and no other options are available. Where specialist involvement is required to support the assessment, such as mental health, the department supports the process of joint assessments.

The department told us that, as part of the Council of Australian Governments reform initiatives, it conducted a structural review in 2007 of the ACAP in NSW. This review included looking at the appropriateness of ACATs conducting licensed boarding house screening assessments where they do not fall within Aged Care Assessment Program guidelines.

The review identified that clients with a primary disability assessment need are not core ACAT business, and the use of ACATs for these clients developed historically with no evidence of either policy or joint agency (DADHC and Health) agreement and guidelines.

According to NSW Health, the report recommends that it would be appropriate to discontinue the practice and only conduct ACAT assessments where these clients meet current ACAP guidelines and priorities.

Our comments

In relation to people with disabilities with needs related to ageing, NSW Health's advice suggests that they will continue to be able to access ACAT services. Assessment of the needs of people with disabilities without ageing issues, such as use of the screening tool for entry to licensed boarding houses, is likely to be addressed through the current review

of the screening tool. We will monitor the provision of aged care assessment services to people with disabilities in care through our review work.

Home enteral nutrition

Recommendation 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.

NSW Health told us that the NSW Greater Metropolitan Clinical Taskforce issued *Guidelines for Home Enteral Nutrition Services* in April 2007, which provides clinical guidance on the management of both adult and paediatric patients requiring Home Enteral Nutrition (HEN) services. The guidelines include advice on the organisation of HEN services, initiation, implementation, monitoring, transition and termination of HEN across NSW.

NSW Health told us that there is no further work in relation to developing guidelines and procedures for HEN therapy scheduled at this point.

Our comments

While the Greater Metropolitan Clinical Taskforce guidelines are on the NSW Health website, it is not clear what requirement health services have to implement the guidelines or develop local policies and procedures regarding HEN.

Through discussions with NSW Health and DADHC, we are aware that meetings have commenced involving both agencies and the Taskforce regarding the care of people who require HEN in group homes.

We consider that this is a positive development towards addressing some of the issues we raised in last year's report. We will continue to monitor the progress of this work.

DADHC and NSW Health

Recommendation 8

DADHC and NSW Health should 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,

DADHC and NSW Health response

DADHC has engaged a consultant to conduct a review of the screening tool for entry to licensed boarding houses. A key goal of the review is to identify characteristics of agencies suitable to undertake screening of potential licensed boarding house residents. The future role of ACATs in conducting licensed boarding house resident screenings will be examined when the review findings are available.

Our comments

This issue will be addressed at the conclusion of the review of the screening tool for entry to licensed boarding houses, currently underway (see recommendation 1(g)). We will pursue this issue through our monitoring of recommendation 1(g).

- b) finalisation of the evaluation undertaken by NSW Health of DADHC's *Palliative Care* policy,

DADHC and NSW Health response

The evaluation of DADHC's *Palliative Care* policy has commenced. The Statewide Centre for the Improvement of Palliative Care (SCIP) is managing the project, and Mercury Consulting has been contracted to conduct the evaluation.

The evaluation will consider the extent to which the policy has improved the coordination, planning and delivery of palliative care services for people living in DADHC operated and funded accommodation support services. It is due to be completed in December 2008.

Our comments

There has been considerable progress in relation to evaluating the policy. As the evaluation is still underway, we will continue to monitor agency action in this area.

- 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,
 - the development of a procurement framework for therapy services delivered by non-government services.

DADHC and NSW Health response

DADHC is leading the development of a Memorandum of Understanding (MoU) between DADHC, NSW Health, the Department of Education and Training, and the Department of Community Services. The purpose of the MoU is to clarify interagency roles and responsibilities in the delivery of therapy services to people with disabilities in NSW.

The development of a procurement framework for therapy services delivered by non-government services will be progressed as part of this MoU.

DADHC has established the *NSW Steering Committee for the Provision of Therapy Services in the Disability Sector* (Therapy Taskforce). The taskforce includes representatives from NSW Health, the Department of Education and Training, non-government organisations, professional associations and peak bodies.

Current or planned work includes:

- the strengthening of relationships with the university sector to increase the awareness of new graduates of the disability sector as a potential employer,

- mapping the location of therapy services to assist in the allocation of additional therapy places funded under *Stronger Together*,
- a review of DADHC operated therapy services to improve the career structure and retention of therapy staff. A report on the review will be provided to the relevant Minister by June 2008.

Our comments

Work in relation to this issue is continuing. We note that this work is a priority for action under *Better Together* — an interagency policy and service delivery framework for disability services in NSW 2007–2011. We will monitor the progress of the work to improve the coordination and delivery of therapy services through public reporting against *Better Together*.

- 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,

DADHC and NSW Health response

The Intellectual Disability Mental Health Working Party — a reference group of senior personnel from NSW Health and DADHC — was formed in December 2007 to progress this work in 2008. The Working Party has been established for an initial period of 12 months until December 2008.

The framework includes the integration of key initiatives, including the establishment of a University Chair and an Advanced Psychiatric Fellowship program in Disability Mental Health, and the updating of the interagency roles and responsibilities in relation to supporting people with a mental illness and an intellectual disability.

NSW Health is also supporting a number of short-term projects that aim to address the needs of children and young people with mental health problems and intellectual disability, including:

- developing a curriculum for professional learning and development,
- identifying pathways and transition care for older adolescents,
- interagency care planning,
- developing intervention programs,
- providing recommendations on service access strategies and service models for children and adolescents.

Our comments

There has been considerable progress in this area. The work of both agencies has been positive, and may address some long-standing issues, including the need for improved interagency cooperation in relation to people with an intellectual disability and mental illness. As the work is in its early stages, we will continue to monitor progress.

- 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.

DADHC and NSW Health response

NSW Health is leading the development of a service framework to improve the health care of people with intellectual disabilities with DADHC and the NSW Council for Intellectual Disability.

The (then) Minister for Health has endorsed in principle the proposed service framework, and has approved NSW Health to develop a more detailed business case to implement it. This work includes scoping specialist Health Resource Teams in each Area Health Service and establishing a statewide centre of excellence in the long term.

NSW Health expects to complete the business case in 2008, but no funds have been identified to date for the implementation of the framework.

In the interim, and within the broader objectives of the proposed service framework, the department is exploring funding opportunities for CDDS to support the operation of clinical services.

Our comments

Work in this area is continuing. Given the significance of this work and its potential to address some of the concerns we have identified from our reviews of the deaths of people with disabilities in care, we will continue to monitor NSW Health's activities in this area.

Appendix 1: Deaths of people with disabilities in care in 2007: data



1. Demographic information

Age

The ages of people with disabilities who died in care in NSW in 2007 ranged from four to 94 years.

- The average age at death for group home residents was 47 years. Just below two-thirds of people living in group homes in NSW are younger than 44 years of age.⁶⁰
- The average age at death for people who had lived in residential centres was 62 years. Just below two-thirds of the people living in residential centres in NSW are 44 years of age and older.⁶¹
- The average age at death for licensed boarding house residents was 62 years.

Gender

In 2007, the deaths of men outnumbered the deaths of women in both disability services and licensed boarding houses. This is consistent with previous years, and reflects the same trend as in the wider community.

- Of the 83 people who lived in disability services, 48 were male (58%).
- Ten of the 15 licensed boarding house residents were male (67%).

For disability services residents, the average age at death was lower for females (55 years) than for males (59 years), which differs from the general community, where women have greater life expectancy than men. In NSW, men can expect to live 78.9 years and women can expect to live 83.7 years.⁶²

In relation to licensed boarding house residents, the average age of the men who died was 57 years. The age of the five women who died ranged from 47 to 85 years.

Table 7: Age at time of death — disability services residents

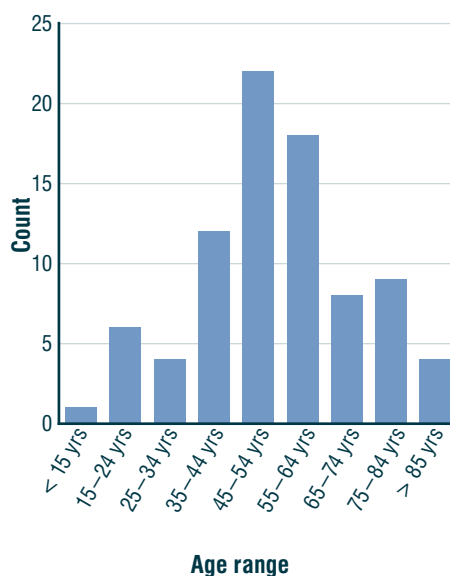
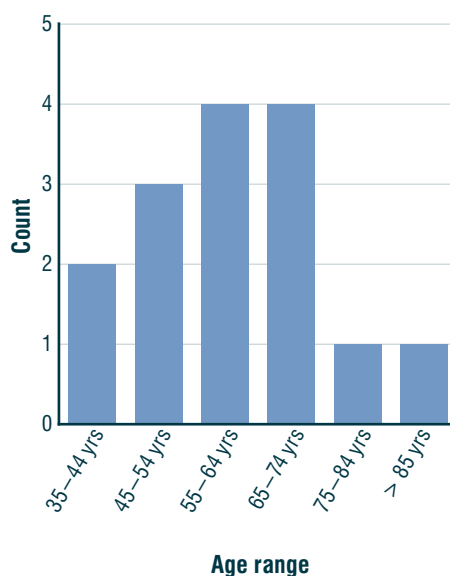


Table 8: Age at time of death — licensed boarding house residents



60 DADHC Client Information System and the Minimum Data Set 2005-06.

61 Ibid.

62 Report of the NSW Chief Health Officer, December 2006.

Cultural background

Two people who had lived in disability services were identified as being of Aboriginal or Torres Strait Islander background. Three disability services residents were identified as being from a culturally and linguistically diverse (CALD) background.

From the available records, none of the licensed boarding house residents who died were from Aboriginal, Torres Strait Islander or CALD background.

2. Service provision

Time in residential care

Disability services residents had spent from one to 81 years in care. The average length of time that they had lived in care was 30 years. On average, disability services residents had lived at their most recent location for 10 years.

On average, residents in DADHC operated services had lived at their most recent location (28 years) for longer than residents of funded services (nine years). People who had lived in residential centres had lived at their most recent location (27 years) for much longer than group home residents (seven years).

For licensed boarding house residents, the length of time they had spent in care and at their most recent location was known for 13 people. On average, boarding house residents had lived in care for 10 years, and at their most recent location for eight years.

Table 9: Total lifetime in care by service provider

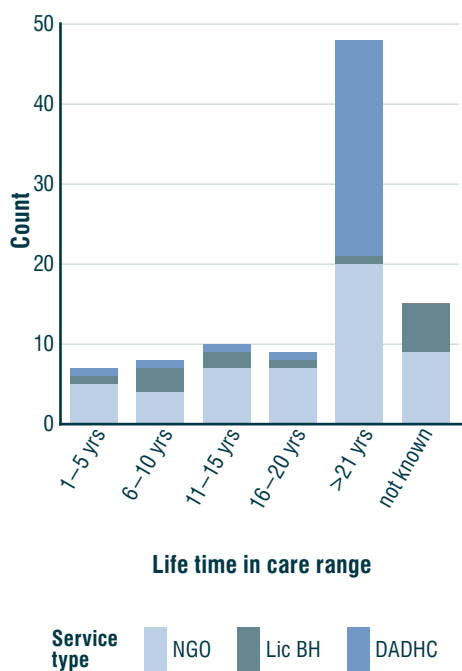
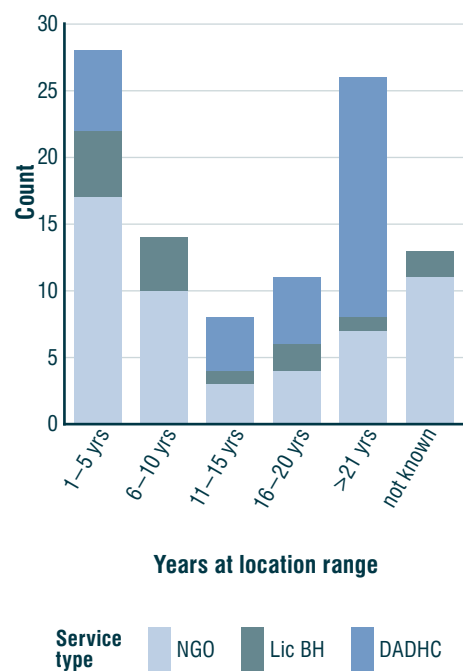


Table 10: Number of years at most recent location by accommodation type



3. Disability, health and support needs

Disability

Of the people who lived in disability services, the majority (59 people, 71%) had two or more disabilities. The majority of boarding house residents had one disability (10).

Consistent with previous years, the most commonly reported disability for disability services residents was intellectual disability (71 people, 86%). Residents of DADHC operated services were more often reported to have had a severe or profound level of cognitive impairment (23 people, 74%) than the people who lived in the care of funded services (10 people, 19%).

There were 12 people (14%) in disability services who were recorded as not having had an intellectual disability. All 12 people lived in funded services.

Just under half of the people who lived in the care of disability services had a physical disability (36 people, 43%), a third had a sensory impairment, and a quarter had a psychiatric disability. The majority had more than one of these impairments.

Among licensed boarding house residents, psychiatric disability was the most commonly reported disability (14 people, 93%). 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: rising from 50% in that year to 93% in 2007.

Seven people who had lived in licensed boarding houses had some form of cognitive impairment — four people had an acquired brain injury, and three people had an intellectual disability.

Health issues

The most common health conditions reported for the people who died in 2007 are consistent with those reported last year.

Dysphagia (swallowing problems) was the most common health condition for disability services residents, and high blood pressure was the most prevalent health condition for licensed boarding house residents.

Table 11: Number of disabilities by accommodation type

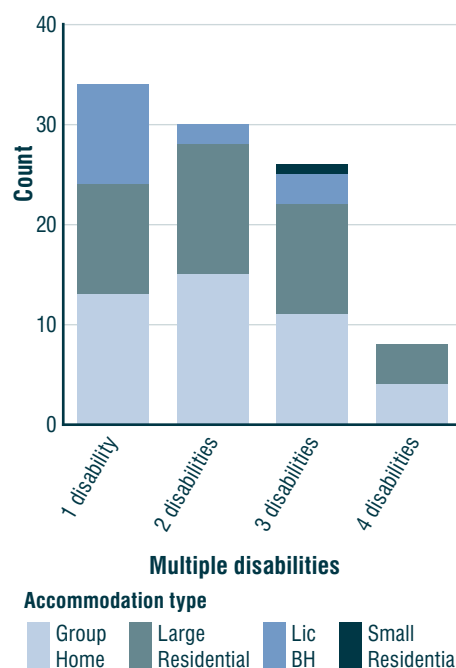


Table 12: Health conditions most commonly reported for disability services residents

Condition	Percentage
Dysphagia	57
Double incontinence ⁶³	55
Constipation	49
Epilepsy	49
GORD	34
Recurrent respiratory illness	33
Hypertension	23
Cancer	23
Osteoporosis	19
Heart problems	18
Asthma	15
Diabetes	15
Skin problems	13

Table 13: Health conditions most commonly reported for licensed boarding house residents

Condition	Percentage
High blood pressure	40
Constipation	33
Asthma	27
Diabetes	27
Arthritis	20
Epilepsy	13
Recurrent respiratory illness	13

Mealtime management

Of the 83 people who lived in disability services, 47 had swallowing difficulties. Six people relied exclusively on a PEG tube for food and fluids.

Over half (57%) of the people who had lived in the care of disability services required assistance with meals. Two of the boarding house residents required assistance.

⁶³ While 54 people who lived in disability services had some form of incontinence, 46 people were doubly incontinent.

Weight

It was possible to calculate the Body Mass Index (BMI) for 81 of the 83 disability service residents.⁶⁴ Of the 81 people, 36 (44%) were within a healthy weight range. The weight of 27 disability services residents was above the healthy weight range, while 18 people were below the healthy weight range.

BMI information was available for 13 of the 15 boarding house residents. Half of the residents were above the healthy weight range (eight people), including three people who were severely obese. Five boarding house residents were in the healthy weight range and a further two people were underweight.

Mobility

The majority of the people who had lived in disability services (57, 69%) had some form of mobility limitation, including 41 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.⁶⁵

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

Table 14: Weight range by accommodation type

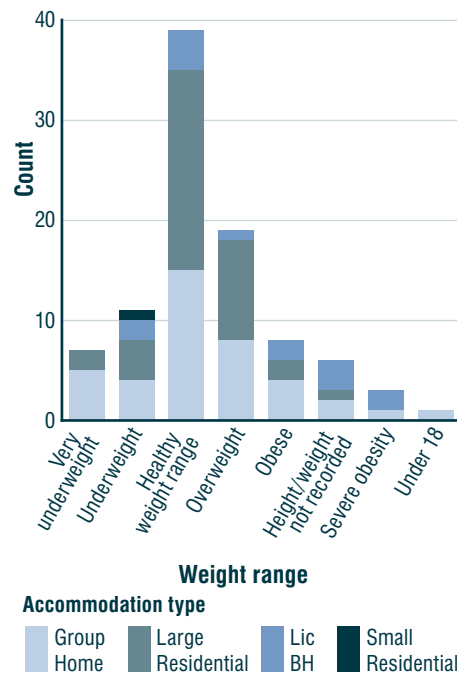
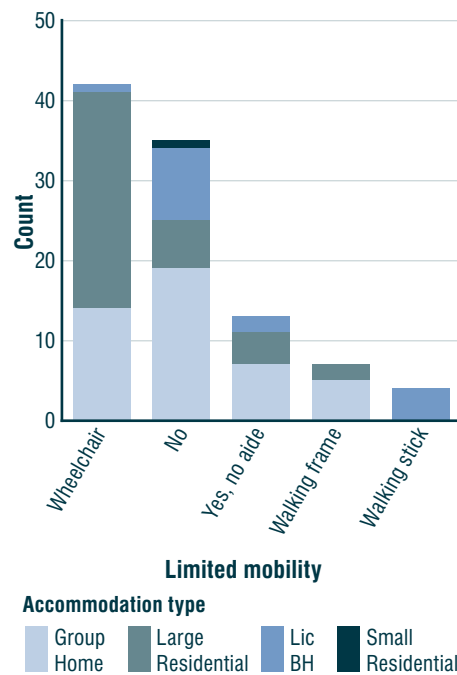


Table 15: Mobility by accommodation type



⁶⁴ For the two people for whom BMI was unable to be calculated, one did not have their height recorded in the service records, and the other was a child aged four years.

⁶⁵ DADHC Client Information System and the Minimum Data Set 2005–06.

Communication

Almost half (41 people, 49%) of disability services residents required some form of communication support, including nine people who communicated via pictures, and three people who used sign language.

One boarding house resident was 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.

Consent provider

Almost all of the people who had lived in disability services (73 people, 88%) were reported as having a 'person responsible' for providing consent to medical and dental treatment. Family members were the main people involved in consent decisions for disability services residents. Guardianship orders were in place for 14 people.

Ten people who lived in the care of funded disability services were recorded as having had the capacity to consent to treatment themselves.

Of the 15 licensed boarding house residents, 10 people provided their own consent to medical and dental treatment. One person had a family member responsible for consent decisions, one person was under a guardianship order, and two people had a person other than family provide consent on their behalf.

Table 16: Communication support by accommodation

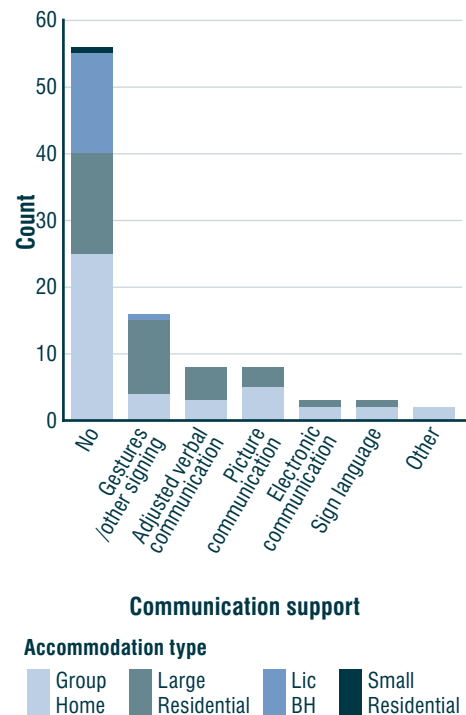
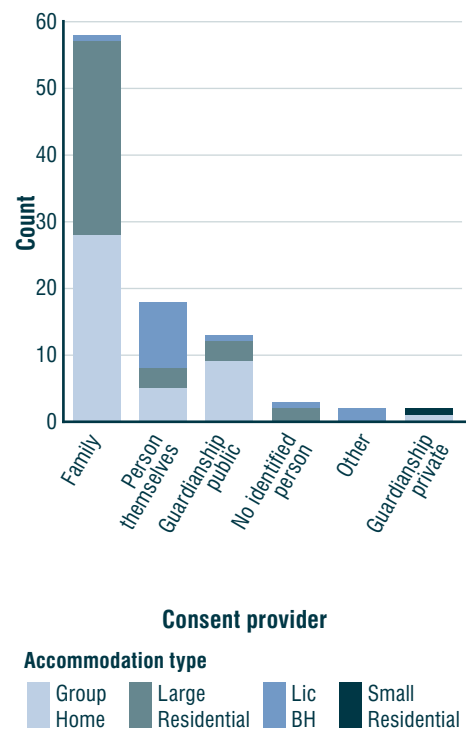


Table 17: Consent provider by accommodation type



Smoking

The large majority of disability services residents (76 people, 92%) did not smoke. Seven people were current smokers, ranging from approximately 10 cigarettes per day (one person) to more than 20 cigarettes per day (two people). Of the seven people who smoked, six resided in funded disability services.

Eleven boarding house residents (73%) were current smokers, ranging from occasional cigarettes (one person) to more than 20 cigarettes per day (seven people). Two people did not smoke and one person was an ex-smoker.

Immunisation

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

Three-quarters of disability services residents (62 people), and just under half of licensed boarding house residents (seven people) were recorded as having been vaccinated against influenza in the 12 months before their death.

In addition, 36 (43%) disability service residents and almost half (seven) of the licensed boarding house residents were vaccinated against pneumococcal disease.

Table 18: Season of death by accommodation type

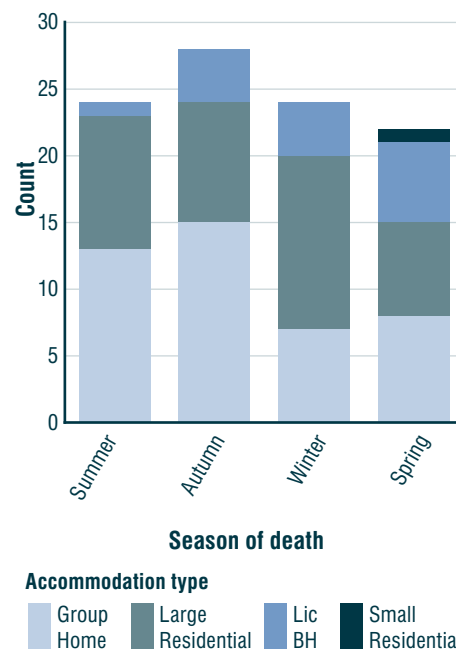
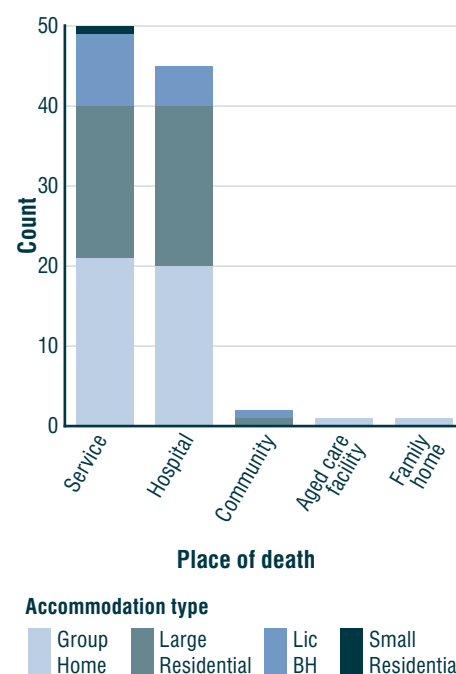


Table 19: Place of death by accommodation type



4. When and where people died

Season of death

Most of the people who resided in disability services died in summer and autumn (23 and 24 people respectively). For the past three years, autumn has been the most common season in which disability services residents have died.

Spring was the most common season in which licensed boarding house residents died (six people). In four of the past five years,⁶⁶ spring has been the most common season in which licensed boarding house residents have died.

Place of death

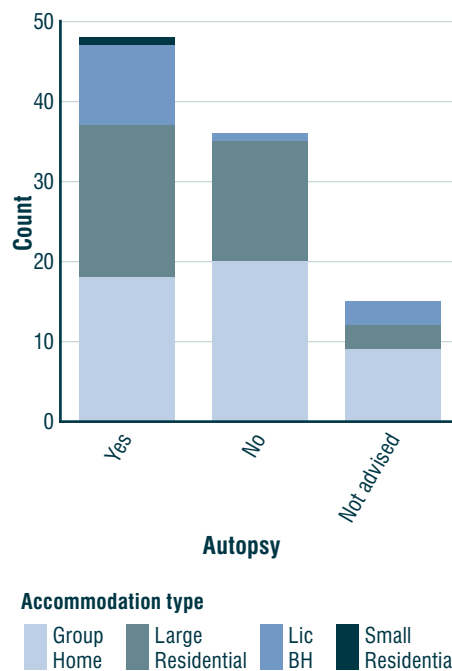
Close to half of the disability services residents (39, 47%) died in hospital. Most of the licensed boarding house residents died at home (nine people), five people died in hospital, and one person died in the community.

Autopsy

Of the 82 people for whom we have received coronial advice, autopsies were conducted for 47 people (57%).

Objections to autopsies were raised in relation to 13 people. An autopsy was not conducted in these cases.

Table 20: Autopsy by accommodation type



⁶⁶ In 2006, most of the 16 licensed boarding house residents died in winter.

Appendix 2: Reviewable Disability Deaths Advisory Committee: Members



Advisory Committee: Members

Mr Bruce Barbour	Ombudsman (chair)
Mr Steve Kinmond	Deputy Ombudsman and Community and Disability Services Commissioner
Ms Margaret Bail	Human services consultant
Professor Helen Beange	Public Health Physician, Tutor, 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



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Telephone Interpreter Service (TIS): 131 450
We can arrange an interpreter through TIS or you
can contact TIS yourself before speaking to us.
