NSW Ombudsman

Report of Reviewable Deaths in 2005

Volume 1: Deaths of people with disabilities in care

November 2006

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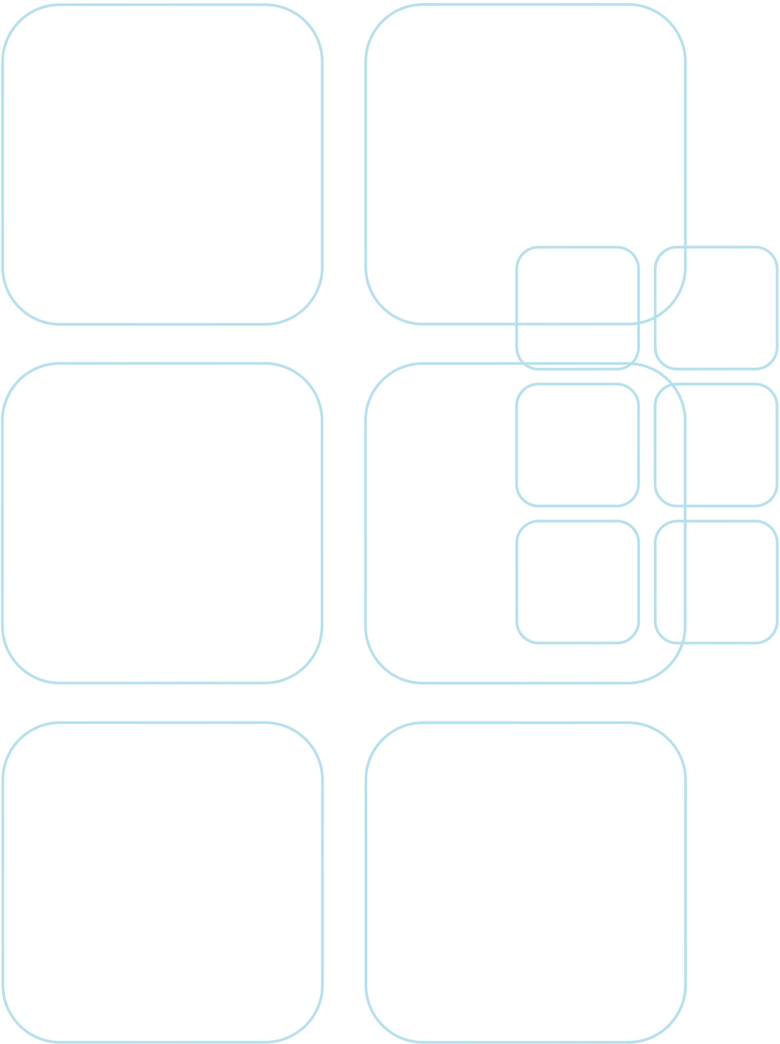

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November 2006

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

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

Dear Madam President and Mr Speaker

I am pleased to present the NSW Parliament with volume one of our third report on reviewable deaths. This volume concerns the deaths of people with disabilities in care.

The report contains an account of our work and activities and is made pursuant to s43 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993*. The report includes data collected, and information relating to, reviewable deaths that occurred in the period ending December 2005; our recommendations; and information with respect to the implementation or otherwise of previous recommendations. The report includes material on developments and issues current at the time of writing.

I recommend that this report be made public forthwith.

Yours faithfully

Bruce Barbour
Ombudsman

Ombudsman's message

Bruce Barbour
NSW Ombudsman

This is our third reviewable deaths annual report. It differs from previous years in that we have decided to release the report in two volumes: the first on the deaths of people with disabilities in care and the second on the deaths of certain children. Separation of the report into two volumes recognises the unique yet diverse issues, challenges and priorities of the disability and child protection sectors, and reflects the specialised work undertaken by my officers in each area.

This volume concerns the deaths in 2005 of 67 people with disabilities in care, encompassing residents of government and non-government disability services, and licensed boarding houses.

This year we have seen the introduction of critical whole-of-government and interagency planning and work in relation to people with disabilities in NSW. Of particular note are *Stronger Together*, the NSW government's 10-year plan for the direction of disability services; the establishment of an interagency standing committee on disability; and the progression of DADHC and NSW Health's joint work towards developing a service framework for the health care of people with an intellectual disability.

The interagency approach is a positive one, with the potential to benefit the lives of many people with disabilities in care. Our work this year has indicated that there is significant work to be done, and has emphasised the importance of progressing these recent whole-of-government initiatives in order to effect change.

In tandem with our review work, this year we consulted broadly with key parties in the disability sector and obtained their views on what they consider to be the key issues currently impacting on the interaction of people with disabilities in care with the NSW health system. We heard of fundamental obstacles in the way of better care, including queues, limited resources, misunderstanding or lack of knowledge of people with disabilities, and disagreements between government agencies about responsibility for the provision of service.

These matters — and others that we identify in this report — require the close and consistent attention of the relevant agencies and services.

Many of the concerns we have highlighted in this report are not new. Indeed, many of the issues are longstanding and have been the subject of previous recommendations by us and initial work by relevant agencies. We recognise that such longstanding issues will not be addressed or removed in the short term. Our challenge and commitment is to ensure concentrated and sustained effort by agencies to achieve progress and effect change and improvement in the provision of services to people with disabilities in care. To achieve this, we will closely monitor the progress of agencies towards meeting our recommendations and implementing the stated interagency and whole-of-government initiatives.

Bruce Barbour
Ombudsman

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Executive summary

People with disabilities who died in care in 2005

In 2005, the deaths of 67 people with disabilities in care were reviewable.

26 people lived in services provided by the Department of Ageing, Disability and Home Care and 28 people were with non-government services funded by DADHC. Another 13 people were residents of licensed boarding houses.

Generally, there were some differences between the 54 people who died in the care of disability services, and those who had been living in licensed boarding houses.

Disability services residents tended to have an intellectual disability in addition to two or three other disabilities. They also tended to have co-existing chronic health conditions in the period leading up to their deaths, often required support for daily activities, and needed someone else to make decisions on their behalf about matters such as medical treatment. The average age at death was 49 and the most common cause of death was respiratory illness.

Typically, the licensed boarding house residents had been diagnosed with a mental illness, mainly schizophrenia, but had not seen a psychiatrist in the 12 months before their deaths. They mainly provided their own consent to medical treatment. Their residential history was generally unknown, and they had occupied their last residence for five years or less. The average age at death was 63. The most common causes of death for licensed boarding house residents were cardiovascular disease, respiratory illness or external causes.

Key issues and developments

Our reviews this year continued to highlight concerns identified in our two previous reports. At the same time, there were some significant changes and signs of progress in the disability sector. These included the NSW Government's 10-year plan for disability services, a range of policy developments, and interagency initiatives relating to people with disabilities in care.

We added to our review work this year by undertaking a consultation process that aimed to identify stakeholder's views on the key issues for people with disabilities in care and their service providers, in their dealings with the NSW health system. We did this by consulting widely across NSW with disability accommodation service providers and people who work with, or advocate for, people with disabilities in care.

Identifying and managing risk

Among the issues arising from our work that continued to be of concern was the identification and management of risks for people with disabilities. This has been raised in each of our reports on reviewable deaths. This year we noted matters where services did not effectively identify health risks. In other cases, the risks were identified but the service did not take adequate steps to address or minimise those risks.

Of particular note was the identification and management of swallowing and nutrition risks. When we looked at the people who were recorded as having swallowing difficulties, we found that most services had completed a nutrition and swallowing checklist to determine what risks those individuals faced. However, only half of the assessments accurately recorded all of the risks and indicated what needed to happen to minimise or address them.

Planning to meet individual needs

Our reviews continued to highlight gaps in planning to meet the needs of individuals. There were some cases where it was not clear how services were providing adequate information to staff about the health or other individual needs of people in their care. For example, in some cases we found no evidence of a health related plan or other document to record an individual's health needs or outline how staff should respond to those needs.

Sometimes a person's health needs changed or risks increased but plans were not reviewed or updated. We identified matters where health care plans for individuals with complex health needs were either not developed or were not reviewed for an extended period of time due to delays in obtaining the assistance of community nurse casework support.

Response to critical incidents

A number of our reviews continued to raise concerns about the first aid assistance provided by disability services and licensed boarding houses in response to critical incidents. In some cases, the records we reviewed indicated that first aid had not been provided, or had not been provided in a timely and effective way. These matters raised questions about the adequacy of emergency protocols in the services concerned, and the training of staff in first aid and emergency response.

Primary and secondary health care

For licensed boarding house residents, we identified particular concerns about their access to primary and secondary health care. DADHC funds NSW Health under a boarding house program to provide access to primary services — such as podiatry and dental care — and secondary services such as health education. However, information obtained through our consultation project and from reviewing the deaths of licensed boarding house residents indicated that there are variations among regions in terms of the types of services provided, the delivery of those services, and the extent of casework support.

Hospital admissions

Our review and consultation work identified concerns relating to hospital admissions and readmissions. More than half of the people whose deaths we reviewed in 2005 had at least one hospital admission in the 12 months before they died. In some cases, the individuals were readmitted to the same hospital either the same day they were discharged, or the day following discharge. Our reviews raised questions about discharge planning processes, noting variable quality in discharge summaries, and the possible premature discharge from hospital of some people who were readmitted shortly afterwards.

End-of-life decision-making

Our reviews continued to identify issues around end-of-life decisions, including decision-making in relation to not for cardiopulmonary resuscitation (no-CPR) orders. We noted matters where no-CPR decisions were documented without reasons for the decision, or were documented prior to discussion with the person or family members.

We identified areas of possible concern in relation to treatment limitation decisions for people with disabilities in care. We reviewed several matters that raised questions about whether perceptions about the 'quality of life' of the person may have had an impact on the decision to limit treatment.

We also raised particular concerns about end-of-life decision-making for people with disabilities in care who do not have any family or other significant parties in their lives to make decisions on their behalf. These individuals are highly vulnerable at a time when such significant decisions about their lives are being made. We consider that there may be a place for the involvement of service providers in discussions concerning end-of-life care, particularly for these individuals.

Record keeping

Record keeping was again a matter of concern this year. We found instances of inaccurate records in services, and failure to keep relevant and contemporary records about the health needs of individuals. There were examples of missing documents, gaps in progress notes, poor recording of incidents and incomplete records. In relation to record keeping in licensed boarding houses — a subject we focused on last year — we again identified problems. In many cases, the records we reviewed were insufficient for us to ascertain the health or support needs of the residents who died.

Good practice

Our reviews of people who died in 2005 also identified good practice by service providers. In our reviews of the deaths of people whose health conditions progressively deteriorated before death, we found that, on the whole, services continued to meet the health needs of those individuals as their conditions worsened, calling on relevant professionals and practitioners where required.

We also identified good practice by some services in meeting the challenge presented by individuals who had made informed decisions that were contrary to the recommendations of their health care practitioners. We found that, in the main, the services concerned clearly and comprehensively documented the discussions relating to the decision. As a result, it was evident what steps those services had taken to assess and manage the risks associated with their client's rejection of professional health care advice.

Consultations on the interaction of people with disabilities in care with the health system

In consultations we undertook this year with funded services, DADHC managers, licensed boarding house representatives, peak agencies and advocates, we identified a number of issues relating to the health system.

Access to health assessments

Many of the people we consulted raised issues about access to health risk screening, the capacity and willingness of GPs to undertake comprehensive health assessments in relation to people with disabilities, and the quality of health assessments. We were told that people with disabilities who had challenging behaviours, communication difficulties, or physical disabilities were more likely to miss out on health screening or comprehensive health assessments.

However, consultation participants told us that access of people with disabilities in care to health risk screening and to quality health assessments improved when service providers had established health care planner or coordinator positions, had developed a relationship with their local Division of General Practice, and when their clients were referred to a multidisciplinary health clinic.

Allied health services

Consultation participants reported problems with access to allied health services such as speech pathology, physiotherapy and dietetics. Barriers to access were attributed to extensive waiting lists for public therapy services, the prohibitive cost of private services, and reportedly contested views as to whether Community Health or DADHC were responsible for the provision of therapy services to people with disabilities in care.

Wide variations in access to allied health services were reported across (and within) regions, and were attributed to the differing availability of services as well as access decisions being reportedly based on existing relationships or contacts. In addition, inequities in access to allied health services were reported in relation to licensed boarding house residents, where access was said to occur only in regions that had a primary and secondary health care caseworker in place.

Dental services

People with disabilities who have multiple, complex or chronic health conditions are also prone to extra risk because of untreated dental conditions. Although DADHC policy recommends dental reviews every six months for clients, disability services reported that this has not been happening, because of waiting lists for public services and clients' limited financial resources.

Other concerns raised in the consultations included the additional complications faced by people with disabilities who require general anaesthetic for dental assessment or treatment, the health impacts of significant delays in receiving dentures, and the often limited access of licensed boarding house residents to dental services.

Hospitals

Most of the people we consulted raised concerns about the interaction between people with disabilities in care and hospitals. Many of the issues raised, such as end-of-life decision-making and discharge planning, were also identified in our review work. One of the main areas of concern related to the impact that an individual's disability can have on many aspects of their hospital experience, including their initial assessment, treatment decisions, the provision of appropriate support, the general quality of care, and the adequacy of their discharge plans. For example, most of the services involved in the consultations raised concerns about being asked by treating hospitals to provide staff to support their client for the duration of their hospital stay, regardless of the actual support needs of the individual or their presenting health issues.

Many participants reported concerns with the quality of discharge planning by hospitals, including discharge planning not occurring, premature discharge of people with disabilities, the exclusion of service staff from important discussions while the person is in hospital, and the provision of poor quality discharge summaries. In addition, participants raised concerns that discharge planning for people with disabilities in care may be affected by the misconception held by many hospital workers that the individuals live in nursing homes and that disability service staff are nurses.

Mental health services

Most of the people we consulted who had been in contact with mental health services identified that the key barrier to people with disabilities accessing those services concerns an issue relating to primary diagnosis and a lack of clarity about agency responsibility for providing mental health services to people with intellectual disabilities. Participants advised that, if intellectual disability is considered to be the person's primary diagnosis, then DADHC is viewed as having responsibility for providing services; but if mental illness is the primary diagnosis, and then NSW Health takes on the primary responsibility. Many services reported that clients have been unable to access any mental health services as a result of this division.

The licensed boarding house population typically has a high proportion of people who have been diagnosed with some form of mental illness. Our consultations indicated that, where Mental Health Liaison positions are in place, they provide significant benefit to both residents and staff.

Ageing

Consultation participants told us that the aged care system's focus on a chronological number excludes some people with disabilities. The fact that some people with disabilities age much earlier than the general population means that they are cut off from accessing services that set age as the criteria for eligibility, or for prioritisation, such as the Aged Care Assessment Team services.

There was also a common view that issues surrounding primary diagnosis, and a lack of clarity about state and federal responsibilities, were matters that affected access to aged care services. For example, a primary diagnosis of an intellectual disability was viewed as requiring DADHC to take responsibility, while an age-related primary diagnosis meant that the Commonwealth took responsibility.

Most of the people we consulted pointed to the increasing support needs of people with disabilities who are ageing, and raised concerns about how those needs would be met. Participants noted that there is currently a lack of policy direction in relation to 'ageing in place' and what it means for people with disabilities in care.

Challenges and recommendations

The issues that have emerged from our reviews and consultations demonstrate the need for more work to be done on improving the adequacy and quality of services for people with disabilities in care.

However, we acknowledge that new policies are being developed and rolled out. These positive initiatives will need to be tested and evaluated. Our challenge will be to monitor the impact of these initiatives on service delivery to ensure effective outcomes are achieved.

This year we have made a total of 28 recommendations that are directed to DADHC and NSW Health. Some of the recommendations relate to critical policies in areas such as end-of-life decision-making and the hospitalisation of people with disabilities. Other recommendations concern new areas that arose from our work in relation to deaths in 2005, including epilepsy management, primary and secondary health services for boarding house residents, mental health services for people with intellectual disability, and issues relating to people with disabilities in care who are ageing.

Recommendations

Identification and management of risks

The identification and management of risks for people with disabilities in care has been raised as a concern in each of our reports on reviewable deaths. This year we drew attention to matters where services did not effectively identify health risks for individuals in their care, and matters where risks had been identified but services had not taken adequate steps to address or minimise those risks.

DADHC is currently revising its *Managing Client Risks* policy to apply to DADHC operated and funded services.

1. **DADHC should report on progress towards releasing the revised *Managing Client Risks* policy to DADHC operated and funded accommodation services. In doing so, DADHC should advise how it intends to monitor and evaluate the implementation of the policy.**

The *Ensuring Good Nutrition* policy provides the bedrock for the identification and management of swallowing and nutrition risks. This year we continued to highlight the importance of monitoring health care planning, and particularly the implementation of the *Ensuring Good Nutrition* policy. We raised concerns about the quality of the nutrition and swallowing checklists conducted in relation to people with swallowing difficulties, including examples where services did not identify all risks, or did not take steps to address the swallowing or nutrition risks that had been identified.

2. **In the context of monitoring the implementation of the *Ensuring Good Nutrition* policy in DADHC operated and funded accommodation services, DADHC should provide advice regarding:**
    - **a) Progress towards conducting a formal evaluation of the policy following its implementation in funded services.**
    - **b) The Health Care Review Team's progress towards developing and releasing the audit tool for monitoring the implementation of the policy in DADHC operated services.**
    - **c) How DADHC monitoring staff ensure funded services' compliance with performance indicator 2.3.2, in relation to the implementation of the *Ensuring Good Nutrition* policy.**

Identification and management of risks *(continued)*

The screening tool for entry to licensed boarding houses is the key means for preventing the inappropriate placement of people with high support needs into boarding house accommodation. Our reviews of deaths in 2004 identified concerns with the application of the screening tool, including the accuracy of assessments, application following admittance to hospital, and identification of additional services to minimise risks.

Last year we recommended that DADHC undertake a review of the current application of the screening tool. During 2006, DADHC formed an expert review group to revise the tool, and advised that it would be forming a Screening Tool Steering Committee to oversee and direct the review, which it anticipates finalising by March 2007.

3. **In relation to the review of the screening tool for entry to licensed boarding houses, DADHC should:**
    a) **Provide advice on progress towards completing the review of the current application of the screening tool, including an audit of the quality and accuracy of the assessments.**
    b) **At the completion of the review, provide a copy of the final report, and provide advice regarding any action it intends to take in relation to the review findings and recommendations.**

Last year we highlighted the vulnerability of people with disabilities in care to adverse events as a result of medication, such as drug toxicity. We recommended that DADHC develop a system for ensuring regular reviews of medication in DADHC operated and funded services, with consideration of the use of Domiciliary Medication Management Reviews.

DADHC advised that the draft *Managing Client Health* policy provides for medication reviews as part of the annual health care review conducted by the treating medical officer, and monitoring of medication reviews is encompassed within the Quality and Safety Framework for DADHC operated services. The department advised that staff would be able to identify risk criteria during regular health reviews and alert the person's GP if they identify any issues of concern, for possible referral for a Domiciliary Medication Management Review. Further, DADHC is reviewing its *Medication* policy.

Our consideration of the draft *Managing Client Health* policy, the existing *Medication* policy, and the Comprehensive Health Assessment Plan (CHAP), has raised some questions about how, in practice, this system will safeguard people with disabilities in care from adverse events due to medication.

4. **In the context of DADHC's review of its *Medication* policy, it should consider whether adequate guidance is provided to:**
    a) **Ensure that staff are able to identify risk criteria during regular health reviews to alert the person's GP for possible referral for a Domiciliary Medication Management Review.**
    b) **Adequately prompt staff and GPs in relation to the need for medication reviews.**

Identification and management of risks *(continued)*

5. **DADHC and NSW Health should consider ways in which Domiciliary Medication Management Reviews may be promoted with disability accommodation services and General Practitioners in NSW for use with people with disabilities in care.**

The chest care checklist developed by DADHC's Hunter Region for identifying people at risk of respiratory illness or who require regular chest care has consistently featured in our recommendations over 2004 and 2005. This year DADHC advised that it had completed its review of the checklist, and had linked the use of the tool to the nutrition and swallowing checklist.

6. **DADHC should provide a copy of the final document(s) relating to the review of the chest care checklist, including any guidelines or procedures for use.**

Planning to meet individual needs

We consider that good practice concerning epilepsy management includes the development of a plan or other document that refers to the fact that the person has epilepsy, and provides some guidance to staff as to the frequency / nature of the person's seizures, and what staff need to do to appropriately support the individual. We found that of the 37 people with disabilities in care who died in 2005 and had epilepsy, 16 did not have an epilepsy management plan or similar guiding document. DADHC's current *Support of Clients with Epilepsy* policy does not currently apply to funded services or boarding houses.

7. **DADHC should report on progress towards finalising the revised *Support of Clients with Epilepsy* policy, including details of release to DADHC operated and funded accommodation services, and training for staff.**

The key document guiding health care coordination and management in DADHC operated services is the *Managing Client Health* policy. Since 2004 the policy has been in the process of being reviewed in preparation for its roll out to DADHC funded services. The final policy has not yet been released.

8. **In relation to DADHC's review of the *Managing Client Health* policy and its roll out to funded services, DADHC should:**
    a) **Provide a copy of the final document(s).**
    b) **Report on progress towards developing and releasing briefing and training materials to DADHC operated and funded services to support the release of the policy.**
    c) **Report on progress of the Centre for Developmental Disability Studies' work on establishing baseline data, and provide advice as to how the implementation of the policy in funded services will be monitored and evaluated.**

Planning to meet individual needs *(continued)*

In our two previous reports we recommended that DADHC review the clinical nurse specialist model of health care case management that operates in the Illawarra region, and advise of the department's view as to the potential for wider application in DADHC operated and funded services. The review was conducted in 2006 by a consultant engaged by DADHC to assist the Health Care Review Team, and a report has been drafted.

9. **In relation to the review of the clinical nurse specialist model of health care case management, DADHC should provide advice on:**
    a) **The findings and recommendations of the review.**
    b) **The department's view as to the potential for wider application of the clinical nurse specialist model in DADHC operated and funded accommodation services.**
    c) **If the department considers that the model does have potential for wider application, outline what action DADHC intends to take in this regard.**

Last year we reported that licensed boarding houses are not subject to policies and standards that govern disability services, and operators of licensed boarding houses largely operate without comprehensive guidance. We noted that this situation has clear implications for the provision of care to boarding house residents in relation to health needs. We recommended that DADHC provide relevant information to licensed boarding houses concerning good practice in health care, including provision of good practice information contained within policies such as *Ensuring Good Nutrition*, *Managing Client Health*, *Palliative Care*, *Managing Client Risks*, and *Decision-Making and Consent*.

In response, DADHC advised that it was reviewing and updating the *Licensing, Monitoring and Closures* policy manual, including updating the appendices to incorporate contemporary information in relation to good practice that DADHC officers may use to assist licensed boarding house operators. In addition, the department would facilitate access to relevant information by placing links to the suggested documents on the DADHC website on a site specific to boarding houses.

10. **In relation to the provision of health care information to licensed boarding houses, DADHC should:**
    a) **Provide a copy of the updated *Licensing, Monitoring and Closures* policy manual and appendices, when completed.**
    b) **Ensure that the information is promoted and available through alternative means for licensed boarding houses without internet access.**

Response to critical incidents

Last year we highlighted the need for people with disabilities in care to be supported by staff with first aid qualifications. We recommended that DADHC require that the services it operates, funds or licenses have at least one staff member on each shift with current first aid qualifications, and provide assistance to funded and licensed services to achieve that requirement.

Response to critical incidents *(continued)*

DADHC has discussed this recommendation with its Boarding House Advisory Group, and is considering the issue for its Home and Community Care funded services, but has yet to provide advice as to whether it will implement this recommendation.

Our reviews of deaths in 2005 have again raised concerns in relation to the first aid assistance provided by disability services and licensed boarding houses in response to critical incidents, including instances where it appeared that first aid was not appropriately sought or provided.

11. **DADHC should provide further advice in relation to the recommendation that it should:**
    a) **Require that the disability accommodation services it operates, funds or licenses have at least one staff member on each shift with current first aid qualifications.**
    b) **Provide assistance to funded and licensed disability accommodation services to achieve this requirement.**

Boarding House Reform Program

This report has drawn attention to the importance of the primary and secondary health services under the Boarding House Reform Program for improving the access of licensed boarding house residents to necessary health care. We have raised concerns regarding reported variation across NSW in the delivery of primary and secondary health services to licensed boarding house residents, and apparent gaps in the provision of these services in some areas, including access to dental and podiatry services, and the identification and coordination of significant health issues.

12. **In relation to the provision of Boarding House Reform Program services to licensed boarding house residents, DADHC should advise this office of:**
    a) **Progress towards developing new auspice and service model arrangements for primary and secondary health services, including review of the service type description.**
    b) **Details as to how and when primary and secondary health services will be incorporated into the Integrated Monitoring Framework.**
    c) **The findings of the review of the health needs of licensed boarding house residents in the inner-west area of Sydney.**
    d) **Progress towards filling the eight additional casework positions, and the allocated primary and secondary health casework positions across NSW.**

Contact with hospitals

Last year, we reported issues raised by funded services relating to the hospitalisation of people with disabilities in care, including the separation of responsibility between hospital staff and service staff.

We recommended that NSW Health evaluate the implementation of its *People with Disabilities: Responding to their needs during hospitalisation* policy directive, released in October 2005, and provide details as to how it intended to monitor the development and implementation of local policies and procedures in NSW Health services.

NSW Health advised that it would be engaging a consultant by August 2006 to evaluate the implementation of the policy directive, and that the evaluation would include the development of indicators to assist in the monitoring of implementation at the Area Health Service level.

Our consultation project this year has continued to highlight concerns relating to the interaction of people with disabilities in care with hospitals.

13. **NSW Health should provide advice as to progress towards evaluating the implementation of the *People with Disabilities: Responding to their needs during hospitalisation* policy directive across Area Health Services.**

For the past two years we have identified concerns relating to discharge planning for people with disabilities in care undertaken by hospitals. Last year we drew particular attention to discharge planning for licensed boarding house residents, including the lack of application of the screening tool for entry to licensed boarding houses prior to discharge. We recommended that NSW Health report on progress towards finalising its framework for effective discharge planning, and that NSW Health and DADHC discuss how the screening tool may be incorporated into the discharge planning framework.

NSW Health advised that it was rolling out its *Discharge Planning: Responsive Standards*, and that monitoring of the implementation of the standards would be done through the *Relative Stay Index*. NSW Health also advised that it had incorporated the screening tool into the standards, with prompts to re-screen all patients returning to a licensed boarding house following a hospital admission.

Concerns regarding discharge planning continued to be identified this year through our reviews and the consultation project.

14. **NSW Health should provide this office with advice as to how the *Relative Stay Index* will be used to monitor the implementation of the *Discharge Planning: Responsive Standards* in relation to people with disabilities, such as the use of the screening tool for entry to licensed boarding houses.**

Concerns regarding end-of-life decision-making for people with disabilities in care were highlighted last year, and continued to be a significant issue identified through our work this year.

Last year we recommended that NSW Health evaluate the implementation of its *Guidelines for end-of-life decision-making*, and provide advice as to how this would be undertaken.

Contact with hospitals *(continued)*

NSW Health advised that it was considering a range of options for evaluating the guidelines, and its Research and Ethics Branch was liaising with the Area Health Services regarding the progress of their policy committees in considering local implementation needs.

15. **NSW Health should provide advice on progress towards evaluating the implementation of the *Guidelines for end-of-life decision-making* across Area Health Services.**
16. **NSW Health should consider the role of disability services staff in end-of-life decision-making for the people with disabilities in their care.**

Palliative care

Last year we identified concerns regarding the provision and coordination of palliative care, including the involvement of the person with a disability in decision-making. This year we highlighted concerns about palliative care decisions for people without family or other parties involved in their lives.

In 2005, we recommended that DADHC report on progress towards finalising its *Palliative Care* policy, and that DADHC and NSW Health commence joint work on the coordination of palliative care for people with disabilities in care.

DADHC advised that it has released its *Palliative Care* policy, and has commenced discussions with NSW Health on evaluating the effectiveness of the policy in facilitating the coordination of palliative care for residents of DADHC operated and funded accommodation services. Further, the coordination of palliative care for people with disabilities would be included on the agenda of future meetings of the interagency Senior Officers Group.

NSW Health advised that the issue of coordinating palliative care services would be addressed through the implementation of its Role Delineation Framework, and that recurrent funds had been made available in Area Health Services for project officers to implement the Framework. In addition, a mapping exercise of palliative care services is underway which will enable NSW Health to monitor the implementation of the Framework.

17. **DADHC should provide advice as to the progress of its discussions with NSW Health on evaluating the effectiveness of the *Palliative Care* policy in facilitating the coordination of palliative care for residents of DADHC operated and funded accommodation services.**
18. **NSW Health should provide advice as to progress towards implementing the Role Delineation Framework across Area Health Services.**

Record keeping

Last year we raised concerns about the adequacy and accuracy of records kept for licensed boarding house residents, and the impact of poor record keeping on the ability of licensed boarding house staff to meet individual client needs. We recommended that DADHC undertake a review of record keeping practices in licensed boarding houses. DADHC has completed the review, and identified actions it will take to strengthen the compliance of licensed boarding houses to this Licence Condition, and encourage better practice.

Our reviews this year have continued to identify concerns about record keeping in licensed boarding houses, including lack of, or limited, records relating to the residents' medical, health care, and support needs.

19. DADHC should provide advice as to progress towards implementing the following actions identified through its review of record keeping practices in licensed boarding houses:

a) Review of the Monitoring Tool associated with Licence Condition 4.

b) Setting good practice benchmarks for Licence Condition 4.

c) Developing a resource to support the sector to improve compliance and practice in regard to Licence Condition 4.

We have also identified concerns regarding record keeping in disability services. In this report we noted that, at times, services kept inaccurate records and failed to maintain relevant and contemporary records in relation to client health needs. We identified significant gaps in progress notes, poor recording of incidents, incomplete records, and missing documents.

In 2003 we made a recommendation concerning the need for DADHC to develop strategies to ensure that staff in DADHC operated and funded services were provided with the support necessary to maintain complete and accurate records. DADHC advised that it had developed and would be implementing the Records Management Procedures for Group Homes for DADHC operated services, and would be reviewing the large residential and respite sectors as part of the preparation for the roll out of the file management system in early 2006. Further, DADHC advised that discussions had occurred in relation to funded services.

20. In relation to improving the reliability and accuracy of records in disability services, DADHC should provide advice regarding:

a) Progress towards implementing the Records Management Procedures for Group Homes in DADHC operated services.

b) Whether DADHC has, or intends to, roll out the Records Management Procedures to DADHC operated large residential centres and respite services.

c) Whether DADHC has, or intends to, roll out the Records Management Procedures to DADHC funded accommodation services.

Access to health services for people with disabilities in care

The consultation project highlighted a number of reported barriers affecting the access of people with disabilities in care to health services such as health screening, allied health, and dental services. These included barriers relating to the exclusion of people with disabilities due to prioritisation of limited resources, questions of primary diagnosis, and the cost of private health services.

21. **In relation to improving the access of people with disabilities to the health system, DADHC and NSW Health should:**
    a) **Advise of progress towards finalising and implementing the Health Care of People with an Intellectual Disability Service Framework.**
    b) **Advise of the outcomes of the Disability Service Mapping Project, and how this information has or will be used to improve the access of people with disabilities in care to the health system.**
    c) **Advise of specific plans for training health workers on health care for people with intellectual disabilities.**
    d) **Consider the potential for broader application of multidisciplinary health teams across NSW for people with intellectual disabilities, such as the developmental disability clinic model operated by the Centre for Developmental Disability Studies.**
22. **DADHC and NSW Health should provide advice on the progress of work by the Interagency Standing Committee on Disability in relation to access to health services for people with disabilities.**

Access to allied health services was identified as an issue last year, particularly in relation to speech pathology services. We recommended that DADHC negotiate with NSW Health to access alternative services, work with disability agencies to determine priorities for access, and track, monitor, and report on the average waiting periods for access to DADHC speech pathology services.

DADHC advised that it was reviewing the structure of its Community Support Teams, including the provision of therapy services, and the review would encompass an analysis of strategic issues such as service access and responsiveness, models of service delivery, service fragmentation and coordination, and workforce capacity. DADHC was also reviewing its *Prioritisation and Allocation* policy, which guides access to Community Support Team services, as part of this process.

23. **DADHC should provide advice on the outcomes of its review of the structure of Community Support Teams and review of the *Prioritisation and Allocation* policy. In doing so, DADHC should provide advice as to any action it intends to take to improve the department's capacity to respond to requests for services.**

Access to mental health services was identified as a particular concern through the consultation project, particularly for people with intellectual disabilities.

Access to health services for people with disabilities in care *(continued)*

24. **Through the DADHC and NSW Health Senior Officers Group, DADHC and NSW Health should:**
    a) **In the context of the issues raised in this report, consider the adequacy of access to mental health services for people with dual diagnoses of intellectual and psychiatric disabilities.**
    b) **Provide advice on the outcomes of these discussions.**
25. **In relation to mental health services for licensed boarding house residents, NSW Health should consider extending the provision of Mental Health Liaison positions across NSW.**

Participants in the consultation project commonly voiced concerns regarding access to accommodation and support for people with disabilities in care who are ageing, including a lack of policy guidance for disability services around ageing in place.

26. **DADHC should provide advice on progress towards developing and implementing a policy for the care and support of people with an intellectual disability who are ageing.**
27. **DADHC should provide advice on the outcome of its discussions with the Commonwealth government regarding accommodation for people with disabilities in relation to ageing.**
28. **Through the DADHC and NSW Health Senior Officers Group, DADHC and NSW Health should consider the issues raised in this report regarding people with disabilities who are ageing, and discuss possible options to ensure adequate access to appropriate aged care assessment services.**

1. Introduction

1.1 Reviewable deaths

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

- a child 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.

Our focus in reviewing deaths is to identify procedural, practice or systems issues that may contribute directly or indirectly to deaths that are preventable, 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 ultimately may help to prevent reviewable deaths.

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

The Act 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 report is the third annual report we have prepared. It differs from previous years in that we have decided to release the report in two volumes: the first on the deaths of people with disabilities in care and the second on the deaths of children. The separation of the report into two volumes will allow for more focused consideration of the unique issues associated with the disability and child protection sectors. This volume of the report is about the deaths in 2005 of people with disabilities in care.

In NSW in 2005, the deaths of 184 individuals were reviewable deaths. Of these deaths, 67 were of people with disabilities in care.

1.2 The scope of our work

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

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

The brief to consider prevention or reduction of deaths of people with disabilities in care 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.

Our reviews therefore aim to identify any shortcomings in agency systems or practice that may have directly or indirectly contributed to the death of a person who has lived in care, or that may expose others to risks in the future. The work involves examination of relevant records and information relating to the person who died. These include 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*, we can make preliminary inquiries for the purpose of deciding whether to investigate the conduct of an 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 about issues identified through 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 have currency and warrant specific action. Particularly in relation to preliminary inquiries and investigations, we consider the seriousness of the concerns raised and whether they are of a systemic nature. We also consider any action that an agency may be taking to address these concerns. We may also delay any direct action where the matter is subject to inquest by the NSW Coroner, or subject to internal review by the relevant agency.

1.3 Reviewing deaths

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

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

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

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

The Act also requires relevant government agencies and service providers to give us full and unrestricted access to records that we need to perform our reviewable deaths function. This means that we are able to review all relevant documented information about the characteristics and circumstances of 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.

Membership of the disability deaths advisory committee is detailed in Appendix 1. The committee participated in the preparation of this report through providing advice and feedback.

1.4 Overview of this report

This report concerns the deaths in 2005 of 67 people with disabilities who lived in care, our work in relation to these deaths, and research and other work consistent with our functions.

Section 2 of the report provides information about the characteristics and circumstances of the people with disabilities in care who died in 2005, gleaned from our register of reviewable deaths. Where relevant, we have compared the data on deaths in 2005 with the data from 2003 and 2004. In general, the demographic data on the deaths of people with disabilities in care has been consistent over the three-year period. Where we have identified differences in the data, we should be cautious in considering these changes as indicative trends. The numbers of deaths we review are relatively small, particularly when we separate licensed boarding house and disability services residents.

In section 3 we discuss the service and systemic issues arising from our reviews of the deaths of the people who died in 2005. These include the identification and management of health risks, as well as the planning and management undertaken to meet the health, behaviour, and social needs of the people who died. Some of the issues we identified in our reviews, such as end-of-life decision-making, are explored in greater depth in this section. We also consider some of the trends and themes that emerged from the 67 deaths, including the deaths of people from progressively deteriorating health conditions, and challenges faced in relation to duty of care for people who have the capacity to make informed decisions about their own health care.

This year, an important component of our report explores the findings from our consultations that examined the interaction of people with disabilities in care with the NSW health system, reported in section 4.

Section 3 provides comment on developments in the disability and health fields in the context of us assessing agency progress in implementing the relevant recommendations of our *Report of Reviewable Deaths in 2004*. We also refer to agency progress in implementing our recommendations in section 4. More detailed commentary on the progress of all recommendations can be found in Appendix 3.

Prior to publication, all the agencies whose work is referred to in this report were given an opportunity to comment on those sections relevant to them. All comments received have been considered, and where appropriate, are reflected in this report.

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

1.5 Developments since our last report

There are three cross-agency initiatives relating to people with disabilities in care that have commenced since our last report.

- In May 2006, the NSW government released a ten-year plan, *Stronger Together*, which outlines the direction for disability services from 2006–2016. It includes government plans to improve and/or expand on such areas as day programs, therapy services, accommodation, ageing, and health care.
- During the last year an Interagency Standing Committee on Disability (ISCD) has been created. It is chaired by DADHC, and includes departments such as NSW Health, Housing, and Education. Its role is to oversight the development of a 'whole-of-government' policy and service delivery framework for disability services in NSW. The framework intends to identify ways to improve services for people with disabilities through improved planning and interagency coordination of services. There are seven priority areas for the ISCD, including early intervention, access to therapy services, diagnosis and assessment, and research.
- The third cross-agency initiative is the joint work by DADHC and NSW Health to develop a Service Framework for the Health Care of People with an Intellectual Disability. The framework will look at how to improve access to health services for people with an intellectual disability, and will address areas such as training for health workers on the health care needs of people with intellectual disabilities. The framework document is expected to be completed for Directors-General consideration by the end of September 2006.

DADHC and NSW Health have undertaken other specific work in the past year that is relevant to people with disabilities in care:

NSW Health

- Released the *Discharge Planning: Responsive Standards* policy directive in July 2006, including a prompt for hospital staff to apply the screening tool for all patients returning to a licensed boarding house following a hospital admission.
- Commenced an evaluation of the implementation of the policy directive: *People with Disabilities: Responding to their needs during hospitalisation.*

DADHC

- Commenced a review of the *Managing Client Health* policy, and issued a draft policy for consultation.
- Released a draft *Decision-Making and Consent* policy.
- Commenced a review of the clinical nurse specialist model of health care case management in terms of the model's potential for wider application.
- Completed a review of record keeping in licensed boarding houses.
- Released and rolled out the *Palliative Care* policy to DADHC-operated and funded services.
- Commenced a review of the *Medication* policy.
- Commenced a review of the structure of Community Support Teams, including the provision of therapy services.

2. Deaths of people with disabilities in care in 2005

In 2005, the deaths of 67 people with disabilities in care in NSW were reviewable. Of the 67 people who died:

- 26 people lived in DADHC operated accommodation;
- 28 people lived in DADHC funded accommodation operated by 18 funded services; and
- 13 people lived in ten licensed boarding houses.

As with last year's report, where relevant we have separated the data relating to the deaths of people in DADHC operated or funded services (referred to in this report as 'disability services') from the data relating to the deaths of people in licensed boarding houses. The separation of these two groups reflects the differences in the legislation and service provision framework.

Changes in the number of deaths and number of people accommodated by residence type

Type of residence	No. of people accommodated	Change since 2004[1]	No. of deaths in 2005[2]	Percentage of population who died in 2005	Percentage of reviewable deaths in 2005	Percentage change since 2004[3]
Group home (funded)	1833	-287	18	1.0	27	+9.8
Group home (DADHC)	1324	+40	9	0.7	13	-1
Small residential centre (funded)	187	-10	0	0	0	-1.1
Small residential centre (DADHC)	32	+14	0	0	0	0
Large residential centre (funded)	333	-192	10	3.0	15	-4.4
Large residential centre (DADHC)	1169	-80	16	1.4	24	+1.4
Licensed boarding house	1041	-17	13	1.2	19	-6.8

2.1 Characteristics and circumstances of the people who died

This year, in considering the key information about the characteristics and circumstances of people with disabilities in care who died in 2005, we have compared it with the data from the previous two years. Where relevant or noteworthy, we have reported the comparison.

In comparing this year's data with the previous years we have found the data we collect and report on has been largely consistent.

On average, the people who died in 2005 who had lived in disability services:

- Were 49 years old, approximately thirty years younger than the life expectancy of people in the general community.
- Were more likely to be men, although women died at an earlier age.
- Had lived in care for most of their lives, and had not moved recently.
- Had an intellectual disability in addition to two or three other disabilities, typically physical and sensory impairments.
- Had co-existing chronic health conditions in the period leading up to their deaths that required ongoing management and regular review, and were receiving at least one type of major medication.[4]
- Required support with activities of daily living, including mobility and eating and drinking, and required another party to make decisions and/or provide consent on their behalf to medical and dental treatment.

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

On average, the people who died in 2005 who had lived in the care of licensed boarding houses:

- Were 63 years old, approximately 15 years younger than the life expectancy of people in the general community.
- Were much more likely to be men, although women died at an earlier age.
- Had a residential history that was unknown, and had lived in the licensed boarding house where they were residing at the time of their death for five years or less.
- Had been diagnosed with a mental illness, mainly schizophrenia, but had not seen a psychiatrist in the 12 months before their deaths.
- Were receiving more than one type of major medication, and provided their own consent to medical and dental treatment.

As in the previous two years, leading causes of death for people living in licensed boarding houses were external causes, cardiovascular disease, and respiratory illness.

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

2.2 Cause of death

The following table identifies the primary cause of death in 58 of the 67 people who died in 2005 (87%), categorised according to ICD-10-AM codes.[5] At the time of writing, the Coroner had not made a determination of cause of death for the other nine deaths.

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

Numbers of deaths in each ICD-10-AM cause of death category[6]

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.	21
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.	13
Neoplasms (C00-D48) A new and abnormal growth, any benign or malignant tumour, often referred to as cancer.	8
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.	5
Diseases of the digestive system (K00-K92) Includes diseases that affect the breakdown of food for absorption by tissue in the body. For example, gingivitis and periodontal disease, oesophagitis, gastro-oesophageal reflux, haematemesis.	3
Injury, poisoning and certain other consequences of external causes (S00-T98) Includes injuries such as fractures, traumatic amputation and burns, poisoning by overdose or the wrong substance taken in error, toxic effects of non-medicinal substances, effects of deprivation, and complications of surgical and medical care.	3
Certain infectious and other parasitic diseases (A00-B99) Includes diseases generally recognized as communicable or transmittable. For example, tuberculosis, tetanus, meningococcal, septicaemia, viral meningitis, but excluding HIV, diseases related to perinatal period, influenza and other acute respiratory infections.	2
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99) Includes congenital conditions such as spina bifida and congenital heart problems, and conditions related to chromosomal differences such as Down syndrome.	1
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99) Includes signs and symptoms, abnormal results of clinical or other investigative procedures, and other conditions not classifiable elsewhere. For example, dyspnoea, asphyxia, respiratory arrest, sudden death, dysphagia, senility.	1
External causes of morbidity and mortality (U50-Y89) 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
Not yet determined	9
Total	**67**

Disability services

The NSW Coroner provided the cause of death for 47 people who had lived in disability services. The cause of death is not yet known for seven people. As has been the case over the last three years, the dominant cause of death for people in the care of disability services was respiratory illness. This was the primary cause of death for 18 of the 47 people for whom we have received cause of death information. Including antecedent information, the deaths of almost half of the people (21) in the disability services group were related to respiratory illness.

The proportion of people in this group whose deaths were related to respiratory illness has remained fairly constant over the past three years, averaging around half.

Licensed boarding houses

The NSW Coroner has advised us of the cause of death for 11 of the 13 people who had lived in licensed boarding houses. Out of these 11 people, the main causes of death were those related to respiratory illness (three people), those related to cardiovascular disease (three people), and those related to injury or other external cause (three people). The three external cause deaths were due to accidental drowning, suicide, and accidentally being hit by a train.

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

Deaths related to respiratory illness

As highlighted above, the dominant cause of death for people with disabilities in care in NSW has consistently been related to respiratory illness. As a result, we are currently undertaking a group review of respiratory deaths in 2005.

As well as looking at deaths where respiratory illness was a primary or contributing factor in the cause of death, the group review also includes matters where the person had a history of respiratory related infection in the 12 months leading up to their death. We are therefore reviewing 28 deaths.

The group review is obtaining expert advice from a respiratory consultant.

Our previous group review of respiratory related deaths in 2003 identified a range of factors common to people with high support needs who die from respiratory related illness. These factors include high dependency needs, a history of recurrent respiratory illness, a diagnosis of gastrointestinal reflux and swallowing difficulties. Our review is considering the factors that place this group of people at a higher risk of developing respiratory related illness, and the factors associated with the prevention of respiratory related deaths.

Our work in this area will be reported in next year's report on reviewable deaths.

Data on respiratory related deaths in 2005

Of the 21 people whose primary cause of death in 2005 was related to respiratory illness, 12 people lived in large residential centres, six people lived in group homes, and three people lived in licensed boarding houses.

In the disability services group, aspiration pneumonia was either the primary or antecedent cause of death for nine of the 47 people where cause is known. Pneumonia or bronchopneumonia was the primary or antecedent cause of death for 11 people, including four people with Down syndrome.

Of the 18 people in the disability services group whose primary cause of death was related to respiratory illness, the large majority had swallowing difficulties (14 people), and required assistance with meals (15 people). In addition, almost all of the 18 people had limited mobility (17 people), and many had weight outside the healthy weight range (nine people). Six people were overweight or obese, and three people were very underweight. Most people had been vaccinated against influenza in the 12 months before their deaths (14 people).

Six people who died as a result of respiratory illness had a history of recurrent respiratory infections. Only one of these six had seen a respiratory specialist in the 12 months before their death.

The presence of gastro-oesophageal reflux disease (GORD)[7] has implications for respiratory health. The respiratory complications commonly associated with GORD include chronic cough and chronic lung disease due to recurrent aspiration. Eight people were recorded as having gastro-oesophageal reflux disease (GORD).

We have previously reported that positive management of suspected or diagnosed GORD includes referral for a review by a gastroenterologist, prescription of GORD medication, and review of eating and drinking by a speech pathologist. Of the eight people with GORD in disability services whose deaths were related to respiratory illness, six people were receiving medication for the condition, and one person had seen a gastroenterologist in the three years before their death. Four of the eight people with GORD had seen a speech pathologist in the 12 months before their deaths.

Of the three licensed boarding house residents whose deaths were related to respiratory illness, one person died of an acute asthma attack,[8] and the other two people died of pneumonia or bronchopneumonia. The person who died of pneumonia had a history of recurrent respiratory infections, and had received the influenza vaccine in the 12 months before her death. She had not seen a respiratory specialist. The person who died of bronchopneumonia was not reported to have had a history of recurrent respiratory infections, and her immunisation status was unknown.

Deaths related to aspiration[9]

All of the nine people whose deaths in 2005 were related to aspiration lived in the care of disability services. Three of these deaths were the result of aspirating during a sudden event, such as a massive nosebleed, or vomiting during a seizure.

Of the nine people whose deaths were related to aspiration, two received enteral nutrition, and one of these people was nil by mouth.

Most of the nine people had a nutrition and swallowing checklist (eight people), but only four included a completed action plan. The action plan for two people did not address all of the identified risks, and the nutrition and swallowing checklist for two people did not include an action plan despite identified risks. All nine people had an eating and drinking plan or equivalent guiding document.

Five people had seen a speech pathologist or attended a Dysphagia Clinic in the 12 months prior to their deaths.

GORD is also associated with death due to aspiration pneumonia. Four people had been diagnosed with GORD, three of whom were receiving medication for the condition. None of the four people with GORD had seen a gastroenterologist for the condition, but three people had seen a speech pathologist in the 12 months before their deaths.

Sudden and/or unexpected deaths

At least 26 of the 67 deaths in 2005 (39%) were sudden and/or unexpected, including the deaths of some people who services would not previously have identified as being at particular risk. Half of the 26 people whose deaths were sudden and/or unexpected were living in group home (or respite) accommodation at the time of their deaths, four people were living in large residential centres, and nine people were residents of licensed boarding houses.

Cause of sudden and/or unexpected deaths

Seven of the unexpected deaths occurred over a short period of time, including four people who died shortly after developing what appeared to be a routine illness such as a cold, a chest infection, or diarrhoea.

Nineteen people either died suddenly, or the event that caused their death was sudden and they died a short time later. The sudden and unexpected deaths included two people who choked on food, and three people whose deaths were due to external causes, such as accidentally being hit by a train.

Of the remaining 14 sudden and unexpected deaths, five were related to epilepsy, six were related to heart conditions, one was due to an acute asthma attack, and two were as a result of pneumonia. Eight of the 19 people whose deaths were sudden and unexpected died overnight and were found deceased by staff in the morning.

Sudden and unexpected deaths related to epilepsy

Of the five people whose deaths in 2005 were related to epilepsy, one person died from aspiration pneumonia following a seizure, and four people died from Sudden and Unexpected Death in Epilepsy (SUDEP).[10] Sudden unexpected death in epilepsy is, by definition, a fatal event that occurs without notice and for which no explanation can be found. The mechanism of death is unclear, but research indicates that SUDEP is most likely to occur during sleep, and the cause of death probably involves a number of factors resulting in interruptions to respiratory and cardiac function.

Although the cause of SUDEP is still unknown, research has indicated some common risk factors, including:

- 20–40 years of age
- male
- early onset seizures
- chronic epilepsy
- poor seizure control
- intellectual disability
- generalised tonic clonic[11] seizures
- multiple anticonvulsant medications
- non-therapeutic levels of anticonvulsant medications in bloodstream
- sudden or drastic changes in the anticonvulsant medication regime.

One person who died of SUDEP in 2005 had eight of the ten risk factors outlined above, two people had six risk factors, and one person had five risk factors. All four people had the three risk factors of intellectual disability, early onset seizures, and chronic epilepsy.

Each of the four people whose deaths were due to SUDEP died overnight while in bed, and were found by staff early the following morning. At least two of the four people were regularly checked by staff during the night. Two of the four people who died from SUDEP had been reviewed at least once by a neurologist in the 12 months before their deaths.

Sudden deaths related to heart conditions

Of the 16 people whose deaths were sudden and/or unexpected, but unrelated to epilepsy, choking, or external causes, nine people were identified as having heart complaints, either before or after death. This included six people who lived in the care of disability services, and three licensed boarding house residents.

Out of the six disability services residents with heart conditions whose deaths were sudden and/or unexpected, four people had congenital heart conditions, including three people with Down syndrome.

In our reviews of the deaths of these four individuals who had had heart conditions since birth, we found that all had regular cardiology reviews, and the consistent advice was that there were no medical or surgical treatment options available for those conditions. In addition, we noted active and generally comprehensive health management by the accommodation services that were involved in providing care.

Five of the six people in disability services with heart conditions whose deaths were unexpected died shortly after collapsing, and one person died in bed overnight.

All of the three licensed boarding house residents with heart conditions whose deaths were sudden and unexpected died at the moment of collapse, or shortly afterwards. One of the three had an identified heart condition, one had a family history of heart problems, and one was discovered to have coronary artery disease after his death. Two of the individuals, aged 44 and 57, were heavy smokers, and the third man was 81 years old.

Other than our continuing review of the death of one of the residents due to questions associated with first aid provision, no issues of concern regarding service action or potential preventability have been identified for these deaths.

2.3 Health conditions

Many of the people who died in 2005 had a number of co-existing health conditions, emphasising the importance of a coordinated approach to supporting the health needs of people with disabilities in care. The following tables identify the most commonly reported health conditions for disability services and licensed boarding house residents.

Health conditions most commonly reported for disability services residents

	Percentage
Epilepsy	61
Dysphagia	56
Double incontinence	48
Constipation	35
GORD	28
Osteoporosis	22
Cancer	22
Recurrent respiratory illness	22
Hypertension	18
Asthma	11
Diabetes	9

Health conditions most commonly reported for licensed boarding house residents

	Percentage
Constipation	31
Epilepsy	31
GORD	15
Recurrent respiratory illness	15
Urinary incontinence	15

In relation to key health conditions for both disability services and licensed boarding house residents, we noted that the proportion of the people who lived in disability services who were reported to have osteoporosis has increased over the last three years, and the number of disability services and licensed boarding house residents reported to have epilepsy has increased.

Osteoporosis

Since 2003, the number of people in disability services who died and who were reported to have osteoporosis has increased: 14% in 2003, 19% in 2004, 22% in 2005. Twelve people in disability services in 2005 were recorded as having osteoporosis, nine of whom had limited mobility and relied on wheelchair support.

Three of the 12 people in the disability services group with osteoporosis had experienced at least one fracture in the five years before their deaths, with two people having had two fractures in that period. Two people who were reported to have osteoporosis were also reported to have vitamin D deficiency.[12]

One licensed boarding house resident was recorded as having osteoporosis. That person did not have limited mobility, and had not had any fractures in the five years before their death.

Of the 13 people who were reported to have osteoporosis, four people were receiving medication for that condition, including the licensed boarding house resident.

Epilepsy

The number of people in disability services and licensed boarding houses who died and who were reported to have epilepsy has increased since 2003.

For people in disability services, the number reported to have epilepsy was 9% in 2003, 41% in 2004, and 61% in 2005. For people in licensed boarding houses, the number reported has increased from 14% in 2003, 0% in 2004, to 31% in 2005.

Overall, epilepsy was a reported health condition for over half (37) of the people who died in 2005.

Medical practitioner review

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

The Epilepsy Association of Australia recommends annual review by a neurologist for all people with a diagnosis of epilepsy, and this view is shared by the neurologist on our disability deaths advisory committee. DADHC's *Managing Client Health* policy requires that an epilepsy management plan is completed for all residents of DADHC-operated accommodation and respite services, and that the plan is signed by a neurologist. The policy indicates that the plan is only to be signed by a GP if the person is unable to access a neurologist (such as people accessing rural and remote services).

Of the 33 disability services residents who had epilepsy, just under half (14) had seen a neurologist in the 12 months before their deaths. Nine of these people lived in DADHC accommodation. Of the 19 disability services residents with epilepsy who had not seen a neurologist, 11 lived in the care of funded services, and eight lived in DADHC accommodation.

None of the four licensed boarding house residents with epilepsy had seen a neurologist in the 12 months before their deaths.

Risk assessment and epilepsy management plans

Effective management of epilepsy is reliant on an assessment of the individual and the risks associated with that person's epilepsy, and control of those risks. Assessment should take into account such factors as the nature and pattern of the person's seizures, any triggers, and the supports that the person requires, including the amount of supervision they need, medication management, and seizure response.

While DADHC's *Support of Clients with Epilepsy* and *Managing Client Health* policies do not currently apply to funded services or licensed boarding houses, we consider that good practice concerning epilepsy management includes the development of a plan or other document that refers to the fact that the person has epilepsy, and provides some guidance to staff as to the frequency / nature of the person's seizures, and what staff need to do to appropriately support the individual.

Of the 33 people in disability services who had epilepsy, about two-thirds (21) had an epilepsy management plan or similar guiding document. 14 of the 21 people with an epilepsy management plan lived in the care of DADHC. Of the 12 people with epilepsy who did not have an epilepsy management plan, three lived in the DADHC accommodation. Most of the people with epilepsy who did not have an epilepsy management plan lived in large residential centres. None of the four licensed boarding house residents who had epilepsy had an epilepsy management plan or similar guiding document.

2.4 Nutrition and swallowing

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

Dentition

In our report of deaths in 2003, we reported the association between poor oral health and the development of chronic respiratory disease. We noted that poor oral / dental status has been identified as a major risk factor for the development of aspiration pneumonia.

81% of the disability services residents who died in 2005 had all, or at least some, of their teeth (44 people). This was an increase on the previous two years where around 55% of the disability services groups had all or some of their teeth.

None of the 13 licensed boarding house residents who died in 2005 had all their teeth. However, almost half (six people) had some of their teeth, and a third (four people) wore a dental aid, such as dentures. Only one person was recorded as not having any teeth.

Over the past three years, the number of licensed boarding house residents who died and who were recorded as not having any teeth has been declining: from 18% in 2003; to 12% in 2004; and 8% in 2005. Conversely, the numbers of licensed boarding house residents recorded as wearing a dental aid has steadily increased, from 14% in 2003; to 25% in 2004; and 31% in 2005.

Dentist within the 12 months prior to death

DADHC's *Managing Client Health* policy requires that people in the care of DADHC operated services have a dental review every six months. There are no dental review benchmarks or policy requirements for people living in funded disability services or licensed boarding houses.

In the disability services group, around a quarter (13 people) had seen a dentist in the 12 months before their deaths. This included 11 of the 44 people who had all or some of their teeth.

Out of the people who had lived in licensed boarding houses, only one person had seen a dentist in the 12 months before their death (they had some of their teeth). The low recorded access to dental services for licensed boarding house residents is significant given the role of the primary and secondary health care program within the Boarding House Reform Program to assist residents with access to dental care, and the capacity for these funds to be used for private dental services where required. In sections 3.8 and 4 of this report, we discuss the primary and secondary health care program further.

Enteral nutrition[13]

Five people who lived in the care of disability services received enteral nutrition. Of these, four had percutaneous endoscopic gastrostomy (PEG) [14] tubes, and one person had a jejunostomy tube.[15] All five lived in large residential centres. The deaths of three of the people who relied on enteral nutrition were related to respiratory illness.

Of the five people receiving enteral nutrition, two were in the healthy weight range, two were very underweight, and one person was overweight.

DADHC's *Ensuring Good Nutrition* policy applies to people living in DADHC operated and funded services. This policy requires that people who are tube fed have their nutritional care plans reviewed at least six monthly, and notes that good practice calls for the involvement of a dietitian in the review. All five of the individuals receiving enteral nutrition had been reviewed by a dietitian in the 12 months before their deaths, and two had been reviewed at a Dysphagia Clinic.

One person received food orally as well as via a feeding tube. They were underweight at the time of their death. The other four people relied exclusively on enteral nutrition. Two of these four people had seen a dentist in the 12 months before their deaths.

Swallowing difficulties (dysphagia)

Thirty-one people out of the 54 people in disability services had swallowing difficulties (57%).[16]

Nutrition and swallowing checklist (risk identification and management)

The *Ensuring Good Nutrition* policy requires that services identify and address individual risks related to food intake, nutrition and nutrition support needs by using an appropriate checklist, such as the nutrition and swallowing checklist. The policy recommends that the checklist is completed annually in tandem with the individual planning process.

Of the 31 people who had swallowing difficulties, the majority (28 people) had a current nutrition and swallowing checklist on record. This is an increase on the 67% reported in relation to the people with swallowing difficulties who died in 2004.

However, when we had a closer look at the quality of the nutrition and swallowing checklists completed in relation to the people with swallowing difficulties who died in 2005, we identified some concerns regarding risk management. In terms of quality, we considered:

- whether the checklist recorded all of the swallowing and nutrition risks of the individual
- where risks were identified, whether the action plan at the end of the document addressed all of those risks.

We found that only half of the completed nutrition and swallowing checklists recorded all the known risks and addressed them in the action plan.

For just under a third (nine) of the people with swallowing difficulties, the action plan did not address all of the risks that had been identified in the checklist. Most of these people (seven) lived in DADHC operated accommodation.

For four of the 31 people with swallowing difficulties, the action plan had not been completed at all, despite identified risks. All of these people lived in DADHC operated accommodation.

A nutrition and swallowing risk checklist had not been completed for one person with swallowing difficulties who lived in funded accommodation.

Eating and drinking plans

An eating and drinking plan is intended to be an easy to understand record of how to best assist a person to eat and drink. It may provide details on positioning and seating, equipment, assistance required, food and drink preferences and consistencies, and suggested food items and quantities.[17] The information contained in the plan needs to be updated regularly, according to the needs of the person.

Of the 31 people with swallowing difficulties, the majority (26 people) had a document on file that provided guidance to staff about how to support the person in relation to eating and drinking.[18] Three people were recorded as having swallowing difficulties but did not have an eating and drinking plan or equivalent. These three people lived in group home accommodation — two were in the care of funded services, and one was living in DADHC accommodation.[19]

Twenty-eight people in disability services were recorded as requiring assistance with meals, such as help to chop up food or use utensils. Of these 28 people, 25 had an eating and drinking plan or equivalent guiding document. Two people recorded as requiring assistance with meals did not have eating and drinking plans. Both lived in group home accommodation.[20]

The *Ensuring Good Nutrition* policy requires that people who have difficulty swallowing have their nutritional care plans reviewed at least six monthly, and notes that good practice calls for the involvement of a speech pathologist in the review. Of the 31 people who had swallowing difficulties, just over half (16) had seen a speech pathologist in the 12 months before their deaths.

Deaths due to choking

Two people died in 2005 after choking on food. One man lived in a DADHC group home, and the other man lived in a funded large residential centre.

In relation to the man who lived in a DADHC group home, we found that the nutrition and swallowing checklist that had been completed did not identify all of his swallowing risks and, although some risks were identified, the action plan was blank. In addition, although swallowing risks had been identified the previous year, there was no record of any action taken as a result, such as seeking assistance from a speech pathologist or developing an eating and drinking plan.

The department's own review into the man's death identified that he had experienced four choking episodes before the last incident that were not documented or reported, and that *'a referral for a speech pathology assessment may have changed the circumstances surrounding the death'* of this man.[21] The review recommended a number of actions, which have been acted on, including training for staff in dysphagia, mealtime management, and incident reporting.

In relation to the person who lived in a funded large residential centre, the service completed an investigation into the circumstances of the man's death that identified eight contributing factors to the incident. These factors included the lack of a structured process for the supervision of residents for morning and afternoon tea and supper (which allowed the person to access food contrary to his mealtime management plan); a failure to follow the mealtime management plan; and staff knowledge of getting a choking person out of a wheelchair promptly.

The service has developed and fully implemented an action plan to address the contributing factors of the incident in order to lessen the risks of recurrence.

Endnotes

[1] Figures indicate change between numbers of people accommodated in each type of residence from 2004 to 2005.

[2] One death occurred in a DADHC respite house, and has not been included in this chart.

[3] Figures indicate percentage change between numbers of reviewable deaths from 2004 to 2005.

[4] For our purposes, we have considered ‘major medication’ to be antipsychotic, antidepressant, anticonvulsant, anti-anxiety, or sedative medication.

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

[6] Table only includes categories in which deaths of this group of people were coded.

[7] GORD is a condition in which the liquid contents of the stomach regurgitates (backs up) into the oesophagus. Stomach contents can also be aspirated into the lungs.

[8] We were unable to obtain service records to consider this person’s asthma management as the boarding house closed in 2005.

[9] Aspiration refers to the entry of material (food, liquid, or saliva) into the airway. Over time, damage can occur to the lung. In addition, if a large quantity of food or drink is aspirated it can cause respiratory illness.

[10] SUDEP is the sudden, unexpected, non-traumatic and non-drowning death in an individual with epilepsy, witnessed or unwitnessed, where death was not the direct result of a seizure or status epilepticus, and in which post-mortem examination does not reveal an anatomical or toxicological cause.

[11] Tonic clonic seizures used to be called ‘grand mal’ seizures. A generalised tonic clonic seizure involves the whole brain and entails loss of consciousness, stiffening of the body, and then jerking of the limbs.

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

[13] Enteral nutrition is the delivery of liquid nutritional formula via a tube.

[14] A PEG involves the placement of a feeding tube directly into the stomach to provide fluids and nutrition when a person has difficulty swallowing.

[15] A jejunostomy tube has the same role as a PEG tube, but is inserted into the jejunum (a section of the small intestine) rather than the stomach.

[16] No boarding house residents were recorded as having swallowing difficulties.

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

[18] We included eating and drinking plans, mealtime management plans, any allied health report that outlined the person’s needs and what staff needed to do, and any other document that provided adequate guidance in relation to eating and drinking.

[19] Two people recorded as having swallowing difficulties were excluded from the data regarding eating and drinking plans, as we did not examine their service records as part of our review of their deaths.

[20] One person recorded as requiring assistance with meals was excluded from the data regarding eating and drinking plans, as we did not examine their service records as part of our review of their death.

[21] DADHC Internal report following review of a death. Report dated 4 August 2005.

3. Deaths of people with disabilities in care in 2005: Our work

This part of the report provides observations from our reviews of the deaths of 67 people who died in 2005. At the time of writing, we had completed 51 reviews. We made reports to agencies about concerns we had identified in 16 cases. [22] In all 16 cases, we sought advice from agencies about their current or planned action to address the issues we identified.

Services have responded to our reviews in a number of ways, including internal reviews and amendments to service policies and procedures. In a number of cases, DADHC made reference to implementation of its Quality and Safety Framework, which is the basis for monitoring and measuring performance in DADHC operated accommodation services. DADHC has indicated that the Framework will enable performance measurement in key areas such as nutrition and swallowing checklists, client risk profiles, restricted practice authorisation, and individual planning.

Generally, we have continued to monitor the actions outlined by the services to ensure that steps are implemented to address the identified issues and minimise recurrence.

Our reviews are continuing in relation to 16 of the people who died in 2005.

In the main, our work on deaths in 2005 has identified some concerns with, or raised questions about:

- identification and management of risk
- planning to meet the needs of individuals
- response to critical incidents
- primary and secondary health care services for licensed boarding house residents
- readmissions following discharge from hospital
- end-of-life decision-making
- record keeping.

Many of the themes and issues we have identified within these areas are similar to those considered in our reviews of deaths in 2004. In this context, our discussion below incorporates comment on the progress agencies have made in implementing relevant recommendations from our *Report of Reviewable Deaths in 2004.*

Our reviews also identified good practice on the part of service providers. This was evident in our consideration of duty of care issues, and support of clients who had experienced deteriorating health prior to their deaths. These issues are also discussed below.

3.1 Identification and management of risks

In our reports on reviewable deaths in 2003 and 2004, we noted concerns about the identification and management of risks for people with disabilities in care. Last year we reported that:

> *The identification and management of risks are critical to meet the health needs of people with disabilities in care, and reduce preventable deaths.*[23]

Swallowing and nutrition risks

In a number of cases this year, our reviews indicated that services had failed to effectively identify risks for an individual in their care, such as swallowing and nutrition risks. In addition, we found that in some cases where risks were identified, the service did not take adequate steps to address or minimise those risks, as illustrated in the case study below.

Smoking and licensed boarding house residents

Eleven of the 13 licensed boarding house residents who died in 2005 were daily smokers. The proportion of the licensed boarding house group who were recorded as being daily smokers has increased over the past three years, from 50% in 2003 to 71% in 2004, and 85% in 2005. It is well documented that people who smoke are at significantly higher risk of developing chronic obstructive pulmonary disease, cancer, and heart disease. A survey conducted by the Central Sydney Boarding House Team in 1999[24] identified relatively high smoking rates in the boarding house population when compared to the general population. The survey found that 61.3% of the 470 residents surveyed were smokers, compared to a rate of 25% in the general population at that time.

CaseStudy1

Our review of the death of a man who died after choking on food identified several concerns regarding risk management. We noted that although swallowing and nutrition risks were identified on various documents in the man's file, these were not recorded in the nutrition and swallowing checklist. Although the checklist did record some risks, the action plan was blank. In addition, the Client Risk Profile did not identify dysphagia or choking as a risk for the man.

Our review also noted that while potential swallowing risks had been identified in the year before the man's death, there was no record on file of any actions taken to manage these risks, such as seeking assistance from a speech pathologist, or developing an eating and drinking plan.

In response to our review report, the service advised that it had conducted an internal review of the man's death that had identified similar concerns regarding risk identification and management. The review recommended nine actions, which have been acted on, including training for staff in mealtime management, the completion of nutrition and swallowing checklists, follow-up actions, and monitoring.

In addition to the significant physical, financial, and psychosocial costs associated with the high levels of smoking for this group, there are also health risks to others owing to the effects of passive smoking. We are aware that some licensed boarding houses have introduced smoking cessation programs, such as the introduction of nicotine patches for residents willing to participate in the program, and that some primary and secondary health care caseworkers provide nicotine patches out of the program funds.

It is important that any activities or programs introduced to address the continued high smoking rates in licensed boarding houses are monitored and evaluated to determine their effectiveness and the possibility of broader application of successful models across the boarding house sector.

Duty of care and dignity of risk

Some people with disabilities in care are able to make informed decisions in relation to some or all areas of their lives. Depending on the decisions made by the person living in care, it can sometimes be difficult for service providers to balance their duty of care to the individual with the person's right to make their own decisions.

In 2005, almost a quarter of the 67 people with disabilities in care who died (15 people) provided their own consent to medical and dental treatment, and made decisions in relation to health care. This included nine people who did not have a cognitive impairment, and six people who had some form of cognitive impairment but were able to provide informed consent and make decisions on their own behalf.

In our reviews of the deaths of three of these 15 people, we noted that the health care decisions made by those individuals presented real challenges for the services involved. All three individuals had decision-making capacity, and lived in group home accommodation provided by funded services. One of these individuals made lifestyle choices that adversely affected her health, including smoking heavily, eating food high in fat and sugar, and sometimes refusing to take her medication. In the other two matters, the individuals made the decision to eat and drink at levels that placed their lives at risk.

Both were assessed by speech pathologists as having swallowing difficulties that placed them at significant risk of aspiration. Recommendations were made for both individuals to have food of a pureed consistency, and thickened fluids. The individuals chose not to follow the speech pathologists' recommendations as they preferred the texture and/or consistency of their existing diet, which included thin fluids.

In both cases our reviews indicated that the risks and likely consequences of the decision were fully explained to the individuals on a number of occasions, by the speech pathologists and support staff. It was evident that a number of methods were employed to emphasise what that decision meant in terms of aspiration and choking risks, including showing a video on swallowing. In both cases the decisions made by the individuals were clearly recorded by both the speech pathologists and the service staff in file documents, including the mealtime management plans.

According to the records we reviewed, while it was clear that the speech pathologists and service staff did not agree with the decision made in both cases, they respected the right of both individuals to make that informed decision. Strategies were developed and documented in the mealtime management plans to try to minimise the risks as much as possible given the decision, including positioning and safe feeding techniques.

The deaths of both individuals were related to aspiration. Although following the speech pathologists' recommendations may have prevented or delayed their premature deaths, both people made it clear that they were placing the quality of their daily lives above the consequences to their health in the longer term. The fact that the discussions and decisions were clearly and comprehensively documented meant that it was evident what steps the service had taken to assess and manage the risks to the individuals in light of the decisions that compromised their health.

Our previous recommendations on identification and management of risks

In our *Report of Reviewable Deaths in 2004*, we made four recommendations relevant to risk identification and management.

- We recommended that DADHC should report on progress towards releasing the revised *Managing Client Risk* policy to funded services. In September 2006, DADHC advised that the draft revised policy would be distributed for consultation in October, with an anticipated release to DADHC operated and funded services of 31 January 2007.
- In relation to identifying and managing risks related to swallowing and nutrition, we sought specific advice from DADHC about its monitoring of nutrition-related health management practices in DADHC operated and funded services. DADHC indicated that it is monitoring areas such as completion of nutrition and swallowing checklists and client risk profiles through its Quality and Safety Framework.

  The department advised that it intends to conduct a formal evaluation of the *Ensuring Good Nutrition* policy following its implementation in funded services.

  DADHC also advised that the guidelines issued to staff monitoring funded services require them to gain evidence from services about compliance with key performance indicators, and that this evidence includes review of risk assessments, health plans and monitoring in accordance with the *Ensuring Good Nutrition* policy. In our review of these guidelines, we could not locate any reference to the required evidence. It is not clear how monitoring staff ensure compliance in relation to *Ensuring Good Nutrition*.
- In 2003 we recommended that DADHC review the Hunter region's chest care checklist for identifying clients who require regular chest care. Last year we recommended that DADHC report on the outcome of the review. In September 2006, DADHC advised that the review has been completed and the checklist will be linked to the nutrition and swallowing checklist. When the respiratory trigger questions (16–18) on the nutrition and swallowing checklist identify risks, the chest care checklist is to be completed also.
- In relation to decision-making capacity and clarifying consent requirements, we recommended that DADHC report on progress towards finalising its *Decision-Making and Consent* policy. DADHC released the draft of the revised policy in June 2006 for sector consultation until the end of August 2006. The department advised that it intends to roll out the policy to DADHC operated and funded services, with a two-month period for the briefing and training of staff.

3.2 Planning to meet individual needs

In our previous two reports on reviewable deaths, we have raised issues related to planning and coordination of health care for people with disabilities in care. Last year, we noted that:

> *Ensuring that health needs are identified early, appropriate services are coordinated to meet those needs, and*

> *there is adequate monitoring and follow-up, is a key strategy to reduce premature deaths of people with disabilities in care.*[25]

Our reviews of people who died in 2005 continued to highlight gaps in planning to meet the needs of individuals. For example, we found in some cases:

- No evidence of an individual plan.
- No evidence of a health care plan or other document to record the persons existing health issues or indicate how staff should meet their needs.
- Individual and health related plans were not reviewed, despite changing needs or increasing risks being evident.
- Poor management of specific health needs, such as epilepsy. Our reviews identified cases where client files did not contain an epilepsy management plan and client files did not contain seizure charts. In some cases, there was poor recording of seizures and/or poor description of seizure activity.

In relation to licensed boarding house residents in particular, we identified poor coordination of mental health needs, as illustrated in the case study below.

CaseStudy2

We are continuing to review the death of a licensed boarding house resident who had schizoaffective disorder. In the period leading up to the person's death, we noted the involvement of the local mental health team, the licensed boarding house, and a private psychiatrist. However, available records indicate a lack of coordination of the person's mental health needs, including little contact between the parties involved, and poor communication about presenting issues such as gaps in taking antipsychotic medication, and increasing suicidal ideation.

Where planning was undertaken to meet the identified health needs of individuals, our reviews highlighted some issues with the implementation and review of health related plans. In one matter we are continuing to review, a person was diagnosed with diabetes, and the service developed strategies to manage this condition. The strategies included details of actions staff needed to take if blood sugar levels were high or low. Although the records indicated that the service regularly checked and recorded the person's blood sugar levels, there was no record of any action taken in response to identified high and low readings.

We found a number of cases where health related documents were not updated to record change, such as a decline in the person's condition or amendments to the actions required to meet the person's needs. We also identified matters where health care plans were either not developed or were not reviewed for an extended period of time due to delays in obtaining the assistance of community nurse casework support. In one case, the person's health care plan was not reviewed for 18 months due to delays in accessing community nurse casework support. This person had considerable health concerns, including chronic bowel problems.

In another case we reviewed, the person waited for over 20 months for allocation of a referral for the development of a comprehensive health care plan, despite having significant health concerns such as a very low body weight. In response to our review report, the service advised that it had conducted a review of all current service requests to the local Community Support Teams, and identified concerns regarding the amount of information provided with requests for service and prioritisation of the requests. The service indicated that it would address the concerns through conducting a specific assessment of each service request.

In relation to planning to meet individual needs, our reviews of the deaths of people in 2005 also raised some concerns about the involvement of individuals in activities in the community, and their general access to services outside of the residential centre. In some cases it seemed that the individuals very rarely left the unit in which they lived. While community access or outside activities may enhance a person's sense of involvement and integration in the community, it can also have important health benefits.

Our previous recommendations on planning to meet individual needs

In our *Report of Reviewable Deaths in 2004*, we made three recommendations relevant to health care planning and coordination for people with disabilities in care.

- *Managing Client Health* is DADHC's key policy on health care management for people in DADHC operated services. DADHC had advised in 2004 that it would revise the policy and roll it out to DADHC operated and funded services. We recommended that DADHC report on progress towards rolling out the policy to funded services and evaluating the implementation of the policy in those services.

  The department told us that it intends to release the revised policy to DADHC operated and funded services in December 2006. Briefings will occur prior to the policy taking effect by the end of March 2007. DADHC advised that it has contracted the Centre for Developmental Disability Studies to establish baseline data to measure the impact of the policy in funded accommodation services, with a report on this work to be available in September 2006.
- In 2003 we identified a DADHC program in the Illawarra area that used clinical nursing specialists to work with services in managing the health needs of residents, and recommended that DADHC review the model for consideration of wider application in DADHC operated and funded services. Last year, DADHC advised that its Health Care Review Team was reviewing this model of health care management along with other models being used in NSW and other jurisdictions. We recommended that DADHC report on the outcome of its review.

  DADHC told us that it had engaged a consultant to assist the Health Care Review Team to undertake the review. In September 2006 the department told us the review has been completed and a report was drafted in June for consideration. DADHC advised that the department is yet to consider the recommendations from the review in relation to functions of specialist nurses and job descriptions, establishment of positions and their locations, and development of an operational plan for the role. As at September 2006, revised timeframes had not been finalised.
- In relation to health management in licensed boarding houses, we recommended that DADHC provide relevant information to licensed boarding houses concerning good practice in health care, including provision of good practice information contained within policies such as *Ensuring Good Nutrition* and *Managing Client Health*. In response, DADHC advised that it is reviewing and updating the *Licensing, Monitoring and Closure* policy manual, including updating the appendices to incorporate good practice information that DADHC officers may use to assist licensed

boarding house operators. DADHC told us that to facilitate access to relevant information to licensed boarding houses concerning good practice in health care, it is placing links to the relevant documents on the DADHC website on a site specific to boarding houses by October 2006.

3.3 Response to critical incidents

Last year in relation to licensed boarding houses, we noted that in a number of reviews of people who died in 2004, first aid either did not appear to be administered to residents when they were in critical situations, or provision of first aid was inconsistent with best practice principles.

A number of our reviews of deaths in 2005 have raised similar concerns in relation to the first aid assistance provided by disability services and licensed boarding houses in response to critical incidents. In some cases, the records we reviewed indicated that first aid had not been provided, or had not been provided in a timely and effective way. In two matters it appeared that there were delays in calling for an ambulance.

Our reviews of these matters have again raised questions about the adequacy of the emergency protocols of the services concerned, and the training of staff in first aid and emergency response.

Our previous recommendations on response to critical incidents

In our *Report of Reviewable Deaths in 2004*, we recommended that DADHC should require that the services it operates, funds or licenses have at least one staff member on each shift with current first aid qualifications. We also recommended that DADHC provide assistance to funded and licensed services to achieve this requirement. In response, the department advised that it would assess the implications of this recommendation for DADHC operated, funded and licensed services by the end of September 2006.

3.4 Primary and Secondary Health Care services for licensed boarding house residents

Under the Boarding House Reform Program (BHRP), DADHC provides funding to NSW Health for the provision of primary and secondary health care to licensed boarding house residents.[26] The funding includes casework and brokerage components. The aim of the program is to provide residents with access to mainstream health, welfare, and support services.

Information obtained through our consultation project and reviews of deaths in 2005 indicates that there is variation across regions in terms of the delivery of primary and secondary health care services to licensed boarding house residents. We found differences across regions in the casework support provided to residents as well as differences in the type of services provided under the program. For example, residents in one region have access to physical health screening assessments undertaken by an independent medical practitioner as part of the primary health care program. This activity was not evident in other regions. In another region, the managers of two different licensed boarding houses advised that they were not aware of the primary and secondary health care program and that residents were not receiving casework services.

Last year we reported that we saw little evidence of the involvement of BHRP services, such as primary and secondary health care services, in the matters that we reviewed. This was also the case in our reviews of the deaths of licensed boarding house residents in 2005. Very few of the matters we reviewed indicated any involvement of primary and secondary caseworkers, although a number of our reviews indicated the person required coordination of their health needs.

In our reviews of the deaths of residents with chronic health issues such as diabetes and epilepsy, we could not easily identify how those conditions were being reviewed or supported on a day-to-day basis at the licensed boarding house. As noted earlier, we identified that a low number of licensed boarding house residents had accessed dental or podiatry services in the 12 months before their deaths, although access to these services is a key part of the primary and secondary health care program.

In 2006 we made inquiries of DADHC in relation to its funding, brokerage, and oversight of the BHRP, with particular reference to primary and secondary health care services. In response, the department advised that:

- New accountability mechanisms for the primary and secondary health care program would commence on 1 July 2006, and would include agreed performance indicators. One of the performance indicators in the Service Description Schedule for the primary and secondary health care program with NSW Health is that 100% of licensed boarding house residents will have health care plans.
- It has reviewed the arrangements for the expenditure of primary and secondary health care services. DADHC, in consultation with NSW Health, is currently developing new auspice and service model arrangements for primary and secondary health services, with a view to commence in early 2007.
- Primary and secondary health services are being brought into the monitoring arrangements of the department's Integrated Monitoring Framework, and DADHC is developing a paper that will articulate the contract management and monitoring arrangements for statewide services.
- DADHC is initiating and will fund a review of the health needs of licensed boarding house residents in the inner-west area of Sydney.

In March 2006 DADHC announced funding for eight additional caseworkers to support licensed boarding house residents. The department advised that the new casework positions would assess support services required by residents, plan for future needs, and ensure equitable access to specialist and mainstream services.

Information provided by participants in our consultation project highlighted the improved access to health services and coordination of health needs where primary and secondary health care caseworkers are in place. Concurrently, our reviews of the deaths of licensed boarding house residents in 2005 have continued to underline the gaps in health care management when these positions are vacant. Given the importance of primary and secondary health care services to the health and welfare of licensed boarding house residents, we intend to monitor the progress of the initiatives and arrangements referred to above.

3.5 Readmission following discharge from hospital

Many of the people whose deaths we review have had at least one hospital admission in the 12 months preceding their deaths and some have had multiple admissions. In 2005, 38 people (56.7%) had at least one admission to hospital in the 12 months before their deaths.

Last year we identified some issues with hospital discharge planning in relation to licensed boarding house residents, highlighting the importance of a coordinated discharge process and application of the screening tool assessment to determine existing needs, and the associated accommodation and supports required to meet those needs.

Participants in our consultations around health care this year also raised discharge planning as an issue. Some were critical of the discharge planning that occurs for the people with disabilities in their care, including concerns about the absence or poor quality of discharge summaries, lack of consultation regarding the discharge process, and early discharge.

In our reviews of the deaths of people with disabilities in care in 2005, we noted that some were readmitted to hospital either the same day they were discharged, or the day following discharge. Of the 38 people who had had at least one hospital admission in their last 12 months, at least seven had been readmitted shortly after discharge. All were readmitted to the same hospital from which they had been discharged. In a small number of cases, individuals were readmitted the day after discharge on more than one occasion.

We had a closer look at the matters where the individuals were readmitted shortly after discharge from hospital in order to identify any trends or patterns.

Health issues on readmission

According to hospital records, most people were readmitted with the same conditions they had on discharge, with either a continuation or a slight worsening of their condition. One readmission was prompted by a change in condition, with the person's PEG tube becoming blocked within hours of being discharged, but otherwise very few were readmitted due to a dramatic change in their condition. The fact that the majority were readmitted in the same or only slightly worse condition than when they were discharged a short time earlier, suggests that the condition in which the person was discharged may have warranted continued hospital admission, and raises questions about early discharge and the discharge planning process.

Follow-up identified on discharge

On discharge, few were identified as requiring significant intervention or further tests. The individuals were largely discharged with a change in medication (such as the addition of antibiotics), and the recommendation that they be followed up by their GP. In some cases the person was readmitted before the GP had a chance to review them, and in some cases it was the review by the GP that prompted the readmission.

CaseStudy3

A 56-year-old man who had Down syndrome with a profound level of intellectual disability and late stage dementia was admitted to hospital due to a decreasing level of consciousness as a result of mild aspiration pneumonia. He was discharged four days later for GP follow-up. The following day he was readmitted to hospital following seizures and a decreased level of consciousness. He was discharged 15 days later for follow-up with his GP.

The day following his discharge, the man was again readmitted to hospital with laboured breathing, a seizure, and a decreased level of consciousness that affected his ability to take medications, drink, and eat. The hospital noted that there had not been any real change in his condition since discharge, and discussed the admission with a staff member at the disability service who advised that the readmission had been as a result of a review by a GP that did not know the man well.

Early discharge

In most of the matters we looked at, it was not clear whether the person was discharged prematurely, or, if the person was discharged early, the possible reasons for this. However, we reviewed one death where it was evident that the person was discharged from hospital early on more than one occasion, with at least one of those discharge events seemingly due to staffing and nursing care management issues (see case study below).

While this matter raises concerns about provision of care in hospital and the possible transfer of responsibility of care to disability service providers rather than medical or nursing staff, we note that these events occurred prior to release of the NSW Health policy directive *People with Disabilities: Responding to their needs during hospitalisation*.

CaseStudy4

A 48-year-old man lived in a regional licensed boarding house until two years before his death. For the last two years of his life he lived in transition accommodation in a retirement complex, in the care of a non-government service. He had a moderate level of cognitive impairment, and significant health issues including heart problems, swallowing difficulties, shingles, and was underweight.

He was admitted to hospital as he had a poor appetite and nutritional intake, a cough, was moaning on and off, and was cyanosed and clammy. He was discharged the same morning, and hospital records indicated that there were a range of nursing care management issues during the short admission, including the man pulling out his cannula, scratching his shingles, and calling out.

Later the same day he was taken to hospital again due to obvious pain and breathing distress, and was discharged three days later with pain relief.

He was admitted to hospital again the evening of the same day, in significant pain. He was administered Morphine for pain relief, and hospital staff contacted the disability service the next morning to request that a staff member attend the hospital to sit with the man, indicating that his agitation and distress would compromise his health.

The disability service indicated that it did not have staff available, and a decision was made by hospital staff to discharge him that afternoon as his distress was considered to be adversely affecting his cardiac condition. An agreement was reached between the hospital and the disability service that a staff member would accompany him for any future admissions. He was again admitted to hospital four days later with acute renal failure, and died two days after admission.

Discharge planning

NSW Health's policy directives on *People with Disabilities: Responding to their needs during hospitalisation*, released in October 2005, and *Discharge Planning: Responsive Standards*, released in July 2006, both refer specifically to discharge planning for people with disabilities. The former document states that:

- Discharge planning for people with disabilities must include assessment of the adequacy of existing support systems for the person post discharge.
- The person with a disability, their family, advocate and support staff should be involved in discharge planning.
- Hospital staff should not assume that the person is being discharged to nursing care.

The latter document reinforces these requirements, and adds that the discharge process for a patient with a disability must include post-surgery links with community health services. The *Standards* indicate that every GP should receive a written discharge referral when their patient is discharged, or within 48 hours of discharge, and the minimum information required in a discharge referral includes medical specialist contacts and appointments, GP advice for follow-up, patient advice about treatments, and community health and/or community service provider contacts.

The quality of the discharge planning, and particularly the discharge plan, was variable across the seven people who were readmitted shortly after discharge from hospital. Most appeared to have been discharged with some form of document that summarised their stay, diagnosis, and any continuing requirements, but the quality of the document varied. For example, while four people had discharge summaries or equivalent completed that indicated what follow-up needed to occur, in relation to the man in Case Study 4, we found variable discharge processes within the one hospital, including a letter to the service, a Nursing Transfer Summary Sheet, and a Patient Advice and Transfer of Care Summary.

Our previous recommendations on discharge planning

In our *Report on Reviewable Deaths in 2004*, we made three recommendations relevant to hospitalisation and discharge planning.

- We recommended that NSW Health should report on progress towards finalising its discharge planning guidelines, including details of planned evaluation. NSW Health advised that roll out of the *Standards* would occur in 2006, and that indicators for training, monitoring and evaluation were built into the *Standards*. The department indicated that monitoring the implementation of the *Standards* would be done through the Relative Stay Index (RSI), a data collection tool that compares length of stay between institutions, standardised for age and diagnosis related groups.
- In relation to the discharge process for licensed boarding house residents, we recommended that DADHC and NSW Health should discuss how the screening tool for entry to licensed boarding houses might be incorporated into the discharge planning policy under development. NSW Health advised that it had discussed the matter with DADHC, and had incorporated the screening tool into the *Standards*, with prompts to refer for re-screening all patients returning to a licensed boarding house following a hospital admission. DADHC advised in September 2006 that invitations would be extended to NSW Health for

membership on the Screening Tool Steering Committee, which would review the links between screening for entry to licensed boarding houses and the *Discharge Planning: Responsive Standards*.

- More broadly in relation to hospitalisation of people with disabilities in care, we asked NSW Health to advise us about implementation, monitoring and evaluation of its *People with Disabilities: Responding to their needs during hospitalisation* policy directive. NSW Health advised us that it would be engaging a consultant by August 2006 to evaluate the implementation of the policy directive, and that the project was expected to take up to 24 weeks to complete.

3.6 End-of-life decision-making

NSW Health released its *Guidelines for end-of-life care and decision-making* in March 2005. As highlighted in our report last year, the guidelines:

- Outline a process for reaching decisions about the use of life-sustaining treatments.
- Emphasise that end-of-life decisions should be informed by the person's medical condition and prognosis, values and wishes (where known), and that these decisions should be non-discriminatory.
- Outline the requirements for documentation of end-of-life decisions, including recording of the medical facts leading to the decision (including prognosis), the persons involved in the discussion, a statement of the patient's wishes (where known), the goals of treatment, and details about the medical treatments to be provided, the timeframe before review, or details about treatments to be withdrawn or withheld.

Last year we commented on some issues around end-of-life decisions, including decision-making in relation to not for cardiopulmonary resuscitation (no-CPR) orders. We noted that while most of the end-of-life decisions were made following a consultation process with family members, very few of the decisions involved the person with a disability, and reasons for the decisions were not always documented.

Participants in our consultation project this year raised end-of-life decision-making as a significant issue for people with disabilities in care. Participants expressed their belief that questions as to the person's resuscitation status are sometimes asked upon the person's admission, regardless of their medical condition; and that end-of-life decisions are sometimes largely based on the person's disability, rather than their clinical prognosis.

In our reviews of deaths in 2005, we continued to identify a number of concerns about end-of-life decision-making for people with disabilities in care.

No-CPR orders

From our consideration of hospital records, decisions regarding end-of-life care often begin with discussions as to whether, in the event of cardiorespiratory arrest, the person should be resuscitated. While we saw examples of no-CPR decisions being made in consultation with the person's family, we also found examples of no-CPR decisions:

- Being documented without reasons for the decision.
- Being documented in the hospital records prior to discussion with family or relevant others.
- Being inadequately documented so that it was not clear who initiated the discussion, or whether it was a consensus decision.

As an illustration of the last point, we reviewed the death of a 59-year-old man from a licensed boarding house who was admitted to hospital with a diagnosis of sepsis as a result of a chest infection. He was delirious throughout the hospital admission, preventing medical staff from gaining his wishes regarding end-of-life care. Two days after admission, a doctor spoke with the man's brother about his prognosis and documented '*Understand prognosis — might deteriorate. Poor quality of life for 30 years. Stated in case he has cardiopulmonary arrest that he is not for resuscitation!!*' It was unclear from the scant documentation regarding the no-CPR decision which party had initiated that discussion. It was also unclear whether the decision was solely made by the man's brother, or was a consensus decision reached between medical staff and the family.

Treatment limitation decisions

In addition to decisions regarding no-CPR, end-of-life decision-making for a person in hospital also typically involves consideration of whether the person should receive all of the treatment options available, or whether there should be limitations to the treatment provided. Examples of this include decisions as to whether the person should be admitted to an Intensive Care Unit (ICU), whether they should be intubated, whether the Medical Emergency Team (MET) should be called if their condition deteriorates, and whether they should be ventilated. We noted some areas of possible concern in relation to these decisions.

The impact of perceptions of 'quality of life'

We reviewed several matters that raised questions about the documented reasons for treatment limitation decisions. These included three people with significant chronic health issues who lived in large residential centres. The following dot points provide two examples.

- A 40-year-old man was admitted to hospital with sepsis secondary to severe bilateral pneumonia. The day after admission, the hospital MET reviewed the man and noted that *'Usual level of fitness is poor: he is bed / chair bound (doesn't transfer, doesn't reach for objects), he doesn't communicate. Has marked flexion contractures. This man may benefit from IV fluids, O2 and antibiotics but as his usual level of functioning is poor, if he deteriorates further, ICU intervention would be futile and therefore should not be initiated'.*
- A 56-year-old woman was admitted to hospital with respiratory failure, and a review was conducted to determine her suitability for transfer to the ICU. It was decided that the woman was a) not for transfer to the ICU; b) not for intubation or BiPAP;[27] and c) not for CPR. The rationale for these decisions was documented as *'poor quality of life, in nursing home fully dependent on all cares and aspiration risks'.* Risk of aspiration was the only factor identified by the treating team that appeared to relate directly to the woman's presenting medical condition.

Parties involved in the decision

Many of the decisions regarding end-of-life care documented the involvement of family members. However, some of the matters we reviewed raised questions about the nature of this involvement, including whether family members were part of the decision-making process, or conversely were informed once the decision had been made.

This was particularly the case where we considered hospital progress notes against those of disability services. In some cases, while the hospital progress notes recorded that the family member was involved in the treatment limitation discussion, and parties were in agreement with the decision, the disability service progress notes recorded that the same family member contacted service staff to raise concerns about the decision, or to ask questions about the person's condition. Two such examples are listed below.

- A 31-year-old man who lived in a large residential centre was admitted to hospital with aspiration pneumonia following recurrent seizures. Hospital progress notes indicated that a doctor spoke with the man's mother twice about her son's poor prognosis, and that she agreed that he was not for CPR, not for MET call, not for non-invasive ventilatory support, and not for intubation / ICU. However, service progress notes indicated that the man's mother had spoken with the service's staff on the same day as the second discussion with the doctors, and indicated that she wanted her son to be resuscitated. The service progress notes also indicated that the man's mother had *'begged the specialist to continue his antibiotics which he has agreed to do until Monday'.*
- We also reviewed one matter that raised questions about the involvement of family in the treatment limitation decision-making process, and the resolution of disagreements in relation to such decisions. On the day of the 40-year-old man's admission, it was noted by medical staff in the emergency department that he was not for intubation or ventilation, ICU admission or CPR, and noted that 'mum happy with this'. The following day a medical registrar contacted the man's mother to update her on her son's situation, and documented that 'she clearly stated that she wants her son to be fully treated and resuscitated'. The registrar recorded that he then received a phone call from the man's sister, who confirmed her mother's wishes. A member of the MET then reviewed the man and made a number of treatment limitation decisions, contacted the man's mother and *'informed we will treat for pneumonia in ward with antibiotics, IV therapy, oxygen but he is not for ICU treatment such as intubation or assisted respiration'.* The hospital documents did not record any actions taken to resolve the disagreement between the man's mother and the treating practitioners regarding the treatment decisions.

Treatment limitation decisions for people without family or other parties

Of particular concern to us in relation to the parties involved in end-of-life decisions, are the people with disabilities in care who do not have any family or friends, and who do not have a guardian appointed to make decisions on their behalf. In such cases, the responsibility for making such decisions lies with the treating medical team. One such example concerned an 83-year-old man who lived in a large residential centre and was admitted to hospital with pneumonia, increased blood sugars, and dehydration. He did not have any relatives or other persons to make substitute decisions on his behalf.

On the evening of the day of his admission, the medical registrar recorded that he should not be intubated or resuscitated in the event of cardiorespiratory arrest, but did not provide any reasons for this independent decision. The Resident Medical Officer then reviewed the man and contacted the Guardianship Tribunal as to who should be involved in the decision-making, and was informed that the decision whether or not the person was for resuscitation was up to the clinical judgement of the medical team. The Resident Medical Officer recorded a discussion of the matter with the medical registrar '*who has decided that pt is not for resuscitation — to which I agreed*'. There is an additional note made by the medical registrar to indicate that s/he discussed the matter with another doctor '*who agrees that resuscitation / intubation / CPR would be inappropriate for this man*'. No reasons were recorded for the decision by any of the medical staff.

We consider that people without an identified person responsible, and without family, friends or other outside parties involved in their lives, should have a level of advocacy and a potential safeguard that is afforded to other individuals. They are highly vulnerable at a time when such significant decisions about their lives are being made. We consider that there is a place for the involvement of service providers in discussions concerning end-of-life care, particularly for these individuals.

While we would not advocate for service providers to make decisions regarding end-of-life care on behalf of the people in their care, there is room for their involvement in the discussions to inform this decision. Service providers may have the best available understanding of the people with disabilities in their care, including the 'quality' of their lives, their goals, and potentially their wishes.

Review of treatment limitation decisions

The NSW Health *Guidelines for end-of-life care and decision-making* highlight the importance of regularly reviewing decisions such as those that involve withdrawing or limiting treatment, in accordance with fluctuations in the patient's condition, given that such decisions are often based on probabilities rather than certainties.

In two of the matters we reviewed, the individuals' conditions improved after treatment limitation decisions were made. In line with the guidelines, these treatment limitation decisions should have been reviewed and their family consulted about end of life care, given the change in the individuals' conditions. However, there was no indication in the hospital records that the decisions were reviewed in those matters. It appeared that the treatment limitation decisions and no-CPR orders remained static over time.

Treatment limitation decisions and life-sustaining treatment

It is important to note that treatment limitation decisions are not incompatible with the provision of life-sustaining treatment. Although a no-CPR or not for intubation decision may have been made in relation to an individual, they may still receive active treatment for their presenting medical condition, including IV antibiotics, oxygen therapy, IV fluids, investigative tests, and so on. In the main, we noted that where treatment limitation decisions had been made in relation to the matters we reviewed, the individuals continued to undergo tests and receive active treatment to address their illnesses.

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

Last year we recommended that NSW Health should evaluate the implementation of its guidelines, and report how this would be done. NSW Health advised that its Research and Ethics Branch had undertaken a seminar series in metropolitan Sydney and regional NSW to health care professionals regarding the key messages of the guidelines and related issues with their implementation. NSW Health advised that its Research and Ethics Branch is liaising with Area Health Services regarding progress of local implementation of the guidelines.

Our reviews of the deaths from 2005 have raised some questions as to the implementation of the policy in Area Health Services, and its uptake by medical practitioners. Consequently we will continue to monitor NSW Health's evaluation of the implementation of the guidelines.

Palliative care

As was the case in 2004, some of the people who died in 2005 received palliative care before they died. At least 15 of the 67 people who died in 2005 received palliative care, including 12 of the 13 people who had some form of cancer. For most people, palliative care was provided in their own homes, with on-going support provided by the disability service or licensed boarding house in conjunction with drop-in support and advice provided by the local palliative care team.

In general, our reviews found that individuals received a good service from the palliative care team, particularly people living in the care of disability services. We found that the palliative care team provided particular assistance in relation to pain management, and were a useful source of guidance for the service staff and GPs who were supporting people who were dying.

Palliative care decisions for people without family or other parties

As in the case of treatment limitation decisions, we continue to have concerns about the end-of-life decision-making, including palliative care decisions, for individuals that do not have family or other outside parties involved in their lives.

CaseStudy5

We reviewed the death of a man in 2004 who lived in a departmental large residential centre, and raised concerns regarding end-of-life decision-making with the service. We identified that although a palliative care plan had been developed for the man, there was no record of his involvement in the meeting, and there was no indication that consent had been provided either for the plan, or for the decision to initiate palliative care. The plan included comments that the man was not to be admitted to hospital for his current medical condition or exacerbations, and that he was not for CPR.

We raised concerns with the service about the lack of consent, and the service's failure to identify that the man required the appointment of a substitute decision-maker in relation to his ongoing treatment and palliative care decisions. In response, the department advised that previous applications to the Guardianship Tribunal in relation to palliative care issues had been declined due to the Tribunal being unable to make end-of-life decisions. The department reported that it had been informed by the Tribunal that it would not make decisions in relation to end-of-life or appoint a guardian solely for this reason, as end-of-life decisions do not fall within the parameters of the legislation governing the Tribunal.

The department added that, notwithstanding the advice of the Tribunal, it proposed to initiate applications to the Tribunal for consent to implement developed palliative care plans for any client without an identified person responsible.

This year, we reviewed the death of a man in 2005 who lived in the same departmental large residential centre, and identified the same issues. The man died prior to the department providing the above advice.

As with our comments in relation to treatment limitation decisions for people without persons responsible or other parties, we consider that these individuals are particularly vulnerable at a point in their lives when decisions are critical. We have had some initial discussions regarding this issue with the Office of the Public Guardian, and intend to discuss this issue in the near future with the Guardianship Tribunal.

Our previous recommendations on palliative care

Last year we recommended that DADHC report on progress towards finalising its *Palliative Care* policy. DADHC advised that the policy commenced in DADHC operated services on 1 February 2006, and became effective for funded services from 1 April 2006. We also recommended that DADHC and NSW Health commence joint work on the coordination of palliative care for people with disabilities in care. DADHC advised that it had commenced discussions with NSW Health on evaluating the effectiveness of the *Palliative Care* policy in facilitating the coordination of palliative care for residents of DADHC operated and funded accommodation services. In September 2006 DADHC told us that while the agencies had not commenced work on the coordination of palliative care for people with disabilities in care, it would be included on the agenda of future meetings of the interagency Senior Officers Group.

NSW Health advised that the provision of palliative care services around NSW varies considerably between Area Health Services, in regard to service quality, availability and scope. The department advised that the issue is to be addressed through the implementation of the Role Delineation Framework, which will develop a single system of care with referral and case management of patients, and facilitate a collaborative relationship with primary care workers and specialist palliative care teams. NSW Health advised that it has made available recurrent funds from 2006/07 to Area Health Services to employ project officers to develop and implement strategic reforms in palliative care, and one of their key tasks will be the implementation of the Role Delineation Framework. The Framework was being finalised as at June 2006. In addition, NSW Health advised that a mapping exercise of palliative care services is currently underway, and this information would enable the department to monitor the implementation of the Framework.

3.7 Record keeping

Good record keeping is a critical aspect of providing quality care to residents. It is essential that staff providing care to an individual are aware of their current health needs and the actions that staff need to take to ensure those needs are met.

In our *Reviewable Deaths Annual Report 2003–2004*, we noted a range of concerns about the adequacy of records we had reviewed, and recommended to DADHC that the department address this issue in DADHC operated and funded services. Last year, we raised specific concerns about the adequacy and accuracy of records kept for licensed boarding house residents, and the impact of poor record keeping on the ability of licensed boarding house staff to meet individual client needs. In our *Report of Reviewable Deaths in 2004*, we focused our concerns about record keeping on licensed boarding houses, and recommended that DADHC review record keeping practices in licensed boarding houses.

Our reviews of deaths in 2005 have continued to identify concerns about record keeping.

We found that, at times, services kept inaccurate records and failed to maintain relevant and contemporary records in relation to client health needs. In different cases, we identified significant gaps in progress notes, poor recording of incidents, incomplete records, and missing documents. In some cases, important health information, such as immunisation status, was not included in a client's file.

In relation to licensed boarding houses, boarding house records were provided for nine of the 13 deaths that occurred in 2005.[28] For two of the deaths, the licensed boarding houses concerned advised that they did not keep records in relation to residents, and provided letters outlining personal details about the residents.

While we received a register of involvement in community activities for four licensed boarding house residents, we found that records relating to medical, health care, and support needs were very limited. One licensed boarding house provided us with a health care plan. In the main, the licensed boarding house records provided were insufficient for us to ascertain the health or support needs of the residents who died. In many cases we needed to seek additional records held by outside parties such as GPs and psychiatrists.

Our previous recommendations about record keeping

In our *Reviewable Deaths Annual Report 2003–2004*, we recommended to DADHC that it develop strategies to ensure staff in DADHC operated and funded services were aware of the importance of reliable and accurate records, and were provided with the support necessary to ensure good record keeping. DADHC advised us in 2005 that it was addressing this issue through its Electronic Records Management Procedures for Group Homes. DADHC also noted it was looking at strategies to improve record keeping in the large residential and respite sectors, and had commenced discussions in relation to the development of record-keeping in accordance with DADHC standards by funded services.

In our *Report of Reviewable Deaths in 2004*, we recommended that DADHC undertake a review of record keeping practices in licensed boarding houses, implement the results of the review, and evaluate and report on the outcomes. DADHC advised that in 2006 its Service Development and Planning Branch liaised with the regions to coordinate a review of Licence Condition 4, which relates to the record keeping responsibilities of the Licensee and Licensed Manager. A sample of 47 out of a possible 55 licensed boarding houses were reviewed. The review found that, while in most cases the licensed boarding houses had met record keeping requirements under Licence Condition 4 to a significant degree, full compliance with this condition was often not achieved by operators, and required strengthening.

The department outlined a number of actions it would take, in consultation with the relevant peaks, agencies and Expert Advisory Group, to strengthen compliance to Condition 4 and encourage better practice. These actions include reviewing the monitoring tool associated with Condition 4, setting good practice benchmarks for that condition, and developing a resource to support the sector improve their compliance and practice to Condition 4.

3.8 People with progressively deteriorating health conditions

While some of the deaths of people with disabilities in care in 2005 were sudden and/or unexpected, others were the end point of a progressive deterioration in health. For some people the deterioration was related to the ageing process, while for others it was the flow on from new health issues, or as a result of the progression of chronic and longstanding health concerns.

Service management of deteriorating conditions

Services have often reported to us that the ageing of people with disabilities in care presents challenges in terms of meeting increased support needs, and tapping into appropriate assistance to ensure those needs are met. We took a closer look at some of the deaths of people whose conditions progressively deteriorated before death in order to identify particular concerns or questions about the adequacy of the care provided to those individuals over the course of the decline.

We found that, on the whole, services continued to meet the needs of those individuals as their conditions worsened, calling on relevant professionals and practitioners where required. This appeared to be particularly the case for the individuals who were living in departmental large residential centres, where nursing staff were at hand, and allied health services were in-house and readily accessible for assessment and intervention.

By way of illustration, we reviewed the death of a 29-year-old woman who had lived in the same departmental large residential centre since she was three years old. She had multiple and complex health issues and her health had deteriorated in the two years prior to her death, with her respiratory function becoming increasingly diminished. The service held a number of case conferences with medical professionals and the woman's legal guardian to discuss the worsening of her condition, and her associated support needs. The service developed a detailed health care plan for the woman that provided clear guidance to staff in how to support her complex health needs.

The woman received appropriate and timely intervention from health professionals, including regular reviews by her GP, neurologist, dietitian, physiotherapist, and respiratory physician. In addition, although the woman's health condition was deteriorating, it was evident from our review that the service had taken steps to maximise her involvement in activities, including providing day program services in her room when she was no longer able to travel to the day program site due to her declining health.

Ageing in place

As highlighted in our consultation project in section 4 of this report, services are reporting that they are largely unclear as to whether, and how, 'ageing in place' might apply to people with disabilities in care. That is, whether people with disabilities in care who are ageing should reside in disability accommodation for life, or whether a transition to aged care accommodation is required and appropriate.

Interestingly, in the matters we reviewed where the individual's declining condition was related to ageing, there did not appear to be any question by the service that the person would continue to be supported by the disability service, regardless of their additional and increasing support needs.

For example, we reviewed the death of a 90-year-old woman who had lived in a funded large residential centre for 82 years before moving to a group home with the same service when they devolved three months before her death. She was largely bed-bound, and in the last few years of her life her health had started to decline, as she became increasingly drowsy during the day, developed tremors, had a reduced appetite resulting in significant weight loss, and developed muscle wasting.

Over this time she had geriatric, neurology, psychiatric and GP reviews, and the involvement of appropriate allied health services. In addition, the local palliative care team twice reviewed her and provided advice to the service for the continuing support of the woman at home. The service had ongoing contact with the woman's niece, and agreed that the woman would continue to be supported at home as her condition deteriorated and palliative care commenced.

Support for people with non-ageing related decline

We noted that, for people whose declining condition was related to an illness or the progression of their health issues, there seemed to be greater consideration of what accommodation type may be more appropriate to meet their increasing support needs, and a greater propensity to transition the individual from the disability service into the other accommodation. This appeared to relate to the amount of support available in the disability service.

This included a 43-year-old man who moved from departmental group home accommodation to a palliative care unit as his needs became too great to be met by the disability service. Prior to the progression of his liver cancer, the man had had low support needs, and had been accommodated in one of a group of four two-bedroom units that was supported by one staffing position.

We also reviewed the death of a man who had lived in a funded group home, where concerns about its ability to meet the man's increasing support needs resulted in the service admitting him to hospital for a definitive assessment of those needs. The following case study highlights the rapid change in the man's condition and support needs, and outlines how the service responded to those changing, and increasing, needs.

CaseStudy6

When the man first moved into the group home, he required support for personal care, but could mobilise independently using a wheelchair, weight-bear, transfer himself from his wheelchair to another seat, and eat meals with minimal assistance. In 2005 the man had a stroke, and his health continued to deteriorate over the next three months. Over this period he saw his GP and neurologist regularly, and our review of the file information indicated that the service was trying to manage the man's increasing support needs, but was finding it difficult to continue to do so.

Three months later, the service transferred the man to hospital, due to its concerns about his continuing deterioration in health. The service requested that an assessment be conducted to determine the cause of his deterioration. At the time of this hospital admission, the man's condition had declined to the extent that he had a reduced level of consciousness, was not responding to pain triggers, was unable to swallow solid foods, was only able to give one-word answers, was unable to sit upright, lacked the strength to mobilise his wheelchair, and had become incontinent.

A case conference was held while the man was in hospital, involving the man's family, service staff, and medical professionals. It was agreed that he needed a level of nursing care that was greater than that able to be provided by the non-nursing, disability service. While in hospital the Aged Care Assessment Team assessed him as appropriate for nursing home accommodation because of his support needs. His condition continued to decline despite treatment, and he died two months later.

Amount of change in support needs

From the matters we reviewed, we noted that where a disability service was already providing a high level of support before the deterioration in the person's condition, it appeared more likely that they would continue to be accommodated at home. Where the support needs of the individual had initially been relatively low prior to the decline in their condition, services seemed more inclined to indicate that they could no longer meet the changing needs of the person.

Consequently, we found examples of group homes that had already been providing an intensive service to the individuals in their care that continued to heighten the amount of support provided to meet the individuals' support needs as they increased.

This included one departmental group home that supported a 60-year-old woman with considerable mental and physical health needs. Over the years the woman had been receiving intensive support from the service in relation to her health needs, including significant inter-service work with the mental health team, rehabilitation units, and psychiatric and general hospitals.

When her physical health continued to decline in the 12 months before her death, the service organised for an assessment by the Aged Care Assessment Team, and included the woman in the local Aged Care Disability Pilot to ensure her additional support needs could continue to be met at home. It was evident that the service went to some lengths to continue to provide appropriate and adequate support to the woman at home as her condition declined.

Meeting needs other than health

Our reviews of the people with disabilities in care whose conditions progressively deteriorated prior to their deaths in 2005 indicated that generally their health needs had been well met. However, we did note that few of these individuals had access to the community, involvement in meaningful activities, or interaction with their peers.

It was evident from the matters we reviewed that a person's declining health tends to reduce or stop their participation in regular activities, such as attendance at a day program or access to the community, as their physical health begins to dominate over other concerns. For many of the people we reviewed in this section, their daily activities typically involved watching television, eating, sitting, and sleeping.

We appreciate that it can be difficult to balance the social needs of people with high support needs or unstable conditions with the service's responsibility to maximise the person's health and wellbeing, and that some of these concerns also apply to elderly or frail members of the general community. However, given that a large proportion of the existing disability service population is ageing and will increasingly fit the profile of many of the people outlined in the above examples, it is important that the social and recreational needs of these individuals are considered now, and included in any planning for the future.

Endnotes

[22] Fifteen people lived in the care of disability services; one person was a boarding house resident.

[23] NSW Ombudsman (2005) *Report of Reviewable Deaths in 2004*, p 41.

[24] Norberry and Millard (2000) *Tobacco consumption of residents in boarding houses.*

[25] NSW Ombudsman (2005) *Report of Reviewable Deaths in 2004*, p 21.

[26] Primary health care services funded under the program include podiatry, dental and physiotherapy services. Secondary health care includes health and lifestyle education and awareness programs.

[27] BiPAP stands for bilevel positive airway pressure, a method of respiratory ventilation that uses an electronic circuit to monitor the patient's breathing.

[28] Records were not able to be obtained in relation to two boarding house residents who died in 2005, as the boarding house closed before the records could be sought.

4. People with disabilities in care and the health system

4.1 Background

Last year we completed a review of health care planning in funded disability accommodation services. The ten services involved in the review reported a number of challenges that impacted on the health care planning and coordination they were able to provide the people with disabilities in their care. Most of these challenges concerned the health system, including extensive waiting lists for speech pathology services, ensuring a high quality of care to people with disabilities in hospital, and locating GPs with knowledge of disability.

This year we have built on that work by reviewing the interaction of people with disabilities in care with the NSW health system. Our aim was to identify the key issues facing people with disabilities in care and disability service providers in their dealings with the health system, and the possible reasons for the existence of those issues.

4.2 Methodology

Over three months from April 2006 we conducted focus groups around NSW with a wide range of disability accommodation service providers and other parties who represent or work with people with disabilities in care. The 33 consultations were held with:

- 45 funded services (17 groups)
- DADHC Network Managers (five groups)
- Licensed boarding house managers or caseworkers (five groups)
- Disability peak agencies and statewide advocacy agencies (two groups)
- Advocacy groups (two groups)
- Official Community Visitors (one group)

The information contained represents the key issues identified by participants in our consultations relating to their experience supporting or advocating for people with disabilities in care and their contact with the health system. We have provided copies of the original summary document to NSW Health, DADHC, the Royal Australian College of General Practitioners, the Alliance of NSW Divisions, and to the disability deaths advisory committee. Comments provided have been considered in the development of the final report.

In our consultations, we separated the discussion into seven key health areas: health screening, allied health, dental services, hospitals, mental health, aged care, and the Boarding House Reform Program (BHRP). We have structured this section of the report in the same way.

4.3 Health screening / early intervention and prevention

In our previous reviewable deaths annual reports, we have highlighted the importance of health risk screening for people with disabilities in care. Health risk screening enables early intervention to address identified health risks, and can possibly prevent some health concerns progressing to a point where it negatively impacts on, or threatens the life of, the individual concerned.

Our reviews of the deaths of people with disabilities in care in 2005 identified some concerns about the adequacy of health assessments. While many of the people whose deaths we reviewed had some form of assessment document (such as CHAP) on file, few appeared to have been comprehensively completed.

Key issues identified in the consultations

Many of the people we consulted raised concerns about access to health screening, the capacity and willingness of GPs to undertake comprehensive screening or health assessments in relation to people with disabilities, and the quality of health assessments. Some of the specific concerns raised that related to people with disabilities in care were:

Lack of comprehensive assessments or screening for health risks

Consultation participants told us that although people with disabilities in care generally see GPs regularly, the focus of the GP is often on the presenting problem rather than on comprehensive assessment or screening with a preventative or early intervention focus. Participants put forward a number of possible reasons for this, including:

- Many GPs consider that people with disabilities do not 'need' health screening, and may query the value of preventing potentially serious health issues for that group of individuals.
- The amount of paperwork that GPs need to complete in relation to comprehensive health assessments can be onerous.
- Few GPs have knowledge of disability or indicate an interest in developing that knowledge. Services advised in the consultations that they 'shop around' for GPs who have knowledge of, or an interest in the disability field, or who are willing to work with people with disabilities, and those GPs then tend to be flooded by the disability services in that area. Further, many services indicated that once they locate a 'good' GP, they go to great lengths to develop and maintain a relationship with the GP and their receptionists in order to receive a more responsive and comprehensive service for the people with disabilities in their care.

Access inequities

We were told that some people with disabilities in care are more likely to miss out on health screening or comprehensive health assessments, including people with challenging behaviours, people with communication difficulties, and people with physical disabilities. In relation to people with physical disabilities, consultation participants pointed to the lack of accessible examination tables, the absence of lifting equipment, and difficulties being able to physically access x-ray and other screening equipment. In particular, concerns were raised about the limited breast screening options put forward for women with cerebral palsy who are unable to access mammogram equipment.

Ways to improve access

From the consultations, there were a number of strategies that were reported to improve the access of people with disabilities in care to health risk screening and the quality of the assessments. These strategies included:

- The creation of health care planner / coordinator positions. A number of services indicated that they had created these positions, typically filled by people with a nursing background, to take responsibility for managing and coordinating the health care needs of the people with disabilities in their care. Their roles included liaising with medical practitioners and hospitals, developing health care plans, and ensuring any recommendations are implemented. Consultation participants said that the involvement of these positions in the health care management of people with disabilities in their services had resulted in an improved GP response and better outcomes for clients.

- Development of relationships with Divisions of General Practice. Services reported that where they had developed working relationships with their local Division of General Practice, it had improved the quality of the service provided to the clients by the GPs. Generally these services commented that there were fewer difficulties with GPs who were closely associated with their Division.
- Involvement of multidisciplinary health clinics. A large number of participants indicated that health screening for people with disabilities in care is most effectively, and comprehensively, achieved through multidisciplinary clinics such as the Developmental Disability Clinic operated by the Centre for Developmental Disability Studies.

  Participants reported that staff at the developmental disability clinic have a knowledge of disability and pull all the disability and health 'silo' areas together to provide a holistic picture of the health risks and needs for the individual. They refer to appropriate allied health and other services, and make it easier to access traditionally difficult to access services such as speech pathologists and Aged Care Assessment Teams. Services that had used the developmental disability clinic consistently commented that it had helped to coordinate and connect everything together for the person, and had helped to educate staff, families, and GPs.

Enhanced Primary Care

Under the Enhanced Primary Care (EPC) / Chronic Disease Management items of the Medicare Benefits Schedule, GPs can refer people with chronic health issues to a maximum of five allied health and three dental care services in each 12 month period. This allows people to access these services from registered private providers at greatly reduced cost.

Consultation participants indicated that EPC is not commonly known or used by GPs or disability services. Some services commented that for allied health providers there is poor compensation and significant paperwork, resulting in some providers not accepting EPC vouchers.

Agency initiatives in relation to health screening / early intervention

In 2004, NSW Health funded the Centre for Developmental Disability Studies (CDDS) to deliver an educational strategy on health care for people with developmental disabilities to GPs, which was also extended to Community Health workers. The Primary Health Care Capacity Building Project was rolled out in 2005, and the final report was delivered in January 2006. NSW Health is currently considering the outcomes of the project.

NSW Health has also advised that, in conjunction with DADHC, it is in the process of developing a Service Framework for the Health Care of People with an Intellectual Disability. The Framework will specifically address training to health workers on health care for people with intellectual disabilities.

In response to our recommendation, NSW Health has advised us that in early 2006, the NSW Minister for Health wrote a letter to the Federal Minister for Health and Ageing in support of a proposal for a Medicare funded annual comprehensive health assessment for people with intellectual disability. DADHC advised that in March 2006 the NSW Minister for Disability Services also wrote a letter to the Federal Health Minister in support of the proposal.

4.4 Allied health services

The key issues raised by the people we consulted in relation to allied health or therapy services concerned access barriers and inequities, quality of service delivered to some people with complex health needs, and gaps in allied health provision to people with disabilities in care.

Barriers to access

Participants raised concerns about the number of barriers to accessing therapy services that exist for people with disabilities in care, including:

- Waiting lists. Extensive waiting lists for therapy services provided by DADHC through its Community Support Teams (CSTs), and by NSW Health through Community Health services. Some services reported that the onerous wait times for access to DADHC therapy services were such that they no longer referred clients.
- Contested responsibility for service provision. Some participants reported that people with disabilities in care are unable to access Community Health services due to some Community Health services referring responsibility for the provision of allied health services to people with disabilities to DADHC. This was reported to be the case for most allied health services, but particularly in relation to access to dietitians and occupational therapists.
- The cost of accessing private therapy services. The cost of private services was reported as a burden on people largely dependent on the Disability Support Pension, and a restriction on the other services they can access. For example, the decision to use client funds to access a speech pathologist means that there are unlikely to be funds to access a private dentist. Some services reported trying to cover the cost of private therapists through fundraising activities.

Access inequities

Wide variations in access to allied health services were reported across (and within) regions. For example, within one region, services in one area reported easy access to DADHC speech pathology, but services in the neighbouring area reported very difficult access. Similarly, services reported that clients in one area could access a dietitian through the hospital, but clients in the neighbouring area had to pay for the same service.

While some of these variations could be ascribed to the differing availability of services, others were attributed to access decisions being based on existing relationships or contacts. Many services reported that the success of referrals often depends on the relationship between the service and the allied health provider. For example, some services reported that while hospital-based Community Health staff will be instructed that provision of therapy services to people with disabilities in care is DADHC's responsibility, some will continue to provide the service due to the local contacts and relationships that have been established.

In addition, inequities in access to allied health services were reported in relation to licensed boarding house residents. Access to allied health services for people living in licensed boarding houses was reported as occurring only in regions that had a primary and secondary health care caseworker position in place. Allied health services were reported to have little involvement with licensed boarding house residents where these positions were absent.

Quality of service

Some participants raised issues about the quality of the service provided by some allied health providers.

Participants raised concerns about the lack of knowledge of some allied health providers in relation to people with disabilities. Services reported that some dietitians, for example, provide adequate advice about low-fat diets, but either do not want to work with people with more complex needs, such as enteral feeding, or their level of expertise is inadequate.

Services reported that for physiotherapy, in particular, there is typically a long wait. Services also said that due to high demand there were often limitations to public service provision, with cases closed after six weeks despite ongoing need.

Gaps in service provision

Aside from the general gaps in allied health provision due to workforce vacancies, the people we consulted identified some specific gaps relating to the provision of nursing services that impact on people with disabilities in care.

Access to community nursing was reported to be variable, and there were gaps identified in relation to specific nursing tasks. Particular concerns were raised by DADHC staff about the costs of paying private nurses to perform tasks that require a registered nurse, such as insulin injections, while simultaneously employing people with registered nurse qualifications as Residential Support Workers but not permitting them to use those skills.

In addition, many participants, including DADHC staff, considered that there would be significant benefits if nurses were employed by CSTs, to fill existing gaps and provide advice relating to health needs, particularly in relation to clients with complex health needs. For example, services in one region expressed concern that the only stoma nurse they could access was based in a different region, and they could only receive telephone advice as a result. Some funded services have created similar positions (for example, in the role of Health Care Coordinator) out of existing funds due to the existing need and absence of alternative options.

Agency initiatives in relation to allied health services

In relation to therapy services, there are five key areas of work that have been initiated by government agencies.

- *Stronger Together*, the NSW Government's framework for the direction of disability services over the next ten years, indicates that the number of therapy places provided by DADHC for adults with disabilities will increase by 25% over the next five years. DADHC has advised that the allocation of the first round of places will be finalised in October 2006.
- DADHC has advised that it is currently reviewing the structure of its CSTs, including the provision of therapy services, as part of a broader refocus of CSTs. The review, due for completion by the end of 2006, encompasses an analysis of strategic issues such as service access and responsiveness; models of service delivery; service

fragmentation and coordination; and workforce capacity. It will also involve a review of the department's *Prioritisation and Allocation* policy, which guides access to CST services.

- DADHC is also continuing its review of the existing clinical nurse specialist model of health care case management to determine its potential for wider application in DADHC operated and funded services.
- NSW Health's Workforce Action Plan takes a 'whole of health' approach to health workforce, and includes initiatives such as the development and delivery of an Allied Health Clinical Leadership course, creation of Area Allied Health Advisor positions in each Area Health Service, and establishment of an Allied Health Discipline Advisors network to foster greater clinician-led involvement in workforce development.
- An Interagency Standing Committee on Disability (ISCD) has been created to oversight the development of a 'whole-of-government' policy and service delivery framework for disability services in NSW, and is chaired by DADHC. There are seven priority areas for the ISCD, one of which is access to therapy services. NSW Health has advised that a stock take of therapy services is to be undertaken as the first stage of the project to improve access to therapy intervention services for clients with priority needs by better integration of services.

4.5 Dental services

In March 2006, the NSW Parliament Legislative Council Standing Committee on Social Issues released a report on its inquiry into dental services.[29] The inquiry found that there is a sizeable minority of people who are deprived of access to acceptable dental care, 'due to the overstrained public system and their inability to purchase adequate private dental services'.[30] This was also the message communicated by the participants in our consultations. Participants' views echoed much of the information reported through that inquiry, including:

- Waiting times for public dental services are unreasonably lengthy for both the initial examination and subsequent treatment. Participants reported long waits for many clients between the extraction of teeth, and the fitting of dentures.
- The cost of accessing private dentists is not able to be met by many clients, leaving them with no option but to wait with ongoing dental problems for public dental services.
- The treatment options available to clients who access public dental services are more limited than those presented to private dental patients, with the emphasis on the extraction of affected teeth rather than restoration.

Additional risk factors for people with disabilities

Participants communicated that there are additional factors impacting on the dental care provided to people with disabilities, and affect the dental health of those individuals.

The existence of multiple and complex health issues for many people with disabilities in care place them at additional risk from untreated oral conditions. People with chronic health conditions are more susceptible to respiratory and other illnesses. For these people, the additional risks posed by poor oral health and/or untreated dental conditions can have serious implications.

In addition, there is an increased need for regular and comprehensive dental reviews for people with specific health issues such as GORD,[31] and people receiving enteral nutrition.[32] While DADHC's *Managing Client Health* policy recommends dental reviews every six months, services report that this is not occurring due to the waiting lists for public services, and the limited financial resources of clients.

Dental care can be complicated by the need for some people with disabilities to be examined and/or receive treatment under general anaesthetic. Participants reported that the limited provision of these services adds to the waiting and travel time, and general anaesthetic carries risks, particularly for individuals with compromised health or who are prone to respiratory illness.

Services reported that they are told by public dental clinics that unless the person is complaining of pain, they will have to wait. This prioritisation process can tend to exclude many people with disabilities who may never complain of pain, regardless of the discomfort felt. Lack of intervention can impact on their ability to eat, and affect their ability to undertake regular daily activities.

Participants reported that the significant length of time that some people with disabilities in care wait for dentures can place them at risk of malnutrition, and affects the capacity of some individuals to accept and wear the dentures when finally received. This was reported particularly in relation to licensed boarding house residents.

Boarding House Reform Program primary and secondary health care

Participants reported significant local variability in relation to access to dental services by licensed boarding house residents. While the primary and secondary health care caseworkers in some regions indicated that they use their allocated funds to pay for residents to access private dental services, others indicated that residents in their area have to wait to access public services as they have no funds to pay for private practitioners.

Agency initiatives in relation to dental services

One of the recommendations made in the *Dental Services* inquiry relevant to the issues identified by participants in our consultations was that the new oral health strategic plan for NSW should consider the issues related to special needs groups, including priority for treatment, appropriate training for dental practitioners and the need for ongoing education programs and dissemination of information. In September 2006, in response to this recommendation, the NSW government advised that it would conduct a review of access to dental services by persons with special needs in 2006–2007. The outcomes of the review would be included in the development of the special needs program, which is part of the framework of the oral health strategy linked to $40 million budget enhancements.

4.6 Hospitals

The majority of the people we consulted raised concerns about the interaction of people with disabilities in care with hospitals. Many of the concerns expressed by participants in our consultations have also been identified in our reviews of the deaths of people with disabilities in care over the past two years, and are reported in section 3 of this report, including end-of-life decision-making and discharge planning.

One of the dominant messages communicated by participants in relation to hospitals concerned the impact of an individual's disability on the breadth of their hospital admission, from assessment, to treatment decisions, requests for support, quality of care, and discharge planning. Some of the specific concerns included:

Impact of disability on treatment and end-of-life decisions

Participants reported their perception that decisions regarding treatment and investigations can appear to be largely based on the person's disability rather than their presenting medical condition. Many services raised concerns about judgements being made about the perceived 'quality of life' of people with disabilities in care, and the effect those judgements can have on treatment and investigation decisions. The following example was provided during the consultations:

> *A woman with cerebral palsy went down to 38kg while she was a patient in hospital. The hospital advised the disability service that it would be discharging the client, despite her dangerously low weight. In discussions with the hospital the service found that medical staff had made an assumption that the client's low weight was related to her cerebral palsy, and that no investigations had been undertaken, or were planned, to consider possible reasons for her being underweight, or possible treatment options.*

Concerns about decisions being based on disability rather than diagnosis and prognosis were raised particularly in relation to end-of-life decision-making. Participants reported that treatment limitation decisions are sometimes made in relation to people with disabilities in care while in hospital, regardless of the illness or condition the person is admitted for. Some services expressed their belief that disability and perceived quality of life can be used as reasons for rationalising treatment. The following example provided through our consultations highlights their concerns:

> *A 33-year-old woman was admitted to hospital with a diagnosis of pneumonia. The service discovered that a no-CPR order had been placed on the woman's medical record. When the service discussed the decision with the Medical Registrar, they were advised that the no-CPR order was considered valid because a) the client was unable to communicate, b) the client relied on others for all activities of daily living, and c) the client had lived in a large residential centre for years, and would spend the rest of her life there.*

Requests for in-hospital support

Most services raised concerns about being asked by treating hospitals to provide staff to support their client for the duration of their hospital stay. Participants said this was regardless of the support needs of the individual or their presenting health issues, and the cost involved to the service. In relation to this issue we noted that:

- Many participants, including DADHC staff, raised concerns about the cost of providing personnel during hospitalisation to provide 1:1 support, yet few indicated that they had taken steps to resolve the issue, such as commencing discussions with the Area Health Service.
- Most services were unaware of the NSW Health policy directive *People with Disabilities: Responding to their needs during hospitalisation*, and very few had a local area agreement with their Area Health Service or specific hospitals. Where written agreements had been developed, services reported that they work well, with services generally being reimbursed by NSW Health for the provision of staff.

Quality of care

A common view put to us was that the quality of care provided to people with disabilities during hospitalisation is often inadequate to fully meet their needs, and heightens their vulnerability. By way of illustration, participants reported that:

- Trays of food are sometimes delivered to patients who require assistance to eat. If they are not given assistance, the food is likely to be removed without the person having eaten anything.
- Meals are sometimes given to people with swallowing difficulties that do not meet their requirements, and therefore place them at risk. For example, a person on a blended diet was reportedly given sandwiches in hospital.
- Patients with disabilities are sometimes admonished by hospital staff due to a lack of understanding of the person's disability or individual needs. An example was provided of a service being told by hospital staff that a particular person had behaviour issues because she wouldn't stand up, but the person had been in a wheelchair since a young age.

Pain management

Participants reported that pain diagnosis and management can be inadequate for some people with disabilities. They said that because some people with disabilities do not verbally communicate that they are in pain, there is an assumption made by hospital staff that no pain is felt, and no pain management is required. Participants indicated that this issue can affect many aspects of hospitalisation, including the diagnosis, decisions by medical staff as to whether to investigate and the length of stay.

Adequacy of assessment

Many of the people we consulted reported that assessment in the Accident and Emergency department of hospitals is a 'weak link' for people with disabilities in care. Participants raised concerns about inadequate assessments undertaken in relation to some people with disabilities who present to Emergency, particularly people with communication difficulties. By way of illustration, the following example was provided during the consultations:

> *A man had a fall and was having difficulties walking. He was seen in hospital and had several x-rays, but they couldn't find anything. He kept pointing to his knee as being sore. When he went into an appointment with a psychologist, they said he has a broken hip. He then had an x-ray that showed that he clearly had a broken hip, and we heard that the knee pain was a common transference of pain, which most people have with a broken hip. Only the knee was x-rayed when they were going off what the client was pointing to rather than considering more broadly what the issues could be. In the meantime, he had been walking for 5–6 weeks on a broken hip.*

Discharge planning

Most services reported concerns with the quality of discharge planning by hospitals, including the quality of the discharge summary (where provided), the process followed, involvement of services, and referrals for supports. Specific concerns raised by participants were:

- Discharge planning for people with disabilities in care may be affected by the misconception held by many hospital workers that the individuals live in nursing homes and that disability service staff are nurses. Participants indicated that this can lead to the assumption that clients can be discharged earlier to a setting that provides nursing care around the clock, that little information needs to be provided in discharge summaries, and that referral to therapy or other support services is unnecessary.

- Discharge planning rarely occurs. Many participants commented that discharge planning often consists of a call to the service to advise that the person is being discharged. Some services are contacted only at the time of discharge as the person is being transferred back to the service.
- Some people with disabilities are discharged early, compromising their health. The following example was provided during our consultations:

  > *We had one instance where the client was on oxygen in hospital, and they wanted to discharge him without testing that he could make it through the night without oxygen. We refused to accept discharge — it was a fight, but he stayed in hospital. Hospital staff told me the next day that it was the right decision.*

- Services reported that they generally receive poor quality discharge plans or summaries, if they are provided. Services indicated that they have received discharge summaries with nothing on them, that they have to ask for any discharge document to be provided, and that few summaries contain referrals for other services or support.
- Service staff are largely excluded from any discussions while the person is in hospital, but are expected to be able to understand and meet support needs at the time of discharge. Services advised that information about the client is often only provided to family members or the person responsible, but not to service staff. This restricts the services' ability to liaise with family, and be informed about changes in client needs.

Many services indicated that as a result of experience with a combination of early discharge, poor discharge planning, and poor discharge summaries, they have taken steps to control this process as much as possible from their end.

Services indicated that they have started setting their own requirements for discharge. Examples of this included service policies of not accepting discharge unless the service manager or equivalent position has agreed, only accepting discharge if there has been involvement from the discharge planner, and only accepting discharge if a clear discharge summary is provided that staff can understand.

Services that have created the health care coordinator / planner positions advised that they involve those positions to liaise with relevant hospital staff, such as the discharge planner. Services advised that the discharge process is improved where the service has a good relationship with the discharge planner, or if the service's nursing or health care coordinator positions are involved.

Agency initiatives in relation to hospitals

NSW Health has undertaken three key pieces of work that are relevant to the issues identified by participants in our consultations. In summary, NSW Health:

- Is in the process of engaging a consultant to evaluate the implementation of the *People with Disabilities: Responding to their needs during hospitalisation* policy directive in Area Health Services.
- Has recently released the *Discharge Planning: Responsive Standards*, which provide the framework and policy direction for discharge planning across health services. The *Standards* make particular reference to discharge

planning requirements for people with disabilities who are admitted to hospital.

- Has undertaken a seminar series in metropolitan Sydney and regional NSW to health care professionals regarding the key messages of the *Guidelines for end-of-life decision-making* policy directive, and is liaising with Area Health Services to examine their progress with the development of policy committees to consider local implementation needs in relation to the *Guidelines*.

4.7 Mental health services

In March 2006, the Senate Select Committee on Mental Health issued its first report on a national approach to mental health.[33] The inquiry found that mental health inpatient and crisis services are under significant strain, with treatment and other interventions available only in the most immediate life-threatening situations; very limited access to psychiatrists, particularly in the public system; and lack of discharge planning following psychiatric admissions. These issues were echoed in our consultations. In addition, participants raised concerns about difficulties or barriers that appear to be particular to people with developmental disabilities.

They told us that their clients were highly vulnerable when admitted to mental health facilities, including being at risk of assault. They also advised that there is a very limited pool of psychiatrists who have an understanding of intellectual disability. Services reported travelling long distances to access psychiatrists who have this knowledge, and indicated that this has resulted from accessing public or local psychiatrists first and finding the assessment and support to be inadequate to meet the needs of the person. Participants also reported a gap in the availability of options for clinical detoxifications or reviews for people with intellectual disabilities, where a person's antipsychotic or other medication may be stopped or adjusted to see what works best for their individual needs.

Primary diagnosis and agency responsibilities

Most of the people we consulted who had had contact with mental health services identified that the key barrier to people with disabilities accessing those services is the issue of primary diagnosis and the lack of clarity about which agency has responsibility for providing mental health services to people with intellectual disabilities.

Participants advised that if intellectual disability is considered to be the person's primary diagnosis, then DADHC appears to have responsibility for providing services, but if mental illness is the primary diagnosis, then NSW Health seems to have primary responsibility. Many services reported that clients have been unable to access any mental health services as a result of this division. Participants identified additional difficulties that heighten this barrier:

- It can be difficult to accurately make a psychiatric diagnosis when the individual also has an intellectual disability, particularly if the level of cognitive impairment is severe to profound. In tying provision of service to diagnoses, services are reporting that people with disabilities in care are largely being cut off from accessing mental health supports.
- Some mental health services fail to recognise that an individual may have an intellectual disability and a mental illness. Participants in different regions stated that they had been told by mental health services that people with intellectual disabilities cannot have a mental illness, and that the individuals are just demonstrating 'behaviours' associated with their intellectual disability.

Impact of poor discharge planning

Participants noted that poor discharge planning can have significant consequences for the individuals in their care. The following example provided in the consultations illustrates this point:

> *We had a man who was manic, and was put on a bus and sent home. They rang us up and told us to pick him up off the bus. The client got off in a different town in error. These things cause problems but are extremely dangerous for the individual concerned… and do not give a good impression of disability. They did not contact us before putting him on the bus.*

Mental health liaison positions

The licensed boarding house population typically has a high proportion of people who have been diagnosed with some form of mental illness. Our consultations indicated that where Mental Health Liaison positions are in place, they benefit both residents and staff, performing such functions as organising Clozapine clinics, arranging psychiatric reviews, providing support to residents, liaising with psychiatrists and mental health services, and responding to requests for assistance from licensed boarding house staff.

Agency initiatives in relation to mental health

Stronger Together states that DADHC will establish a joint professorship with a university in NSW in disability and mental health to build the evidence base for good practice, at a cost of $0.7 million over five years.

4.8 Ageing

In June 2005, the Senate Community Affairs Reference Committee released a report following its inquiry into Quality and Equity in Aged Care,[34] significant sections of which considered young people with disabilities living in aged care facilities, and funding for residents with special needs. The inquiry found that in some areas Aged Care Assessment Teams are refusing to assess anyone who is under the age of 65; that even when accommodation is being sought in an aged care facility it can be difficult to get an assessment or find a place; and that aged care facilities are sometimes ill-equipped to provide appropriate rehabilitation and allied health services. These findings mirror some of the information provided in our consultations.

Barriers to access

Participants told us that the focus of the aged care system on a chronological number excludes some people with disabilities. The fact that some people with disabilities age much earlier than the general population means that they are cut off from accessing services that set an age as the criteria for eligibility, or for prioritisation.

Participants variously reported that in relation to Aged Care Assessment Team (ACAT) services:

- People with disabilities are unable to access ACAT due to not meeting the age barrier.
- People with disabilities in care are unable to access ACAT services because they live in supported accommodation.
- There is no difficulty gaining access to ACAT assessments, but there is nowhere for people with disabilities in care to go once they have been assessed as needing high level support.
- There is no difficulty accessing ACAT assessments, and clients then move into nursing home accommodation.

We found that the variability existed within regions, and sometimes even within the same area in a region, raising questions about equity of access.[35]

There was also a common view that access to aged care services for people with disabilities is affected by the issue of primary diagnosis and the lack of clarity about whether the State or Federal government has primary responsibility for people with disabilities in care who are ageing. Services indicated that if the person's primary diagnosis is considered to be intellectual disability, then DADHC has responsibility, but if the primary diagnosis is age related, the Commonwealth has responsibility. Participants identified additional difficulties that heighten this barrier:

- It can be difficult to diagnose dementia in people with intellectual disabilities, and people with a possible diagnosis are less likely to receive support and access to services than someone with a definitive diagnosis.
- Participants raised concerns that the standard test for dementia is not appropriate for people with intellectual disabilities, but alternatives are rarely offered.

Participants told us that people with disabilities in care are prevented from accessing some aged care services due to being in supported accommodation. Services indicated that services such as Dementia Advisors are Home and Community Care-funded, and are thereby unable to be accessed by people living in the care of disability services.

Meeting the increasing needs of people with disabilities who are ageing

Most of the people we consulted pointed to the increasing support needs of people with disabilities who are ageing, and raised concerns about how, and where, those needs would be met.

Participants noted that there is currently a lack of policy direction in relation to 'ageing in place' and what it means for people with disabilities in care. Our consultations indicated that services were not clear on the position of either the state or federal government with regard to the appropriate provider of services to ageing clients.

The people we consulted expressed disparate positions on the topic. While many indicated that people with disabilities in care should be supported in disability accommodation for life, others argued that ageing in place is only appropriate until the age-related support needs of the individual overwhelm the capacity of the service to meet those needs.

Services said that it is becoming difficult for them to meet the increasing support needs of ageing clients without additional funding. They raised concerns about the level of resources needed to make necessary changes such as increasing staff during peak support times, providing day support for people no longer able to work, modifying accommodation for accessibility, and purchasing additional equipment, in order to meet the needs of ageing clients.

Some services indicated that the increasing support needs of ageing clients had raised viability issues, and had resulted in applications to DADHC for increased funding. Services reported variable responses by the department to such applications, ranging from advising the service that support for people who are ageing is a Commonwealth issue, through to approval of the application and provision of extra funds.

In 2001–02, the Commonwealth Department of Health and Ageing established an Aged Care Innovative Pool that funds a number of projects designed to test new approaches to providing aged care, including 'disability pilots'. This has involved a number of pilot projects examining how to meet the needs of ageing people with disabilities who are at risk of being admitted to aged care facilities because their increasing care needs cannot be met through disability support services alone. There are four such pilot projects underway in NSW, with DADHC a stakeholder in three.

The pilots have been roundly applauded by the disability services that have used them. These services told us that involvement in the pilots has reduced hospital and nursing home admissions for the clients involved. However, they also raised concerns about the uncertainty that exists as to what will happen once the pilots end this year, indicating that they could not match the level of support provided under the pilots with their existing funding.

Access to aged care accommodation

Some of the services we consulted pointed to difficulties that can exist for people with disabilities trying to access aged care accommodation. We were told that aged care facilities tend to take people with lower support needs, some nursing homes tend not to accept people with disabilities, and people who are already in supported accommodation are not considered to be a priority for placement in an aged care facility.

Participants also raised concerns about the quality of care provided to people with disabilities in aged care facilities. Concerns included lack of access to advocacy for individuals, particularly when there is no family involvement, and a lack of understanding on the part of nursing home staff about the needs of some people with disabilities. Many services expressed the view that disability services can provide better quality care and support to people with disabilities in care as they age.

Agency initiatives in relation to ageing

Stronger Together indicates a number of pieces of work relevant to the issues raised above, including that:

- The NSW Government will work with the Commonwealth Government to improve the interface between disability and ageing, including signing an agreement to assist younger people with a disability living in nursing homes. Part of the focus is on preventing younger people entering nursing homes in the first place.
- New models for day programs will be developed, including day programs for older people who are retiring.
- DADHC will commence research on the effects of ageing on people with an intellectual disability.
- DADHC will develop a retirement village specialising in aged care for 100 older people with disabilities, near Peat Island.

In addition, DADHC:

- Has commissioned a review of the NSW Aged Care and Disability Pool pilots to determine the impact of the models on the CSTDA funded services, document ageing-related learning by disability service providers, identify barriers to accessing mainstream aged care, and identify the need for further policies and guidance in relation to supports for people with a disability who are ageing.
- Is developing a policy for the care and support of people with an intellectual disability who are ageing.
- Is participating in a national research project commissioned by the National Disability Administrators about access for people with a disability to the aged care system and the merits of ageing in place for the same client group.

4.9 Boarding House Reform Program

Our consultations highlighted the positive impact of the primary and secondary health care program in terms of access to health services for licensed boarding house residents, but also raised some questions about existing inequities.

Participants reported improved delivery of health care services for licensed boarding house residents where primary and secondary health care caseworkers are in place. This was reported to be the case across health areas, including health screening, involvement of allied health services, access to dental services, coordination and receipt of mental health services, and involvement of appropriate aged care services. However, not all regions currently have primary and secondary health care caseworkers, and some have been instructed to only provide services to residents who have a mental illness.

There were also significant differences reported regarding how regions use the primary and secondary health care funds. We were told that some primary and secondary health care caseworkers employ available funds in creative ways to ensure residents receive adequate health care, including paying for access to private practitioners, and paying for nicotine patches. However, other caseworkers indicated that their use of the funds is much more limited, and focused on dental and podiatry services.

As highlighted in section 3.4 of this report, our reviews of the deaths of licensed boarding house residents in 2005 indicated gaps in the provision of primary and secondary health care in some areas, including access to dental services and podiatry, and the identification and coordination of significant health issues.

Agency initiatives in relation to the Boarding House Reform Program

Section 3.4 of this report outlines the advice provided by DADHC in relation to the primary and secondary health care program. The key developments relevant to the above issues include the recruitment of eight additional caseworkers to support licensed boarding house residents, the requirement for primary and secondary health care caseworkers to develop health care plans for all residents as part of the new Service Description Schedule, and the development of new auspice and service model arrangements for primary and secondary health care services.

4.10 Future directions

Some of the areas of concern identified by participants, most notably dental and mental health services, have been the subject of recent state and federal government inquiry. While there are additional factors that are particular to people with disabilities, work to implement the recommendations of those inquiries will be of benefit to the community at large, including people with disabilities in care.

We also noted that 2006 has been a key year for the development of whole-of-government and interagency work in relation to people with disabilities, including *Stronger Together*, the ISCD, and the developing Service Framework for the Health Care of People with an Intellectual Disability. Much of this work has the potential to address many of the issues raised above.

Some of the issues identified through our consultations are also the subject of current work by individual agencies, including improving discharge planning and responses to people with disabilities who are hospitalised, and addressing issues related to people with disabilities in care accessing nursing services.

However, most of the work is either still in development or is in the early stages of implementation. In either case, the work will require concentrated and sustained effort to have sufficient impetus to achieve progress and effect change for people with disabilities in care. We consider that a key role for the Ombudsman in this process will be to closely monitor the progress of the above work.

Endnotes

[29] *Dental services*, NSW Legislative Council Standing Committee on Social Issues, March 2006.

[30] *Dental Services* inquiry report, p 5.

[31] The incidence of dental erosion is high for individuals with gastro-oesophageal reflux disease.

[32] The potential for accumulation of dental calculus is high among people receiving enteral nutrition.

[33] *A national approach to mental health — from crisis to community*, The Senate Select Committee on Mental Health, March 2006.

[34] *Quality and Equity in Aged Care*, Senate Community Affairs Reference Committee, June 2005.

[35] In response to the draft of this report, NSW Health advised that ACATs assess younger people with a disability for entry to Residential Aged Care Facilities only after all other care alternatives have demonstrably been exhausted. ACATs are funded by the Commonwealth for a specific purpose and must prioritise use of finite resources for that purpose. Revising or expanding the role of ACATs would require a renegotiation of the funding agreement with the Commonwealth and a revision of the national guidelines for ACAT operations.

Appendices

Appendix 1

Reviewable disability deaths advisory committee — membership

Mr Bruce Barbour:	Ombudsman (chair)
Mr Steve Kinmond:	Deputy Ombudsman and Community and Disability Services Commissioner
Ms Margaret Bail:	Human services consultant
Dr Helen Beange:	Clinical Lecturer, Faculty of Medicine, University of Sydney
Mr Michael Bleasdale:	Director, NSW Council on Intellectual Disability; Senior Researcher, Disability Studies and Research Institute (resigned September)
Ms Linda Goddard:	Course Coordinator, Bachelor of Nursing, Charles Sturt University
Assoc Professor 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 (appointed January)
Dr Rosemary Sheehy:	Geriatrician/Endocrinologist, South West Sydney Area Health Service
Ms Anne Slater:	Physiotherapist, Allowah Children's Hospital
Assoc Professor Ernest Somerville:	Prince of Wales Clinical School, Neurology (appointed April)

Appendix 2

Data: deaths of people with disabilities in care in 2005

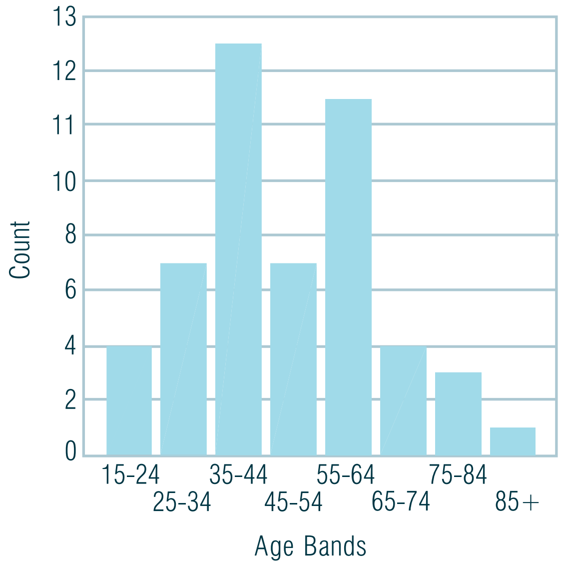
1. Demographic information

Age

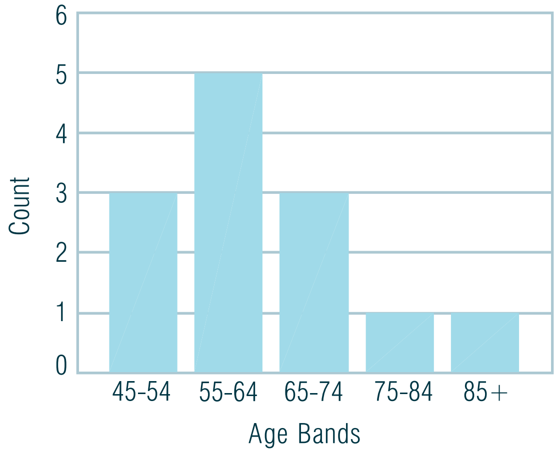
The age range of the people who died in 2005 was 20–90 years.

- The mean age at death for people who lived in group homes was 47 years.
- The mean age at death for people who lived in large residential centres was 51 years.
- The mean age at death for people who lived in licensed boarding houses was 63 years.

Age at time of death — disability services residents



Age at time of death — licensed boarding house residents



Gender

In 2005, the deaths of males outnumbered those of females in both disability services and licensed boarding houses, reflecting the trend in the broader community.

- Of the 13 people who died who lived in licensed boarding houses, 11 were male.
- Of the 54 people who died who lived in disability services, 33 were male.

The higher number of deaths of men with disabilities in care compared to women is also indicative of the greater use of disability support services by men in general.

For both disability services and licensed boarding houses, the average age at death was lower for females than it was for males, which differs from the situation reported for the general community. In NSW, men can expect to live 78 years, and women can expect to live 83 years.[36] On average:

- In relation to licensed boarding house residents, males died at 64 years, and females died at 60 years.
- In relation disability services residents, males died at 50 years, and females died at 47 years.

Cultural background

Of the five people who died who were reported as being from a non-English speaking background, four were living in licensed boarding house accommodation. No individuals were identified as being of Aboriginal or Torres Strait Islander background.

The number of people reported as being from a non-English speaking background who died while resident in a licensed boarding house has steadily increased since 2003, rising from 4% in 2003 to 31% in 2005.

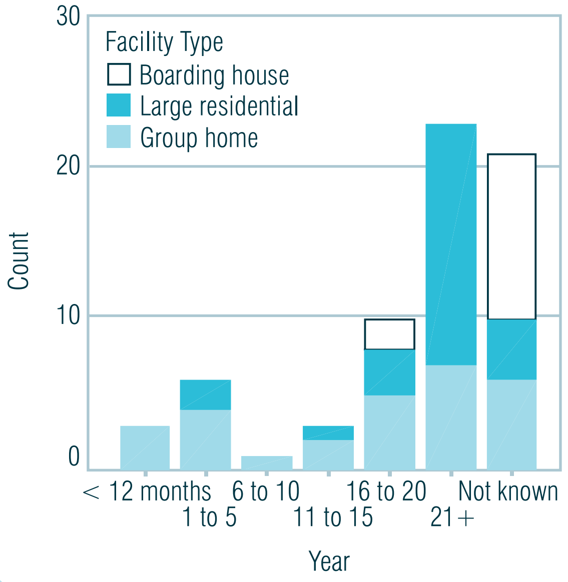
2. Service provision

Time in residential care

On average, the disability services residents who died in 2005 had been in care for 27 years, and had lived at their most recent location for 16 years. Residents of DADHC large residential centres had spent the longest periods of time at the same residence, averaging 31 years.

For licensed boarding house residents, the length of time in care was known for only two people, and they had lived in care for over 16 years. On average, the licensed boarding house residents who died in 2005 had lived at their most recent location for eight years, although the greatest proportion had lived there for one to five years.

Total lifetime years in care by accommodation type



3. Disability, health, and support needs

Disability

Most commonly reported disabilities

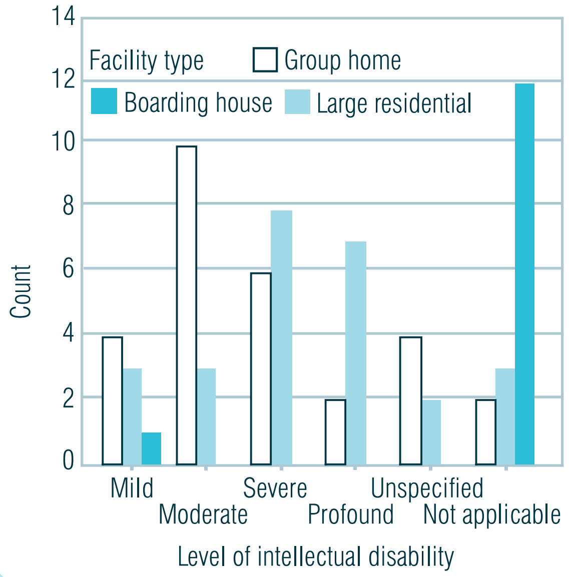
As was the case last year, the most commonly reported disability for disability services residents was intellectual disability (48 people). The people who lived in DADHC accommodation tended to be reported as having had a more severe level of cognitive

Number of years at most recent location by accommodation type

		Facility Type			Total
		Group Home	Large Residential	Boarding House	
Years at Location	<12 months	6	0	1	7
	1 to 5	8	4	8	20
	6 to 10	3	1	0	4
	11 to 15	6	3	0	9
	16 to 20	2	1	2	5
	21+	1	17	1	19
	Not known	2	0	1	3
Total		28	26	13	67

impairment than those who lived in the care of funded services. The cause of the cognitive impairment for nine people was Down syndrome.

Reported level of intellectual disability by accommodation type



In addition, two people who lived in the care of disability services had an acquired brain injury. Of the 54 people who died who had lived in disability services, there were only three people who did not have some form of cognitive impairment.

For the licensed boarding house residents who died in 2005, psychiatric disability was the most commonly reported disability, and most had been diagnosed with schizophrenia. The percentage of licensed boarding house residents who had a psychiatric disability was higher than the previous two years, accounting for 59% of the people who died in licensed boarding houses in 2003, and 50% in 2004.

Conversely, the number of licensed boarding house residents who were reported as having a cognitive impairment was lower than in previous years. 31% of the licensed boarding house residents who died in 2005 had some form of cognitive impairment, including one person who had Alzheimer's disease, two people who had acquired brain injuries, and one person who had a mild intellectual disability. In previous years over 50% of the licensed boarding house residents who died had some form of cognitive impairment.

Number of people with psychiatric disability by accommodation type

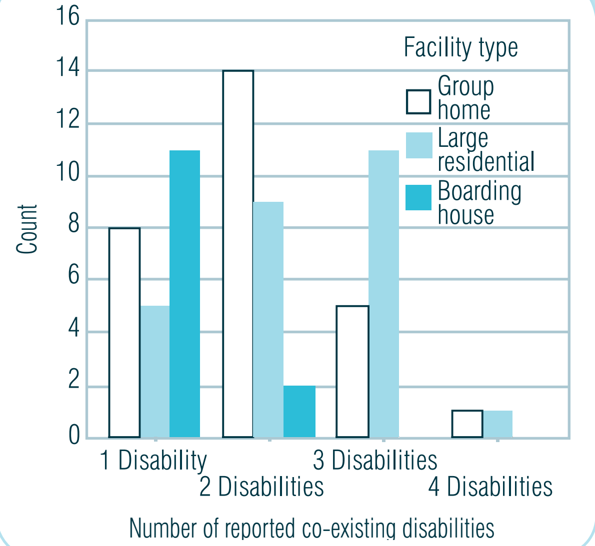
		Facility Type			Total
		Group Home	Large Residential	Licensed Boarding House	
Psychiatric Disability	Yes	8	2	9	19
	No	20	24	4	48
Total		28	26	13	67

Number of reported co-existing disabilities

Most of the disability services residents had an intellectual disability in addition to one or two other disabilities. Besides intellectual disability, the main recorded disabilities were physical disability (43%, mainly cerebral palsy), sensory disability (39%, mainly vision impairment), and psychiatric disability (18%, mainly schizophrenia).

While the majority of disability services residents who died in 2003 had one or two disabilities, the majority of those who died in 2004 and 2005 had two or three disabilities.

Total number of reported co-existing disabilities by accommodation type

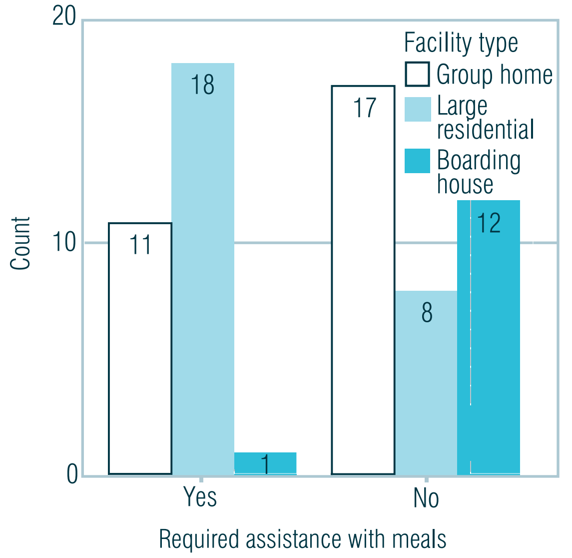


Most of the licensed boarding house residents who died in 2005 had one disability, with only two people recorded as having two disabilities. Over the three years, licensed boarding house residents have consistently been recorded as having one disability, but the proportion has been increasing. In 2003 45% of the licensed boarding house residents who died had one disability. This increased to 71% in 2004, and 85% in 2005.

Assistance with meals

Over half of the 54 disability services residents who died in 2005 required assistance with meals (either to chop food or to use utensils). While most of the people who resided in large residential centres required help with meals, most of the group home residents did not. Only one licensed boarding house resident required assistance with meals.

Number of people who required assistance with meals by accommodation type



Mobility

Most of the people who lived in disability services accommodation had some form of limited mobility (41 people), including 25 people who relied on wheelchairs for mobility. Three licensed boarding house residents had limited mobility, with walking sticks the only aides used.

Number of people with limited mobility by accommodation type

		Facility Type			Total
		Group Home	Large Residential	Licensed Boarding House	
Limited mobility	Yes	8	1	0	9
	Yes, no aide	3	0	1	4
	Wheelchair	6	19	0	25
	Walking frame	1	2	0	3
	Walking stick	0	0	2	2
	Other aide	0	1	0	1
	No	10	3	10	23
Total		28	26	13	67

Immunisation

The Australian Immunisation Handbook[37] indicates that people with disabilities in care should receive annual influenza vaccination, and that people with chronic illness should also receive pneumococcal vaccination.

Number of people who received the pneumococcal vaccine by accommodation type

		Facility Type			Total
		Group Home	Large Residential	Licensed Boarding House	
Pneumococcal	Yes	9	6	1	16
	No	8	13	0	21
	Don't know	5	4	7	16
	Not recorded	6	3	5	14
Total		28	26	13	67

Most of the people with disabilities who died in care in 2005 had been vaccinated against influenza, including just over half of the licensed boarding house residents, and three-quarters of the disability services residents.

Number of people who received the influenza vaccine by accommodation type

		Facility Type			Total
		Group Home	Large Residential	Licensed Boarding House	
Influenza	Yes	18	23	7	48
	No	3	2	0	5
	Don’t know	4	0	4	8
	Not recorded	3	1	2	6
Total		28	26	13	67

Communication

21 of the 54 disability services residents who died in 2005 required some form of communication support, including three people who communicated via pictures. None of the licensed boarding house residents were recorded as requiring communication support.

Number of people who required communication support by accommodation type

		Facility Type			Total
		Group Home	Large Residential	Licensed Boarding House	
Required Communication Support	Yes	9	3	0	12
	No	16	17	13	46
	Electronic communication	0	1	0	1
	Picture communication	3	1	0	4
	Adjusted verbal language	0	1	0	1
	Sign language	0	1	0	1
	Other	0	2	0	2
Total		28	26	13	67

Weight

It was possible to calculate the Body Mass Index (BMI) for 47 of the 54 people in the disability services group, and only one person in the licensed boarding house group.

Of the 20 disability services residents who died whose weight was above the healthy weight range, seven had seen a dietitian in the 12 months before their deaths. The one licensed boarding house resident for whom a BMI could be calculated was severely obese. They had not seen a dietitian in the 12 months before their death.

Of the eight people whose weight was below the healthy weight range, six had seen a dietitian in the 12 months before their deaths.

Smoking

Over three-quarters of the disability services residents who died in 2005 did not smoke, with only four people recorded as being current smokers at the time of their deaths. In contrast, most of the licensed boarding house residents who died were recorded as being current smokers at the time of their deaths (11 people). Six of the 11 people smoked more than 10 cigarettes per day, including one person who smoked more than 20 cigarettes per day.

Number of people in each weight range by accommodation type

		Facility Type			Total
		Group Home	Large Residential	Licensed Boarding House	
Weight Range	Very underweight (<16.9 kg/m)	2	5	0	7
	Underweight (17–18.4 kg/m)	1	0	0	1
	Healthy weight range (18.5–24.9 kg/m)	7	12	0	19
	Overweight (25–29.9 kg/m	9	3	0	12
	Obese (30–34.9 kg/m)	2	4	0	6
	Severe obesity (>= 35 kg/m)	2	0	1	3
	Not recorded	5	2	12	19
Total		28	26	13	67

Tobacco use by accommodation type[38]

		Facility Type			
		Group Home	Large Residential	Licensed Boarding House	Total
Tobacco Use	No	23	20	2	45
	Occasional	1	0	0	1
	Current– up to 10/day	1	0	5	6
	Current– up to 11–20	0	0	5	5
	Current >20/day	2	0	1	3
	Ex-smoker	1	5	0	6
Total		28	25	13	66

Consent provider

Most of disability services residents were reported as having a 'person responsible' for making substitute decisions on their behalf in relation to medical and dental treatment. Family members were the primary people involved in consent decisions for people living in the care of disability services, with 35 people having a family member act as person responsible. Six disability services residents were recorded as providing their own consent to medical and dental treatment.

Consent provider by accommodation type

		Facility Type			
		Group Home	Large Residential	Licensed Boarding House	Total
Consent Provider Modified	Family	17	18	1	36
	Person Themselves	4	2	9	15
	Public Guardianship	6	4	0	10
	Private Guardianship	1	1	0	2
	No response	0	0	2	2
	Other	0	1	1	2
Total		28	26	13	67

The majority of the licensed boarding house residents that died in 2005 were recorded as providing their own consent to medical and dental treatment. This year saw an increase in the proportion of licensed boarding house residents that were their own consent providers, and a reduction in the involvement of family members as persons responsible. Only one licensed boarding house resident was recorded as having a family member provide consent on their behalf, and that person had a mild intellectual disability.

Medications

Most of the people who died in 2005 were receiving at least one type of major medication, including 42 disability services residents, and 10 licensed boarding house residents. Of these people, most were receiving two or more types of major medication. A small number of people were receiving three or more types of major medication, including four disability services residents, and three licensed boarding house residents.

Eleven disability services residents were receiving antipsychotic medication. Of these 11 people, eight had seen a psychiatrist in the 12 months before their deaths, and six had been diagnosed with a mental illness. All had an intellectual disability.

Of the five people who were receiving antipsychotic medication without a diagnosed mental illness, three had seen a psychiatrist in the 12 months before their deaths.

Ten licensed boarding house residents were receiving antipsychotic medication. One person was receiving antipsychotic medication without a diagnosis of a mental illness, but this was used as PRN medication only.

Although ten of the licensed boarding house residents who died in 2005 were receiving antipsychotic medication, only three had seen a psychiatrist in the 12 months before their deaths.

4. When and where people died

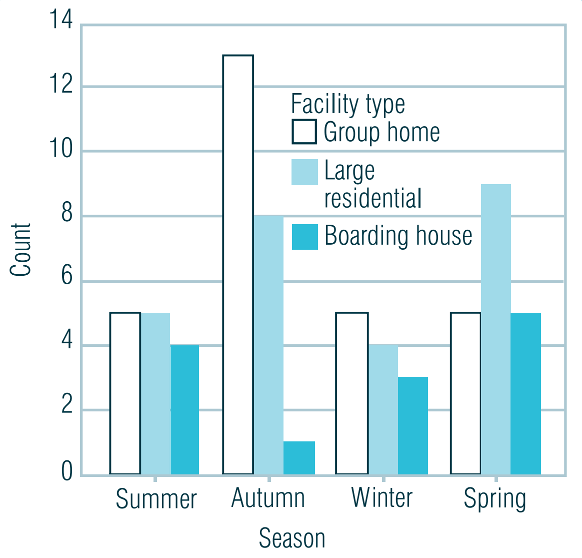
Season of death

Most of the disability services residents died in autumn (21 people), followed by spring (14 people). Spring was the most common season in which licensed boarding house residents died (five people), followed by summer (four people).

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

Antipsychotic Medication			Facility Type			Total
			Group Home	Large Residential	Licensed Boarding House	
Yes	Psychiatric Disability	Yes	6	-	9	15
		No	5	-	1	6
	Total		11		10	21
No	Psychiatric Disability	Yes	2	2	0	4
		No	15	24	3	42
	Total		17	26	3	46

Season of death by accommodation type



Place of death

For people who lived in disability services, almost three-quarters died while in hospital (39 people). For licensed boarding house residents, the location of death was more evenly distributed between hospital (five people), the licensed boarding house (five people), and the community (three people).

Place of death by accommodation type

		Facility Type			
		Group Home	Large Residential	Licensed Boarding House	Total
Place of Death	Hospital	20	19	5	44
	Community	0	0	3	3
	Service	7	7	5	19
	Family Home	1	0	0	1
Total		28	26	13	67

Appendix 3

Report on progress with recommendations from 2005

Recommendation 1
Review and roll out of the Managing Client Health policy

In the context of its review of the *Managing Client Health* policy, and its roll out to funded services, DADHC should:

a) Report on progress towards rolling out the policy to funded services, including details of training and resources to implement the policy.

b) Report on plans for, and progress towards, evaluating the implementation of the policy in funded services.

DADHC response

DADHC released the revised *Managing Client Health* policy in December 2005 for community consultation. The department intends to release the finalised policy, and a companion policy for children, in December 2006, six months later than originally advised. DADHC has advised that the policies will come into effect for DADHC operated and funded services by the end of March 2007.

In terms of assisting funded services to implement the policy, the department has indicated that it is developing a briefing presentation that those services can use to brief their staff, and is considering making available to funded services a training package that it is developing for departmental staff.

Given that the *Managing Client Health* policy is a new policy requirement for funded services, we considered that it would be important for DADHC to evaluate its implementation in those services. The department has advised that it has contracted the Centre for Developmental Disability Studies (CDDS) to establish baseline data to measure the impact of the policy in funded accommodation services, with a report on this work to be available in September 2006.

Our comments

As the policy has not yet been rolled out to funded services, we will continue to monitor the department's work in this area.

Recommendation 2
Consent

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

DADHC response

DADHC released the draft of the revised *Decision Making and Consent* policy in June 2006 for community consultation until the end of August. The department indicated that it intends to roll out the policy to DADHC operated and funded services on 30 November 2006, with a two-month period for the briefing and training of staff.

In relation to training packages to support the release of the revised policy, DADHC advised that it would review existing training packages, and consider the feasibility of making any revised training packages available to funded services.

Our comments

It was not clear from this advice whether the briefing and training of staff included those of funded services, or what training materials may be provided to assist funded staff to implement the policy. As the policy has not yet been rolled out to funded services, we will continue to monitor the department's work in this area.

Recommendation 3
Chest care

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

DADHC response

DADHC has advised that the review has been completed, and was undertaken by DADHC Grade 3 Physiotherapists, a DADHC Respiratory Nurse, a Senior Physiotherapist, and a Gastroenterologist from the Dysphagia Clinic at Westmead Hospital.

When the respiratory trigger questions (16–18) on a client's nutrition and swallowing checklist identify risks, the draft chest care checklist is to be completed also.

Our comments

The checklist is to be linked to the *Managing Client Health* policy, which has not yet been rolled out to funded services. We will continue to monitor the department's work in this area.

Recommendation 4
Review of Illawarra region clinical nurse specialist model of health care case management

DADHC should:

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

DADHC response

In 2006 DADHC engaged a consultant to assist the Health Care Review Team to undertake the review. The review was conducted and a report was drafted in June 2006 for consideration.

DADHC has advised that recommendations from the review have yet to be considered by DADHC in relation to functions of specialist nurses and job descriptions, establishment of positions and their locations, and development of an operational plan for the role. As at September 2006, revised timeframes had not been finalised.

Our comments

The department has yet to report on the outcome of the review. As a result, we will continue to monitor the department's work in relation to this recommendation.

Recommendation 5
Individual planning and risk assessment

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

DADHC response

DADHC has advised that a draft policy is under development and the principles will apply to DADHC operated and funded services. Initial planning is complete, and a workshop has been conducted to provide input to policy development.

DADHC has advised that the draft revised policy would be distributed for consultation in October 2006, with policy briefings for staff in December 2006 and January 2007, and an anticipated implementation date in DADHC operated and funded services of 31 January 2007.

Our comments

As the draft revised policy has not yet been issued, we will continue to monitor the department's work in this area.

Recommendation 6
Communication issues and health care

In the context of its review of the *Managing Client Health* policy, DADHC should ensure that adequate guidance is provided in the revised policy on:

- **a) The importance of considering resident communication issues in relation to health care needs.**
- **b) When referral for a communication assessment is required.**

DADHC response

DADHC has advised that it has considered and incorporated this recommendation into the final draft *Managing Client Health* policy, with the development of a new section titled *Communication and Participation*. This section includes information on communication systems, participation in the planning process, differences in receptive and expressive language skills, and links to individual planning goals for communication system needs.

DADHC has advised that it anticipates that the policy will be ready for endorsement by the end of September 2006.

Our comments

The revised policy has not yet been endorsed, and this office has not seen the above-mentioned information regarding communication needs. We note that communication issues were identified in our consultation project as a significant barrier for some people with disabilities accessing the NSW health system, and that our reviews of deaths in 2005 again highlighted communication as a key issue, particularly in relation to pain management. As a result, we will continue to monitor progress towards meeting this recommendation.

Recommendation 7
Monitoring of health care planning / implementation of the *Ensuring Good Nutrition* policy

In the context of its monitoring of health care planning and policy implementation in DADHC operated and funded services, DADHC should provide advice as to:

- **a) The 26 key performance indicators that form the basis of the Quality and Safety Framework in DADHC operated services.**
- **b) The terms of reference of the DADHC Health Care Review Team, with particular reference to the role of the team in monitoring implementation of the *Ensuring Good Nutrition* policy.**
- **c) What specific aspects of health care planning in funded services are monitored in the Service Review Instrument (SRI) of the Integrated Monitoring Framework, including nutritional health management practices.**

Recommendation 7 *(continued)*

DADHC response

DADHC provided a copy of the Quality and Safety Framework performance indicators, one of which relates to health care plans. DADHC has advised that an additional indicator to monitor compliance with the *Ensuring Good Nutrition* policy will be incorporated in the revised version of the Quality and Safety Framework planned for release in January 2007.

In relation to the DADHC Health Care Review Team (HCRT), the department provided a copy of the terms of reference that indicated that the HCRT is responsible for monitoring and making recommendations on the quality and implementation of health care plans in accordance with the *Managing Client Health* policy. One of the specific functions of the HCRT is to audit and make recommendations on the quality and implementation of health care plans in DADHC operated services. In order to do this, the HCRT has developed a draft audit tool that makes provision for examining a range of criteria including checks on consent and consultation, inclusion of documentation from health professionals, documentation of health risks, and evidence of healthy lifestyle practices including exercise and sunlight plans.

The department advised us in July 2006 that the tool is in the early stages of design and development. DADHC advised in September 2006 that the Audit Tool will monitor the implementation of the *Ensuring Good Nutrition* policy, including key indicators that require evidence to ensure that all aspects of the policy have been implemented.

The department indicated that resource constraints had impeded its ability to conduct a formal evaluation of the *Ensuring Good Nutrition* policy following its implementation in funded services to date, but it has initiated contact with the Department of Public Health at the University of Sydney to explore the feasibility of a doctoral or research masters student in public health conducting this evaluation. The department advised that it would also hold discussions with the University's dietetics department.

In relation to the specific aspects of health care planning in funded services that are monitored in the SRI, DADHC advised that the SRI is an evidence-based performance assessment, and that one of the key performance indicators specifically assesses maintenance and promotion of health and wellbeing (2.3.2). DADHC advised that the guidelines issued to its monitoring staff specifically refer to the review of risk assessments, health plans and monitoring in accordance with the *Ensuring Good Nutrition* policy as evidence required from organisations to demonstrate compliance.

Our comments

The audit tool for DADHC operated services is in the early stages of development by the Health Care Review Team. In relation to the SRI, DADHC provided this office with a copy of the guidelines for monitoring staff. In our review of these guidelines, we could not locate any reference to the evidence required to demonstrate service compliance with performance indicator 2.3.2.

Recommendation 7 *(continued)*

We will continue to monitor the department's work in relation to monitoring implementation of the *Ensuring Good Nutrition* policy in DADHC operated and funded services.

Recommendation 8
Provision of health care information to boarding houses

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

DADHC response

DADHC has advised that it is reviewing and updating the *Licensed Residential Centres (LRC) Licensing, Monitoring and Closures* policy manual in two stages:

1) The update of the policy manual is being finalised and is planned for release by October 2006.
2) The appendices are being updated to incorporate contemporary information in relation to good practice that DADHC officers may use to assist boarding house operators. It is estimated that stage two will be finalised by February 2007.

DADHC has advised that to facilitate access to relevant information to boarding houses concerning good practice in health care, links to the suggested documents will be placed on the DADHC website on a site specific to boarding houses by October 2006.

Our comments

To date there is no site specific to boarding houses on the department's website, although most of the above policies (or their draft equivalents) are on the policies and publications site. It is currently unclear how the department intends to make the information available to boarding houses without internet access.

We will continue to monitor the department's work in relation to providing information to boarding houses about good practice in health care.

Recommendation 9
Screening tool for entry to licensed boarding houses

In relation to the screening tool for entry to licensed boarding houses, DADHC should:

a) Review current application of the screening tool to determine whether it is being used in line with existing guidelines. A component of this review should be an audit of the quality and accuracy of the assessments.

b) At the completion of the review evaluate the findings and advise what action, if any, it intends to take in relation to the effectiveness and ongoing use of the tool.

DADHC response

DADHC advised that its LRC Reference Group[39] convened in late March 2006 to examine current issues on the screening tool to inform an expert review group.[40] The role of the expert review group would be to revise the tool to align with current developments in screening and assessment in DADHC and NSW Health, and ensure transparency and effectiveness of the tool. DADHC advised in July that it expected to convene the first meeting of the expert review group in August, and that the group will scope the work to be done and develop a project plan with timelines that will allow any changes to screening arrangements to be implemented in the first half of 2007.

In September 2006, DADHC advised that it would be forming a Screening Tool Steering Committee of DADHC officers and external stakeholders to oversee and direct the review of the Boarding House Screening Tool. The department advised that the Committee would be convened by October 2006, and it anticipates that the review will be finalised by March 2007.

Our comments

The review of the Screening Tool for Entry to Licensed Boarding Houses is in its early stages. As a result, we will continue to monitor DADHC's progress towards meeting this recommendation.

Recommendation 10
Record keeping in boarding houses

In order to improve the adequacy of records kept by licensed boarding houses, DADHC should:

a) Undertake a review of record keeping practices in licensed boarding houses.

b) Implement the results of the review.

c) Evaluate and report on the outcomes of the review.

Recommendation 10 *(continued)*

DADHC response

DADHC advised that its Service Development and Planning Branch liaised with the regions to coordinate a review of Licence Condition 4, which relates to the record keeping responsibilities of the Licensee and Licensed Manager. A sample of 47 out of a possible 55 licensed boarding houses were reviewed. The review found that in most cases the licensed boarding houses had met record keeping requirements under Licence Condition 4 to a significant degree, but full compliance with this condition was often not achieved by operators, and required strengthening.

The department outlined a number of actions it would take, in consultation with the relevant peaks, agencies and Expert Advisory Group, to strengthen compliance to Condition 4 and encourage better practice. These actions include reviewing the monitoring tool associated with Condition 4, setting good practice benchmarks for that condition, developing a resource to support the sector improve their compliance and practice to Condition 4, and considering relevant issues in the Review of the Screening Tool.

Our comments

Record keeping by licensed boarding houses continued to be identified as an issue in our reviews this year. As a result, we will monitor the implementation of the actions DADHC has identified it will take to strengthen compliance in this area.

Recommendation 11
Hospitalisation of people with disabilities

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

NSW Health response

NSW Health advised that it would be engaging a consultant by August 2006 to evaluate the implementation of the policy directive, and that the evaluation would include the development of indicators to assist in the monitoring of implementation at the Area Health Service level. The project is expected to take up to 24 weeks to complete.

Our comments

As progress towards implementing this recommendation is in the initial stages, we will continue to monitor the department’s evaluation of the policy directive.

Recommendation 12
Discharge planning

NSW Health should report on progress towards finalising its *Effective Discharge Planning Framework*, including details of planned roll out, training, and evaluation.

NSW Health response

NSW Health advised that the retitled *Discharge Planning: Responsive Standards* would be rolled out in 2006, and that indicators for training, monitoring and evaluation would be built into the *Standards*. Health has also advised that the *Standards* are linked to the Clinical Services Redesign Program, which encompasses many Area Health Services projects that have better discharge planning as an essential element.

In terms of monitoring the implementation of the *Standards*, NSW Health has indicated that this will be done through the *Relative Stay Index*, a data collection tool that compares length of stay between institutions, standardised for age and diagnosis related groups.

Our comments

The *Standards* have been released, and the department has commenced work in relation to monitoring implementation. We will seek additional information from the department to clarify how the *Relative Stay Index* will provide information about implementation of the *Standards* and discharge requirements that are particular to people with disabilities.

Recommendation 13
Discharge planning

DADHC and NSW Health should discuss how the screening tool for entry to licensed boarding houses may be incorporated into the Effective Discharge Planning Framework.

NSW Health response

NSW Health advised in March 2006 that it had discussed the matter with DADHC, and had incorporated the tool into the *Discharge Planning: Responsive Standards* with prompts to refer for re-screening all patients returning to a licensed boarding house following a hospital admission.

DADHC advised in September 2006 that invitations would be extended to NSW Health for membership on the Screening Tool Steering Committee. The Committee will review the links between screening for entry to licensed boarding houses and the *Discharge Planning: Responsive Standards*.

Recommendation 13 *(continued)*

Our comments

Our review of the *Discharge Planning: Responsive Standards* has noted the inclusion of the use of the screening tool as a key action to improve discharge practice, as well as the requirement that the discharge process for a patient with a disability must include a determination of the suitability of existing home support systems, and should ascertain whether the pre-admission support system can continue to meet the level of care required.

Recommendation 14
End of life decision-making

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

NSW Health response

NSW Health advised in March 2006 that it was considering a range of options for evaluating the guidelines that take account of the particular challenges in measuring practice change in this area, and that revision of the guidelines in five years will be informed by such evaluation results.

NSW Health advised in August that its Research and Ethics Branch has undertaken a seminar series in metropolitan Sydney and regional NSW to health care professionals regarding the key messages of the guidelines and related issues with their implementation. Area Health Services were instructed when the guidelines were released to nominate an appropriate policy committee to consider local implementation needs. Research and Ethics Branch is liaising with the Areas regarding progress of these groups.

Our comments

NSW Health's evaluation of the implementation of the policy directive is still in the initial stages. Our reviews of the deaths from 2005 have raised some questions as to the implementation of the policy in Area Health Services, and its uptake by medical practitioners. Consequently we will continue to monitor NSW Health's evaluation of the implementation of the guidelines.

Recommendation 15
Palliative care

DADHC should report on progress towards finalising its *Palliative Care* policy, including details of consultation, planned roll out and training.

DADHC response

DADHC's *Palliative Care* policy was endorsed in November 2005, commenced in DADHC operated services on 1 February 2006, and became effective for funded services from 1 April. The department advised that a briefing package was provided to regional staff to assist in the briefing of DADHC operated and funded service staff, and that a copy of the policy and briefing package was made available to ACROD to load onto its website in March 2006.

Our comments

DADHC has finalised and rolled out the policy. We will not continue to monitor this recommendation.

Recommendation 16
Palliative care

DADHC and NSW Health should commence joint work on the coordination of palliative care for people with disabilities in care.

DADHC and NSW Health response

DADHC advised that its *Palliative Care* policy requires all clients with a diagnosis of a terminal illness or progressive advanced disease to be referred to the appropriate Area Health Palliative Care Service. The department advised that it had commenced discussions with NSW Health on evaluating the effectiveness of the policy in facilitating the coordination of palliative care for residents of DADHC operated and funded accommodation services.

In September 2006, DADHC advised that the agencies had not commenced work on the coordination of palliative care for people with disabilities in care but this item will be included on the agenda of future meetings of the interagency Senior Officers Group.

NSW Health advised that the provision of palliative care services around NSW varies considerably between Area Health Services; evident in palliative care service quality, availability and scope. NSW Health noted that the provision of palliative care services to people with intellectual disabilities is best improved through effective systemic change, which will also benefit a range of other groups needing to access palliative care services, such as people with dementia.

The department advised that the issue is to be addressed through the implementation of the Role Delineation Framework. The Framework has been developed to assist service providers to develop a single system of care with seamless referral and case management

Recommendation 16 *(continued)*

of patients, and will facilitate a collaborative relationship with primary care workers and specialist palliative care teams. NSW Health advised that it has made available recurrent funds from 2006–2007 to Area Health Services to employ project officers to develop and implement strategic reforms in palliative care, and one of their key tasks will be the implementation of the Role Delineation Framework. The Framework was being finalised as at June 2006.

In addition, a mapping exercise of palliative care services is currently underway, and this information will enable NSW Health to monitor the implementation of the Framework.

Our comments

Discussions between NSW Health and DADHC regarding evaluation of the effectiveness of DADHC's *Palliative Care* policy are in the initial stages, as is NSW Health's work on implementing the Role Delineation Framework and mapping palliative care services. We will continue to monitor the work of both agencies in this area.

Recommendation 17

Comprehensive health assessments

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

NSW Health response

NSW Health advised that the NSW Minister for Health approved a letter to the Federal Minister for Health and Ageing, in support of a proposal for a Medicare funded annual comprehensive health assessment for people with intellectual disability. DADHC advised that in March 2006, the NSW Minister for Disability Services also wrote a letter to the Federal Health Minister in support of the proposal.

Our comments

This recommendation has been met.

Recommendation 18
Training of health providers on providing health care to people with intellectual disabilities

In relation to the Primary Health Care Capacity Building Project, NSW Health should:

a) Evaluate the project and report on the outcomes.

b) Following completion of the evaluation, advise what further action, if any, it intends to take in relation to providing training to health workers on health care for people with intellectual disabilities.

NSW Health response

NSW Health advised in March that it received the Primary Health Care Capacity Building Project's final report on 30 January 2006, and was in the process of evaluating the outcomes. In August, the department advised that the evaluation identified a number of gaps in the outcomes that were achieved by the Project, and the completion of the evaluation has been delayed while NSW Health seeks further information and clarification on these issues.

NSW Health has also advised that, in conjunction with DADHC, it is currently developing a Service Framework for the Health Care of People with an Intellectual Disability. The Framework will specifically address training to health workers on health care for people with intellectual disabilities.

Our comments

The evaluation of the Primary Health Care Capacity Building Project, and the development of the Service Framework are still in progress. We will continue to monitor NSW Health's progress in relation to this recommendation.

Recommendation 19
First aid

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

DADHC response

DADHC advised that it would assess the implications of this recommendation for DADHC operated, funded and licensed services by the end of September 2006.

In September 2006 DADHC advised that the Boarding Houses Expert Advisory Group meeting on 4 September included discussion on the implications of requiring staff in

Recommendation 19 *(continued)*

licensed boarding houses, and those working within programs funded through the Boarding House Reform Program, to have current first aid qualifications. The Group endorsed the principle in general, but noted the difficulties in enforcing such conditions because of the limitations of the current *Youth and Community Services Act* and the *ultra vires* issue.

The department also advised that the issue would be considered for its Home and Community Care (HACC) funded services in the context of the DADHC Learning and Development Framework, which it expects to finalise by January 2007.

Our comments

As yet, the department has not provided to this office its assessment of the implications of this recommendation for DADHC operated, funded and licensed services. We will continue to monitor the department's work in this area.

Recommendation 20
Medication reviews

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

DADHC response

DADHC advised that the draft *Managing Client Health* policy and *Maximising Health and Well-being of Children and Young People in Out of Home Care* policy require clients to have an annual health care review conducted by their treating medical officer, which includes review of medication. In addition, the Client Information System allows staff to record the review date for a client's medical review, and the monitoring of medication reviews is a key performance indicator under the Quality and Safety Framework for DADHC operated accommodation services.

DADHC has commenced reviews of its *Medication* and *Managing Client Risks* policies. Within the revision of these two policies and the *Managing Client Health* policy there are health review processes (such as the CHAP tool) that provide opportunities for staff to identify risk factors for clients, particularly in relation to medication matters.

DADHC advised that referral for a Domiciliary Medication Management Review is at the discretion of the medical practitioner, however staff will be able to identify risk criteria during regular health reviews and alert the client's GP if they identify any issues of concern.

Recommendation 20 *(continued)*

Our comments

As part of our comments to DADHC in relation to its review of the *Medication* policy, we noted that the draft *Managing Client Health* policy refers to 'a medication review' being part of the requirements for the completion of the CHAP tool, but the CHAP tool itself does not refer to medication, other than a listing by the key worker or family member of the client's current medications, and there is no reference to the need to review those medications. Further, we noted that the draft policy does not provide guidance to staff as to what is meant by 'medication review', or how that might be documented as being completed. There is no other reference to medication reviews in this draft document or in the existing *Medication* policy.

DADHC's review of the *Medication* policy is in the initial stages. We will continue to monitor the department's progress towards meeting this recommendation.

Recommendation 21
Access to allied health

In order to improve access to speech pathology services, DADHC should:

- **a) Negotiate with NSW Health to access alternative services.**
- **b) Work with disability agencies to determine priorities for access.**
- **c) Track, monitor, and report on the average waiting periods for access to DADHC speech pathology services.**

DADHC response

DADHC advised that the structure of Community Support Teams (CSTs), including the provision of therapy services, is being reviewed as part of a broader refocus of CSTs in 2006–2007. The review will encompass an analysis of strategic issues such as service access and responsiveness; models of service delivery; service fragmentation and coordination, and workforce capacity. It will also include an analysis of operational issues including CST functions and policies, CST composition, and funding arrangements. The department's *Prioritisation and Allocation* policy, which guides access to CST services, will be reviewed as part of this process. The review of CST structures is due for completion by the end of 2006.

DADHC advised that in 2006–2007 the department would increase its capacity in the delivery of speech pathology services through the allocation of 600 additional therapy places under the *Stronger Together* ten-year government plan. The allocation of the first round of places will be finalised in October 2006.

Recommendation 21 *(continued)*

The department also advised that it recurrently funds some non-government services to provide therapy places. To complement this work, DADHC provided $300,000 in 2005–2006 to the Spastic Centre to purchase augmentative equipment to assist children with communication difficulties. Further, DADHC advised that it is improving the management of its funded programs by improving its Service Description Schedule, which has included defining priorities for access and outputs for services provided by non-government services, such as those delivering therapy services.

In terms of tracking, monitoring, and reporting on average waiting times for access to DADHC speech pathology services, DADHC advised that the Client Information System (CIS) has improved its capacity to do this. Regional Community Access managers and staff track and monitor individuals through the CIS, and compile quarterly reports, along with the Community Access Branch in Central Office.

Our comments

DADHC's review of Community Support Teams and the *Prioritisation and Allocation* policy are still in progress. We will continue to monitor the department's work in relation to improving access to allied health services, and more specifically, speech pathology services.

Recommendation 22

Access to allied health

NSW Health should provide advice as to how its Workforce Action Plan will address workforce issues in relation to allied health staff.

NSW Health response

NSW Health advised that the Workforce Action Plan is an overarching document that takes a 'whole of health' approach to health workforce, and strategies included in the plan can be applied to allied health professions, including:

- Development of a re-entry model applicable for allied health disciplines.
- Development of a competency and credentialing framework to ensure clinical governance requirements of difference service areas are met.
- Development of a central deed of agreement between NSW Health and the university and training sector with regard to clinical training placements to ensure students receive appropriate levels of clinical training.

Recommendation 22 *(continued)*

In addition, workforce initiatives undertaken include:

- Development and delivery of an Allied Health Clinical Leadership Course.
- Creation of Area Allied Health Advisor positions in each Area Health Service.
- Establishment of an Allied Health Discipline Advisors network to foster greater clinician-led involvement in workforce development.
- Continuing investment in Rural Allied Health undergraduate and post graduate scholarships.
- Funding of additional 14 pre-registration pharmacy traineeship positions in Area Health Services in 2006.
- Development of a pilot model for a pharmacy re-entry program.

Our comments

This recommendation has been met.

Recommendation 23
Progress of DADHC / NSW Health joint work

DADHC and NSW Health should:

a) Report on outcomes of discussions on the DADHC Complex Care Needs model of supported accommodation for identified clients relocating from large residences who require full-time nursing support.

b) Report on progress towards mapping specialist and generic services provided by DADHC and NSW Health, and provide advice as to how this information will be used.

c) Advise what the work on 'identifying models of care to improve access for people with intellectual disability and the management of their health care issues' involves, and what progress has occurred to date.

d) Outline any other joint projects on the current agenda of the DADHC / NSW Health Senior Officers Group, and advise what progress has occurred to date.

Recommendation 23 *(continued)*

DADHC and NSW Health response

Responsibility for reporting on progress towards meeting this recommendation was split between the two agencies, with DADHC reporting against a) – c), and NSW Health reporting against d).

DADHC advised that a model for supported accommodation for people with complex health care needs relocating from large residential centres has been developed for internal use. The model comprises three components: *Guidelines for Staff Resource Allocation in the Provision of Health Care*, *Promoting Community Participation for People with Complex Health Care Needs* policy, and a financial model of the internal allocation of resources. The department advised in September 2006 that the model has been in use for over a year, and is currently being revalidated.

DADHC advised that the Disability Service Mapping Project is progressing and is a preliminary stage of the broader commitment towards equitable access and enhanced quality of medical services and health outcomes for people with a disability. When completed, the mapping of health and disability services currently available to adults and children with an intellectual disability or developmental delay will provide a clear picture of existing capacity and identify areas of unmet demand. It will inform how to proceed at the next phase towards achieving this commitment, including the identification of models of care to improve access for people with intellectual disability and the management of their health care issues. DADHC further advised that as the work progresses DADHC / NSW Health officers will attend the General Practice Council and raise awareness about the issues and current systems in place.

DADHC advised in September 2006 that a report on progress to date in development of the plan is being submitted to government as part of a whole of government plan for disability.

NSW Health has advised that the current agenda of the DADHC / NSW Health Senior Officers Group includes the following priorities:

- Joint workforce planning including education issues, human services training and shortages. A joint agency submission to the Productivity Commission Review of Health Workforce was prepared.
- Rationalisation and integration of services including Program of Appliances for Disabled People (PADP), carers and diagnosis and assessment services. The review of PADP has been completed and the report is being finalised. NSW Health has developed a draft NSW Carers Action Plan in conjunction with other relevant departments, which will be submitted shortly to Cabinet for approval.
- Reform and improvement of services including bilateral approaches to services delivery; for example therapy services and access to health services for people with a disability.

Recommendation 23 *(continued)*

- Therapy services: Improving access to therapy intervention services for clients with priority needs by better integration of services is included in the ISCD work plan as a priority project. A stock take of therapy services is to be undertaken as the first stage of this project.
- Access to health services for people with a disability: NSW Health and DADHC have agreed to lead the development of the Health Care of People with an Intellectual Disability Service Framework for NSW. The Framework aims to address the enhancement of intellectual disability health resources in NSW. A final Framework document is expected to be completed for Director-General consideration by end September 2006.
- Accommodation and Support Models Working Group: The aims of objectives are to 1) Identify the quantum and level of accommodation support needs of people with a disability in health facilities; 2) Review existing NSW Health and DADHC fixed infrastructure and identify potential opportunities for collaboration; and 3) Identify specific sites where co-location of clients with common support needs is feasible and identify specific actions required for this to occur.

NSW Health advised in June 2006 that health care and support issues relating to people with disabilities, which were being addressed by the DADHC / NSW Senior Officers Group, have been transferred to the Interagency Standing Committee on Disability (ISCD). The ISCD is chaired by DADHC, and has been established to oversight the development of a 'whole-of-government' policy and service delivery framework for disability services in NSW. The Framework intends to identify ways to improve services for people with disabilities through improved planning and interagency coordination of services. It will cover the broad spectrum of services for people with a disability ranging from universal services that are available to the whole population, to adapted services, through to highly specialised services for people who are unable to access universal or adapted services.

Our comments

The mapping project is still in progress, with future directions in relation to improving access to health services and management of the health issues of people with disabilities to be identified through this work. We will continue to monitor DADHC's work in this area.

Key aspects of NSW Health's advice on joint projects on the agenda of the DADHC / NSW Health's Senior Officers Group, including reform and improvement of therapy services and development of a Service Framework, are in the initial stages of development. In addition, the ISCD is new, and its work has only just started. Given the significant impact on people with disabilities in care of any developments in the advised joint projects, we will continue to monitor the work of both agencies in this area.

Endnotes

[36] Report of the NSW Chief Health Officer (2002).

[37] 8th Edition (2003).

[38] Tobacco use was not recorded for one person.

[39] The LRC Reference Group is an internal group comprised of regional DADHC officers who are monitoring licensed boarding houses and managing the Boarding House Reform Program. They meet once a quarter to discuss policy and practice issues associated with licensing and the reform program.

[40] The expert review group is a specific and time-limited group with relevant expertise, formed to provide advice on the review of the screening tool. As at May 2006, this group was in the process of being established, and was expected to include two members from the LRC Reference Group, a Licensee or Licensed Manager, a member of an ACAT, Health, Mental Health, and Case Worker representatives, and a representative with experience in or knowledge of the current developments in screening and assessment. In October 2006, DADHC advised that the expert advisory group will be called a 'steering committee'.

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