

**Report of Reviewable  
Deaths in 2010 and 2011**

**Volume 2: Deaths of people with  
disabilities in care**

**May 2013**

**NSW Ombudsman  
Level 24, 580 George Street  
Sydney NSW 2000**

**Phone 02 9286 1000  
Toll free (outside Sydney Metro Area): 1800 451 524  
Facsimile: 02 9283 2911  
Telephone typewriter: 02 9264 8050  
Website: [www.ombo.nsw.gov.au](http://www.ombo.nsw.gov.au)  
Email [nswombo@ombo.nsw.gov.au](mailto:nswombo@ombo.nsw.gov.au)**

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## Ombudsman's message

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This is my seventh report on the deaths of people with disabilities in care. It concerns the deaths of 220 people in 2010 and 2011, and also draws on our reviewable deaths work over the past decade.

This report is being released at a time of significant change for people with disabilities in NSW. Firstly, the NSW Government has recently legislated to deliver much-needed reform of the boarding house sector, including substantial improvements to the safeguards and standards of care for people with disabilities living in boarding houses.

This has been a persistent area of focus for my office, and our work in reviewing the deaths of people in licensed boarding houses has highlighted the need for significant change. Indeed, this report continues to underline the importance of the reforms, with serious problems identified in relation to the deaths of at least eight residents in 2010 and 2011.

In addition, there are major changes underway – through the *Stronger Together 2* reforms in NSW and the National Disability Insurance Scheme (NDIS) – to ensure that people with disabilities have maximum choice and control over the supports they require. Importantly, the key findings and messages from our reviews of the deaths of people with disabilities in care align with, and reinforce the importance of, these reforms.

In particular, our work illustrates the importance of key aspects of the reforms in preventing avoidable deaths. This includes person-centred support; appropriate access to mainstream health and other services; and coordination of support between mainstream health services and specialist disability services.

Our report identifies the vital need for disability and health services to work effectively together to support the access of people with disabilities to health services and programs and reduce key health risks that are associated with preventable deaths. Following the release of this report, we will seek to meet with the Departments of Health and Family and Community Services to discuss these issues, and the broader work of both agencies that will be important in resolving them – including the disability sector reforms and the NSW Service Framework.

Finally, our report emphasises the critical role of General Practitioners and direct-care staff in preventing avoidable deaths. This year, in addition to tabling this report, we will be releasing factsheets that are targeted at GPs, and support workers in disability accommodation and licensed boarding houses. To reduce the preventable deaths of people with disabilities in care, it is important that the messages in the factsheets are read, understood, and reflected in practice.



Bruce Barbour  
**Ombudsman**



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# Executive summary

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We review the deaths of people in, or temporarily absent from, disability accommodation services and licensed boarding houses, and make recommendations to reduce preventable deaths.

## About the people who died in 2010 and 2011

In 2010 and 2011, the deaths of 220 people with disabilities in care were reviewable.

- 97 people lived in Ageing, Disability and Home Care (ADHC) accommodation
- 98 people lived in NGO (ADHC-funded) accommodation, and
- 25 people lived in licensed boarding houses.

On average, the people who had lived in 'disability services' (ADHC or NGO accommodation) were 52 years old when they died in 2010 and 2011. This was 14 years younger than the licensed boarding house residents who died during that period, and around 30 years younger than the general population.

## Main causes of death

The leading underlying causes of death of people in disability services in 2010 and 2011 were:

- Nervous system diseases – mainly epilepsy and cerebral palsy
- Cancers – mainly bowel cancer and oesophageal cancer
- Respiratory diseases – primarily aspiration (where food and fluid goes into the lungs), pneumonia, and chronic lower respiratory diseases (such as asthma)
- Circulatory diseases – mainly ischaemic heart diseases, other heart diseases and cerebrovascular diseases, and
- External causes – mainly choking on food.

The leading underlying causes of death of people in licensed boarding houses in 2010 and 2011 were:

- Circulatory diseases – mainly ischaemic heart diseases

- Respiratory diseases – primarily pneumonia and chronic lower respiratory diseases (such as chronic obstructive pulmonary disease – COPD)
- External causes – mainly choking on food, and
- Neoplasms – primarily lung cancer.

## Respiratory diseases

Respiratory diseases are a major cause of death of people with disabilities in care, including the leading contributory cause of death of people in disability services. In 2010 and 2011, respiratory diseases contributed to almost half of all deaths in the disability services population.

Many people with disabilities are at risk of death from respiratory illness because they have multiple risk factors, including requiring help with meals; problems with swallowing, eating and moving around; conditions such as epilepsy, cerebral palsy and Down syndrome; dental problems; gastrointestinal problems such as gastro-oesophageal reflux disease (GORD); and smoking (mainly people in licensed boarding houses). These risk factors were prevalent amongst the people who died from respiratory diseases in 2010 and 2011.

As with previous years, our reviews of people who died from respiratory diseases in 2010 and 2011 have highlighted the need to:

- identify people with known risk factors and support them to minimise those risks
- understand and carry out the recommendations of health providers (including meal and fluid requirements), and
- have respiratory specialist involvement and access to chronic disease management programs. We found that few of the people who had considerable ongoing respiratory problems (such as recurrent respiratory infections and COPD) had access to specialist reviews of their respiratory health, or to a chronic disease management program.

## Choking on food

In 2010 and 2011, nine people died as a result of choking on food, representing over one-third of the 22 deaths from choking on food in the nine years since 2003.

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Deaths from choking on food are highly preventable. Factors in the deaths of people who choked on food in 2010 and 2011 included risks relating to:

- eating problems, including eating quickly, putting too much food in at once, and eating without chewing
- behaviour-related issues, including taking food off others, taking food from bins, and taking food that had not been prepared for them, and
- the side-effects of psychotropic medication, including tardive dyskinesia (involuntary movements that can interfere with speaking and eating).

In some cases, the person's choking risks were known, but the health or disability service did not take adequate steps to address the risks, such as providing guidance for staff on the meal requirements.

Our reviews of deaths from choking on food in 2010 and 2011 have indicated the need for:

- support staff to be aware of the different factors that can place people at risk of choking
- active support for people to minimise their choking risks
- support staff to respond to gagging or near-choking incidents, and
- compliance with first aid requirements.

## Key issues identified through our work

### Preventing injury and death

Our reviews of deaths in 2010 and 2011 have continued to highlight the importance of effective risk management in preventing injury and death. In particular, our reviews have indicated the need for collaborative work between the person with a disability, support staff, health providers and relevant others to identify the risks for the person, and to assist them to try to minimise the risks.

Our reviews have also shown the importance of services responding adequately to an incident or 'close call' to prevent or reduce the chances of that event happening again. We found that, while some of the people who died had experienced previous incidents that were similar to those that caused their deaths (such as choking on food), effective action did not appear to be taken to identify the risks or to stop the events from recurring.

### Recognising and responding to changing health and support needs

#### Response to critical health changes

Our reviews of deaths in 2010 and 2011 have stressed the importance of staff being alert to health changes, and seeking medical assistance without delay. Some people with disabilities go from ill to critically ill within a very short period of time – including 13 people who died in 2010 and 2011.

Often, we found that support staff did not appear to recognise that the person's condition had become critical. In some cases this appeared to be because they had not known the person for long, or because the person had recently seen their GP. However, in a small number of matters, we found that services did not seek medical assistance for the individuals they were supporting, despite evidence that they were seriously unwell.

#### Response to changing support needs

While some of the people who died in 2010 and 2011 became critically ill very quickly, others experienced a decline in their health – and a marked increase in their support needs – over an extended period (for example, due to ageing or the progression of conditions such as dementia or multiple sclerosis).

We found that support staff often struggled to deal with the person's increasing support needs, including knowing when to escalate the matter with senior management. Overall, while services reacted to individual events (such as falls or behavioural incidents), they rarely identified the need to have a comprehensive review of the person's circumstances and needs.



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Central to our reviews of these deaths has been the need for better coordination of care. Our work has demonstrated the importance of comprehensive and multidisciplinary reviews of people with complex or increasing support needs – to facilitate a coordinated approach to identifying and responding to the person's changing needs.

### **Care coordination between health and disability services**

Our reviews of deaths in 2010 and 2011 have highlighted the need for better inter-service collaboration to support people with disabilities in their contact with health services (in hospital and the community).

- We identified at least 17 people whose behaviour or decisions affected their medical treatment and health. This included people who refused to attend medical appointments; were resistant to physical examination, tests or procedures; refused to follow medical advice or health recommendations; and/or declined surgery and other treatment. The impact of these decisions was sometimes very significant – including missing out on critical treatment, and delayed diagnosis of life-threatening conditions.

It was not always clear to us what health and disability staff had done to assist the person to overcome their objections, or to make it an easier process. Our reviews of these deaths have highlighted the importance of health and disability services working together, and with the person with a disability, to minimise the person's resistance to health services and treatment, and to make sure they are making an informed decision (where possible).

- We also continued to identify the need for improved support for people with disabilities when they are in hospital. We found problems relating to communication between health and disability services, and in the level of cooperation between their staff in coordinating and providing support. We identified at least 10 people whose behaviour and non-compliance in hospital (such as refusing treatment and pulling out tubes) affected their medical treatment and health.

Our reviews also point to the need for coordinated and comprehensive planning for the transfer of care of people with disabilities from hospital to home.

Given the health and support needs of many people with disabilities in care, it is important that their discharge from hospital is planned and coordinated. However, our reviews of deaths in 2010 and 2011 identified at least 10 people for whom the transfer of care from hospital to home was inadequate. This included people who had significant risks related to asthma, swallowing, choking, and placement of their feeding tube, and who subsequently died from related causes.

### **Access to preventative health support**

Our reviews of deaths in 2010 and 2011 have continued to highlight the multiple health risks faced by people with disabilities in care that are related to lifestyle factors, including obesity, poor diet and insufficient physical activity. People in licensed boarding houses also face significant risks related to high rates of smoking.

- Of the people in licensed boarding houses who died in 2010 and 2011, 56% were daily smokers; half of whom smoked more than 20 cigarettes per day. Overall, 88% of the licensed boarding house residents who died during this period had smoked, including all of the residents who died from lung cancer, pneumonia, COPD, and three-quarters of those who died from ischaemic heart diseases.
- Over one-third of people in disability services and over half of the people in licensed boarding houses who died in 2010 and 2011 were overweight or obese. At the top end of the scale, 34 people were obese or severely obese: from this group were individuals who died from heart attack, heart disease and COPD.

Our reviews have indicated the need for health practitioners and support services to take concerted and collaborative action to assist people with disabilities in care to reduce these preventable health risks.

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## Support for people in licensed boarding houses

Our reviews of the deaths of eight people in two licensed boarding houses in 2010 and 2011 highlighted some of the ongoing systemic problems in the boarding house sector, and the importance of the legislative reforms introduced in 2012 that are intended to improve standards.

- Our reviews of the deaths of six people in a licensed boarding house in 2009 and 2010, and a subsequent Coronial inquest into the deaths, identified significant concerns about the adequacy of the care provided. The Coroner's findings included that the six people were 'uncared for, poorly treated medically, and neglected'; medication administration was 'dangerously ill-supervised'; and the standards of hygiene and nutrition at the hostel were poor.
- Our work in relation to the deaths in 2011 of four residents of a licensed boarding house raised questions about the support needs of people living there, the adequacy of the support provided, and the quality of the accommodation. Amongst other things, information indicated that staffing levels were inadequate; the quality and quantity of food provided to residents was poor; two of the people who died were malnourished on admission to hospital; and the bedroom of a woman who died from pneumonia reportedly had mould and rising damp.

# Recommendations

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## Guidance for disability services

1. ADHC should provide detailed advice to us on the progress of its actions to develop and roll out the Health and Wellbeing policy framework, including the implementation and training strategy for the framework in ADHC-operated and funded services.
2. ADHC should provide us with a copy of the revised *Nutrition and Swallowing* policy, tools and practice guide.

## Monitoring disability services

3. ADHC should provide detailed advice to us on the progress of its actions to:
  - a) develop and implement the NSW Quality Framework with ADHC funded services, and
  - b) develop a quality management system to improve on existing processes to monitor the quality of ADHC-operated services.
4. ADHC should provide us with a copy of its Risk Identification and Monitoring Guidelines.

## Antipsychotic medication and behaviour management

5. By 30 August 2013, ADHC should provide detailed advice to us on how it will review current practice in ADHC-operated and funded accommodation services in relation to the use of antipsychotic medication as a primary behaviour management strategy. ADHC's advice should include details as to:
  - a) how it will identify individuals who receive antipsychotic medication for behaviour management purposes and do not have a current behaviour support plan
  - b) the timeframes for the review, and
  - c) how it will report the outcomes of this work.

## People with disabilities who are ageing

6. In relation to the *Ageing in Place: Impact on Accommodation Services* project, ADHC should:
  - a) provide us with a copy of the project report and associated action plan, and
  - b) provide advice to us on its progress towards implementing the action plan.

## Access to health services for people with dual diagnosis

7. In relation to the implementation of the *Memorandum of Understanding between ADHC & NSW Health in the provision of services to people with an intellectual disability and mental illness*, ADHC and Health should:
  - a) provide us with a copy of the formative evaluation of the implementation process, and
  - b) inform us of any action they intend to take in response to the formative evaluation findings.

## Improving support in the community for people with disabilities and chronic illnesses

8. The Agency for Clinical Innovation (ACI) should provide detailed advice to us on the progress of its actions to improve the access of people with disabilities in care to the Connecting Care and other out-of-hospital programs. This should include advice as to the progress and outcomes of its consultations and other work with:
  - a) GP representatives, including GPNSW and other GP clinical leaders on barriers to service provision for this population and possible strategies for increasing the development of shared care plans for people with disability
  - b) the disability sector, including ADHC
  - c) carer supports, including Carers NSW and LHD Carer Liaison Officers, and
  - d) the ACI Intellectual Disability Network.
9. In relation to improving access to community-based and coordinated care for people with disabilities who have chronic and complex respiratory disease, NSW Health should provide detailed advice on:
  - a) the progress and outcomes of the preliminary collaborative work between the Clinical Excellence Commission and the ACI on addressing the preventable causes of aspiration pneumonia, and
  - b) the progress of the Trapeze program to improve support for people with disability aged 16-24 years with chronic conditions, and any plans for evaluating the program.

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10. The ACI should provide advice to us on the progress of its Transition Care Network in developing models of care for young people with complex chronic illnesses and disabilities who currently have poor access to adult services.

### **Supporting people with disabilities in their contact with health services**

11. Health should report to us on its progress in implementing actions under the NSW Implementation Plan for the National Disability Strategy to:
  - a) improve services to people with disability and carers attending, being admitted to, or leaving hospital by:
    - i. developing consistent processes to ensure the safe and effective transfer of care of patients who are transferred home or to ongoing care from the acute hospital service (Action 6.c.i), and
    - ii. encouraging more flexible non-emergency transport services that meet the needs of patients who currently have access issues (Action 6.c.iv).
  - b) implement strategies in the NSW Oral Health Strategic Directions 2011-2020 to improve oral health care for people with disability (Action 6.d).
12. In relation to the Health/ADHC Joint Guideline to support residents of disability accommodation services who attend or are admitted to a NSW public hospital:
  - a) Health and ADHC should:
    - i. provide advice to us as to the intended date of release of the Joint Guideline
    - ii. provide us with a copy of the Joint Guideline and any supporting documents, and
    - iii. provide detailed advice to us on joint plans for evaluating the implementation of the Joint Guideline and its effectiveness in improving support for people with disabilities in hospital.
  - b) Health should:
    - i. provide us with a copy of its letter to the LHD Chief Executives regarding the release and implementation of the Joint Guideline, and
    - ii. provide advice to us on the details and outcomes of its work with the ACI Intellectual Disability Network in relation to the ongoing implementation and monitoring of the Joint Guideline.
  - c) ADHC should provide advice to us on:
    - i. how it will support disability services staff to implement the Joint Guideline, and
    - ii. how it will monitor the implementation of the Joint Guideline.
13. Health and FACS should report to us on their progress in implementing actions under the NSW Implementation Plan for the National Disability Strategy (Action 6.b) to:
  - a) develop enhanced models of care for people with intellectual disability
  - b) improve referral pathways, with particular emphasis on aspects of care related to challenging behaviour
  - c) investigate the establishment of a state-wide patient/client database to improve client outcomes
  - d) map health services for people with intellectual disability, and link with services provided by agencies such as ADHC, Community Services and Department of Education and Communities, and
  - e) work with key education providers to enhance the curriculum and teaching resources related to health care for people with intellectual disability.
14. Health should provide advice to us on the department's plans for, and the progress of its work in, implementing the broader service framework, including implementing the strategies identified in relation to Tiers 1-3 to:

### **Health service framework to improve the health care of people with intellectual disability**

- a) promote the involvement of people with intellectual disability in strategic health policy and population health<sup>1</sup>
  - b) improve primary and community health services' identification of, and response to, the health needs of people with intellectual disability,<sup>2</sup> and
  - c) improve the capacity of the secondary health care system to care for and manage the additional health needs of people with intellectual disability.<sup>3</sup>
15. Health should inform us of its progress in appointing an organisation to undertake an independent evaluation to assess the effectiveness of the ACI Intellectual Disability Network and the three clinical service pilots in meeting the aims of the Service Framework.

### **Access to preventative health support**

16. Health should report to us on its progress in implementing actions under the NSW Implementation Plan for the National Disability Strategy to:
- a) improve access to information and support to help people with disability make lifestyle changes relating to healthy eating, being physically active, and achieving and maintaining a healthy weight, through the Get Healthy Information and Coaching Service (Action 6.g), and
  - b) develop a cross-agency Overweight and Obesity Plan, which encourages and promotes healthy lifestyles through better eating behaviours and physical exercise (Action 6.h).

17. The Department of Education and Communities should report to us on its progress in implementing actions under the NSW Implementation Plan for the National Disability Strategy to:
- a) enhance information provided on specific sports for people with disability (Action 1.i.i)
  - b) develop local level inclusive sports directories to provide information, support and network opportunities available in the community for people with disability (Action 1.i.ii)
  - c) develop an online calendar of events for sport for people with disability (Action 1.i.iii), and
  - d) develop Phase 2 of the You're in the Game: NSW Disability Sport and Physical Activity Framework (Action 1.j)

### **Support for people in licensed (assisted) boarding houses**

18. Health should report to us on its progress in developing and implementing the Boarding House Support Initiative (BHoSI) to provide outreach support for people with mental illness living in boarding houses.

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1. As identified on page 13 of the NSW Health Service Framework to Improve the Health Care of People with Intellectual Disability.

2. As identified on page 13 of the NSW Health Service Framework to Improve the Health Care of People with Intellectual Disability.

3. As identified on page 14 of the NSW Health Service Framework to Improve the Health Care of People with Intellectual Disability.



**Part One:**  
**Deaths in 2010**  
**and 2011**

# Chapter 1. Introduction

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This report is the seventh report of reviewable deaths, and covers the period 1 January 2010 – 31 December 2011. In this two-year period, the deaths of 220 people with disabilities in care were reviewable.

## 1.1 Reviews of the deaths of people with disabilities in care

Our reviewable deaths functions are detailed in Part 6 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CS CRAMA).

In addition to reviewing the deaths of certain children, CS CRAMA requires the Ombudsman to review the death of any person living in, or temporarily absent from, residential care authorised or funded under the *Disability Services Act 1993*, or a licensed boarding house.

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

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

This work involves examination of relevant records and information relating to the people with disabilities who died, and we may also request specific information from agencies to assist in our review.

## 1.2 Our work arising from deaths in 2010 and 2011

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

related to reviewable deaths, or issues that arise generally from our work, and to seek information about these issues.

In the years 2010 and 2011, the deaths of 220 people in residential care or licensed boarding houses were reviewable. In relation to 46 deaths, we took additional further action. In some cases, action related to more than one agency. Most of our work focused on the disability services or licensed boarding houses that had provided direct support to the individuals, with a number of matters also involving health services and other government agencies.

### Investigations and reports to agencies

We made 19 reports to agencies under section 43(3) of CS CRAMA arising from our reviews of the deaths of 34 people. The reports were directed to:

- ADHC (five reports about five people)
- NGO disability services (nine reports about 24 people), and
- NSW Health services (three reports about three people)

In the main, we used these reports to provide agencies with information to assist their work or to draw attention to issues that we believed the agency needed to consider and, where appropriate, respond to.

We made preliminary inquiries of ADHC under section 13AA of the Ombudsman Act in relation to the deaths of two people.

We met with service providers to obtain further information and discuss our concerns about the deaths of 21 people. The majority of these matters (18 people) also involved reports or preliminary inquiries.

Arising from our reviews of the deaths of four people in a licensed boarding house (see page 61), and eight people in accommodation provided by a funded disability service, we referred issues to ADHC to investigate and report back to us under section 25 of CS CRAMA.

The issues identified through our reviews of deaths in 2010 and 2011, including those raised in our reports to services, are reported in Chapter 4.



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## Other action

We made complaints to the Health Care Complaints Commission (HCCC) regarding issues pertaining to a general practitioner and psychiatrist that we identified in our reviews of the deaths in 2010 of four people in a licensed boarding house (see page 61).

## Panel of Expert Advisers

We have established a Panel of Expert Advisers<sup>4</sup> to assist us in our work. The Panel provides us with valuable advice on complex disability death matters and on relevant policy and practice issues. We obtained advice from members of our Expert Panel in relation to the deaths of 26 people in 2010 and 2011.

A list of members of the Reviewable Disability Deaths Expert Panel is provided in Appendix 1.

## 1.3 Developments since our last report

Since our last report in September 2011, much has been done in the disability sector to address issues that have frequently featured in our recommendations.

In particular, there has been significant action taken to reform the boarding house sector. In October 2012, the NSW Government brought in the *Boarding Houses Act 2012*, which provides an improved regulatory framework for the delivery of services to residents of registrable (licensed and unlicensed) boarding houses.

Key changes include the mandatory registration of all registrable boarding houses, the introduction of occupancy rights for all boarding house residents, and strengthened requirements and provisions relating to 'assisted' (formerly licensed) boarding houses.<sup>5</sup>

In March 2013, ADHC released the draft *Boarding Houses Regulation 2013* for comment. The proposed Regulation provides improved safeguards and standards for people in assisted boarding houses, including requirements to:

- ensure that a broader range of incidents involving residents are reported (including assaults, serious accidents and medication administration errors)
- improve residents' ability to get help when they need it, including by installing call bells and ensuring that at least one staff member is present at all times, and
- meet the nutritional needs of residents, including undertaking menu planning with reference to published dietary guidelines or, when necessary, the advice of a qualified dietician or nutritionist.

There have been other changes in the past year to improve support for boarding house residents, including:

- Development of the Boarding House Support Initiative – involving collaboration between Health, the non-government sector, and FACS (including ADHC) to provide in-reach support services to assist people with mental health issues in boarding houses.
- Introduction by ADHC of changes to the Primary and Secondary Health Care service model to improve the health outcomes of people living in licensed boarding houses. Primary and Secondary Health Care services are now required to assess the health needs of all licensed boarding house residents, develop individual health plans, and review them annually.

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4. The Expert Panel operates in place of the Reviewable Disability Deaths Advisory Committee. We established the Panel in 2012 in order to obtain advice on specific deaths; consult on systemic issues arising from, or related to, preventable deaths; obtain assistance in progressing key strategies to reduce preventable deaths; obtain advice on our functions and options for strengthening the work; and convene group (or sub-group) meetings of expert advisers on particular topics as required.

5. While the provisions of the new Act that relate to the register and initial compliance investigations by local councils commenced on 1 January 2013, the remainder of the Act will not commence until regulations have been finalised (expected in 2013). Until the Act comes into force, the *Youth and Community Services Act 1973* and the *Youth and Community Services Regulations 2010* continue to apply.

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## Changes following the deaths of people with disabilities in care in 2010 and 2011

In addition to broader sector reform, numerous changes and improvements have been made by services following the deaths of people with disabilities in care during 2010 and 2011. Notably, this has included:

- requirements to improve guidance and support for people with asthma on discharge from hospital, and follow-up care for complex and re-presenting patients (see case study 5 on page 34)
- changes to the screening tool for entry to licensed boarding houses to identify people with choking risks (see case study 12 on page 43)
- independent reviews of practice and systems in two services, with action plans to address issues including health care and behaviour support, and monitoring of staff practice (see case study 16 on page 48)
- work on developing state-wide standards for the insertion, replacement or ongoing care of all gastrostomy and jejunostomy tubes, and a model of care for Home Enteral Nutrition (see case study 21 on page 55)
- training for staff to improve: support for clients with complex health needs; recording and response to incidents; medication management; first aid; and compliance with Health guidelines on support for people with disabilities in hospital, and decisions relating to 'no CPR' orders, and
- the introduction of clinical nurse consultant positions to provide guidance to disability services staff, and act as intermediaries with health services, in relation to people with complex and/or increasing support needs.

## Development of factsheets on the key findings and messages from our reviews of the deaths of people with disabilities in care

Effectively communicating the important findings from our work is essential in helping to reduce preventable deaths. This year, we have sought to improve our communication methods by developing specific factsheets for support staff in disability accommodation services and licensed boarding houses, and GPs.

These factsheets include information about:

- the critical findings from our reviews
- the main causes of death
- key risk factors for people with disabilities in care relating to those causes of death, and
- the steps staff and GPs should take to help individuals improve their health and reduce preventable deaths.

We are also developing strategies for ensuring sector-wide education on this material and assessing the level of take-up of the key messages at the 'coal-face'.

## 1.4 This report

This seventh report will be released in two volumes. The first volume concerns the deaths of certain children. This second volume relates to the deaths in 2010 and 2011 of 220 people with disabilities in care.

Of the 220 people with disabilities who died, eight were children or young people. The reviews of these eight individuals are therefore included in both volumes of this report.

**Part One** provides information on the deaths of people with disabilities in 2010 and 2011:

- **Chapter 2** outlines the demographic and other data relating to the people who died.
- **Chapter 3** details data and other information relating to the main causes of deaths.
- **Chapter 4** reports on the main findings from our reviews of deaths in the two-year period. Where appropriate, we have provided case studies to illustrate the issues. Some of the issues are consistent with those we have reported in previous years. As a result, and where relevant, we have outlined our previous recommendations and subsequent agency actions.

**Part Two** details the recommendations we made in our last report and the progress of ADHC and NSW Health in implementing them.

## Chapter 2. Deaths of people with disabilities in 2010 and 2011

Our responsibilities include reporting on data and information relating to deaths in each two-year period, as well as analysing data relating to all deaths to identify patterns and trends.

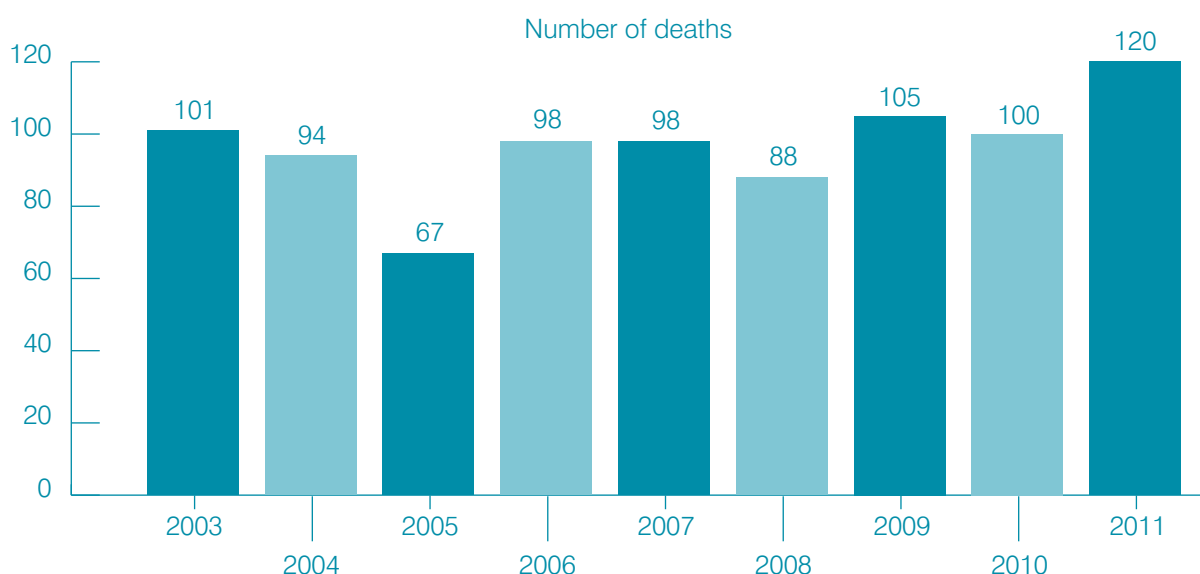
In this section we report demographic and other information relating to the people who died between 1 January 2010 and 31 December 2011. Where relevant, we have compared deaths

in this period to those that occurred across the nine years between 2003 and 2011 and noted differences, where they exist.

### 2.1 Reviewable disability deaths in 2010 and 2011

Of the 220 reviewable deaths of people with disabilities in care in 2010 and 2011, 100 people died in 2010, and 120 people died in 2011.

**Figure 1: Deaths of people with disabilities in care between 2003 and 2011.**



- 97 people (44%) lived in ADHC accommodation
- 98 people (45%) lived in NGO (ADHC-funded) accommodation, and
- 25 people (11%) lived in licensed boarding houses.

Where relevant, we have separated the data on the deaths of people in ADHC or NGO services (referred to in this report as 'disability services') from the data on the deaths of people in licensed boarding houses.

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

**Table 1: Deaths in 2010 and 2011<sup>6</sup>**

Accommodation	Estimated total number of residents 2010-11 <sup>7</sup>	Number of deaths 2010-2011 (N <sub>Tot</sub> = 215 <sup>8</sup> )	Percentage of population who died in 2010-11	Percentage of reviewable disability deaths
Group home (funded) <sup>9</sup>	3,132	64	2.0	29.1
Group home (ADHC) <sup>10</sup>	1,601	41	2.6	18.6
Residential centre (funded) <sup>11</sup>	402	30	7.5	13.6
Residential centre (ADHC)	1,039	55	5.3	25
Licensed boarding house	675	25	3.7	11.4

People in NGO group homes accounted for the highest proportion of reviewable deaths in 2010 and 2011; they also comprise the largest number of people with disabilities in care.

## 2.2 Age, gender and cultural status

### Age

The age at death of people in disability services ranged from nine to 92 years. The mean age was 52 years, consistent with the average for deaths in the nine years from 2003.

The age at death of people in licensed boarding houses ranged from 53 to 82 years. The mean age at death of people in licensed boarding houses was 66 years, slightly higher than the average for the nine-year period (63 years).

### Gender

In 2010 and 2011, over half of the people in disability services (115) and over three-quarters of the licensed boarding house residents who died (21) were male. The prevalence of males reflects the broader population of people with disabilities in care, where males outnumber females in all accommodation and service types.

Data relating to the age and gender of people who died between 2003 and 2011 is provided in Appendix 2.

### Cultural status

Five people who died in disability services were identified as Aboriginal or Torres Strait Islander.<sup>12</sup> Eighteen people were from a CALD background, most of whom (13) were in disability services.

## 2.3 Disability and support needs

Information relating to disability and the support needs of people who died in 2010 and 2011 is largely consistent with previous years.

### Disability

Most of the disability services residents who died (94%) had a cognitive impairment (whether intellectual disability, dementia, acquired brain injury, and/or developmental delay). Many also had other impairments, including sensory and physical disabilities.

Most of the licensed boarding house residents who died had a psychiatric disability (76%). Most also had a cognitive impairment (60%), whether intellectual disability or acquired brain injury (typically alcohol-related brain damage).

6. Not included in the table are five people who died in 2010-11 in other accommodation. Two people died in short-term respite care with ADHC. Two children and one young person lived in host family placements that were funded by NGO services.
7. The total number of people in care in 2010-11 has been estimated based on data provided by ADHC. The data related to the numbers of people in care for the financial years of 2009/10 and 2010/11.
8. Does not include the five people who were living in other accommodation.
9. Includes one person who lived in a cluster of six bed-sits; a man who lived in a duplex with another resident; a man who lived in a granny flat adjoining a group home; two people who received drop-in support in accommodation owned by an NGO; and one person who lived alone with 24/7 staff support.
10. Includes one person who was living in ADHC centre-based respite for an extended period of time.
11. Includes one person who was living in an NGO residential service on extended respite; a woman who lived in a cluster of units; and a man who lived alone in a cluster of 11 units with 24/7 staff support.
12. Aboriginal or Torres Strait Islander status was indicated by services on the Client Death Notification form and recorded in the person's service records.

**Table 2: Number and percentage of people by type of impairment 2010 and 2011**

	Disability services (N=195)		Licensed BH (N=25)		Total (N=220)	
	N	%	N	%	N	%
Intellectual	174 <sup>13</sup>	89.2	9 <sup>14</sup>	36.0	183	83.2
Sensory	123	63.1	5	20.0	128	58.2
Physical	98	50.3	1	4.0	99	45.0
Psychiatric	75	38.5	19	76.0	94	42.7
Neurological	24	12.3	0	0.0	24	10.9
Acquired Brain Injury	14	7.2	8	32.0	22	10.0
Developmental	19	9.7	0	0.0	19	8.6

### Consent to treatment

For the majority of disability services residents, other people provided consent to medical or dental treatment on their behalf, mainly family members (134; 69%). Twenty-seven people in disability services provided their own consent.

Over three-quarters of licensed boarding house residents (21) provided their own consent to medical or dental treatment.

### Mobility and communication support

Over two-thirds of the people in disability services who died (133) required help with mobility, and largely relied on wheelchair support. The same proportion needed assistance to communicate, using mainly adjusted verbal language or other signing (such as gestures).

Only five licensed boarding house residents needed mobility assistance, using either a walking stick or walking frame. None were reported to have needed communication support.

### Assistance with meals

Over three-quarters of the disability services residents (156) needed help with meals. Only two of the licensed boarding house residents required assistance with meals.

### Enteral nutrition

Nineteen of the people in disability services who died relied on enteral nutrition (tube feeding), mainly via a PEG tube. The majority (17) relied on enteral nutrition exclusively, and did not have any oral intake of food, fluids or medication.

None of the licensed boarding house residents required enteral nutrition.

### Swallowing difficulties

Almost three-quarters of the people in disability services (139) were reported to have had swallowing difficulties (also known as dysphagia). Only three licensed boarding house residents were reported to have had swallowing difficulties.

### Speech pathology review

The vast majority of people in disability services with swallowing difficulties had seen a speech pathologist (121), mainly within the 12 months prior to their death (100). One of the three people in licensed boarding houses with swallowing difficulties had seen a speech pathologist.

### Nutrition & swallowing risk checklist

Since 2005, all disability accommodation services have been required to identify and address the nutrition and swallowing risks of the people in their care using an appropriate checklist. ADHC's *Nutrition and Swallowing* policy includes a nutrition and swallowing risk checklist for services to use.

13. Most of the disability services residents with intellectual disability had a moderate or severe level of cognitive impairment.

14. Most of the licensed boarding house residents with intellectual disability had a mild level of impairment.

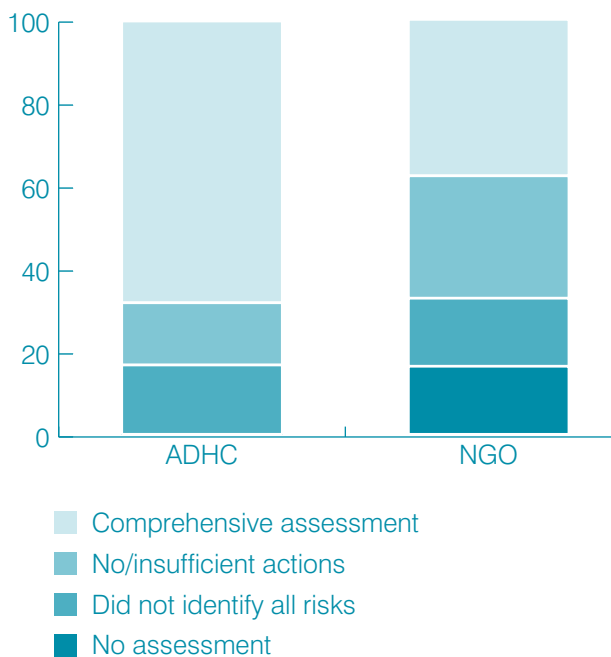
Of the 61 people in NGO services with swallowing difficulties who died in 2010 and 2011:

- ten people did not have a nutrition and swallowing risk assessment, and
- less than half had a comprehensive assessment (23).

Of the 78 people in ADHC services with swallowing difficulties who died in 2010 and 2011:

- most had a comprehensive nutrition and swallowing risk assessment (53), but
- for almost one-third, staff had either not identified all of the person's risks (13), or had not recorded actions that needed to be taken to address the risks (12).

**Figure 2: Nutrition and Swallowing Checklist quality for people with swallowing difficulties who died in 2010 and 2011 by service provider**



## Mealtime support guidance

The vast majority of people in disability services who had swallowing difficulties who died in 2010 and 2011 (112) had a mealtime management plan (or similar document) in place at the time of their death.

## 2.4 Health needs

### Dentition

**Table 3: Dentition status of people who died in 2010 and 2011**

	Disability services		Licensed BH		Total	
	N	%	N	%	N	%
None	44	22.6	2	8.0	46	20.9
Some	82	42.1	10	40.0	92	41.8
All	49	25.1	4	16.0	53	24.1
Dental aid	20	10.3	7	28.0	27	12.3
Don't know	0	0	2	8.0	2	0.9
<b>Total</b>	<b>195</b>	<b>100%</b>	<b>25</b>	<b>100%</b>	<b>220</b>	<b>100%</b>

As indicated in table 3, only one-quarter of the people in disability services (49) and four licensed boarding house residents had all of their teeth.

### Dental review

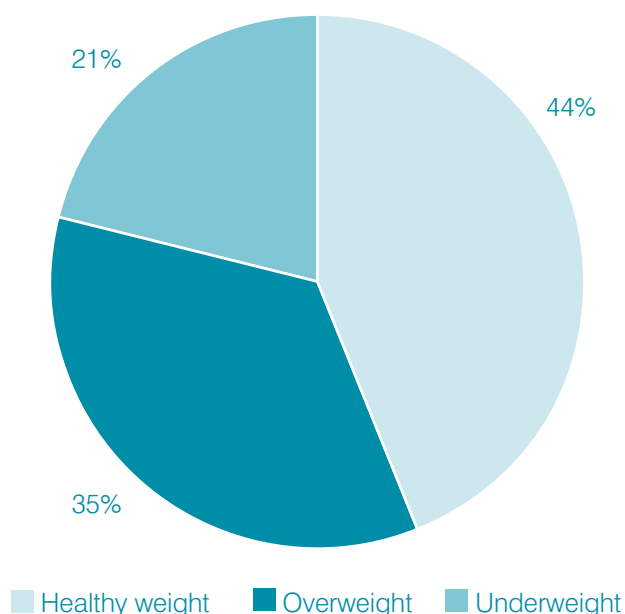
The majority of the people in disability services who died in 2010 and 2011 (142) had seen a dentist, and most in the 12 months before their death (113).

Less than half of the licensed boarding house residents (10) had seen a dentist at any time. Six of the 10 had seen a dentist in the 12 months before they died.

## Weight

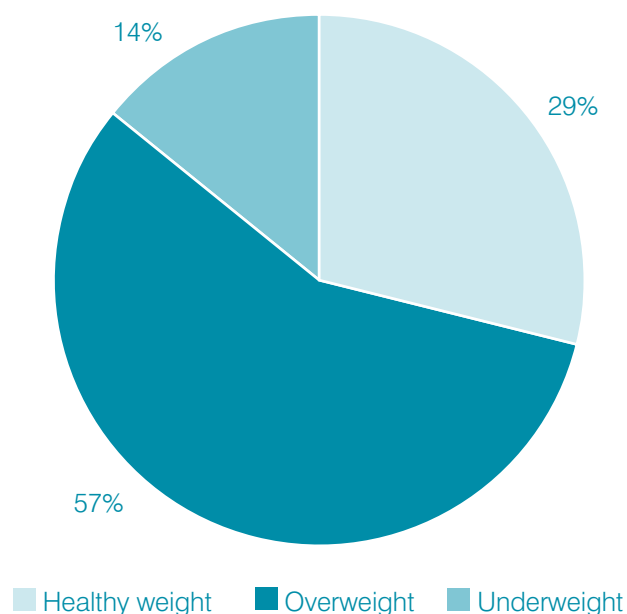
In 2010 and 2011, less than half of the people in disability services who died<sup>15</sup> (85) were in the healthy weight range. Over one-third were overweight (67), and just under one-quarter (41) were underweight.

**Figure 3: Weight range of people in disability services who died in 2010 and 2011**



In relation to licensed boarding house residents, less than one-third of the people who died<sup>16</sup> were in the healthy weight range (6). Over half (12) were overweight. Three licensed boarding house residents who died were underweight.

**Figure 4: Weight range of people in licensed boarding houses who died in 2010 and 2011**



15. Weight status information was available for 191 people in disability services (98%). The percentages in this section are based on the 191 people.

16. Weight status information was available for 21 people in licensed boarding houses (84%). The percentages in this section are based on the 21 people.

## Other key health issues

**Table 4: Main health issues of people in disability services who died in 2010 and 2011**

Health issue	N	%
Incontinence <sup>17</sup>	151	77
Constipation	144	74
Gastro-oesophageal reflux disease	101	52
Epilepsy	92	47
Recurrent respiratory infections	74	38
Osteoporosis	66	34
High blood pressure	54	28
Heart problems <sup>18</sup>	49	25
Asthma	39	20
High cholesterol	37	19
Recurrent urinary tract infections	32	16
Hypothyroidism	32	16
Hernia	29	15
Diabetes	27	14
Arthritis	25	13
Recurrent pressure areas	24	12

**Table 5: Main health issues of people in licensed boarding houses who died in 2010 and 2011**

Health issue	N	%
High blood pressure	11	44
Chronic obstructive pulmonary disease <sup>19</sup>	11	44
Gastro-oesophageal reflux disease	10	40
Heart problems <sup>20</sup>	9	36
High cholesterol	8	32
Incontinence <sup>21</sup>	8	32
Diabetes	7	28
Asthma	7	28
Recurrent respiratory infections	6	24
Anaemia	5	20

Seventy-one people in disability services (36%), and five licensed boarding house residents (20%) were taking supplements to treat Vitamin D deficiency. It was not always clear whether the condition had been diagnosed or the vitamin was given as a preventative measure.

### Respiratory review

Just over one-quarter of the people in disability services (19) and half of those in licensed boarding houses (3) with recurrent respiratory illness who died in 2010 and 2011 had seen a respiratory specialist at any point.

17. Mainly double incontinence

18. Includes congestive cardiac failure, congenital heart disease, cardiomyopathy, atrial fibrillation, and ischaemic heart disease

19. Also includes emphysema

20. Includes cardiomyopathy, angina, ischaemic heart disease, congestive cardiac failure, and atrial fibrillation

21. Mainly urinary incontinence



## Smoking

The vast majority of licensed boarding house residents who died in 2010 and 2011 had smoked (22), and most of these people were still smokers at the time of their death.

Twenty-nine people in disability services who died in 2010 and 2011 had smoked, and most of these people were smokers at the time of their death.

**Table 6: Smoking rates by residence type for people who died in 2010 and 2011**

	Disability services	%	Licensed BH	%	Total	%
No	166	91.2	3	12	169	76.8
Ex-smoker	12	6.6	7	28	19	8.6
Current > 20/ day	9	0	7	28	16	7.3
Current ≤10/ day	5	0	3	12	8	3.6
Current 11-20/ day	2	1.7	4	16	6	2.7
Occasional	1	0.6	1	4	2	1.0
<b>Total</b>	<b>195</b>	<b>100%</b>	<b>25</b>	<b>100%</b>	<b>220</b>	<b>100%</b>

Data relating to smoking rates amongst people with disabilities in care who have died has been highly consistent across the nine-year period since 2003. On average over that period, 81% of the licensed boarding house residents and 17% of the disability services residents who died had smoked.

## Vaccination

All people with severely impaired immunity are at increased risk of morbidity and mortality from influenza and invasive pneumococcal disease.<sup>22</sup>

### Influenza vaccination

The administration of influenza vaccine to people at risk of complications from infection is 'the single most important measure in preventing or attenuating influenza infection and preventing mortality.'<sup>23</sup>

Annual influenza vaccination is strongly recommended for people at increased risk of complications from influenza infection, including people ≥6 months of age with:

- chronic respiratory conditions
- heart disease
- other chronic illnesses requiring regular medical follow-up or hospitalisation in the preceding year (including diabetes mellitus and chronic renal failure)
- chronic neurological conditions (such as multiple sclerosis, spinal cord injuries, and seizure disorders), and
- people with impaired immunity.

22. The Australian Immunisation Handbook, 9th Edition.

23. Op cit

In 2010 and 2011, just below three-quarters of the people in disability services (145) and just below two-thirds of the licensed boarding house residents who died (16) had received the influenza vaccination in the year before their death.

### Pneumococcal vaccination

In adults, pneumococcal pneumonia is the most common clinical presentation of invasive pneumococcal disease (IPD).<sup>24</sup>

People who are recommended to receive the pneumococcal vaccine include:<sup>25</sup>

- all people aged  $\geq 65$  years
- Aboriginal and Torres Strait Islander people  $\geq 50$  years of age and those 15-49 years who have underlying conditions placing them at risk of IPD
- people aged  $\geq 10$  years who have underlying chronic illnesses predisposing them to IPD, including:
  - conditions associated with impaired immunity
  - chronic illness, including chronic heart, renal or respiratory disease, diabetes, and alcohol-related problems, and
- tobacco smokers.

In 2010 and 2011, less than half of the people in disability services (94) and less than one-third of licensed boarding house residents had received the pneumococcal vaccination in the five years before their death.

### Comprehensive health assessment

ADHC-operated and funded disability accommodation services are required to support clients to have an annual GP health assessment.

The Medicare Benefits Schedule (MBS) provides for extended consultations to enable annual comprehensive health assessments for people with known health risks, including people with intellectual disability and people aged 45-49 who are at risk of developing chronic disease.

Other MBS items provide for regular medical practitioner assessment and review of people with a chronic medical condition, such as asthma, cancer, cardiovascular disease, diabetes mellitus, musculoskeletal conditions and stroke.

The vast majority of the people in disability services (172) and less than half of the licensed boarding house residents (11) who died in 2010 and 2011 had a comprehensive health assessment in the year before their death.

24. Op cit

25. For all of the groups, revaccination five years after the first dose is recommended. For the majority of the groups, a second revaccination is recommended five years after the first revaccination or at 50 years of age for Indigenous adults and 65 years for non-Indigenous adults (whichever is later).

## Chapter 3. Causes of death

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The underlying cause of death (UCOD) is most frequently used for analysis of mortality statistics and reporting. It refers to the disease or injury that started the sequence of events leading directly to the person's death.<sup>26</sup>

### 3.1 Broad underlying causes of death

- The vast majority of people with disabilities in care who died in 2010 and 2011 died from natural causes (182 people; 83%). This is largely consistent with deaths since 2003.
- Twenty-nine people (13%) died from unnatural/unintentional/undetermined causes.<sup>27</sup> This included 23 people in disability services (12%) and almost one-quarter of the licensed boarding house residents who died (6). The main unnatural/unintentional cause of death in 2010 and 2011 was choking on food (9 people).
- No-one in 2010 or 2011 died from unnatural/intentional causes, such as suicide.

### 3.2 Leading underlying causes of death

#### Leading underlying causes of death of people with disabilities in care<sup>28</sup>

As indicated in table 7, the leading cause of deaths in 2010 and 2011 of people with disabilities in care was nervous system diseases (37 people; 17%). Other main causes of death were respiratory diseases (32 people; 15%); circulatory system diseases (31 people; 14%); cancers (30 people; 14%); and external causes (29 people; 13%).

However, to gain an accurate picture of the main causes of death, it is important to examine the underlying causes of death of people in disability services separate from people in licensed boarding houses. There are notable differences in the main causes of death of the two populations.

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26. Nationally and internationally, morbidity and mortality data are coded according to the International Statistical Classification of Diseases and Related Health Problems (ICD) system. The ICD is the international standard health classification published by the World Health Organisation (WHO) for coding diseases for statistical aggregation and reporting purposes. The ICD provides structured rules guiding how the underlying cause of death is determined. Use of these rules assists with standardisation of coded data and facilitates comparability with other collections of mortality data.

27. Deaths from unnatural/unintentional causes are those due to unintentional external causes such as accidents and complications of medical and surgical care.

28. At the time of writing the report, we had cause of death information for 211 people (96%), including all of the licensed boarding house residents and 186 people in disability services. Our reporting and calculations relating to causes of death in 2010-11 are based on the 211 people.

**Table 7: Underlying causes of death in 2010 and 2011 of people with disabilities in care at ICD chapter level**

ICD Chapter	Disability services						Licensed BH					
	Male		Female		Total		Male		Female		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Infectious and Parasitic (A00-B99)	3	2.7	0	0	3	1.6%	0	0	0	0	0	0%
Neoplasms (C00-D48)	15	13.5	11	14.7	26	14.0%	3	14.3	1	25	4	16%
Blood, Blood-Forming Organs (D50-D89)	1	0.9	0	0	1	0.5%	0	0	0	0	0	0%
Endocrine, Nutritional, Metabolic (E00-E90)	4	3.6	2	2.7	6	3.2%	0	0	0	0	0	0%
Mental and Behavioural (F00-F99)	1	0.9	2	2.7	3	1.6%	1	4.8	0	0	1	4%
Nervous System (G00-G99)	22	19.8	15	20	37	19.9%	0	0	0	0	0	0%
Circulatory (I00-I99)	15	13.5	10	13.3	25	13.4%	6	28.6	0	0	6	24%
Respiratory (J00-J99)	12	10.8	14	18.7	26	14.0%	5	23.8	1	25	6	24%
Digestive (K00-K99)	8	7.2	3	4	11	5.9%	0	0	0	0	0	0%
Musculoskeletal and Connective Tissue (M00-M99)	0	0	1	1.3	1	0.5%	0	0	0	0	0	0%
Genitourinary (N00-N99)	2	1.8	0	0	2	1.1%	0	0	0	0	0	0%
Perinatal (P00-P96)	1	0.9	0	0	1	0.5%	0	0	0	0	0	0%
Congenital and chromosomal (Q00-Q99)	13	11.7	5	6.7	18	9.7%	0	0	0	0	0	0%
Symptoms and signs NEC (R00-R99)	2	1.8	1	1.3	3	1.6%	2	9.5	0	0	2	8%
External Causes (V01-Y98)	12	10.8	11	14.7	23	12.4%	4	19	2	50	6	24%
<b>Total</b>	<b>111</b>	<b>100%</b>	<b>75</b>	<b>100%</b>	<b>186</b>	<b>100%</b>	<b>21</b>	<b>100%</b>	<b>4</b>	<b>100%</b>	<b>25</b>	<b>100%</b>

### Leading underlying causes of death of people in disability services

Consistent with previous years, the leading underlying causes of death of people in disability services in 2010 and 2011 were:

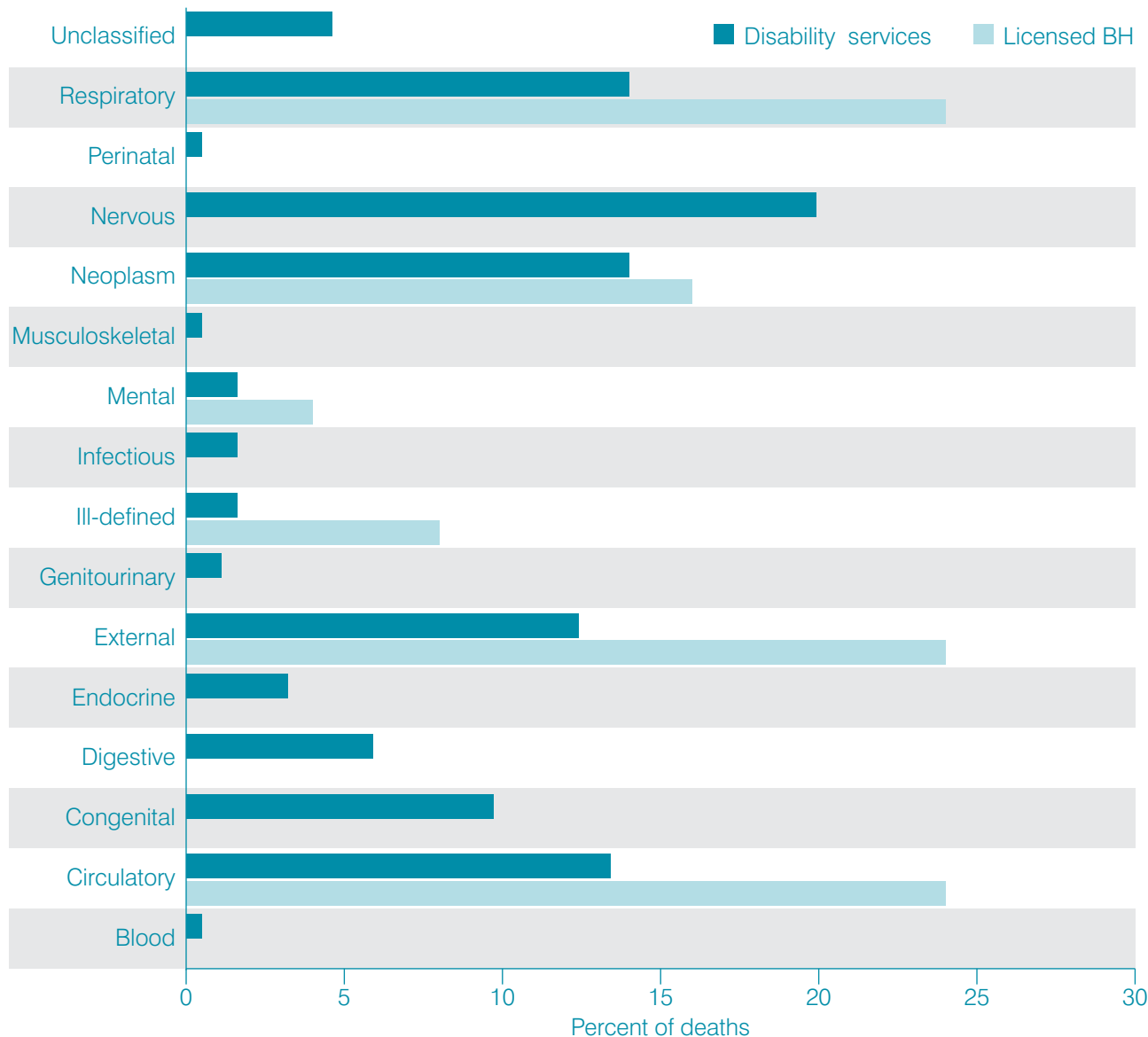
1. **Nervous system diseases** (37 people; 20%) – primarily epilepsy (15 people; 8%) and cerebral palsy (12 people; 6%)
2. **Neoplasms** (26 people; 14%) – mainly bowel cancer (5 people; 3%) and oesophageal cancer (3 people; 2%)
3. **Respiratory diseases** (26 people; 14%) – mainly aspiration (12 people; 6%), pneumonia (6 people; 3%), and chronic lower respiratory diseases (5 people; 3%)

4. **Circulatory diseases** (25 people; 13%) – primarily other heart diseases (9 people; 5%), cerebrovascular diseases (7 people; 4%), and ischaemic heart diseases (6 people; 3%)
5. **External causes** (23 people; 12%) – mainly choking on food (6 people; 3%), sequelae of transport accidents<sup>29</sup> (5 people; 3%), and accidental poisoning by exposure to noxious substances<sup>30</sup> (3 people; 2%),<sup>31</sup> and

6. **Congenital causes** (18 people; 10%) – mainly Down syndrome (7 people; 4%).

Nervous system diseases were the leading underlying cause of death for both males and females in disability services. The other leading causes of death for females in disability services were respiratory diseases, cancer, and external causes. For males, the other leading causes of death were circulatory disease, cancer, and congenital causes.

**Figure 5: Underlying causes of death of people with disabilities in care in 2010 and 2011 by type of residence**



29. Includes people who had acquired a disability following a transport accident at an early age (such as a vehicle accident at two years of age), who died as an adult from causes such as respiratory illness.

30. Three people died from multi-drug toxicity.

31. Other external causes of the deaths of people in disability services in 2010 and 2011 included bowel obstruction due to iatrogenic constipation; hypoperfusion due to post-operative haemorrhage; septicaemia and peritonitis due to a misplaced feeding tube; drowning in a pool; and multiple injuries due to being hit by a vehicle.

## Leading underlying causes of death of people in licensed boarding houses

The leading underlying causes of death for licensed boarding house residents were:

1. **Circulatory diseases** (6 people; 24%) – primarily ischaemic heart diseases (4 people; 16%)
2. **Respiratory diseases** (6 people; 24%) – mainly pneumonia (3 people; 12%), and chronic lower respiratory diseases (3 people; 12%)
3. **External causes** (6 people; 24%) – mainly choking on food (3 people; 12%),<sup>32</sup> and
4. **Neoplasms** (4 people; 16%) – primarily lung cancer (2 people; 8%).

The leading underlying causes of death of people in licensed boarding houses in 2010 and 2011 are highly consistent with deaths over the nine years since 2003.

The leading causes of death of males in licensed boarding houses reflected the above. Only four females in licensed boarding houses died in 2010 and 2011. Their leading underlying causes of death were external causes, respiratory disease, and cancer.

## 3.3 Age and cause of death

### People in disability services

Largely consistent with previous years, nervous system diseases were the leading cause of death of people in disability services in 2010 and 2011 up to the age of 55 years. Between 55 and 64 years, cancer was the leading cause of death. Circulatory diseases were the leading underlying cause of death for people over 65 years of age in disability services – similar to the general population.

Of the leading causes of death, people in disability services had a younger median age at death from nervous system diseases (44 years) and congenital factors (50 years). People who died from circulatory disease had the oldest median age at death (63 years).

## People in licensed boarding houses

In 2010 and 2011, respiratory disease was the leading underlying cause of death of people in licensed boarding houses over 65 years of age, followed by circulatory disease and cancer. For those in licensed boarding houses below 65 years, the leading causes of death were circulatory disease and external causes.

Of the leading causes of death, people in licensed boarding houses had a slightly younger median age at death from external causes (61 years) than the other causes. People who died from cancer had the oldest median age at death (69 years).

## 3.4 Leading causes of death

### Leading causes of death of people with disabilities in care in 2010 and 2011

The table below shows the top 10 leading causes of death for people with disabilities in care in 2010 and 2011. These top 10 causes account for almost half of underlying causes overall.

**Table 8: Top 10 leading causes of death in 2010 and 2011 of people with disabilities in care**

Underlying cause of death	N	%
Epilepsy	15	7.11
Cerebral palsy	12	5.69
Pneumonitis due to solids and liquids	12	5.69
Ischaemic heart diseases	10	4.74
Other heart diseases	10	4.74
Pneumonia	9	4.27
Inhalation and ingestion of food causing obstruction of respiratory tract	9	4.27
Chronic lower respiratory diseases	8	3.79
Cerebrovascular diseases	7	3.32
Down syndrome	7	3.32
<b>Total top 10 underlying causes overall</b>	<b>99</b>	<b>46.92%</b>

32. Other external causes of the deaths of licensed boarding house residents in 2010 and 2011 included blunt force head injury as a result of a fall; mixed drug overdose; and hepatic artery aneurysm due to bile duct damage during surgery.

The small number of deaths necessitates examination of the longer time trend data for more reliable estimates of leading causes (see Appendix 2). The leading causes of death in 2010 and 2011 are broadly consistent with those over the nine years since 2003. The key differences are that:

- deaths from choking on food were prominent in 2010 and 2011, but did not feature in the top 10 causes across the nine years, and
- lung cancer was one of the top 10 overall causes of death since 2003, but did not feature highly in deaths in 2010 and 2011.

### Leading causes of death of people in disability services in 2010 and 2011

The leading causes of death of people in disability services are largely consistent with previous years, with epilepsy, cerebral palsy and aspiration pneumonia the most common causes. In comparison with previous years, choking on food and other heart diseases featured more highly as causes of death in 2010 and 2011.

**Table 9: Top 10 leading causes of death in 2010 and 2011 for people in disability services**

Underlying cause of death	N	%
Epilepsy	15	8.06
Pneumonitis due to solids and liquids	12	6.45
Cerebral palsy	12	6.45
Other heart diseases	9	4.84
Down syndrome	7	3.76
Cerebrovascular diseases	7	3.76
Inhalation and ingestion of food causing obstruction of respiratory tract	6	3.23
Pneumonia	6	3.23
Ischaemic heart diseases	6	3.23
Sequelae of transport accidents	5	2.69
Chronic lower respiratory diseases	5	2.69
Malignant neoplasm of colon, rectum and anus	5	2.69
<b>Total top 10 underlying causes in disability services</b>	<b>95</b>	<b>51.08%</b>

### Leading causes of death of people in licensed boarding houses in 2010 and 2011

Consistent with previous years, ischaemic heart disease was the leading cause of death of licensed boarding house residents in 2010 and 2011. Chronic lower respiratory diseases and pneumonia have also featured highly across all years. In comparison with previous years, deaths from choking on food were more common in 2010 and 2011, and deaths from other heart diseases did not feature as highly.

**Table 10: Top 5 leading causes of death in 2010 and 2011 of people in licensed boarding houses**

Underlying cause of death	N	%
Ischaemic heart diseases	4	16
Pneumonia	3	12
Inhalation and ingestion of food causing obstruction of respiratory tract	3	12
Chronic lower respiratory diseases	3	12
Malignant neoplasm of trachea, bronchus and lung	2	8
<b>Total top 5 underlying causes of death for licensed boarding house residents</b>	<b>15</b>	<b>60%</b>

Information relating to our reviews of the deaths of people from most of the above leading causes is provided in the next chapter.

### 3.5 Multiple causes of death

While the underlying cause of death is useful for reporting purposes, it often does not give the full detail that represents the reality for most deaths. In addition to underlying causes of death, death certificates include significant diseases and/or conditions that led or contributed to death (that is, associated causes).

Multiple cause of death reporting includes both underlying and associated causes of death, and can provide a more comprehensive view of mortality patterns.<sup>33</sup>

In relation to disability services and licensed boarding house residents, the following tables show the number and crude death rates for the underlying causes at the ICD-10 chapter level, for associated causes, and for the multiple causes of death.

33. Australian Bureau of Statistics (2003) 3319.0.55.001 – *Multiple Cause of Death Analysis 1997-2001*.

## Multiple causes of death of people in disability services in 2010 and 2011

**Table 11: Number and rates of deaths by underlying, associated and multiple causes of death; and rate ratios for multiple to underlying causes of death, broad categories of disease, 2010 and 2011 for people in disability services**

Disease category	Underlying cause		Associated cause		Multiple cause		UCOD %	Rate ratio
	Number of deaths	Deaths per 1000	Number of deaths	Deaths per 1000	Number of deaths	Deaths per 1000		
Infectious and parasitic	3	0.24	20	1.62	23	1.86	13.04	7.67
Neoplasms	26	2.11	4	0.32	30	2.43	86.67	1.15
Blood, blood-forming organs, immune system	1	0.08	3	0.24	4	0.32	25.00	4.00
Endocrine, nutritional and metabolic	6	0.49	6	0.49	12	0.97	50.00	2.00
Mental and behavioural	3	0.24	50	4.05	53	4.29	5.66	17.67
Nervous system	37	3.00	34	2.75	71	5.75	52.11	1.92
Circulatory	25	2.02	27	2.19	52	4.21	48.08	2.08
Respiratory	26	2.11	61	4.94	87	7.05	29.89	3.35
Digestive	11	0.89	12	0.97	23	1.86	47.83	2.09
Skin and subcutaneous tissue	0	0.00	1	0.08	1	0.08	0.00	..
Musculoskeletal and connective tissue	1	0.08	7	0.57	8	0.65	12.50	8.00
Genitourinary	2	0.16	13	1.05	15	1.21	13.33	7.50
Perinatal	1	0.08	0	0.00	1	0.08	100.00	1.00
Congenital and chromosomal	18	1.46	16	1.30	34	2.75	52.94	1.89
Symptoms and signs NEC	3	0.24	25	2.02	28	2.27	10.71	9.33
Injuries	0	0.00	28	2.27	28	2.27	0.00	..
External causes	23	1.86	6	0.49	29	2.35	79.31	1.26

As indicated in table 11, respiratory diseases were the largest contributory cause of death for people in disability services – this is consistent with previous years. Respiratory diseases contributed to almost half of all deaths in disability services in 2010 and 2011 (87 people), either as an underlying or associated cause of death.

Other leading contributory causes of death for people in disability services were:

- nervous system diseases, which contributed to over one-third of deaths (71 people)
- mental and behavioural disorders (53 people) – primarily as an associated cause, and
- circulatory diseases, which contributed to over one-quarter of deaths (52 people).



## Multiple causes of death of people in licensed boarding houses in 2010 and 2011

**Table 12: Number and rates of deaths by underlying, associated and multiple causes of death; and rate ratios for multiple to underlying causes of death, broad categories of disease, 2010 and 2011 for people in licensed boarding houses**

Disease category	Underlying cause		Associated cause		Multiple cause		UCOD %	Rate ratio
	Number of deaths	Deaths per 1000	Number of deaths	Deaths per 1000	Number of deaths	Deaths per 1000		
Neoplasms	4	2.87	0	0.00	4	2.87	100.00	1.00
Endocrine, nutritional and metabolic	0	0.00	2	1.43	2	1.43	0.00	..
Mental and behavioural	1	0.72	2	1.43	3	2.15	33.33	3.00
Nervous system	0	0.00	1	0.72	1	0.72	0.00	..
Circulatory	6	4.30	7	5.02	13	9.33	46.15	2.17
Respiratory	6	4.30	5	3.59	11	7.89	54.55	1.83
Digestive	0	0.00	1	0.72	1	0.72	0.00	..
Symptoms and signs NEC	2	1.43	2	1.43	4	2.87	50.00	2.00
Injuries	0	0.00	7	5.02	7	5.02	0.00	..
External causes	6	4.30	1	0.72	7	5.02	85.71	1.17

As indicated in table 12, circulatory diseases were the largest contributory cause of death for licensed boarding house residents. This is consistent with previous years. They contributed to just over half of all deaths in licensed boarding houses in 2010 and 2011 (13 people), either as an underlying or associated cause of death.

Other leading contributory causes of death for people in licensed boarding houses were:

- respiratory diseases, which contributed to almost half of deaths (11 people)
- injuries (7 people) – primarily as an associated cause, and
- external causes, which contributed to over one-quarter of deaths (7 people).

### 3.6 Deaths from diseases of the respiratory system

Respiratory diseases are a major cause of death of people with disabilities in care. Consistent with previous years, respiratory diseases were the third leading underlying cause of death in 2010 and 2011 of people in disability services

(26 people; 14%), and the second leading cause of death of licensed boarding house residents in the same period (6 people; 24%).

Respiratory diseases are also a major contributing factor in the overall deaths of people with disabilities in care, with strong links to deaths from epilepsy, cerebral palsy and Down syndrome.

As has consistently been the case, people with disabilities in care died from respiratory diseases in 2010 and 2011 at a much younger age than the general population.<sup>34</sup> In disability services, the median age at death from respiratory diseases in 2010 and 2011 was 56.5 years – almost 30 years younger than the general population. The median age at death for people in licensed boarding houses from respiratory diseases was 71.5 years.

The leading respiratory diseases that cause the deaths of people with disabilities in care are aspiration pneumonia, pneumonia and chronic lower respiratory diseases.

34. In the general population, deaths from respiratory diseases typically occur in older age. For example, in Australia in 2010, the median age at death from respiratory diseases was 83.3 years. (Australian Bureau of Statistics (2012) 3303.0 *Causes of Death, Australia, 2010*).

## Deaths from aspiration pneumonia in 2010 and 2011

Aspiration is a major factor in the deaths of people in disability services. It occurs when food, fluid or saliva enter into the windpipe and lungs.

Aspiration can occur while eating or as a result of other causes, such as stomach contents coming back up the oesophagus and spilling into the lungs.

Aspiration can cause inflammation and injury of lung tissue. If the lungs become infected because of aspiration, it is called 'aspiration pneumonia'. Chronic aspiration can cause irreversible lung damage.

### Risk factors<sup>35</sup>

You are at risk of aspiration if you have:

- feeding and swallowing problems, such as:
  - dependence on others to feed you
  - difficulty sitting upright or holding your head up
  - swallowing difficulties
  - eating problems (such as eating fast, not chewing very much, and swallowing large mouthfuls of food), and
  - a history of choking
- limited mobility
- gastrointestinal problems, including GORD and repeated vomiting/regurgitation
- recurrent respiratory infections
- neurological and neuromuscular conditions, such as cerebral palsy and epilepsy
- drowsiness and reduced alertness
- poor oral hygiene, including gum disease, and
- medications such as antipsychotics, anticonvulsants, sedatives and muscle relaxants.

In 2010 and 2011, aspiration pneumonia was the second leading underlying cause of death of people in disability services, accounting for the deaths of 12 people (6%). It was also a contributing factor in the deaths of another 30 people in disability services – mainly people whose underlying cause of death was cerebral palsy or epilepsy.

The median age at death of the 12 people who died from aspiration pneumonia in 2010 and 2011 was 49 years.

**Many people in disability services are at high risk of aspiration as they have multiple risk factors.** This was reflected in the people who died from aspiration pneumonia in 2010 and 2011, the majority of whom:

- required help with meals, had swallowing difficulties and/or eating problems, and dental problems such as no teeth or only some teeth
- had multiple health problems, many of whom had significant and chronic health conditions, including heart problems, renal failure and type II diabetes
- had mobility problems
- had repeated episodes of respiratory illness, and
- received anticonvulsant, antipsychotic, sedative and anti-anxiety medication.

Four people had a progressive deterioration in their health related to a neurological condition, including cerebral palsy, Parkinson's disease, muscular dystrophy, and dementia. Two people had Down syndrome (and dementia).

The above risk factors were also highly prevalent amongst another nine people for whom aspiration pneumonia was a contributing factor in their deaths from cerebral palsy (6) and Down syndrome (3).

35. Gavriety, N 'Recurrent Aspiration Syndrome', in Rubin, I L., Rubin, L., and Crocker, A (2006) *Delivery of Medical Care for Children and Adults with Developmental Disabilities*; Langmore, S E et al 'Predictors of Aspiration Pneumonia. How important is dysphagia?' in *Dysphagia*, Vol 13, No 2, February, 1998, 69-81; Stewart, J T 'Dysphagia Associated with Risperidone Therapy' in *Dysphagia*, 2003, Fall: 18(4): 274-5; and Dolonsky, P, DMR Medical Advisory No 98-7, *Recommendations to Prevent Aspiration Pneumonia*, August 1998, Department of Developmental Services, State of Connecticut.

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## Our reviews of deaths from aspiration pneumonia in 2010 and 2011

Of the 12 people:

- five developed aspiration pneumonia in association with a gradual decline in their health
- three vomited and aspirated
- two people had repeated aspiration that was no longer responsive to treatment, and
- two unexpectedly died from aspiration with no previous episodes, respiratory illness or swallowing difficulties.

It was a similar picture for the nine people whose underlying cause of death from cerebral palsy or Down syndrome was connected to aspiration pneumonia. Three people developed aspiration pneumonia with a decline in their health; two people aspirated during seizures; two people developed aspiration pneumonia following surgery; and two people died after facing increased risks, as illustrated by the following case study.

### Case study 1 – the importance of following swallowing requirements

A 26-year-old woman with cerebral palsy and a profound intellectual disability who lived in a group home faced serious respiratory and aspiration risks. She had significant swallowing difficulties, GORD, epilepsy, and had repeated episodes of respiratory illness.

The disability service provided comprehensive support to assist the woman to minimise her health risks, including regular allied health and specialist reviews, and clear guidance on chest, asthma, seizure and oral health management.

In light of her considerable aspiration risks, the woman's speech pathologist had recommended that she receive fluids of a honey-thick consistency and pureed food, and stay at a minimum 30° angle for at least 30 minutes after meals. The service had a mealtime management plan that clearly outlined those requirements.

The woman went on holidays over the Christmas period, and returned home with an audible wheeze. The service found that she had been given thin fluids during that period, contrary to her swallowing requirements. The woman's health continued to deteriorate, with increasing

breathing difficulties and hospitalisation for aspiration pneumonia. She died shortly after admission to hospital, despite active treatment.

In the main, we found good practice in disability services staff clearly identifying, communicating and monitoring the aspiration risks faced by the individuals, including risks associated with their seizure activity, swallowing problems, and compromised physical health.

We also noted positive examples of people whose aspiration risks associated with changes in their health were well known and communicated. This included a young man whose eating behaviour, swallowing function, mobility and alertness declined when he was mentally unwell. The service developed a good relationship with the local mental health team; provided clear guidance to staff on the support required depending on his mental health, including meal and fluid consistency; and arranged appropriate training for staff.

We found that the people who died from aspiration pneumonia in 2010 and 2011 tended to have regular access to GPs and allied health providers, including speech pathologists, dietitians, physiotherapists, and occupational therapists. Some individuals also had the involvement of specialist health clinics, such as dysphagia clinics and the Developmental Disability Health Unit, and pain management experts.

### Case study 2 – management of multiple health risks

A 20-year-old man with cerebral palsy and a profound intellectual disability who lived in a group home died in 2011 from aspiration pneumonia. He had multiple health issues, including recurrent respiratory infections, severe osteoarthritis, GORD, epilepsy and a chronic dislocated right hip. He received nutrition via a PEG tube.

There was ongoing tension between meeting the man's nutritional needs and providing effective pressure area care, as he was required to sit up for his PEG feeds, which increased the pressure on his wounds and impaired the healing process. In addition, the man's seizure activity made it difficult to effectively manage his osteoarthritis and hip dislocation.

We found that the man received comprehensive and coordinated health support with the involvement of, and cooperative work between, his GP, disability service, and multiple allied health providers, including community nursing. Following admission to hospital for treatment of pneumonia 11 months before he died, the man was referred to the community palliative care team for assistance with pain management.

A pain specialist recommended the use of a syringe driver to provide intravenous pain relief. While the disability service was initially concerned about its capacity to provide this level of care, they were able to do so following provision of the equipment by community health and staff training.

The disability service provided clear and detailed guidance to disability staff on how to support the man's health and other needs, and regularly reviewed the information as his health declined. Following consultation with the man's family, the palliative care team provided palliative care support in the months before his death.

The majority (10) had a comprehensive health assessment in the year before they died and had received the influenza vaccination. Two-thirds (8) had received the pneumococcal vaccination.<sup>36</sup>

However, it was not always clear how staff were supporting individuals with their oral care. Just over half (7) had been for a dental check-up in the year before they died.

We also found that, while eight people who died from aspiration pneumonia experienced recurrent respiratory infections, only two had seen a respiratory specialist prior to their final hospital admission. This was also the case for the nine people whose underlying cause of

death from cerebral palsy or Down syndrome was related to aspiration pneumonia – only one of the seven people with recurrent respiratory infections had seen a respiratory specialist.

**Consistent with previous years, our reviews of deaths from aspiration pneumonia in 2010 and 2011 highlighted the need to:**

- **Proactively identify people at risk of aspiration and support them to minimise those risks.**
- **Understand and carry out the recommendations of health providers** – including meal and fluid requirements.<sup>37</sup>
- **Have respiratory specialist involvement.** Few of the people who had recurrent respiratory infections, including repeated episodes of aspiration pneumonia, had access to specialist reviews of their respiratory health.

**Deaths from pneumonia in 2010 and 2011**

Pneumonia is an infection in one or both lungs. It is not a single disease – pneumonia can have more than 30 different causes, including bacteria (such as pneumococcus), and viruses.

In 2010 and 2011, pneumonia was the underlying cause of death of nine people, including six people in disability services (3%) and three people in licensed boarding houses (12%).

Pneumonia was also a contributing factor in the deaths of another 27 people,<sup>38</sup> mainly deaths of people from epilepsy, chronic lower respiratory diseases, Down syndrome, and cerebral palsy.

36. This was consistent with the nine people whose underlying cause of death from cerebral palsy or Down syndrome was related to aspiration pneumonia – the majority (7) had a comprehensive health assessment in the year before they died and had received the influenza vaccination; and two-thirds (6) had received the pneumococcal vaccination.

37. Some people with disabilities may make an informed decision not to follow recommendations – for example, a person may make an informed decision to drink thin fluids despite their risk of aspirating. It is important that these decisions are fully informed, and that services have clearly documented the steps that have been taken to assist the person to understand the risks and likely consequences; the person's decision; and the support that is being provided to manage the risks as much as possible in the context of that decision.

38. Pneumonia was a contributing factor in the deaths of 26 people in disability services and one licensed boarding house resident. For most of the people for whom pneumonia was a contributing factor (21), it was the direct cause of death only.

Consistent with previous years, people with disabilities in care died from pneumonia at a much younger age than the general population.<sup>39</sup> In 2010 and 2011, the median age at death from pneumonia was 57 years for people in disability services and 66 years for people in licensed boarding houses – 30 and 20 years younger than the general population respectively.

### Risk factors<sup>40</sup>

In the general community, pneumonia tends to be more serious for the very young, people aged 65 years and older, those with chronic health problems, and people who have weak immune systems. Other risk factors for pneumonia in the general community include:

- smoking
- swallowing difficulties
- crowded living conditions
- hospitalisation
- alcohol and drug abuse, and
- impaired consciousness.

For some people with disabilities, there are additional factors that increase the risks for pneumonia, including:

- intellectual disability
- limited mobility and reliance on others for meals and dental hygiene
- GORD
- history of aspiration and/or previous episodes of pneumonia
- receiving enteral nutrition, and
- dental problems or gum disease.

Consistent with previous years, the nine people who died from pneumonia in 2010 and 2011 tended to have many of the known risk factors for the condition, including intellectual disability

and chronic health problems, such as asthma, type II diabetes and GORD. Most of the people who died from pneumonia also had:

- dental problems, including no teeth or only some teeth
- mobility problems, swallowing difficulties and required help with meals, and
- recurrent respiratory infections, including four people who had previous episodes of pneumonia.

The above risk factors were also highly prevalent amongst another seven people for whom pneumonia was a contributing factor in their deaths from Down syndrome (5) and cerebral palsy (2).

Only one person was a continuing (heavy) smoker at the time that they died. While each of the three licensed boarding house residents had smoked, one had successfully quit, and one other was in the process of quitting with the assistance of nicotine patches and lozenges. The person who was continuing to smoke had been provided with nicotine patches shortly before his death.

### Case study 3 – response to health risks and changes in a licensed boarding house

A 66-year-old man with schizophrenia and a mild intellectual disability who lived in a licensed boarding house died in 2011 from severe pneumonia. The man had risk factors for heart disease and respiratory disease, including diabetes, high cholesterol, high blood pressure, recurrent respiratory infections, and heavy smoking. He had previously experienced two heart attacks.

The man was regularly reviewed by his GP and psychiatrist, had received the pneumococcal and influenza vaccinations, and was provided with nicotine replacement therapy (patches) the month before he died.

39. In the general population, deaths from pneumonia tend to occur in older age. For example, in Australia in 2010, the median age at death from pneumonia was 87.3 years. (Australian Bureau of Statistics (2012) 3303.0 Causes of Death, Australia, 2010).

40. Shepard, J J, *Risk Management for Dysphagia*, Centre for Disability Studies, Ryde, September 2005; and Shepard, J (2005) *Statistical Analysis for Choking Risk Assessment (CRA) and Pneumonia Risk Assessment (PRA)*.

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Three days before the man's death, boarding house staff noted that he was very pale, crouching over, coughing and having difficulty breathing. Following discussion with his GP, boarding house staff sent the man to hospital via an ambulance.

He had been reviewed by his GP one week prior to his transfer to hospital and no issues had been identified at that time. Information provided to the hospital by the boarding house manager indicated that the man had experienced several dizzy episodes over the previous week. There was no indication that there had been contact with the GP in relation to these episodes.

On admission to hospital, the man was found to have pneumonia and acute renal failure with related sepsis. He died three days later, despite active treatment.

Following the man's death, the boarding house manager advised us of steps that would be taken to improve health outcomes for residents, including actions to:

- have a GP review residents who fall or have a hypotensive episode, and three-monthly reviews of every resident's medications
- ensure that management and staff are more proactive in promoting healthy lifestyles, including Quit Smoking programs, daily exercise and healthy eating
- improve health checks at the boarding house, including purchasing a thermometer and blood pressure and heart rate machines, and
- improve record-keeping by boarding house staff, including maintaining records at the end of each shift.

### **Our reviews of deaths from pneumonia in 2010 and 2011**

One man developed pneumonia while in hospital following surgery to remove gallstones, and one woman died from pneumonia while receiving palliative care.

Our reviews of the deaths of the other seven people highlighted the importance of staff being alert to any changes in health, and seeking medical assistance without delay. We found that there was a short timeframe between staff identifying that they were unwell and their

subsequent death. The timeframe ranged from one day to one month. (See section 4.2: *Response to critical health changes*).

It was a similar picture for the seven people whose deaths from Down syndrome or cerebral palsy were connected to pneumonia. Four people developed pneumonia as their health declined with progression of dementia; two people had repeated hospital admissions for pneumonia and did not respond to treatment; and one person died within two days of showing signs of illness.

The majority of people who died from pneumonia in 2010 and 2011 had received the pneumococcal and influenza vaccination (7). The other two people had received either the influenza or pneumococcal vaccination, but not both. Most were in the healthy weight range (5); three people were overweight or obese.

This was largely consistent with the seven people whose underlying cause of death from Down syndrome or cerebral palsy was related to pneumonia, although fewer people had received the pneumococcal vaccination.<sup>41</sup>

### **Case study 4 – recurring episodes of pneumonia**

A 48-year-old woman with Down syndrome who lived in a residential centre died in 2011 as a result of pneumonia. She had a number of risk factors for respiratory illness, including swallowing problems, reliance on others for help with meals, and chronic health conditions that included hypothyroidism and chronic liver disease.

The woman presented to hospital four times in the month before her death with pneumonia, which did not resolve despite active treatment. During her last hospital admission, the respiratory team assessed that her condition was irreversible.

The disability service provided support to the woman while she was in hospital to ensure continuity of care and to meet her additional behaviour and support needs.

We found that the service had clearly identified that the woman was at risk of respiratory illnesses like pneumonia, and worked with

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41. Of the seven people, all had received the influenza vaccination and most (5) were in the healthy weight range. However, less than half (3) had received the pneumococcal vaccination.

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health practitioners to try to reduce those risks. The woman had the involvement of a range of allied health providers, including speech pathologist, dietician, occupational therapist and physiotherapist, and staff had clear guidance in the support required, including swallowing and nutrition requirements and respiratory management.

The woman was regularly reviewed by her GP, and disability staff were responsive to any changes in her health.

### Deaths from chronic lower respiratory diseases in 2010 and 2011

In 2010 and 2011, chronic lower respiratory diseases were the underlying cause of death of eight people with disabilities in care, including five people in disability services (3%) and three people in licensed boarding houses (12%).

Chronic lower respiratory diseases include chronic obstructive pulmonary disease (COPD), emphysema and asthma. COPD was the main chronic lower respiratory disease reported for both disability services (3) and licensed boarding houses (3). The other two people died from an asthma attack, and from bronchiectasis.<sup>42</sup>

Consistent with previous years, the deaths of people with disabilities in care from chronic lower respiratory diseases in 2010 and 2011 occurred at a younger age than the general population.<sup>43</sup> The median age at death of people in disability services was 59 years – 20 years younger than the general population. The median age at death of licensed boarding house residents from this cause was 71 years.

### Health and risk factors

Smoking is the leading cause of COPD. Each of the three licensed boarding house residents who died from COPD were long-term smokers, and all were continuing to smoke at the time of their death. Two of the three smoked over 20 cigarettes per day.

None of the disability services residents who died from COPD had smoked. One woman in a disability service who died from an asthma attack was a smoker at the time of her death; she had previously lived in a licensed boarding house.

Of the eight people who died from chronic lower respiratory diseases:

- All had known respiratory problems, including asthma, COPD, and recurrent respiratory infections.
- Half were aged over 70 years and had multiple additional significant health problems, such as heart failure. Their death came at the end of a progressive deterioration in their overall health.
- Only one person was in the healthy weight range. Half were underweight, including two licensed boarding house residents. Two people in disability services were overweight or obese, and one licensed boarding house resident was morbidly obese.

### Our reviews of deaths from chronic lower respiratory diseases in 2010 and 2011

We found mixed practice in relation to the management of the health risks faced by the people who died in 2010 and 2011 from chronic lower respiratory disease. Positively, we noted that:

- all of the people who died from chronic lower respiratory disease had seen a GP, and all but one person had physiotherapy involvement
- all of the disability services residents had a comprehensive health assessment, and
- five of the seven people outside of the healthy weight range had seen a dietician, including one licensed boarding house resident who was underweight.

However, while all of the people who died from chronic lower respiratory disease had known respiratory problems, only half had seen a respiratory specialist. Positively, this included two of the three licensed boarding house residents.

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42. Bronchiectasis is caused by chronic infection of the airways. The persistent airway infection and the immune response results in chronic inflammation, which damages the lung. (The Australian Lung Foundation, <http://www.lungfoundation.com.au/lung-information/patient-educational-material/fact-sheets/75>).

43. In the Australian general population, deaths from chronic lower respiratory diseases tend to occur at an older age. For example, in 2010, the median age at death was 81.2 years. (Australian Bureau of Statistics (2012) 3303.0 *Causes of Death, Australia, 2010*).

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All had received the influenza vaccination. However, just over half of the people in disability services and none of the licensed boarding house residents had a current pneumococcal vaccination.

Our review of two licensed boarding house residents who died from COPD in 2010 and 2011 raised concerns about the adequacy of the support that had been provided to them. This included:

- an 82-year-old woman with significant health concerns who had repeated admissions to hospital with unresolved pneumonia, was reported by hospital staff to be malnourished, and who local health staff had indicated had mould and extensive damp in her bedroom, and
- a 53-year-old man with morbid obesity and considerable respiratory problems who was reported to have been deceased in his bed for over a day before it came to the attention of staff, and who did not appear to receive adequate support from boarding house staff, his GP, or his psychiatrist.

Both were part of broader action taken by us in response to a number of deaths at both licensed boarding houses (see section 4.5 *Support for people in licensed boarding houses*).

As outlined in the following case study, we also took further action in relation to our review of the death of a disability services resident from an acute asthma attack.

### **Case study 5 – the need for clear guidance in managing respiratory problems**

A 59-year-old woman who lived in a disability service following the closure of a licensed boarding house had significant respiratory conditions, including acute bronchial asthma and COPD. She also had considerable risk factors for respiratory diseases, including obesity and heavy smoking.

Disability support staff regularly encouraged the woman to stop smoking, and her GP linked her in to a quit smoking program and nicotine replacement lozenges. At the time of her death, she was continuing to smoke, but appeared to have reduced her intake.

In the six weeks before her death from an asthma attack in 2010, the woman presented to hospital on four occasions, with breathing difficulties and exacerbation of asthma. On her second presentation, she was admitted under the care of a respiratory physician. She had a chest x-ray that showed bilateral lower lobe infiltrate, was treated with steroids, bronchodilators and antibiotics, and discharged with the recommendation to follow-up with her GP.

The woman was not referred for specialist respiratory review as an outpatient on discharge from hospital, and the discharge plan that was provided to the woman's GP did not highlight the need for a follow-up chest x-ray to be performed.

A member of our Expert Panel told us that the woman needed specialist respiratory review to investigate the potential triggers of the recurrent exacerbations of her asthma, to look at her lung function (degree of asthma versus COPD), and to develop asthma and/or COPD management plans.

We noted that the ongoing management of the woman's respiratory conditions in the weeks before her death was problematic, with repeated hospital presentations and disability support staff noting that she was 'hysterical' and 'panicked' about her breathing problems. We found that disability support staff did not have access to guidance about how to support the woman to manage her asthma and lung disease, or to prevent exacerbations.

We wrote to the local health district with our concerns. Following our review, the local health district acknowledged that the care and treatment the woman had received at the hospital was not optimal, and outlined actions it would take in response.

The health district has reinforced with staff the need to use the asthma pathway and to develop a management plan for patients prior to discharge. Nurse Unit Managers have also been requested to ensure that all patients with a disability have a clear management plan on discharge and to ensure the carer is involved in the discussions.

The health district also discussed the matter in a range of patient safety and medical review meetings to inform and improve practice, including follow-up care after discharge for complex and re-presenting patients.



**Consistent with previous years, our reviews of deaths from chronic lower respiratory illness in 2010 and 2011 continued to highlight the need for:**

- **Proactive support for individuals to quit smoking.** We found that only one of the people who smoked had been provided with practical and repeated assistance to try to quit, including the provision of nicotine replacement therapy and active encouragement and support by staff.
- **Access to respiratory specialists.** Compared with previous years, we noted a slight increase in the number of people who had seen a respiratory specialist. However, our reviews identified that some of the people who had not had specialist involvement had considerable ongoing respiratory problems, and the referral for three of the four people who saw a specialist only occurred a couple of months before they died.
- **Access to chronic disease management programs.** COPD is one of the conditions targeted in home-based chronic disease management programs. From our reviews of the deaths of people from chronic lower respiratory diseases, we did not identify anyone that had involvement in a chronic disease management or other out-of-hospital program.

### 3.7 Deaths from diseases of the nervous system

Consistent with previous years, diseases of the nervous system were the largest cause of death of people in disability services in 2010 and 2011, accounting for the deaths of 37 people (20%).

The main causes of deaths from nervous system diseases of people in disability services in 2010-11 were epilepsy and cerebral palsy.<sup>44</sup>

### Deaths from epilepsy in 2010 and 2011

Epilepsy was the underlying cause of death of 15 people in disability services in 2010 and 2011 (8%).<sup>45</sup> The median age at death was 50 years.

People with epilepsy have an excess mortality rate of two to three times the general population, and the overall risk of sudden and unexpected death in epilepsy (SUDEP) in people with severe forms of epilepsy is high.<sup>46</sup>

Of the 15 people whose underlying cause of death in 2010 and 2011 was epilepsy:

- five people aspirated on food/ fluids or inhaled vomitus during or after a seizure
- the deaths of three people were due to status epilepticus<sup>47</sup>
- three people with epilepsy died following progressive deterioration in their health (two of whom received palliative care)
- two people died following hypoxic brain damage sustained during a seizure
- the death of one person was attributed to SUDEP, and
- the Coroner indicated that the death of one person with epilepsy was due to unascertained natural causes.

### Case study 6 – epilepsy and respiratory illness

A 41-year-old woman with epilepsy who had lived in a residential centre died from aspiration pneumonia following status epilepticus. The woman experienced tonic clonic seizures that tended to occur once a month.

She had severe dysphagia and experienced recurrent episodes of aspiration pneumonia, typically linked to seizure activity. The service implemented strategies to manage the risk of aspiration associated with her seizures, including speech pathology reviews, and close supervision post-seizure.

44. The deaths of the majority of the 12 people whose underlying cause was cerebral palsy were associated with respiratory disease. As a result, analysis of their deaths has been included in the pneumonia and aspiration pneumonia sections.

45. Of the 220 people with disabilities in care who died in 2010-11, 93 people had been diagnosed with epilepsy. Apart from epilepsy itself, the main causes of death were other diseases of the nervous system (such as cerebral palsy), respiratory illness (mainly aspiration pneumonia), and external causes (including choking on food).

46. Epilepsy Australia website, [www.epilepsyaustralia.net](http://www.epilepsyaustralia.net).

47. Status epilepticus refers to a continuous state of seizure.

In the five months before her death, the woman had increased seizure activity and associated respiratory illness. She was regularly reviewed by medical officers, and was seen by a neurologist in the month before her death. The woman received multiple anticonvulsant medications to control her seizures, and the dose increased in response to her increased seizure activity.

Two days prior to her death, the woman went into status epilepticus and she was admitted to hospital. She was found to have pneumonia, and died despite active treatment.

### Our reviews of deaths from epilepsy in 2010 and 2011

All but one of the 15 people had ongoing seizures, despite medication.<sup>48</sup> Five of these individuals had experienced increased seizure activity in the months prior to their death, often due to increased ill health related to dementia or respiratory illness.

We found that the people whose deaths were due to epilepsy had regular reviews with their GP and/or neurologist, which tended to include testing of their anticonvulsant medication levels.

Four people had problems relating to their anticonvulsant medication levels, including the man who died from SUDEP. He was found to have a sub-therapeutic dose of Epilim at the time of his death. Nine months before the man's death, his GP had increased the anticonvulsant medication dosage following blood tests that had identified sub-therapeutic levels.

While the individuals had access to regular medical reviews, we found that for five of the people with ongoing seizures, there was poor recording and charting of their seizure activity. It was difficult to identify the pattern of seizure activity for these individuals, including any recent changes. In these cases, it was not clear to us how the disability service would have been able to provide accurate information to the person's GP and/or neurologist to inform their treatment decisions.

All but two people had epilepsy management plans to provide guidance to staff in how to support the person and respond to their

seizure activity. We found that the majority of the epilepsy management plans provided clear and appropriate guidance. The plans for three people were generic and did not provide sufficient information about the individual's seizures (such as what happens when the person has a seizure, and how to respond).

#### Our reviews of deaths from epilepsy in 2010 and 2011 emphasised the importance of:

- **Accurate and consistent recording of seizure activity** – to identify increases in seizure activity and to inform GP and specialist reviews.
- **Clear guidance for staff about the person's seizures and what support is required.**
- **Regular GP and specialist reviews of people with epilepsy and ongoing seizures.**

## 3.8 Deaths from diseases of the circulatory system

Diseases of the circulatory system are the leading cause of death in Australia, accounting for almost one-third of all deaths.<sup>49</sup> They are also consistently the leading cause of death of licensed boarding house residents.

In 2010 and 2011, circulatory system diseases were the (equal) leading underlying cause of death of people in licensed boarding houses (6 people; 24%), and the fourth leading cause of death of people in disability services in the same period (25 people; 13.4%).

The median age at death from circulatory disease in 2010 and 2011 was 63 years for people in disability services and 64.5 years for licensed boarding house residents – 20 years younger than the general population.<sup>50</sup>

The leading circulatory system diseases that cause the deaths of people with disabilities in care are ischaemic heart diseases and 'other' heart diseases.

48. ADHC's *Epilepsy* policy states that people who have had a seizure during the previous two years, despite taking medication, have 'epilepsy with ongoing seizures'.

49. Australian Bureau of Statistics (2012) *3303.0 Causes of Death, Australia, 2010*

50. In the general population, deaths from this cause tend to occur in older age: in Australia in 2010, the median age at death was 85 years. (Australian Bureau of Statistics (2012) *3303.0 Causes of Death, Australia, 2010*).

## Deaths from ischaemic heart diseases

Ischaemic heart diseases (including angina, blocked arteries of the heart and heart attacks) have been the leading underlying cause of death in Australia since 2000.<sup>51</sup>

They are also a leading cause of death of people with disabilities in care. In 2010 and 2011, ischaemic heart diseases were the underlying cause of death of 10 people, including six people from heart attack and four people from chronic ischaemic heart disease.<sup>52</sup>

- In disability services, ischaemic heart diseases were the underlying cause of death of six people (3%), comprising three people from chronic ischaemic heart disease, and three people from heart attack.
- Ischaemic heart diseases were the leading underlying cause of death of licensed boarding house residents in 2010 and 2011, with the deaths of four people (16%). This comprised three people from heart attack, and one person from chronic ischaemic heart disease.

### Risk factors<sup>53</sup>

There are risk factors that increase a person's chance of developing chronic ischaemic heart disease or having a heart attack. There are risk factors that can't be changed, such as increasing age, being male, and having a family history of the disease.

There are also modifiable risk factors, including:

- smoking
- high blood pressure
- high LDL 'bad' cholesterol and low HDL 'good' cholesterol
- obesity
- diabetes
- insufficient physical activity/exercise, and
- depression.

The median age at death from ischaemic heart disease in 2010 and 2011 was 70 years for people in disability services and 63 years for licensed boarding house residents. The vast majority (9) were male.

Consistent with previous years, the people who died from ischaemic heart diseases in 2010 and 2011 had a number of modifiable risk factors, including:

- **Hypertension** – including two-thirds of the people in disability services and three-quarters of the licensed boarding house residents.
- **Smoking** – three-quarters of the licensed boarding house residents who died from ischaemic heart disease had smoked; all were smokers at the time of their death. Two of the people in disability services had smoked; one was a smoker at the time of their death.
- **Overweight** – two people in disability services and two people in licensed boarding houses were overweight or obese.
- **Lack of physical activity** – two disability services residents and one licensed boarding house resident had some involvement in regular physical activity or exercise, such as a walking program.

Most of the people who died from ischaemic heart disease in 2010 and 2011 had known heart problems prior to death (6), such as angina, congestive cardiac failure, and chronic ischaemic heart disease. For four of the six people, their heart problems were managed via GP and cardiology reviews and medication. The other two people had GP reviews, medication, and tests, but no specialist involvement.

### Our reviews of deaths from ischaemic heart disease in 2010 and 2011

We had concerns about the support provided to one woman in a disability service who died in 2010 from a heart attack caused by coronary artery disease. Our review indicated that the woman's GP had identified the need for her to have an ECG, blood test and cardiology review due to abnormal test results. However, this didn't occur prior to her death due to the woman's resistance. We found that, while the service

51. Op cit

52. Chronic ischaemic heart disease is characterised by reduced blood supply (ischaemia) to the heart muscle, usually due to coronary artery disease, which causes a narrowing of the small blood vessels that supply blood and oxygen to the heart.

53. National Heart Foundation of Australia website: [www.heartfoundation.org.au](http://www.heartfoundation.org.au).

and GP made two attempts to enable the procedures to occur, no further action appeared to be taken in the six weeks leading up to her death. (See case study 18 on page 51).

However, in the main, we found examples of good practice in our reviews of the 10 people who died from ischaemic heart disease, including people who had regular health reviews and involvement of specialists, and guidance for staff on how to recognise and respond to angina attacks.

We identified positive practice in relation to two people in licensed boarding houses, including involvement of dieticians, diabetes clinics, regular health and specialist reviews, and appropriate use of first aid in response to the critical health events.

### Case study 7 – management of significant health issues in a licensed boarding house

A 75-year-old man with alcohol-related brain damage who lived in a licensed boarding house died from a heart attack in 2011. He had multiple significant health conditions and risk factors, including heart failure, diabetes, GORD, hypertension, COPD, asthma and smoking.

We found that the man had good access to allied and specialist health practitioners, including a diabetes clinic, cardiologist, dietician, gastroenterologist and respiratory physician.

He was regularly reviewed by his GP who used the Enhanced Primary Care program to link the man to allied health providers, and monitored his underweight status.

However, while the man was actively supported in managing his health needs, there was no indication that he had been offered assistance to quit smoking.

**Consistent with our reviews of deaths from ischaemic heart disease since 2003, our reviews continued to highlight the need for:**

- **Proactive support for individuals to quit smoking.** In 2010 and 2011, we found that one person had quit smoking, and GPs for two people who smoked had raised with them the importance

of quitting. However, in the main there did not appear to be a comprehensive, consistent or cooperative approach to assisting smokers to quit. This includes provision of nicotine replacement therapy, and cooperative work between GPs and services to provide information to residents about smoking cessation strategies and practical support to take the next step.

- **Proactive strategies to help individuals to address risks related to physical inactivity and obesity, including promotion of regular exercise.** Most of the people who died from ischaemic heart disease did not appear to be regularly involved in physical activity, including some individuals who were noted to be overweight or obese.

Our reviews continue to emphasise the need for people with disabilities in care to access proactive and cooperative support to develop healthy lifestyles. This includes assistance to access a healthy diet; and support to become more physically active, such as by building exercise into activities they enjoy, and involvement in exercise options through Active Linking Initiative (ALI) activities.

### Deaths from other heart diseases in 2010 and 2011

'Other heart diseases' include inflammation of the inner lining of the heart (endocarditis); disorders of the valves of the heart; deterioration of the heart muscle (cardiomyopathy); heart disease; and heart failure.

In 2010 and 2011, other heart diseases were the equal third leading underlying cause of death of people with disabilities in care, accounting for the deaths of 10 people. The vast majority (9) were people in disability services. It was the fourth leading underlying cause of death of people in disability services in that period.

Heart failure – where the heart is unable to pump sufficient blood flow to meet the needs of the body – was the form of 'other heart disease' that featured most often in the deaths of people with disabilities in care in 2010 and 2011, accounting for half of the 10 deaths.

The median age at death of the 10 people was 59 years. Half were in the healthy weight range; three people were overweight or obese, and one person was underweight.

Seven people had known heart problems, including one person who had a pacemaker, and one person who had an aortic valve replacement. All of the people with known heart problems had the involvement of cardiologists.

The majority of the people who died from other heart diseases had multiple significant and chronic health problems in addition to their heart condition, such as emphysema, chronic renal failure and sleep apnoea.

In the main, we noted good access to allied health and medical practitioners, including specialists. The man in the case study below was one of the exceptions.

### Case study 8 – the importance of support in addressing risk factors

A 55-year-old man with multiple mental health diagnoses and a mild intellectual disability had lived in a group home for 11 months after moving out of a boarding house. He died in 2011 from dilated cardiomyopathy, with no specific cause able to be identified.<sup>54</sup>

The man had chronic lung disease, asthma, and risk factors for heart disease, including severe obesity, heavy smoking, and a lack of exercise. His individual plan included weight loss, smoking cessation and increased exercise as personal goals. However, he continued to smoke heavily and had gained weight in the six months before his death. Staff encouraged him to go for walks for exercise and weight loss, but reported that he found it difficult due to breathlessness and a lack of motivation.

The man saw a GP and had a comprehensive health assessment. However, he did not appear to have been linked to health programs or strategies to help him to manage his significant respiratory problems or reduce his health risks, such as quit smoking strategies, a respiratory specialist, dietician or chronic disease management program.

Two days before his death, the man saw his GP because he had a cough, and was prescribed Ventolin. The following day, he was reportedly in good spirits. When staff checked on him the next morning he was deceased.

## 3.9 Deaths from neoplasms (cancer)

Consistent with previous years, cancer was the second leading cause of death of people in disability services in 2010 and 2011, accounting for the deaths of 26 people (14%). The median age at death was 56.5 years. This was almost 20 years younger than the median age at death from cancer in the general population.<sup>55</sup>

Cancer was the cause of death of four licensed boarding house residents in 2010 and 2011. The median age at death was 69 years.

The main form of cancer that caused the deaths of people in disability services was bowel (or colon) cancer.

### Deaths from bowel cancer in 2010 and 2011

Bowel cancer is also known as colon or colorectal cancer. In 2010 and 2011, bowel cancer was the underlying cause of death of five people in disability services (3%).

#### Risk factors<sup>56</sup>

A person has a higher risk of developing bowel cancer if they:

- are 50 years and over
- have a family history of bowel cancer
- have colorectal polyps
- have inflammatory bowel disease (such as Crohn's disease)
- have inherited genetic risk, including a family history of bowel cancer, and
- have a personal history of cancer of the colon, rectum, ovary, endometrium or breast.

54. Dilated cardiomyopathy is where the heart is weakened and enlarged and cannot pump blood efficiently. In many cases, there is no obvious cause.

55. The median age at death from cancer in Australia in 2010 was 75.2 years. (Australian Bureau of Statistics (2012) *3303.0 Causes of Death, Australia, 2010*).

56. Bowel Cancer Australia website: [www.bowelcanceraustralia.org/bca/](http://www.bowelcanceraustralia.org/bca/).

Deaths from bowel cancer amongst people in disability services occur at a much younger age than the general population.<sup>57</sup> The median age at death of people who died from bowel cancer was 50 years.

The people who died from bowel cancer in 2010 and 2011 tended to be younger than those who died from that cause in disability services in the previous seven years, where the median age at death was 61 years.

Most of the people who died from bowel cancer in 2010 and 2011 (3) had limited mobility – using either wheelchairs or a walking frame. Only one person had a personal history of bowel cancer.

Symptoms of bowel cancer can include:

- abdominal pain and tenderness in the lower abdomen,
- blood in the stool,
- diarrhoea, constipation, or other change in bowel habits,
- intestinal obstruction,
- unexplained anaemia, and
- weight loss with no known reason.

Many of these symptoms were present in relation to the five people who died from bowel cancer in 2010 and 2011, including constipation (4 people), blood in stools (3), unexplained weight loss (2), and abdominal pain (2).

### Our reviews of deaths from bowel cancer in 2010 and 2011

We found that for all five people there was a very short period of time between diagnosis of bowel cancer and their death, ranging from two to nine months.

Surgery and treatment options were actively explored for four of the five people:

- Two people had previously had surgery to treat their bowel cancer, but it subsequently returned and was assessed as being inoperable. One of the two received palliative chemotherapy.
- Two people had surgery, but it was ultimately unsuccessful. One of the two also received palliative chemotherapy.

The other person was admitted to hospital for a prospective gastroscopy and colonoscopy in response to abdominal pain and elevated tumour markers in her blood tests. However, her family decided not to go ahead with the procedures given the high risks associated with surgery. The treating oncologist subsequently reviewed her CT scans and found that treatment would not help.

Overall, we noted good practice on the part of the disability services, including taking note of changes in health (such as per-rectal bleeding) and quickly seeking medical assistance and investigation, and active advocacy for earlier specialist appointments.

### Case study 9 – short period of time between symptoms and death from bowel cancer

A 50-year-old man with cerebral palsy and a mild intellectual disability died from colon and rectal cancer in 2011.

Four months before his death, the man consulted his GP about rectal bleeding and constipation. The GP referred him to a gastroenterologist, but there was a long wait time for an appointment. The disability service advocated on his behalf for an earlier appointment, and provided a letter supporting his GP's referral.

Six weeks after the referral was made, the man was admitted to hospital with abdominal pain. He was diagnosed with rectal cancer, and had bowel resection surgery. However, secondary tumours were identified in the man's liver, which were assessed as being inoperable.

The man subsequently transferred to alternative accommodation provided by his disability service in order to receive a higher level of support. He received palliative chemotherapy with intensive support from the disability service and local palliative care team.

Three days before his death he was admitted to hospital with pain and deteriorating health. The disability service liaised with hospital staff and the man's family, and enabled his sister to be with him when he died.

57. In Australia in 2010, the median age at death from bowel cancer was 77.8 years. (Australian Bureau of Statistics (2012) 3303.0 *Causes of Death, Australia, 2010*).

Our review of the death of one man from bowel cancer in 2010 highlighted the importance of services identifying health changes as soon as possible, and providing a full medical history to health practitioners.

### Case study 10 – health changes and bowel cancer

A 56-year-old man with a mild intellectual disability had previously been diagnosed with bowel cancer four years before his death, and had received appropriate treatment and subsequent yearly checks.

In the eight months before he was again diagnosed with cancer, the man lost nine kilograms, including over three kilograms in one month. He also had 12 presentations to hospital emergency departments for abdominal pain, dizziness, vertigo, and dehydration.

We found that the disability service and the man's GP had not consistently monitored his weight, and it was not until the disability service restarted tracking his weight a few months before his death that they raised concerns. We also found that information about the man's history of bowel cancer did not appear to be provided to medical staff until his 10th presentation to hospital.

At his 12th presentation to hospital, he was diagnosed with bowel cancer that had also spread to his liver and lungs. The man died in hospital two months later, following palliative chemotherapy treatment.

**Our reviews of deaths from bowel cancer in 2010 and 2011 have highlighted the importance of staff being alert to any changes in a person's health or behaviour, and helping them to see a GP as soon as possible.**

## 3.10 External causes of death

External causes of death include intentional self-harm (suicide), transport accidents, falls, poisoning, and complications of medical and surgical care. In 2010 and 2011, external causes

accounted for the deaths of 23 people (12%) in disability services and six people (24%) in licensed boarding houses.

In 2010 and 2011, choking on food was the main external cause of death of people in disability services and licensed boarding houses.

### Choking on food

In 2010 and 2011, nine people died as a result of choking on food, most of which (6) occurred in 2011. The deaths in 2010 and 2011 represent over one-third of the 22 deaths from choking on food in the nine years since 2003.

Most of the nine people (6) lived in disability services. The median age at death was 53 years for people in disability services and 60 years for licensed boarding house residents.

Most of the nine people:

- were at home when they choked on food (6)
- had dental problems (6), including only some teeth, no teeth or dentures
- were overweight or obese (6), and
- had a mental illness (7), mainly schizophrenia, and were taking psychotropic medication.<sup>58</sup>

Over half choked on a sandwich or bread (5). Two people choked on pieces of fruit, and two people choked on meat.

### Factors in the deaths of people in disability services who choked on food in 2010 and 2011

For four of the six people in disability services, the service had identified that they had risk factors for choking. However, only one person had swallowing difficulties. In the main, the choking risks related to:

- eating problems, including eating quickly, overfilling mouth, and eating without chewing, and
- behaviour-related issues, including taking food off others, taking food from bins, and taking food that had not been prepared for them.

58. We have previously drawn attention to the links between mental illness, the use of psychotropic medication, and choking risks. Side effects of some psychotropic medications, including many antipsychotic medications, include drowsiness. Some can cause adverse reactions relating to swallowing problems and/or dry mouth. Prolonged use of antipsychotic drugs can also cause side effects such as tardive dyskinesia, which can affect eating.

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We found that for three of the four people, while the services had identified the risks, they had not taken clear steps to help the person to manage these risks. This included one man whose assessments, such as the nutrition and swallowing risk checklist, identified that he 'eats without chewing', but no action had been recorded to guide staff in how to help him to manage this – such as providing supervision at mealtimes and encouragement for him to slow down.

In two of the six deaths, the individuals had previously experienced episodes of choking or gagging on food. In one of these matters, the service appeared to take appropriate action to try to minimise the risks, including organising a speech pathology review, and providing clear guidance in her mealtime management plan about the need for staff to prompt her to slow down if she was eating too quickly.

As noted in the case study below, we had concerns about the adequacy of the action taken by the service to minimise the choking risks for the other person who had previously gagged on food.

### Case study 11 – the importance of identifying risks and responding to close calls

A 59-year-old woman with a severe intellectual disability, autism and obsessive compulsive disorder who lived in a group home died in 2011 after choking on a piece of fruit she had taken from the kitchen.

Prior to her death, the service and a speech pathologist had identified that the woman was at risk of choking due to her swallowing difficulties and eating problems, such as overfilling her mouth and eating without chewing. A mealtime management plan provided guidance for staff to ensure that her meals were of a pureed or 'minced mash' consistency and her fluids were thickened.

Less than two months before her death, the woman gagged on a large piece of fruit that she had taken from a picnic table while on an outing. She had taken the fruit prior to staff preparing it to meet her swallowing requirements.

Staff recorded the event in the service's progress notes. However, there was no indication that any action was taken by the service following the incident to prevent recurrence, such as completion of an incident report to prompt a review of the event.

Importantly, we found that the woman's actions on that occasion (to independently take and attempt to eat food that did not meet her swallowing requirements) presented a new choking risk. This additional risk had not been previously recorded or included in risk management plans, and, as a result, no strategies had been identified for staff to manage it.

We wrote to the service and met with them to discuss our concerns. The service subsequently advised us of actions it had taken to improve and monitor staff practice relating to client risks, including training and reinforcement of incident reporting requirements with staff.

### Factors in the deaths of people in licensed boarding houses who choked on food in 2010 and 2011

Two of the three licensed boarding house residents choked on a sandwich at the premises, and one person choked on a sausage while attending a BBQ in the community. We had concerns about the deaths of each of these individuals.

Two of the people lived in the same licensed boarding house, and their deaths were the subject of a Coronial inquest in 2012 (see also section 4.5: *Support for people in licensed boarding houses*):

- The man who choked on a sausage had tardive dyskinesia,<sup>59</sup> and had been admitted to hospital six weeks before his death with side effects (including fever, excessive perspiration and unsteadiness) as a result of his antipsychotic medications.

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59. Tardive dyskinesia is associated with the prolonged use of antipsychotic drugs. It is a complex syndrome of involuntary movements. It most frequently affects the mouth, lips, tongue and jaws with smacking, tongue writhing, sucking or chewing movements. These movements can interfere with speaking and eating. (*Therapeutic Guidelines: Psychotropic*, 3rd Edition, 1995)



The Coronial inquest into the man's death heard evidence that was critical of the medication he had been prescribed due to its associated choking risks. The Coroner also found that there was no evidence of any communication between the man's GP, psychiatrist, and boarding house manager.

- The woman who choked on a sandwich was seen by another resident to 'gulp down her food' and to subsequently have difficulty breathing. The only staff person on shift at the licensed boarding house attempted unsuccessfully to dislodge the food by hitting the woman on the back a number of times. The staff person contacted the manager of the facility, who then called for an ambulance.

Our review raised concerns about the first aid response of the staff member, with a delay in contacting emergency services despite the woman's life-threatening situation. The Coronial inquest found that the staff member had no first aid training, and was the sole person supervising all of the residents of the boarding house at the time.

As indicated in the case study below, our review of the death of the other licensed boarding house resident who choked on food identified problems with the application of the boarding house screening tool and the communication between hospital and licensed boarding house staff about the man's swallowing requirements.

### Case study 12 – choking risks and licensed boarding houses

A 55-year-old man who died after choking on a sandwich had only been at the licensed boarding house for three weeks. He had previously lived with his parents, and had been discharged to the boarding house following an extended admission in hospital for mental health treatment.

The man was assessed in hospital as having swallowing problems and needing to have a soft chopped diet with no bread, and mildly thick fluids. The hospital speech pathologist noted that the man continued to be at risk of aspiration as he did not have insight into why he needed to have a modified diet, and would take inappropriate food from the trolley and other patients. The man was also noted to eat his food quickly, and hospital staff had instructions to encourage him to slow down.

The boarding house screening tool was applied while the man was in hospital. While the assessor appropriately identified that the man required a soft diet, no further information was provided to the manager of the boarding house to explain what this meant, or why this was important. The additional instructions of the speech pathologist – including that the man not be given bread, that he needed to be monitored, and that he needed to be encouraged to slow down – were not provided to the boarding house manager.

Following the man's death, the hospital reviewed its practice, and identified the need to improve the information provided to facility managers about diet requirements. ADHC made changes to the screening tool to assist assessors to identify people at risk of choking, and to prevent the entry of people with choking risks from entering licensed boarding houses.

#### Our reviews of deaths from choking on food in 2010 and 2011 have highlighted the need for:

- **Staff to be aware of the different factors that can place people at risk of choking.** It is not just people with swallowing problems who are at risk of choking. Most of the people who choked on food in 2010 and 2011 had risks related to eating too fast, swallowing without adequately chewing food, and taking food that was not meant (or safe) for them. Dental problems and psychotropic medications can also present choking risks.
- **Active support for people to minimise their choking risks.** It is important that services support people to access health and medication reviews, follow the recommendations of health and behaviour practitioners, and provide supervision where required.
- **Staff to respond to gagging or choking incidents.** Our reviews have consistently identified people who had experienced previous choking or near-choking incidents. It is important that incidents are reported and action is taken to prevent recurrence.
- **Compliance with first aid requirements, and staff knowing how to confidently respond to critical incidents.**

## Chapter 4. Reviews of deaths in 2010 and 2011

In this chapter, we report our observations from our reviews of the deaths of the 220 people who died in 2010 and 2011.

Many of the key issues identified through our reviews of the deaths of people with disabilities in this period are consistent with those we have reported in previous years. Primarily, the issues relate to:

- services identifying and managing the risks faced by individuals
- services recognising and responding to changes in health and support needs
- the coordination of support between disability and health services
- the access of people with disabilities in care to preventative health support, and
- support for people in licensed boarding houses.

### 4.1 Preventing injury and death

**Our reviews consistently highlight the importance of staff having a good understanding of the risks faced by the people with disabilities they support, and helping them to minimise those risks.**

As indicated in Chapter 3, people with disabilities in care frequently face many risks, primarily related to their health issues, reliance on others for support, and lifestyle factors. Consistent with previous years, key risks for people who died in 2010 and 2011 related to:

- **swallowing, eating and nutrition** – with associated risk of deaths from respiratory illness and choking on food
- **smoking, poor diet and insufficient exercise** – with associated risk of deaths from heart disease, some cancers and respiratory illness, and
- **medication**, particularly psychotropic medication – with associated risk of adverse events such as side effects, toxicity, falls, and swallowing problems.

However, risks are individual to the person, and frequently change – due to changes in factors such as their health, the environment they are in, who they are with, and the support they can access. Our reviews of deaths in 2010 and 2011 have continued to emphasise the need for risk

assessments to be comprehensive and regularly reviewed to assess the effectiveness of the strategies and to address any new risks.

The death of a woman in 2010 from being struck by a vehicle illustrates the critical need for effective risk management for people with disabilities in care.

#### Case study 13 – the importance of following risk management strategies

A 52-year-old woman with a moderate intellectual disability, mild physical impairment, and obsessive compulsive disorder who lived in a residential centre died after being hit by a reversing truck on the grounds of the centre. The woman was alone when she walked into the path of the truck while returning to her unit after attending a day program.

The service had identified that the woman required close supervision to help her to manage a number of existing risks to her health and welfare. In particular, she needed supervision to minimise her risk of falls related to instability and her tendency to rush. Risk management and support plans also indicated that she needed supervision at all times around traffic and strangers, and to manage risks relating to her behaviour.

Around five weeks before she died, the woman fell on a road at the residential centre due to rushing. The incident report following this event identified that staff were to encourage her to slow down, and were to walk with her to and from any destination.

On the day of the incident, the woman walked from the day program to one of the cottages, accompanied by other residents and two staff members. While staff were involved in discussions about a client in the cottage who was exhibiting challenging behaviour, the woman left the premises to walk back to her nearby residence. The woman was hit by the reversing vehicle during the short period of time in which she was alone.

In our review, we noted that it was a short period of time in which the woman was unsupervised, and that staff took immediate action upon discovering that she had left the cottage. However, we found that the identified risk management strategies for the woman had

not been followed in the lead-up to the critical incident, and this was one of the key factors in her death.

The service took a range of actions following the woman's death to prevent similar events recurring. This included actions to improve staff adherence to risk management strategies, and to improve traffic management and the safety of pedestrians across all residences.

### Learning from close calls

**Importantly, our reviews of deaths in 2010 and 2011 have pointed to the need for staff to be alert and respond to new risks as they emerge.**

Two people who died in 2010 and 2011 experienced previous incidents that were similar to those that caused their deaths. However, the services did not appear to adequately identify the new risks for the individuals or take action to stop the events from happening again:

#### Example A

A 62-year-old man with a moderate intellectual disability and schizophrenia who lived in a group home died in 2010 after being hit by a car on his way to work. The man was struck when he ran across the road against a red pedestrian light and into the path of the vehicle.

We found that six weeks before the man died, he had almost been hit by a garbage truck. The incident report completed by service staff noted that he was rushing, and that, while he knew road safety rules, he did not follow them. No action appeared to be taken after this event to look at what needed to be done to minimise the chance of it recurring, such as reviewing the man's travel skills and conducting a travel-training refresher.

#### Example B

A 59-year-old woman with a severe intellectual disability, autism and obsessive compulsive disorder who lived in a group home died in 2011 after choking on a piece of fruit that had not been prepared for her (see case study 11 on page 42).

Two months before her death, the woman had gagged on a large piece of fruit that she had taken from a picnic table while on an outing. She had taken the fruit prior to staff preparing it to meet her swallowing requirements.

We found that staff had not identified the need to complete an incident report in relation to this event, or recognised that the woman's actions (to take food that had not been prepared for her) presented a new choking risk. As a result, no strategies were identified for staff to help reduce the chances of a similar event recurring.

In response to our reviews, both services advised of actions they had taken to improve staff practice relating to client risks, such as better incident reporting, comprehensive risk assessments, and training of staff.

Both matters highlight the importance of effective reporting of incidents to enable improved service provision and the prevention of serious injury and death. In both cases, the event did not prompt staff to review the adequacy of the support provided, or to look at what else needed to be done to help the person to stay healthy and safe.

#### Our reviews indicate the importance of:

- **Collaborative work to identify and manage risks faced by people with disabilities in care.** Our reviews have pointed to the need for the person with a disability, support staff, health providers, and relevant others to work together to comprehensively identify the risks faced by the person, and to assist them to try to minimise the risks.
- **Services taking effective action following an incident or 'close call'** – to prevent or reduce the chances of that event happening again.

#### Previous recommendations and relevant actions

Each of our previous six reports have included recommendations aimed at improving the identification and management of risks faced by people with disabilities in care. These have included recommendations to provide clear guidance to disability services in meeting client health needs and managing specific areas of risk, including nutrition and swallowing and epilepsy.

There has been considerable progress in these areas, including roll out of the *Client Risk* policy in 2008, and continuing work to improve and simplify the guidance for staff on identifying and responding to swallowing and nutrition

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risks. ADHC is currently finalising a new Health and Wellbeing policy framework that aims to aggregate and streamline the guidance for disability services relating to client health needs and risks.

Key to improving risk management in disability services is the training provided to staff and the monitoring and oversight of practice. The implementation and evaluation plans for the Health and Wellbeing framework, and the new quality systems for disability services will be important in this regard.

## 4.2 Recognising and responding to changing health and support needs

### Response to critical health changes

**Our reviews of deaths in 2010 and 2011 have stressed the importance of staff being alert to health changes, and seeking medical assistance without delay. Some people with disabilities go from ill to critically ill within a very short period of time.**

In 2010 and 2011, we noted at least 13 people who died shortly after symptoms of illness were first noticed. For most, it was a matter of days between being ill and critically ill; for some it was a matter of hours.

Often, we found that staff did not appear to recognise that the person's health had become critical.

### Recognising critical illness and the need for urgent medical assistance

In some cases, the ability of staff to recognise that the person was critically ill appeared to be affected by:

- not having known the person for long – including people who had only lived at the service for a matter of days or weeks
- the person having fluctuating health – where overall they were not well, but they had moments where they seemed to be improving (eg: eating a little more, or looking a bit brighter), and
- the views of the person's family – including that they considered that the person was improving, or that transfer to hospital was not necessary.

In other cases, staff recognition of critical illness and need for urgent medical assistance appeared to be affected by recent or upcoming contact with the person's GP, including in the two examples below.

### Case study 14 – the need to seek further medical assistance

#### Example A:

In the month before the death of a 66-year-old woman with Down syndrome and moderate intellectual disability in 2010, staff at a regional group home noted that she was atypically tired and weak. Ten days before her death, the woman saw her GP and received the influenza vaccination. Over the next three days, her health worsened and she became increasingly lethargic, required staff support to stand up, was unsteady and had several falls, declined food, and was noted to be clammy and sweaty.

On the evening of the third day, the woman collapsed and was taken to hospital by ambulance where she was diagnosed with pneumonia and sepsis. Staff did not appear to have sought medical assistance for the woman prior to her collapse, despite the change in her health and increased need for support.

#### Example B:

A 43-year-old man with Down syndrome and a moderate intellectual disability who lived in a group home showed signs of illness one month before he died from pneumonia in 2010. He saw a GP three times in that period, and received two courses of antibiotics. At the last GP appointment four days before his death, the GP advised staff to monitor him, and indicated that he would review him again in two weeks.

Over the next three days the man's health declined, with increased lethargy, frequent coughing, and little sleep. On the evening before his death, the man called for water and help during the night. Staff noted that his temperature was elevated and his breathing was gurgly when lying down, and encouraged him to use an extra pillow to help keep his chest elevated, but he declined. He was found deceased on the floor of his bedroom the next morning.

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An upcoming GP appointment and staffing problems also appeared to affect the response of staff to the critical health needs of the man in the following case study.

### Case study 15 – the importance of recognising when to get medical help urgently

A 37-year-old man with Down syndrome and a severe intellectual disability who lived in a regional group home had a viral infection for two weeks before his death from acute lobar pneumonia in 2010. He had seen his GP three times in that period, and received antibiotics for a urinary tract infection and chest infection in the days before he died.

Early on the morning of the man's death, staff noted that he had an elevated temperature, was pale, and was wheezing. He seemed slightly better after a shower, but was wheezing again within 15 minutes. The support worker arranged for a GP home visit, to occur mid-morning. Shortly after arranging the visit, staff noted a bluish colour around the man's lips and under his fingernails. Ten minutes later, the support worker contacted the man's parents and advised of the appointment for the GP home visit. Within five minutes, he had collapsed. The support worker called for an ambulance and performed CPR until they arrived, but the man was unable to be revived.

We found that the support worker was the only staff member in the house at the time of the incident due to rostering problems. The support worker liaised with other staff and the on-call manager to secure an additional staff member to enable the GP review to occur. Another staff member was arranged to arrive in time for the GP appointment, but the man collapsed before that time.

Following our review, we discussed the man's death with the disability service. The service advised that they had made changes to improve the staff rostering system and their interaction with families. The service also indicated that it would develop a protocol to assist staff in responding to acute and/or unexpected health events.

A small number of matters raised concerns about the adequacy of the service's response to the person's critical health changes. This included services that did not seek medical assistance for the people they were supporting, despite situations that included:

- the person experiencing two days of atypical illness, including vomiting, incontinence and poor appetite, and being noted as weak, quiet and unsteady over that period, and
- staff noting the person lying on the floor of their bedroom with sunken eyes and pale skin following two days of vomiting and diarrhoea.

#### Our reviews indicate the importance of:

- **Staff getting to know the person they are supporting**, in order to recognise changes in their health, behaviour, or other indicators of illness. This is particularly important where the person cannot communicate verbally.
- **Services and GPs providing clear guidance to staff about signs that can indicate illness,<sup>60</sup> and what action to take in response.** This includes assisting staff to understand when they may need to call for an ambulance.
- **Staff seeking urgent medical assistance if they have concerns or any doubts about the person's health** – even if the person has seen a GP recently or has an appointment coming up, or where their family says it is not necessary.

#### Response to changing support needs

Our reviews of deaths in 2010 and 2011 identified people whose support needs increased markedly over an extended period of time due to ageing, the progression of their condition (such as dementia or multiple sclerosis) and decline in their health. We found that services faced considerable challenges in responding effectively to the changing needs and providing appropriate support.

In particular, we found that staff often struggled to recognise what to do in response to the person's increasing support needs, including when to escalate the matter with senior

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60. ADHC's *Health Care* policy and the NSW Council for Intellectual Disability's *Healthier Lives* factsheets provide useful information about signs that can indicate illness in people with disabilities.

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management. Overall, while services reacted to individual events (such as falls or behavioural incidents), they rarely identified the need to have a comprehensive review of the person's circumstances and needs.

**Central to our reviews of these deaths has been the need for better coordination of care. Our reviews have reinforced the importance of a comprehensive, coordinated and multidisciplinary approach to supporting people with disabilities in care.**

### Response to complex needs

A number of the people who died in 2010 and 2011 experienced changes that involved some complexity. This included where:

- the changes and decline affected multiple areas, including health, behaviour and cognition
- the cause of the changes wasn't clear or able to be readily identified, and
- the individuals already had dual diagnoses and complex needs before their support needs increased.

Our reviews of these deaths identified that, while the person frequently had the involvement of multiple parties – including their disability service, GP, hospital staff, specialists and family – there was rarely a coordinated approach. We noted that disability services staff often struggled to know how best to support the person, and found it difficult to get clear guidance in this regard.

For many of these individuals, we found that the changes in their support needs were often viewed in isolation.<sup>61</sup> Communication between the different parties, and consideration of the interplay between all relevant factors, including environmental changes, was not always evident.

Critically, we found that the impact that the changes were having on the individuals was significant, including distress, screaming, hitting others, agitation, disturbed sleep, injury, and considerable health problems (including choking on food, reduced ability to walk, and falls). In our view, given the impact on the individuals and the extended period of time

in which these effects were experienced, comprehensive review of their needs was warranted.

However, we found that services did not always identify the need for a comprehensive and multidisciplinary review of the person's changed needs and the support required, or found it difficult to obtain that review.

### Case study 16 – responding to complex needs

In the eight months before his death, a 53-year-old man who lived in a group home experienced a marked decline in his health and functioning, with increased mobility problems, weight loss, insomnia, swallowing difficulties, agitation and confusion.

The man had frequent falls, and staff noted unexplained injuries, including bruises and grazes. During admission to hospital for a bowel obstruction seven months before his death, he was found to have multiple rib fractures, the cause of which was unable to be determined.

Over the eight-month period, the man had multiple hospital admissions and consultations with specialists in hospital and the community to try to ascertain the reasons for the changes in his health and behaviour. He had numerous medication changes, including the introduction and subsequent withdrawal of various psychotropic medications. During that time, there were also changes to staffing at the man's group home and his routine.

Our review identified that the disability service staff were increasingly overwhelmed by the man's higher support needs and struggled to know what to do to assist him. They did not appear to escalate the matter with senior management at an early point. Importantly, we found that, while service and health staff responded to the man's presenting issues, there did not appear to be a comprehensive or coordinated approach between the providers to responding to his complex and increasing needs.

Shortly before the man's death, the disability service commissioned a medical consultant to provide a view on the likely reasons for

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61. For example, the person's GP prescribed medication for their sleeping problems, a behaviour clinician looked at how to reduce their challenging behaviour, and a psychiatrist considered their mental illness and the effectiveness of their medications.

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the change and escalation in his health and behaviour, and to make recommendations for staff to implement. He died in hospital from bronchopneumonia before the review could occur.

Following discussions with us, the disability service commissioned independent reviews of the circumstances surrounding the man's death and the systemic issues. As a result, the service developed a comprehensive action plan to address the problems, including actions to improve the direction and advice for staff; enhance the response by management and clinicians to incident reports; and strengthen staff's understanding of when and how to escalate issues within the service.

In response to our draft report, the disability service advised that it has implemented all of the recommended actions, and has also established a quality improvement group and new risk and complex case management practices.

### Response to increased support needs related to ageing

In many cases we noted good support provided by services to people with increased needs related to ageing. This included some people in licensed boarding houses, such as the woman in the following case study.

### Case study 17 – good support to meet increased needs related to ageing

A 71-year-old woman with a moderate intellectual disability who lived in a licensed boarding house died from metastatic cancer. Despite the woman having surgery to excise a lesion on her face, and further surgery to treat lymphatic metastases, the cancer spread.

Nine months before her death, the woman tripped and fell at the boarding house, and fractured her hip. She had surgery and rehabilitation in hospital, and was re-screened as suitable for entry to the boarding house prior to discharge.

A month after discharge from hospital, boarding house staff noted deterioration in the woman's mobility, cognitive capacity and continence. A case conference was held within two days, and agreement was reached between boarding house staff, ADHC's Boarding House Team, the woman and her niece that she would receive

increased support from Home Care to help maintain her in the boarding house. An ACAT assessment was also organised in case her needs were no longer able to be met at home.

The woman's health and mobility was noted to improve with the additional support. Although she was assessed as suitable for entry to a nursing home, she remained at the boarding house with additional support, in accordance with her wishes.

However, for at least five people, we found that services responded to the increase in their support needs by seeking their placement in residential aged care (nursing homes), despite the individuals being 51-61 years of age. For most of these individuals, the referral for an ACAT assessment resulted from the person's admission to hospital and the service indicating to hospital staff that they could no longer meet the person's needs.

We had concerns with the approach taken by these services as:

- it did not appear that they had taken all reasonable steps to continue to support the person at home
- it was not clear to us why the services considered that residential aged care support was more appropriate, and
- the suggestion to place the individuals in residential aged care was not consistent with the notion of 'ageing in place' or broader government policy aimed at keeping younger people with disabilities out of nursing homes.

In response to our concerns, we were advised of changes that have since been made to improve the support provided to people with increasing needs. This includes the use of Clinical Nurse Consultant positions with people with complex or increasing support needs to provide guidance to disability services staff and to act as an intermediary with health services, including hospital staff.

### Our reviews indicate the importance of:

- **Flagging problems as early as possible.** It is important that staff supporting people with disabilities in care identify where they are having problems meeting the person's support needs, and escalate this with management as soon as possible.

- **Comprehensive and multidisciplinary reviews of people with complex or increasing support needs** – to facilitate a coordinated approach to identifying and responding to the person’s changing needs.
- **Transition support for people with disabilities moving from paediatric to adult health services** – to maintain a coordinated approach to meeting their health care needs.
- **Multidisciplinary health care assessment and clinical services** – to enable comprehensive reviews, facilitate access to health services, and provide health care coordination and support for people with complex needs.

### Previous recommendations and relevant actions

Our previous recommendations relating to meeting complex needs have related to improving policy guidance on meeting health needs; improving access to therapy services and mental health services; and actions to progress the roll out of the health service framework for people with intellectual disability.

Health’s Service Framework<sup>62</sup> is likely to be important in facilitating improved coordination of care between health and disability services, and better access to specialised and multidisciplinary expertise for people with complex needs. There has been considerable progress in commencing the roll out of the service framework, but it is still early days.

In relation to people with increasing needs related to ageing, our previous recommendations have been aimed at achieving improved clarity regarding ADHC’s position on ‘ageing in place’, and delivering clear policy guidance to assist services’ decision-making and provision of support.

In 2010, ADHC commissioned an *Ageing in Place: Impact on Accommodation Services* project to assist with future planning and development of accommodation supports for people with disabilities who are ageing. The project has been

completed, and the report and associated Action Plan were due to be released in November 2012. We are continuing to monitor this work.

## 4.3 Care coordination between health and disability services

### Support to facilitate access to medical treatment

We identified at least 17 people whose behaviour or decisions affected their medical treatment and health. This included people who:

- refused to attend medical appointments, including GP and specialist appointments
- were resistant to physical examination, tests or procedures; such as a blood test, mammogram, colonoscopy and ECG
- refused to follow medical advice or health recommendations, including did not use a CPAP machine (for sleep apnoea), refused medication, did not follow positioning advice, did not follow their swallowing requirements, and discharged themselves from hospital early, and/or
- declined surgery and other treatment; such as surgery to insert a PEG or excise a tumour.

In a minority of cases, it was clear the person was making an informed decision not to have the treatment or procedure, which was based on how they wished to live their life. However, for others, this did not appear to be the case. Their refusal of treatment, lack of cooperation with tests and examinations, or refusal to attend health appointments, appeared to be based on other factors; such as their dislike of hospitals, their mental health, or their aversion to being touched.

It was not always clear to us what actions had been taken by health and disability staff to actively work with and assist the person to overcome their objections, or to make it an easier process. In some cases, this might have included ensuring that the person is accompanied to appointments by a staff member they like and trust, or talking to the person at different times about the procedure and how staff can help. In other cases, it

62. Health’s *Service Framework to improve the Health Care of People with Intellectual Disability* aims to reduce health inequalities for this population by establishing specialised intellectual disability health services; creating a centre for clinical leadership, education and training; enhancing the capacity of existing services to meet their health needs; and improving access to quality health care services. More details about the Service Framework and its rollout are provided on pages 76-78.



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might have required the development of clear and consistent behaviour strategies and staff training.

The impact of these decisions was sometimes very significant – including missing out on critical treatment, and delayed diagnosis of life-threatening conditions. In addition, we noted that sometimes the person's refusal (and their behaviour in response to attempts to examine them or to provide treatment) affected the medical or support decisions that were made. This included appointments not being made to undertake certain health checks (such as dental or eye examinations) because of a perception that the person wouldn't be able to cope.

### Case study 18 – the need for support regarding medical treatment

A 77-year-old woman with a moderate intellectual disability and schizophrenia who lived in a group home was noted to be resistant to some medical checks and tests. She had a history of refusing health screening such as breast checks, as well as some blood tests, and the influenza vaccination.

In the year before her death, the woman was referred to a gastroenterologist to have an endoscopy, but was subsequently taken off the waiting list because she declined treatment.

Three months before her death in 2010, her GP noted that the woman had an irregular heartbeat and made a referral for an ECG. The woman had the ECG, which identified abnormal results and possible cardiac ischaemia. Her GP made a referral to a pathology service for a blood test, but the woman was largely uncooperative and very little blood was able to be obtained.

The GP indicated that she needed to have a follow-up ECG and blood test, and to see a cardiologist, but the woman was not cooperative with the procedures. Six weeks before her death, the GP and service again attempted to obtain the ECG and blood test by organising for a pathology service to visit the woman at home, and for the procedures to occur under light sedation to assist with her anxiety. The woman continued to refuse.

No further attempts appear to have been made to support the woman to have the ECG and blood test. She died from a heart attack caused by coronary artery disease.

**Our reviews highlight the importance of health and disability services working proactively and cooperatively together, and with the person with a disability, to minimise the person's resistance to health services and treatment, and to make sure they are making an informed decision (where possible).**

### Support for people with disabilities in hospital

For many years, we have reported concerns that have been raised with us by disability services about the support provided to people with disabilities in hospital. This has included concerns about the quality of care provided in hospital, and disability services being asked to provide and pay for staff to support clients during admission. We have also previously reported problems with the quantity and quality of information provided to hospital staff by disability services when clients are admitted.

**Our reviews continue to reinforce the need for a person-centred, coordinated and cooperative approach between disability and health services (and family where relevant) to provide effective support to people with disabilities when they are in hospital.**

Our reviews of deaths in 2010 and 2011 have identified problems relating to communication between key parties, and in the level of cooperation between health and disability staff in coordinating and providing support. These problems have included:

- disability services providing inaccurate written information to hospital staff regarding the person's disabilities and health conditions
- hospital staff refusing to accept written guidance from disability services regarding the person's support needs (such as their Eating and Drinking plan)
- hospital staff providing information about the person and their progress to the person's family, but not providing relevant advice to the disability service
- hospital staff not accurately recording or acting on the wishes of family regarding resuscitation, and
- as illustrated in the following case study, hospital staff not adequately heeding the advice and concerns of the person's carers.

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## Case study 19 – the importance of information from disability support staff

A 60-year-old man who lived in a regional residential centre presented to hospital on the four consecutive days before his death in 2011 from pyelonephritis (kidney infection) due to a urinary tract infection and a kidney disorder.

Following the man's death, Health conducted a root cause analysis (RCA) of the circumstances of his death and actions taken in hospital. The RCA found that contributing factors to the man's death included that:

- the medical team had failed to recognise the man's deterioration because they had not adequately assessed or reviewed the working diagnosis on his third presentation to the hospital, and
- during that presentation to hospital, the man's disability support worker had raised concerns with medical staff about his atypical appearance and behaviour, including that he was very pale, wasn't mobilising, his legs were twitching, and that he was groaning and hypertensive. The RCA found that inadequate attention had been paid to the concerns of the disability support worker, which may have contributed to the inadequate assessment and review during his hospital presentation.

In addition, on discharge from the man's second presentation, hospital staff indicated that he was to receive an antibacterial drug for his urinary tract infection, potassium and magnesium supplements, and an increased dose of his anticonvulsant medication.

However, when the man re-presented to hospital the next day, he had not started the medications as they had not been available the previous evening at the disability service. The RCA identified that, on discharge, the hospital should have provided the man with a minimum of 24 hours of the prescribed medication.

### The importance of effective support to help with diagnosis and treatment in hospital

The need for effective and coordinated support for people with disabilities in hospital was underscored by our reviews of at least 10 people who died in 2010 and 2011 whose behaviour and non-compliance in hospital affected their medical treatment and health. This included:

- A 43-year-old man who was admitted to hospital with aspiration pneumonia who refused oxygen, medications and observations (such as checking his temperature and pulse). Hospital staff subsequently asked the disability service to provide support to the man during the admission.
- A 45-year-old woman who was admitted to hospital due to lung disease who pulled out her cannula and drank thin fluids (against her swallowing requirements). During a previous hospital admission, she had been supported by disability service staff, and no issues had been reported.
- A 47-year-old man who refused to go to hospital for treatment of his pressure wounds despite an ambulance attending his home eight times in five days. He was typically non-compliant with health recommendations and refused treatment, including a blood transfusion.
- A 49-year-old man with abdominal pain, vomiting and diarrhoea whose family made the decision not to send him to hospital because he reportedly did not cope well in that environment. He died at home less than two days later.
- A 50-year-old woman who died from breast cancer who had refused to undergo general anaesthetic, biopsy and treatment for her breast lump and abscess, and was typically uncooperative with physical examinations and tests, such as mammograms. The woman was diagnosed with breast cancer following surgery while involuntarily admitted to a mental health facility five months before her death.

We identified numerous cases in which disability services provided staff to support the person during their hospital admission – sometimes 24 hours a day. We frequently noted the difference and improvement in the person's reported behaviour and wellbeing in hospital where they had the assistance and support of people familiar to them, whether disability staff or family.

The following case study illustrates the importance of people with disabilities receiving coordinated and person-centred support in hospital, and the need for a collaborative approach between all parties, including health services, disability services and families.

## Case study 20 – the importance of support for people with disabilities in hospital

Following her mother becoming seriously ill and her father not being able to care for her, a 50-year-old woman with cerebral palsy and a moderate intellectual disability moved into a group home two years before her death. The group home was located a long way from her former home – resulting in less contact with her family and a change in the day program that she had attended for 30 years.

The woman was noted to become very depressed, lost weight, demonstrated self-harming behaviour, and refused to eat and take medications. She had multiple hospital admissions in the year before her death in 2011 from bowel cancer, and would typically not comply with medical treatment or tests unless her father was with her. Her non-compliance included refusal of medications, blood tests, food and fluids unless they were offered by her father.

The woman's resistance to medical treatment and investigations hampered attempts to diagnose her health problems and their cause, including:

- medical staff abandoning a colonoscopy procedure due to her poor compliance with the necessary pre-preparation (including taking bowel preparations), and
- an inability to examine the woman due to her refusal and physical resistance, including almost breaking the glasses of a medical officer.

The woman primarily relied on gestures, actions and facial expressions to communicate. We found that information about how she expressed herself did not appear to be available to hospital staff to assist with their assessment and communication with her. During the hospital admission in which the woman was diagnosed with cancer, nursing and medical staff recorded difficulties in trying to ascertain her communication needs.

In response to our draft report, the disability service advised that it is developing a support package to accompany people when they go into health settings, including a communication profile. The service is also looking at a health-based initiative called Top 5, which gives a snapshot of the five most important things to know about a person when they are in hospital.

In our reviews of deaths in 2010 and 2011, we noted some encouraging examples of cooperative and collaborative support provided to people both in hospital and in the community, particularly in circumstances where individuals were in advanced or final stages of a degenerative condition or terminal illness. These examples include a 17-year-old young man in the advanced stages of a degenerative condition who received comprehensive and coordinated support from his NGO disability service, hospital staff, his family, the local palliative care team and other community health services.

### Our reviews point to the need for:

- **A collaborative and person-centred approach in disability and health services to supporting people with disabilities in their contact with health services (in hospital and the community).** The focus should be on identifying what support the person needs and how it will be provided, as early as possible.

Amongst other things, support may include:

- physical assistance and comfort to the person during their admission to hospital
- working with the person before a planned admission to hospital or contact with a health service to become familiar with the location/ environment, what will happen, and what support will be provided
- ensuring that everyone has clear information and guidance about the support the person requires, including support related to communication, meals, and behaviour or anxiety, and
- identifying people who are resistant to medical examination or treatment, and working with them to try to identify the reasons why and what help they may need to make it easier.

### Previous recommendations and relevant actions

In October 2009, we met with ADHC, Health and National Disability Services (NDS), to discuss problems relating to support of people with disabilities in hospital. ADHC and Health indicated that they had commenced work

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towards developing a joint state-wide protocol (now a Joint Guideline) to provide best practice guidance for health and disability staff in working collaboratively in identifying areas of risk for people in hospital; agreeing on the additional supports required to reduce the risks; and in negotiations relating to accepting responsibility for providing other additional supports when they are required.

The progress of this work since 2009 has been slow. In October 2012, we were advised that the Joint Guideline was being finalised, and would be implemented with ADHC's Health and Wellbeing policy framework in 2012/13.

The NSW Service Framework for people with intellectual disability is likely to be important in facilitating improved coordination of care between health and disability services, and in supporting people with intellectual disability in contact with health services. There has been considerable progress in commencing the roll out of the service framework, but it is still early days.

We note that the NSW Implementation Plan for the National Disability Strategy includes key actions for 2012-14 related to the service framework; including work to improve referral pathways with particular emphasis on aspects of care related to challenging behaviours.

The NSW Implementation Plan also notes that achievements to date include developing and making available a training package for doctors on the provision of quality services to people with intellectual disability. The plan indicates that both GPs and public hospital registrars have undertaken the training.

### Transfer of care from hospital to home

Given the health and support needs of many people with disabilities in care, it is important that their discharge from hospital to home is planned and coordinated.

Before a person is discharged, Health policies<sup>63</sup> require hospital staff to provide the patient and their carer/service provider with comprehensive information: including referrals, appointments and follow-up information. For people with disabilities, hospital staff are also required to look at whether the pre-admission support that the person had at home will continue to meet

their needs, and to provide relevant education and training to disability staff (where possible and appropriate).

Our reviews of deaths in 2010 and 2011 identified at least 10 people for whom the transfer of care from hospital to home was inadequate. For half of these people, the impact of the poor discharge process was significant. Examples of poor practice included:

- The 59-year-old woman in case study 5 (see page 34) who presented to hospital four times in the six weeks before her death with breathing difficulties and exacerbation of her asthma. On discharge from hospital, she was not referred for specialist respiratory review as an outpatient; the discharge plan to the GP did not note the need for a follow-up chest x-ray; and the woman and disability service were not provided with any guidance about how manage her asthma and lung disease, or how to prevent exacerbations of those conditions. In the lead up to her death in 2010 from an acute asthma attack, the woman was noted to be 'hysterical' and 'panicked' about her breathing problems.
- The 55-year-old man in case study 12 (see page 43) who was discharged from hospital to a licensed boarding house with significant choking risks. The discharge plan noted that the man required a 'soft diet', but no guidance was provided to the boarding house manager about what that meant. The man died in 2011 from choking on a sandwich.
- A 53-year-old woman with advanced multiple sclerosis had four admissions to hospital in the three weeks before her death due to breathing difficulties associated with a reduced ability to clear secretions. On discharge from her second admission to hospital, the disability service was advised to organise a home oxygen concentrator. There is no indication that guidance was provided to the woman or disability support staff regarding when and how the oxygen therapy was to be used.

In some cases, we noted (and received expert advice) that the care and treatment provided in hospital was of a high standard, but the transfer of care on discharge was poor. This included a 53-year-old woman in a licensed

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63. NSW Health (2011) *Care Coordination: Planning from Admission to Transfer of Care in NSW Public Hospitals* policy; and NSW Health (2008) *People with a Disability: Responding to Needs During Hospitalisation* policy.

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boarding house who was admitted to hospital with seizures and hyponatraemia, considered to be caused by her medications. Her discharge information did not include relevant information about her fluid restrictions or her need for a medication review.

### **Feeding tube placements and transfer of care**

Our reviews of the deaths of two men in 2010 and 2011 from misplaced PEG tubes identified very similar problems relating to discharge planning. In both cases, we found that hospital staff did not appear to have done a post-procedure check to make sure the PEG tube had been inserted in the correct position prior to discharging the person back home. In addition, Health requirements were not met in relation to reviewing incidents (such as deaths) in order to identify causes and areas for improvement.

The following case study of the death of one of these men highlights the types of problems that were evident in both matters.

### **Case study 21 – PEG tube placement and transfer of care**

A 29-year-old man who lived in a group home died in 2010 from severe sepsis caused by a misplaced percutaneous endoscopic gastrostomy (PEG) tube. The man had a severe intellectual disability and received nutrition orally and via the PEG.

A month before his death, the man's PEG tube became displaced, and he subsequently had a new PEG inserted in hospital. When he returned to the group home later that afternoon, disability support staff noticed that there were blisters between his skin and the tube, and obtained guidance from the Home Enteral Nutrition clinic to clean the area every two to three hours.

Over the next day, the man experienced pain and discomfort when staff attempted to administer nutrition via the PEG, and refused to accept food orally. The following morning, staff noted that he was vomiting, pale and drowsy, and called an ambulance. In hospital, he was found to have a misplaced PEG and gastric perforation, with gas and copious free fluid in his abdomen. The man's health continued to decline despite active treatment, and he died a few weeks later.

With the assistance of a specialist on our Expert Panel, our review identified problems with the checking of the man's PEG tube prior to his discharge from hospital, and with the use of Health's incident information management system (IIMS) to identify the cause of the incident and areas for improvement.

We found a lack of consistent requirements within Health relating to post-procedure checks of the positioning of feeding tubes, and noted the potentially serious consequences of misplaced feeding tubes – particularly for individuals who are not able to verbally communicate the need for urgent medical attention.

We also found that neither of the hospitals involved in this matter had notified the man's death through the IIMS, despite requirements to do so and existing policy guidance on the management of incidents across health service boundaries.

In response to our review, the Agency for Clinical Innovation (ACI) established a working group to develop state-wide standards for the insertion, replacement and ongoing care of all gastrostomy and jejunostomy tubes; and indicated that it is developing a Home Enteral Nutrition model of care.

In relation to the IIMS process, the Local Health District in which the man died commissioned a district-wide process review, and implemented a range of actions to improve practice (including staff training and the development of useful tools to make it easier for staff to implement the policy).

### **Swallowing risks and transfer of care**

In addition to the licensed boarding house resident who choked on a sandwich (noted above), two other people who died in 2010 and 2011 experienced problems with hospital discharge planning related to swallowing risks. In both cases, hospital staff had noted the need for the individuals to be reviewed by a speech pathologist as outpatients due to their significant aspiration risks. However, there was no indication that hospital staff made a referral, or recorded the need for a review on the discharge plan, or that they otherwise communicated such information either to the patient or disability service staff.

### Our reviews point to the need for:

- **Coordinated and comprehensive planning for the transfer of care of people with disabilities from hospital to home.** Consistent with policy, hospital staff should:
  - consider the support required by the person on discharge and the capacity of the pre-existing accommodation and support arrangements to provide the necessary level of care
  - work with the person and the disability service to identify what additional support may be required and provide assistance to obtain that support (including referrals and equipment on loan)
  - make sure the person, disability service and GP have clear and sufficient information regarding what follow-up is required, and
  - where necessary, provide education and training to disability support staff (including licensed boarding house staff).

### Previous recommendations and relevant actions

Our previous recommendations in this area have focused on the need for clear guidance for health services regarding discharge planning for people with disabilities. In monitoring our recommendations, we have previously noted considerable progress, including the implementation and evaluation of Health's *People with Disabilities: Responding to their needs during hospitalisation* policy directive.

In relation to discharge planning for licensed boarding house residents, our previous recommendations have centred on the use of the screening tool for entry to licensed boarding houses, and the need for the tool to be reviewed. There has also been significant progress in this area – the tool was reviewed; responsibility for applying the screening tool changed from Aged Care Assessment Teams to Home Care assessors; and the screening tool has been modified to improve the identification of key risks, including choking risks.

The NSW Implementation Plan for the National Disability Strategy includes key actions for 2012-14 to improve services to people with disabilities

(and their carers) who are attending, being admitted to, or leaving hospital. These actions involve:

- developing consistent processes for transfer of care (discharge planning) to ensure safe and effective transfer of care for patients who are transferred home or to ongoing care from the acute hospital service
- including carer status in the electronic admissions system of NSW hospitals to record whether a person has or is a carer
- developing a joint guideline on procedures to address patients/outpatients who are residents of ADHC funded accommodation, and
- encouraging more flexible non-emergency transport services that meet the needs of patients who currently have access issues.

## 4.4 Access to preventative health support

Our reviews have highlighted the multiple health risks faced by people with disabilities in care that are related to lifestyle factors, including obesity, poor diet and insufficient physical activity. People in licensed boarding houses also face significant risks related to high rates of smoking.

We recognise that these preventable health risks are not limited to people with disabilities in care. However, our reviews have indicated the need for a greater focus on assisting this population to reduce the health risks.

While we noted some positive examples of preventative health support for people who died in 2010 and 2011 – including the use of nicotine replacement therapy, involvement of dieticians, and commencement of walking programs – these actions were not common.

Overall, our reviews have indicated the need for proactive strategies and support by health practitioners and staff supporting people with disabilities in care to make it easier to make healthy choices.

We found instances where the person's GP had encouraged them to quit smoking and/or increase their physical activity, but there was no indication of collaborative work with boarding house or disability service staff to increase the likelihood that they would do so.

Similarly, we noted examples of Boarding House Reform Program staff indicating that a licensed boarding house resident had indicated they were not interested in stopping their 30 cigarette a day smoking habit or getting exercise, and there was no indication of any further action being taken to continue to discuss these issues with the resident or otherwise provide support options.

**Services and health practitioners should take every opportunity to work together, and with the involved person, to provide support to make it easier for them to improve their health prospects.**

**Our reviews point to the need for a coordinated and comprehensive approach to prevention, including:**

- Identifying people who face health risks related to smoking, obesity, poor diet and lack of physical activity.
- Concerted and collaborative action by health practitioners and support services who are in contact with current and former residents of licensed boarding houses that is focused on supporting them to quit smoking.
- Concerted action to assist people with disabilities in care to increase healthy eating and physical activity and to reduce sedentary behaviour.
- Key service providers looking for opportunities to work together to assist individuals and to influence people to make better health choices.

In licensed boarding houses this may include the GP and Primary and Secondary Health Care staff identifying health risks, providing information, and assisting people to access support. In addition, ALI services might include more options with moderate physical activity, and the boarding house manager might obtain advice from a dietician on improving meal options.

- Ensuring access to respiratory specialists for people with recurrent respiratory problems.

## Support to quit smoking

Smoking is a significant risk factor for deaths due to chronic lower respiratory diseases, ischaemic heart diseases, lung cancer and bowel cancer.

In Australia in 2010, 15.1% of people aged 14 years and over were daily smokers.<sup>64</sup> However, the smoking rate amongst people with mental illness was 32% – more than double the national average.<sup>65</sup>

Of the people in licensed boarding houses who died in 2010 and 2011, 56% were daily smokers; half of whom smoked more than 20 cigarettes per day. Overall, 88% of the licensed boarding house residents who died during this period had smoked; including all of the people in licensed boarding houses who died from lung cancer, pneumonia, COPD, and three-quarters of those who died from ischaemic heart diseases.

Across the nine years of our reviews, the smoking rates among people in licensed boarding houses who have died have been consistently high. It is positive to note that a number of people with disabilities in care who died in 2010 and 2011 had been provided with nicotine replacement therapy to help them to quit smoking, and an increased proportion of licensed boarding house residents were ex-smokers.

However, smoking continues to be a major, preventable factor affecting the health, and limiting the lifespan, of people in licensed boarding houses (and of people who have moved from boarding houses into disability services). While we have noted some improved practice in this area, there is significant work that remains to be done to reduce smoking rates in this population.

**Our reviews highlight the need for concerted and collaborative action to be taken by health practitioners and support services to assist current and former residents of licensed boarding houses to successfully quit smoking.**

Evidence has shown that smoking cessation advice from health professionals is effective in increasing quit rates. The Royal Australian College of General Practitioners has indicated

64. Australian Institute of Health and Welfare (2011) *2010 National Drug Strategy Household Survey report*. Drug statistics series no. 25. Cat. no. PHE 145. Canberra: AIHW.

65. Commonwealth of Australia (2010) *Taking Preventative Action – A Response to Australia: The Healthiest Country by 2020, the Report of the National Preventative Health Taskforce*.

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that '[a]ll health professionals should systematically identify smokers, assess their smoking status and offer them advice and cessation treatment at every opportunity.'<sup>66</sup>

While we identified action by some GPs on this issue, it was neither consistent nor frequent. Importantly, we note that there are many workers from services that have regular contact with people in licensed boarding houses. These include boarding house staff, mental health workers, and staff from Boarding House Reform Program services (including the Primary and Secondary Health Care and ALI services, Home Care, and ADHC caseworkers).

The significant number of health practitioners, services and staff in contact with licensed boarding house residents presents valuable opportunities for cooperative work focused on tackling this issue (including talking with individuals about smoking cessation, reinforcing the benefits of quitting, and providing support to those attempting to quit smoking).

It is important that people with disabilities in care who smoke, and the people who support them, have access to information about the assistance that is available to quit. This includes information about:

- **Nicotine replacement therapy and medication options.** Certain nicotine replacement patches and smoking cessation medications (bupropion and varenicline) are subsidised on the Pharmaceutical Benefits Scheme (PBS).<sup>67</sup>
- **Quit smoking programs and resources.** Cancer Council NSW runs a *Tackling Tobacco* program, which is aimed at helping staff of community organisations to support their clients to quit smoking. The program includes free training for workers and resources that boarding house staff and others can use to provide advice and to support clients to make a decision to quit smoking.<sup>68</sup>

### Previous recommendations and relevant actions

Our previous recommendations related to this issue have focused on the need to improve health outcomes of licensed boarding house residents and to increase their access to Primary and Secondary Health Care services.

In response, ADHC introduced a state-wide standard service model for Primary and Secondary Health Care services in 2012, and new funding agreements with the providers. As part of the new arrangements, these services are now required to assess the health needs of all licensed boarding house residents, develop individual health plans, and review them annually.

These new requirements provide a useful opportunity to tackle smoking cessation in licensed boarding houses on both an individual and systemic basis.

### Support to improve nutrition and physical activity

Obesity, poor diet and insufficient physical activity are associated with deaths from heart disease and bowel cancer, as well as multiple chronic health problems such as type II diabetes.

This cluster of risk factors tends to be prevalent among people with disabilities in care. Over one-third of people in disability services and over half of the people in licensed boarding houses who died in 2010 and 2011 were overweight or obese. At the top end of the scale, 34 people were obese or severely obese: from this group were individuals who died from heart attack, heart disease and COPD.

We identified some areas of good practice, including the involvement of dieticians for just over half of the people in disability services who were overweight or obese, and walking programs for a small number of individuals. However, we rarely noted a comprehensive

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66. Royal Australian College of General Practitioners (2011) *Supporting smoking cessation: a guide for health professionals*, p7.

67. Combining two forms of nicotine replacement therapy (patch plus oral form, such as lozenge or gum) has been shown to be more effective than a single form of nicotine replacement. Nicotine transdermal patch, nicotine gum and nicotine inhaler all increase quit rates by 50-70% at 5-12 months compared with placebo, and regardless of the setting. (RACGP op cit, p22).

68. See the Cancer Council NSW website ([www.cancercouncil.com.au](http://www.cancercouncil.com.au)). Information about the Tackling Tobacco program can be found at: <http://www.cancercouncil.com.au/1384/reduce-risks/smoking-reduce-risks/tackling-tobacco/tackling-tobacco-goals-and-target-groups/?pp=1201>.



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approach to assisting people with obesity; such as the combination of dietary support and exercise.<sup>69</sup>

We found that obesity was not consistently identified by health practitioners or services as an area requiring support. Where it was identified as a problem, it was not always clear what support was being provided.

For licensed boarding house residents in particular, it was often difficult to see what action had occurred in relation to the person's obesity. Only one resident who was overweight had seen a dietician, and that was in hospital shortly before he died. There did not appear to be a proactive approach to supporting residents to address obesity, or cooperative work between health providers and other services.

**Overall, our reviews found that concerted action is required to assist people with disabilities in care to increase healthy eating and physical activity and reduce sedentary behaviour.**

We note that the NSW Implementation Plan for the National Disability Strategy incorporates key actions for 2012-14 that are aimed at assisting people with disabilities to improve nutrition and physical activity. These include actions to:

- improve access to information and support to help people with disabilities to make lifestyle changes in relation to healthy eating, being physically active, and achieving and maintaining a healthy weight through the *Get Healthy Information and Coaching Service*<sup>70</sup>
- develop a cross agency Overweight and Obesity Plan, which encourages and promotes healthy lifestyles through better eating behaviours and physical exercise
- increase information available on sport and physical activity options available to people with disability, and

- increase participation in mainstream sport and recreation, and improve access to sport and recreation facilities across NSW.

### Previous recommendations and relevant actions

Our previous recommendations in this area have focused on improving guidance for disability services in relation to identifying and managing nutrition risks. We note the work that ADHC is undertaking in this regard, including collaboration with Nutrition and Dietetics in the University of Newcastle to develop a streamlined practice guide for nutrition support and management.

In relation to people in licensed boarding houses, the changes to the Primary and Secondary Health Care service model, and the introduction of new requirements, provide a useful means for identifying individuals with risk factors relating to obesity, poor nutrition and sedentary behaviour. In addition, the changes also provide an opportunity to develop strategies for supporting these individuals in order to address or minimise their health risks. It is critical that the overall approach to this issue includes cooperative and collaborative work with GPs, boarding house staff and other services providing assistance and follow-up.

### Access to respiratory services and support

In terms of both underlying and contributing causes, respiratory illness is a major factor in the deaths of people with disabilities in care, particularly those deaths from pneumonia, aspiration pneumonia and chronic lower respiratory diseases. We have previously reported concerns about the infrequent referral to respiratory specialists for people with recurrent and chronic respiratory issues such as COPD/ emphysema or recurrent aspiration pneumonia; and the lack of involvement in chronic disease management programs.

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69. Moderate physical activity (activity that causes a slight, but noticeable, increase in breathing and heart rate and may cause light sweating in some people) is advised on most, or preferably all days of the week for at least 30 minutes per day. Evidence indicates that regular moderate physical activity reduces all cause mortality, incidence of coronary heart disease, hypertension, NIDDM, obesity, osteoporosis, colon cancer, falling, anxiety and depression. (RACGP National Standing Committee – Quality Care (2004) *SNAP: Smoking, Nutrition, Alcohol and Physical activity – A population health guide to behavioural risk factors in general practice*).

70. The *Get Healthy Information and Coaching Service* is a free telephone-based service funded by NSW Health that provides a personal health coach to assist individuals to set and reach personal health goals over a six-month period.

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In our reviews of deaths in 2010 and 2011, we noted the involvement of respiratory physicians with some licensed boarding house residents, including one person who was linked to a chronic disease management program to provide respiratory support at home. However, this kind of specialist support is not common.

**Overall, we found that the individuals who died from respiratory problems had been provided with limited access to expert respiratory clinicians.**

We noted that specialist respiratory review had occurred for:

- just over one-quarter of people in disability services and half of people in licensed boarding houses who had recurrent respiratory infections
- one-quarter of the people with recurrent respiratory infections who died from aspiration pneumonia
- one of the seven people with recurrent respiratory infections whose deaths from Down syndrome or cerebral palsy were associated with aspiration pneumonia, and
- two of the five people in disability services who died from chronic lower respiratory disease.

Our reviews of deaths in 2010 and 2011, including the death of the woman in case study 5, emphasise the importance of access to respiratory specialists for people with disabilities in care who have recurrent respiratory problems.

### Previous recommendations and relevant actions

In our last report, we noted that in July 2010, the ACI Respiratory Network had submitted a proposal to NSW Health for the development of a Severe Chronic Respiratory and Cardiac Care Program. The aim of the proposed program was to deliver community-based coordinated patient-centred care to people with chronic and complex respiratory disease.

In a recommendation related to this proposal, we sought detailed advice from Health on its plans for improving access to community-based coordinated patient-centred care for people with chronic and complex respiratory disease, including people with disabilities in care.

Health provided advice about a range of supports and services that are available in the community to assist people with chronic respiratory diseases, including versions of the Severe Chronic Respiratory and Cardiac Care Model, which currently operate at five sites across NSW. Health also provided advice about actions that the ACI will take to improve the access of people with disabilities to chronic disease management programs, including consultation with GP clinical leaders on barriers to service provision for this population.

Our reviews of deaths in 2010 and 2011 underscore the need for progress in this area. It is important that people with disabilities and chronic respiratory disease have equitable access to community-based and coordinated care, including expert respiratory clinicians.

## 4.5 Support for people in licensed boarding houses

Over many years, we have drawn attention to the need for improved support for people in licensed boarding houses. We have highlighted the significant health concerns of many licensed boarding house residents: including very high smoking rates, considerable chronic health problems such as emphysema, renal failure and diabetes, and the risks faced by residents related to the use of psychotropic medications. We have also consistently raised concerns about the adequacy of the conditions and requirements relating to safeguarding residents.

**Our reviews of deaths in 2010 and 2011 demonstrated the need for improved support for licensed boarding house residents and the importance of the boarding house sector reforms.**

In conducting the reviews, we noted areas of improved practice in relation to some of the people in licensed boarding houses who had died, including improved access to some specialists and out-of-hospital programs, and recognition on the part of one licensed boarding house of the need to work with residents to help minimise their health risks (including in the areas of smoking and diet).

However, our reviews of the deaths of eight people in two licensed boarding houses in 2010 and 2011 – as well as two in 2009 – highlight some of the ongoing systemic problems in the boarding house sector and the importance of

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the legislative reforms that were introduced in 2012 that are intended to improve standards in this sector.

### Coronial inquest into the deaths of six people in a licensed boarding house

The deaths of six people in a licensed boarding house in 2009 and 2010 raise significant concerns about the adequacy of the care provided and highlight the need for reform in the boarding house sector.

The six people ranged in age from 53 to 75 years. They died as a result of Olanzapine (antipsychotic medication) toxicity; pulmonary thrombo-emboli;<sup>71</sup> choking on food (two people); atherosclerotic disease;<sup>72</sup> and cardiomegaly (enlarged heart).

Our reviews of the deaths of the six people identified problems with the adequacy of the support provided in the boarding house, and raised questions about the medical support provided to some of these people.

In March and April 2012, the Coroner held an inquest into the six deaths. We cooperated with the Coroner's office in relation to this matter. In her findings in May, the Coroner concluded that:

- **'There can be no question that the six who died at [the boarding house] were uncared for, poorly treated medically, and neglected.'** The Coroner noted that on weekends there appeared to have been only one, unqualified staff member available for up to 35 residents.
- **'The standards of hygiene and nutrition at the hostel were poor, facilities run down or not usable, and overall care sadly lacking.'** The Coroner also found that the weekend staff member had no training in first aid, and parts of the buildings posed high risks.
- In relation to medical treatment, the Coroner found that it was 'less than adequate', and there was **'little evidence of a co-ordinated approach between doctors and outside services or doctors and management. Reviews of medication, if they took place at all, were not properly recorded, and medical note-taking was negligible to the**

**point of negligence.'** The Coroner stated that there was **'barely any management of the more significant risk factors for any of the six, and no follow up after hospitalisation.'**

- The Coroner found that medication compliance amongst the six people was poor, and **'dangerously ill-supervised.'** The Coroner heard evidence from medical experts and found that **'[t]he need for the use of multiple anti psychotic medication in the treatment of all the deceased was highly questionable'**.

We referred matters relating to the general practitioner and the psychiatrist to the HCCC.

Following the deaths of the six residents, the boarding house closed. In 2012, the government introduced new legislation to reform the boarding house sector (see further information below).

### Systemic problems in a licensed boarding house

Our reviews of the deaths in 2011 of four residents of a licensed boarding house raised questions about the support needs of people living in the boarding house, the adequacy of the support provided, and the physical environment of the accommodation.

The four residents included an 82-year-old woman who died from lobar pneumonia and COPD; a 68-year-old man with alcohol-related brain damage who appeared to choke on food; a 62-year-old man who died from a hepatic artery aneurysm following damage to his bile duct during surgery; and a 56-year-old man who died from acute lobar pneumonia.

Through our reviews of the four deaths, sector liaison, and the exercise of our complaints powers, we found that:

- The 82-year-old woman had significant health issues, relied on a walking frame for mobility, and weighed 33 kilograms. Allegations had made to ADHC that the woman's bedroom had rising damp, mould on the bedroom walls and ceiling, and damp carpet.

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71. Pulmonary thrombo-embolism refers to obstruction of a blood vessel in the lungs due to a blood clot, which blocks a coronary artery.

72. Atherosclerotic disease refers to the progressive narrowing and hardening of the arteries over time.

- Information relating to the death of the 68-year-old man indicated that the staff member on shift at the time was the sole person supervising 59 residents.
- Health staff recorded that two of the people who died were malnourished on admission to hospital.
- Complaints had been made to ADHC about the quality and quantity of food provided to residents, alleged neglect of residents, and inadequate staffing levels. Concerns had also been reported to local media alleging medication administration errors, deactivation of fire alarms, sexual coercion among residents, and lack of criminal record checks on staff.
- ADHC had identified potential breaches of the Youth and Community Services Regulation 2010, issued cautions to the licensee, and indicated an intention to undertake a review of the boarding house.

We discussed these matters with ADHC, and were advised that ADHC staff would be undertaking a comprehensive review of the boarding house against the licence conditions and regulations. We were also advised of a range of actions that ADHC was taking in the interim to improve the identification and management of the health and support needs of residents.

In light of the above information, we referred the matter to ADHC to investigate and report back to us.

ADHC's review identified multiple significant breaches of the licence conditions and regulations, and confirmed many of the concerns that had been raised. We monitored ADHC's subsequent actions in relation to the boarding house, and liaised with the Official Community Visitor (OCV) and other stakeholders regarding the welfare of the residents.

Following ADHC's comprehensive review and issuing of additional cautions relating to staffing levels and food provision, the licensee relinquished the licence and the boarding house closed. In the lead-up to the closure, ADHC undertook considerable work with the residents and other stakeholders to find appropriate alternative accommodation that met both their support needs and stated preferences. The OCV continues to visit the residents,

and has advised that they are positive about the changes, including the improved living conditions, food and support.

### Previous recommendations and relevant actions

Over the past 10 years, we have made numerous recommendations aimed at improving outcomes for people living in licensed boarding houses. The recommendations have targeted a wide range of areas, including the need to improve requirements and practice relating to first aid; medication administration; record-keeping; health care support; hospital discharge planning; palliative care; and the need for legislative change and reform of the broader boarding house sector.

There have been notable improvements over that time, including the introduction of improved regulations in 2010 that included enhanced requirements relating to the administration and recording of medications, and requiring at least one person on each shift to have current first aid qualifications.

Other key actions have included changes by ADHC to improve health coordination and support for licensed boarding house residents provided by Primary and Secondary Health Care Services; and changes to the screening tool and processes to exclude people with choking risks and to enable greater consistency in the quality of the screening assessments.

However, the recent legislative reform presents the most significant change in the boarding house sector to date. In August 2011, we tabled a special report to Parliament that drew on our work over 10 years in relation to licensed boarding houses – this included evidence from our reviews of the deaths of people who had lived in those facilities. Our report noted the steps that had been taken by an interdepartmental committee to develop and consult on options for reform of the sector, and highlighted the need for government to progress the reforms to deliver real and improved outcomes for people in licensed and unlicensed boarding houses.

In October 2012, the NSW Government brought in the *Boarding Houses Act 2012*, which provides an improved regulatory framework for the delivery of services to residents of registrable (licensed and unlicensed) boarding houses. Key changes include the mandatory

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registration of all registrable boarding houses, the introduction of occupancy rights for all boarding house residents, and strengthened requirements and provisions relating to 'assisted' (previously licensed) boarding houses.

While the provisions of the new Act that relate to the register and initial compliance investigations by local councils commenced on 1 January 2013, the remainder of the Act will not commence until regulations have been finalised. The draft Boarding Houses Regulation 2013, released in March, provides improved safeguards and standards for people in assisted boarding houses, including requiring managers of the facilities to:

- report a broader range of incidents involving residents (including assaults, serious accidents, and the making of a complaint about the treatment of a resident)
- install call bells for residents and ensure that at least one staff member is present at all times
- notify the treating medical practitioner of any failure to administer prescribed medication, or any error in its administration, and
- provide food that is adequate in quality, quantity, variety and nutritional value to meet the resident's daily requirements, including undertaking menu planning with reference to published dietary guidelines or, when necessary, the advice of a qualified dietician or nutritionist.

Given the importance of the changes, we are keen to see the new legislation come into full effect as soon as possible.



# **Part Two:**

# **Monitoring our recommendations**

## Chapter 5. Agency progress against recommendations in our last report

### Nutrition and swallowing risk management

1. ADHC should provide detailed advice to us on the progress of its actions to implement each of the *Nutrition and Swallowing* policy evaluation recommendations. ADHC should also provide advice as to:
  - a) the implementation and training strategy for the revised policy and associated resources, in both ADHC-operated and funded services, and the timeframes for completion
  - b) how implementation of the revised policy and associated resources will be monitored in ADHC operated and funded services
  - c) its plans for evaluating the revised policy and associated resources, and
  - d) any plans for extending the provision of nutrition and swallowing risk management guidance to assist licensed boarding house residents, such as work with Primary and Secondary Health Care services.

### Progress

#### Improved guidance

ADHC has advised that the *Nutrition and Swallowing* policy is being revised to reflect a more coherent Health and Wellbeing policy framework that encompasses good nutrition, individual needs and health promotion. As part of this revision:

- the Nutrition and Swallowing Checklist has been strengthened to prompt GP and allied health referral where risk has been identified, and to help staff identify other actions that need to be taken, and
- ADHC is collaborating with Nutrition and Dietetics, University of Newcastle, to incorporate the policy tools and resources into a single streamlined practice guide for nutrition support and management.

The final policy, tools and practice guide will be incorporated into the Health and Wellbeing framework and consolidated procedures guide – this is scheduled for implementation in 2012/13.

#### Implementation and training strategy

In relation to ADHC-operated accommodation support services, ADHC has advised that:

- nutrition training is included in the Regional Learning and Development training calendar and provided at the unit level by Practice Support Coordinators, and
- an implementation strategy is being developed to support the rollout of the revised policy and practice guide, including the development of e-learning models for disability support staff.

ADHC has advised that it is working on the implementation and training strategy for the non-government sector.

#### Monitoring implementation

In relation to ADHC-operated services, ADHC has advised that it will continue to monitor the Nutrition and Swallowing Checklist through the Quality and Safety Framework.<sup>73</sup> Broader nutrition management and support practices will be monitored through the quality management system for ADHC-operated accommodation support services (this is in development).

ADHC has indicated that implementation of the mandatory policy and procedural requirements in ADHC funded accommodation support services will continue to be monitored as part of the annual assurance process of compliance against ADHC's Funding Agreement. Further sector improvement is expected from 1 July 2012 as a result of implementation of ADHC's quality reform for funded services. (Further details are provided under Recommendation 3).

#### Licensed boarding houses

ADHC has advised that, in June 2011, it amended the screening tool for entry into licensed boarding houses to include 10 questions adapted from the Nutrition and Swallowing Checklist (in order to assist assessors to identify whether a person may be at risk of choking and thereby ineligible to live in a licensed boarding house).

73. In relation to the Nutrition and Swallowing Checklist, the Quality and Safety Framework requires ADHC accommodation support services to report on the percentage of people who have an up-to-date Checklist (Parts 1-3 of the Checklist are completed and the date of completion does not exceed 12 months).



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ADHC has also amended the service model that forms part of the Funding Agreement with the six Primary and Secondary Health Care service providers. The services are required to assess the health needs of all licensed boarding house residents, develop individual health plans, and review them annually. The health assessment tool includes an assessment of residents' nutrition and swallowing to assist in identifying any risks.

### Our comments

ADHC has undertaken considerable work to improve the resources and guidance for staff in disability accommodation services in relation to swallowing and nutrition risks. We welcome ADHC's efforts to simplify and strengthen the resources to make them easier for staff to understand and use.

Given the importance of effective nutrition and swallowing risk management and the continuing need to improve practice in this area, staff training and monitoring of implementation is critical. We note that key findings from the evaluation of the (then) *Ensuring Good Nutrition* policy include the need for:

- training to be formalised, provided regularly, and have a practical focus, including developing competencies in: completing the checklist, developing nutrition action plans, using the manual, applying correct strategies when nutrition and swallowing issues arise, and positioning of clients while eating, and
- training in how to implement the policy and procedures, including policy resources, should be mandatory for operated and funded services and for all staff, and regular refresher courses should be available.

It is not yet clear to what extent the above issues will be addressed in the implementation and training strategy for the *Nutrition and Swallowing* policy and practice guide. We note that ADHC is in the process of developing the strategy for both ADHC-operated and funded services, and welcome the agency's advice regarding the use of e-learning modules.

Our reviews emphasise the importance of services having effective quality management systems in place to identify and address any problems with the support being provided to people with disabilities in care – particularly in relation to critical health risks. We note

that the NGO sector is in the early days of quality reforms, and ADHC is in the process of developing its new quality management system.

We will continue to monitor ADHC's work in relation to the rollout and monitoring of the implementation of the Nutrition and Swallowing policy and practice guide.

We are pleased to note the changes that have been made to improve the health care support provided to licensed boarding house residents, and the actions that have been taken to clearly identify people who have swallowing and nutrition risks, including choking risks. Our reviews of the deaths of licensed boarding house residents from choking on food in 2010 and 2011 underscore the importance of the steps that have been taken.

### Monitoring disability services

2. **ADHC should provide detailed advice as to how it currently monitors ADHC-operated and funded services to ensure compliance with ADHC policy requirements.**
3. **ADHC should provide detailed advice as to what action it intends to take in light of the issues raised in this report regarding the absence of key assessment and support documents in funded services and inadequate risk management practice in ADHC-operated and funded services.**

### Progress

#### ADHC-operated services

In relation to ADHC-operated services, ADHC has advised that the Quality and Safety Framework (QSF) currently monitors compliance with key policy requirements through 24 Key Performance Indicators (KPIs). The QSF monitors the development and review of client care plans, levels of incident reporting, completion of health and safety inspections and the levels of staff and service usage.

The completion and currency of client risk profiles and support plans are monitored on a quarterly basis. Performance is reported to a number of Executive Committees (including the Audit and Risk Committee and the Operational Performance Committee) to monitor and improve performance – this

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includes performance in relation to client risk management practice in ADHC-operated services.

ADHC advised that it is currently developing a quality management system to improve on existing processes to monitor the quality of its own services against the Disability Services Standards.

### ADHC funded services

Since 2010, ADHC has operated a risk-based approach to monitoring funded services. ADHC developed Risk Identification and Monitoring Guidelines (RIMG) to provide a standardised approach to support regional staff to identify and assess the extent to which risks can impact on the achievement of desired outcomes for clients. Information from the risk assessment is then used to determine the appropriate and proportionate level of monitoring activity for each service provider.

ADHC has advised that the RIMG process provides the platform for regular risk-based service provider reviews, and links to other ADHC monitoring mechanisms (such as the requirement for services to provide annual assurance of compliance against the requirements of the Funding Agreement). ADHC has indicated that work to build on this risk-based approach is currently underway.

As part of the implementation of the NSW Quality Framework, all ADHC funded providers will be required to have a quality management system in place and engage in third party verification in relation to their implementation of the NSW Disability Services Standards. Providers will be required to demonstrate continuous improvement to assure all stakeholders of the provision of quality services.

In the 2012 annual assurance process of compliance against ADHC's Funding Agreement, funded providers were required to ensure that risk identification, risk management and reporting procedures were in place.

### Our comments

Our recommendations relating to the monitoring of disability services were made in the context of our reviews identifying individuals for whom key risk assessments and planning documents were not in place, despite mandatory requirements. This was particularly noted in relation to people in funded disability services. Key documents that had not been developed included fundamental and important assessments and plans, such as individual plans, nutrition and swallowing and other risk assessments, and health care and behaviour management plans.

Our reviews had also highlighted inadequate and poor quality work by disability services in identifying and managing the risks of the people with disabilities in their care.

We note that important work is underway to improve on existing processes to monitor the quality of ADHC-operated and funded services against the Standards, including independent third-party verification for funded services.

We expect that the Quality Framework will result in improvements in the quality of funded services over time, with a focus on services developing internal quality management systems to enable continuous improvement. We understand that ADHC is developing a guide to assist funded services to capture and measure their performance against the Standards (through the use of a set of measurable, easy-to-use and outcomes-focused KPIs) and will be delivering detailed workshops to help providers in understanding how to implement the updated Standards.

Our reviews continue to identify problems with the work undertaken by disability services to identify and manage risks faced by people with disabilities in care. It is early days in the development of an improved quality management system for ADHC-operated services, and in the development and rollout of the Quality Framework for funded services. Given the importance of this work in helping to reduce preventable deaths, we will monitor ADHC's actions in this area.

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## Antipsychotic medication and behaviour management

4. ADHC should take steps to identify the individuals in its accommodation services who are receiving antipsychotic medication and:
- a) ensure that the reasons for administering the medication are clearly identified, and
  - b) ensure that the people who are receiving the medication for behaviour management purposes have a current behaviour management plan, in line with ADHC's *Behaviour Support* policy.

### Progress

In response to this recommendation, ADHC provided details of the existing policy requirements that relate to medication use and review, including the *Medication, Lifestyle Planning, Behaviour Support* and *Health Care* policies.

In terms of monitoring practice, ADHC referred to its Quality and Safety Framework<sup>74</sup> and the reporting and review arrangements for the use of Restricted Practices in place under the *Behaviour Support* policy.

ADHC's first response to our recommendations included advice that each ADHC accommodation outlet must have a plan for auditing service users' medications that includes a regular audit cycle. The standard interval for auditing medications is one month. In addition, all medications must also be regularly reviewed during the quarterly review of the service users' Health Care Plan. Policy requires that all psychotropic medication is reviewed with the prescribing medical practitioner at least annually.

The *Behaviour Support* manual requires that the rationale, purpose and desired outcomes of a prescribed medication, together with additional details to monitor its effects, are included in a documented behaviour assessment. Regular

work practice supervision of Behaviour Support Practitioners from qualified practice supervisors ensures adherence to this requirement.

### Our comments

This recommendation originated from our reviews of deaths between 2003 and 2009 that raised questions about the use of antipsychotic medication for some people in disability services, and the frequency of use of antipsychotic medication as a primary behaviour management strategy, against policy requirements. We had reported that:

- 29 people in disability services had been prescribed antipsychotic medication without a clearly documented reason for it, such as treatment for mental illness or behaviour management, and
- 14 people in disability services on antipsychotic medication had challenging behaviour and no mental illness but did not have a behaviour support plan.

The information provided by ADHC does not address our recommendation.

While the Quality and Safety Framework looks at restricted practices, we note that the use of antipsychotic medication is only considered a restricted practice when it is prescribed for administration on a PRN basis. The Quality and Safety Framework will not identify individuals who are receiving regular antipsychotic medication for behaviour management purposes without a behaviour support plan.

We understand the policy requirements. However, it was evident from our reviews that practice does not consistently meet the policy requirements in relation to the use of antipsychotic medication for behaviour management purposes.

It does not appear that ADHC has taken steps to review current practice in its accommodation services relating to antipsychotic medication and behaviour support. We will continue to pursue this issue.

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74. With regard to behaviour management, the QSF contains Key Performance Indicators that consider the number of people with an up-to-date Behaviour Support Plan, the number with Restricted Practices, and the number with current Restricted Practice Authorisation Panel approval. In relation to medication, the QSF looks at the number of Category 3 incidents involving missed medication, medication error, or refusal of medication.

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5. ADHC should provide advice to us on how it intends to monitor the disability accommodation services it funds to ascertain their compliance with the *Behaviour Support* policy in this regard.

### Progress

ADHC advised that funded services are required to report annually on their compliance against the Funding Agreement. If it is identified that a service provider is not meeting their contracted obligations under the Funding Agreement, ADHC instigates appropriate remedial and monitoring actions to assist the funded provider to meet their contractual obligations.

ADHC is reviewing requirements for the new Funding Agreement that asserts the need for funded service providers to comply with key support policies including the *Behaviour Support* policy.

### Our comments

No specific action has been taken in response to our recommendation. We note the important role the new Quality Framework will play in improving the delivery of quality services in the funded sector, and the inclusion of independent third party verification of practice against the Disability Services Standards.

However, our concern with ADHC's response to recommendations 4 and 5 is that we do not believe that adequate consideration has been given to either the seriousness of the issue or its potential reach. We note that our reviews of deaths comprise a relatively small proportion of the total number of people in disability accommodation services, yet point to a potential systemic problem.

There are good reasons why ADHC's policy states that psychotropic medication must not be the primary behaviour support strategy for a person with intellectual disability. Our reviews suggest that, for some people with disabilities in care, psychotropic medication is the only behaviour support strategy being used. It is concerning that the policy does not appear to have been consistently applied, and that there has not been action taken in response to our report to examine current practice across the sector.

We will continue to pursue this issue.

### Implementation of ADHC's *Health Care* policy

6. ADHC should provide advice to us on the progress of its review of the *Health Care* policy, including advice as to:
- the scope and timeframes of the review, and
  - the aims and scope of the proposed health and wellbeing policy framework.

### Progress

ADHC has advised that the aim of the *Health Care* policy review is to develop an overarching person-centred Health and Wellbeing policy framework. This will involve the rationalisation and streamlining of a number of current health-related policies under the one policy framework, and the development of a single, more cogent practice guide that covers all aspects of health and wellbeing support and management.

Disability workers and health professionals will support people with disabilities and their families to make informed decisions about their health and wellbeing: including health promotion, treatments, therapy, rehabilitation and disease prevention. They will be supported to access relevant mainstream health services as required, as well as specialist disability health services when necessary.

The framework will support early intervention by highlighting areas where identifying symptoms of illness or monitoring changes in health status require the involvement of health professionals, and include clear intervention and referral pathways.

ADHC has advised that work has commenced on the review of the policy, and a set of person-centred guiding principles for the streamlined Health and Wellbeing policy have been drafted for consultation.

The Health and Wellbeing procedures for ADHC-operated accommodation support services are also being developed. The procedures place greater emphasis on the role of the General Practitioner to coordinate and manage a person's health and wellbeing, and improved access to mainstream services through the use of Medicare items including the Intellectual Disability Health Check.

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Implementation of the practice guide and framework is scheduled for 2012/13.

### Our comments

We note the considerable work that is underway to develop the Health and Wellbeing framework to provide clear and streamlined guidance to disability services on delivering a comprehensive and person-centred health support.

We will be keen to see the draft policy framework, related procedures, and ADHC's implementation plans. We will continue to monitor ADHC's work in this area.

### Health care and licensed boarding house residents

#### 7. ADHC should provide detailed advice to us on the progress of its actions to implement each of the Primary and Secondary Health Care services evaluation recommendations.

#### Progress

ADHC has advised that it engaged consultants to progress the implementation of the recommendations from the Primary and Secondary Health Care services evaluation, which has resulted in:

- a state-wide standard Primary and Secondary Health Care service model that sets minimum service standards
- a model reporting template to enhance accountability and to better understand the mix, range and volume of services provided under the Primary and Secondary Health Care program, and
- the development of high level guidelines to support the new framework and reporting requirements.

The amended service model and reporting requirements took effect with the renewal of funding contracts on 1 July 2012.

As part of the amended service model and the new funding agreement, the Primary and Secondary Health Care services are now required to assess the health needs of all licensed boarding house residents, develop individual health plans, and review them annually (including annual review of

medications by a psychiatrist if the resident is on psychotropic medications). This is separate to, but in conjunction with, GP health plans.

### Our comments

We note the considerable work that has been undertaken to revise the Primary and Secondary Health Care service model to deliver a consistent approach across NSW as part of seeking to improve the health outcomes for people living in licensed boarding houses.

The active involvement of Primary and Secondary Health Care services in identifying the health and support needs of residents and in working with the person, GP and boarding house staff to address the identified needs is a positive and important step forward. Our reviews of the deaths of licensed boarding house residents in 2010 and 2011, demonstrate why this work is essential.

This recommendation has been met. We will monitor the implementation of the Primary and Secondary Health Care changes through our ongoing review work.

### Palliative care

#### 8. ADHC should provide detailed advice to us on the progress of its actions to implement each of the *Palliative Care* policy evaluation recommendations. ADHC should also provide advice as to:

- a) the implementation and training strategy for the revised policy and associated resources, in both ADHC-operated and funded services, and the timeframes for completion, and
- b) how implementation of the revised policy and associated resources will be monitored in ADHC-operated and funded services.

#### Progress

ADHC has advised that in 2011, the Program of Experience in the Palliative Approach (PEPA) delivered palliative care education workshops to ADHC-operated and funded services.

A revised *Palliative Care* policy is being drafted to reflect person centred approaches to palliative care and end-of-life planning and practice – ADHC is seeking to ensure that the proposed new policy aligns with NSW Health's

advance care planning framework. Supporting practice guidelines are also being revised to reflect the Australian National Palliative Care Standards.

Procedures have been improved with a care pathway that shows clear links to mainstream health services and palliative care services. Additional resources have been added to enable disability support staff to more readily access community-based palliative care services.

The final policy and procedures will be incorporated into the Health and Wellbeing framework (and the related consolidated procedures guide). It is scheduled for implementation in 2012/13.

### Implementation

For ADHC-operated services, the implementation strategy for the framework will include resources to help staff to understand and implement the requirements of the revised policy and procedures. It will include links to specialist palliative care resources, as well as person-centred tools such as *Living Well – thinking and planning for the end of your life*. The implementation strategy will incorporate the development of e-learning modules, including a module on advance care planning.

ADHC is currently working on the implementation and training strategy for the non-government sector, including access to e-learning resources.

### Monitoring

Information about the current and planned arrangements for monitoring service delivery and quality in ADHC-operated and funded services has been provided in response to Recommendation 2.

### Our comments

We welcome the focus on strengthening the link with community-based palliative care services, providing clear guidance for staff, and incorporating advanced care planning in the e-learning resources.

We will monitor the rollout of the Health and Wellbeing framework and the associated resources.

## People with disabilities who are ageing

**9. ADHC should provide detailed advice to us on the progress of its work to develop a clear policy position and guidance for services on supporting people with disabilities who are ageing. This should include advice as to:**

- a) the findings and recommendations from the Ageing in Place project, and
- b) progress in developing and implementing the associated action plan, and the timeframes for completing the work.

### Progress

ADHC advised that the *Ageing in Place: Impact on Accommodation Services* project has been completed, and the report would be available in November 2012. The project is seeking to have better information about support services to assist with the future planning and development of accommodation supports for people with a disability who are ageing, and their carers.

The recommendations from the project will be developed into an action plan, which will be released with the report. The proposed actions will be supported by evidence and outline new policy directions designed to re-orient services to allowing clients to age in place. The Action Plan will require discussion with key stakeholders in order to align it with the individual funding reforms currently taking place.

### Our comments

Since 2006, we have highlighted and made related recommendations on the need for ADHC to provide clear policy guidance to disability services on support for people with disabilities who are ageing. Our reviews of deaths in 2010 and 2011 have continued to indicate the need for this policy guidance to enable appropriate support for individuals as they age, and to prevent the entry of younger people with disabilities into residential aged care.

The *Ageing in Place* project was commissioned in May 2010. We are pleased to note that the project has been completed, and will be keen to read the report and the associated action plan.

We will continue to monitor ADHC's work in this area.

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## **Access to health services for people with dual diagnosis**

**10. NSW Health and ADHC should provide detailed advice to us on the progress of work to:**

- a) develop the detailed implementation arrangements for the *Memorandum of Understanding between ADHC & NSW Health in the provision of services to people with an intellectual disability and mental illness (MOU)***
- b) monitor the implementation of the MOU, and**
- c) develop the plan for evaluating the MOU.**

### **Progress**

Health and ADHC have provided us with a copy of the Implementation Plan for the MOU, which includes milestones, timeframes and key performance indicators. Health has advised that all milestones have been met consistent with the timeframes.

The Joint Committee on Intellectual Disability and Mental Health oversees local implementation progress. Nominees to the Joint Committee provide quarterly reports from the 24 Local Health Districts (LHDs) and ADHC Regions on implementation: including reports on the frequency and attendance at joint case management meetings; escalation processes; client information exchange protocols; and promotion of the MOU.

Health has indicated that local nominees are addressing challenges that include:

- coordinating a strategy to include local level meetings across more than one service (such as ADHC's Hunter Region, which includes three LHDs), and
- establishing a local escalation process for frontline meetings to report to senior or executive meetings.

In relation to evaluation of the MOU, ADHC has advised that a working group has been established that will oversee a formative evaluation of the implementation process, which will be presented to the Joint Committee in April 2013. An independent evaluation of the longer-term benefits to clients is also expected to take place in 2014.

### **Our comments**

We note the work that has been undertaken by Health and ADHC in relation to the MOU. Effective oversight of its implementation will be important in advancing the MOU and for improving outcomes for people with dual diagnoses of intellectual disability and mental illness.

In November 2012, we tabled a special report in the NSW Parliament on the need to improve accommodation and support for people with psychiatric disability. The report followed our inquiry into the access of people in mental health facilities to services and support under the *Disability Services Act 1993*.

Our inquiry pointed to the critical need for ADHC and Health to work effectively together to support people with psychiatric disability, and to demonstrate that they are doing so.

Given the importance of the effective implementation of the MOU in delivering improved outcomes to people with dual diagnoses, we will continue to monitor the work of both agencies in this area.

## **Access to NSW Health chronic disease management and out-of-hospital programs**

**11. In relation to the Connecting Care and other out-of-hospital programs, NSW Health should take immediate action to improve the access to people in disability services and licensed boarding houses to these programs, and provide detailed advice to us as to how it intends to do so. This should include advice as to:**

- a) how the department will identify people with disabilities in care who need this support and facilitate their access to the programs, and**
- b) how the department will best meet the needs of the individuals in these programs.**

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## Progress

Health advised in March 2013 that the Agency for Clinical Innovation (ACI) now has responsibility for implementing the Chronic Disease Management Program – Connecting Care in the Community (CDMP),<sup>75</sup> and that the ACI would now initiate meetings with ADHC to progress this recommendation. Health advised that the ACI would:

- consult with ADHC to obtain a list of disability services and licensed boarding houses in order to direct information and advice regarding the CDMP
- consult with GPNSW and other GP clinical leaders to discuss barriers to service provision for this population and possible strategies for increasing the development of shared care plans for people with disability
- approach the ACI Intellectual Disability Network for advice on the best ways to make CDMP accessible to people with intellectual disability, and
- work with Carers NSW and Local Health District (LHD) Carer Liaison Officers to distribute information regarding the CDMP and its potential benefits for people with disability.

## Our comments

We welcome Health's advice regarding the actions to be taken by the ACI to improve the access of people with disabilities in care to the CDMP and other out-of-hospital programs. In particular, we are pleased to note the intention of the ACI to consult with GPNSW and other GP clinical leaders to discuss barriers to service provision for people with disabilities and possible strategies for increasing the development of shared care plans.

This is important work, and we will be keen to see evidence of people with disabilities with chronic diseases being included in these valuable programs to enable them to manage their conditions at home, where possible. However, it is 18 months since we made the recommendation, and the key work has not yet commenced. Our reviews of deaths in 2010 and 2011 have continued to indicate low rates of access of people with disabilities in care to these programs.

We will monitor the progress of the ACI's work in this area.

## 12. NSW Health should provide detailed advice to us on its plans for improving access to community-based coordinated patient-centred care for people with chronic and complex respiratory disease, including people with disabilities in care.

### Progress

In addition to information provided in relation to recommendation 11, Health has advised that it provides funding to LHDs to support the provision of a range of specialist and generalist evidence-based services to people with chronic disease, including asthma and COPD. Health advised that:

- All patients with chronic respiratory and/or cardiac disease or diabetes are eligible for chronic disease services, and referrals are accepted by GPs, medical specialists or following a hospital admission.
- Specific out-of-hospital respiratory services within each LHD include pulmonary rehabilitation programs, asthma and COPD management education, outpatient assessment clinics, and review of people with home respiratory equipment, including home oxygen.
- GORD and swallowing difficulties frequently occur in people with disability, and are recognised as significant risk factors included in comprehensive respiratory assessment and management resources used across primary care, community and acute settings.
- Specialist respiratory nursing and allied health roles within LHDs are available on request to provide respiratory management education to carers groups and staff within local care facilities.
- Aspiration pneumonia has been recognised as an important cause of serious illness and death in residents of residential care facilities as well as hospitalised patients. Preliminary work has been undertaken by the Clinical Excellence Commission and in collaboration with the ACI's Respiratory, Stroke, Neurosurgery, Gastroenterology and

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75. Health advised that it interprets the CDMP to include the relevant out-of-hospital program for the purpose of this report.



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Anaesthesia Perioperative Care Networks to address the preventable causes of aspiration pneumonia.

- The transition issues associated with young people with chronic illnesses is a priority for the Transition Care Network. A new Trapeze program has been established across the Sydney Children's Hospitals Network to assist young people with disability aged 16-24 years to access primary care for early detection of chronic conditions including diabetes or ongoing respiratory compromise due to any cause, and to decrease preventable hospital admissions in the target group.

Health also advised that a limited number of sites in NSW have established specialist multidisciplinary clinical teams that provide home-based assessment, monitoring and treatment of people with a severe respiratory or cardiac condition. ACI Respiratory and Cardiac Networks submitted a proposal to NSW Health to implement the Severe Chronic Respiratory and Cardiac Care Model, and versions of this model currently operate at five sites across NSW.

### Our comments

Health has provided advice about a range of supports and services that are available in the community to assist people with chronic respiratory diseases. We are pleased to note the out-of-hospital respiratory services and supports that are available in LHDs, including home reviews and respiratory management education. We also welcome Health's advice that all patients with chronic respiratory disease are eligible for chronic disease services (not just people with COPD).

However, availability of these services does not equate to access. Our reviews of the deaths of people with disabilities and chronic respiratory disease rarely indicate the involvement of these services and supports.

It is important that people with disabilities have equitable access to community-based and coordinated care for chronic respiratory disease, and that barriers to their access are identified and addressed. We note that the actions that the ACI is intending to take in relation to the CDMP and other out-of-hospital programs (outlined in relation to Recommendation 11) provide a useful starting point for consideration of these issues. We will monitor the progress of this work.

Given the direct relevance to reducing preventable deaths, we will also be keen to obtain further information about:

- the preliminary collaborative work between the Clinical Excellence Commission and the ACI on addressing the preventable causes of aspiration pneumonia, and
- the Trapeze program to improve support for people with disability of transition age with chronic conditions and reduce their preventable hospital admissions.

### Support for people with disabilities in hospital

**13. In relation to the Joint Guideline to support residents of ADHC operated and funded accommodation support services who attend or are admitted to a NSW public hospital, NSW Health and ADHC should provide advice to us as to:**

- a) the expected timeframe for finalising the guideline**
- b) how they will support health and disability services staff to implement the guideline and related policies, and**
- c) how they will monitor the implementation of the guideline.**

### Progress

In July 2012, the Ministry of Health advised that ADHC and Health had agreed in a meeting in March that implementation of the Joint Guideline would be the responsibility of each agency. In relation to implementation of the Joint Guideline in health services, Health advised that this would be included in the LHDs Disability Action Plans.

In October 2012, ADHC advised that the Joint Guideline was being finalised, and would be implemented with the revised Health and Wellbeing policy framework scheduled for release in 2012/13. ADHC indicated that an implementation strategy was under discussion, and would be finalised prior to joint approval of the guideline by the Senior Executive of both agencies. How the guideline would be implemented and monitored would be determined as part of the finalisation of the implementation strategy.

In March 2013, Health advised that:

- The Joint Guideline has been completed, and Health has sought agreement from ADHC to release it publicly. As soon as this is confirmed by ADHC, Health will release it on its website.
- Health will send a letter to all LHD Chief Executives to accompany the distribution of the Joint Guideline once the document is publicly available. The letter will highlight the guideline's release, the Escalation Strategy, and the key people who should be aware of the process. As decision-making, responsibility, and accountability of public healthcare services has been devolved to LHDs governed by LHD Boards, the Ministry will encourage implementation of the Joint Guideline at this level.
- NSW Ministry of Health will work with the ACI Intellectual Disability Network in the ongoing implementation and monitoring of the Joint Guideline.

### Our comments

Our reviews continue to highlight the critical need for this guideline to improve the support provided to people with disabilities in hospital.

We note that ADHC and Health have been developing this protocol/guideline since at least 2009. While the agencies released a draft document in July 2011 for targeted stakeholder consultation, we have not been provided with a copy of the guideline for consideration or comment.

In our last report, we noted the importance of this work being completed as soon as possible, and the need for a clear plan to:

- support health and disability services to implement the guideline and related policies, and
- monitor the implementation of the guideline and to evaluate its effectiveness.

This remains our position. Given the issues in this report relating to the need to improve support for people with disabilities in hospital, finalisation and roll out of this guidance for health and disability services should occur as soon as possible. We will continue to monitor the actions of ADHC and Health in relation to this issue.

## Health service framework for people with intellectual disability

14. In relation to the service framework to improve health care for people with intellectual disability, NSW Health should:

- a) ensure that the service framework document is publicly accessible via NSW Health's website
- b) provide detailed advice to us on the progress of work to implement the Intellectual Disability Network and the specialised clinical service pilot in the Illawarra area, and
- c) provide detailed advice to us about the department's plans for implementing the broader service framework, including expansion of specialised clinical services.

### Progress

The Framework is now available on Health's website, at: [http://www.health.nsw.gov.au/pubs/2012/service\\_framework\\_2012.html](http://www.health.nsw.gov.au/pubs/2012/service_framework_2012.html)

### ACI Intellectual Disability Network

Health has advised that the ACI Intellectual Disability Network has a particular focus on people with intellectual disability who have chronic complex health needs and mental health co-morbidity.

Members of the Network have formed working parties to address specific issues, including models of care and equity of access, and a formal steering committee was formed in November 2011 to manage the ongoing process. An additional \$170,000 p.a. has been committed to the Network under the 2011/12 NSW Budget.

### Metro-Regional Intellectual Disability Network (MRID.net) pilot

The specialised clinical service pilot in the Illawarra area has been renamed the Metro-Regional Intellectual Disability Network (MRID.net). It sits within the South Eastern Sydney Local Health District, but extends to the Illawarra Shoalhaven and beyond.

The pilot project aims to develop an innovative partnership model for integrated health services for people with intellectual disability and their carers living in regional and rural areas of

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NSW. Health has advised that the pilot will demonstrate how an existing metropolitan model for intellectual disability health care can be implemented and supported in a partnered regional and rural area by the use of modern technologies (including the use of broadband networks and Medicare initiatives for video-conferencing).

As at July 2012, progress had included:

- creation of a Project Implementation Team, Steering Committee and detailed Project Plan
- creation of MRID Clinics<sup>76</sup> in regional venues, including Multidisciplinary Clinics, Conjoint Clinics within ADHC and NGOs, Conjoint Clinics with Mental Health, and School Transition Clinics within special schools
- development of intake and referral processes for the Clinics, in collaboration with ADHC, NGOs and the local community
- identification of mobile solutions to address the issue of complex clients residing in group homes in remote areas, and
- identification of priority areas for videoconferencing, testing of the Connecting Classrooms videoconferencing technologies, and operation of the inaugural videoconferencing clinic.

Health has advised that the resources available to the pilot have been enhanced through Commonwealth funding for four registrar positions in the areas of rehabilitation paediatrics, psychiatry and general medicine.

### Additional Intellectual Disability pilots

Health has advised that, in addition to the above pilot, two additional Intellectual Disability pilots commenced in January 2012, located in:

- Northern Sydney Local Health District, with the Centre for Disability Studies, and
- Sydney South West Local Health District, with the Children's Hospital, Westmead – with a specific focus on CALD communities.

### Evaluation of the Intellectual Disability Network and pilots

The Ministry of Health is completing the tender process to appoint an organisation to undertake an independent evaluation over three years to assess the effectiveness of the Intellectual Disability Network and the three pilots in meeting the aims of the Service Framework (and in relation to their overall impact on people with intellectual disability, their family/carers, and on the wider health system).

Quarterly reports by the pilots address process measures that include:

- The number of comprehensive health assessments conducted from baseline
- The number of multidisciplinary health care plans developed from baseline
- The number of referrals to specialists and services from baseline, and
- The number of health professionals who receive education and training and evidence of the impact of education and training.

In order to strengthen and enhance the projects, a reference group with representatives of the three pilots and the Network has been established. These representatives are able to share, inter alia, what they are learning from their experience in running their respective projects. The reference group held its first workshop in May 2012.

In addition to the independent external evaluation by Health, ongoing formative evaluation forms part of the MRID.net pilot.

### Our comments

We note the considerable progress of the MRID.net pilot, and the additional resourcing provided by Health to enable the operation of two additional Intellectual Disability pilots and to enhance the Intellectual Disability Network.

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76. Includes the creation of Youth and Adult Mental Health Clinics at Coniston with ADHC and NGOs; the extension of conjoint services to Goulburn, comprising a Rehabilitation Physician, Psychiatrist; ACI Transition Coordinator; ADHC, Psychiatry trainees, and a local Paediatrician; and Paediatric and adult mental health services provided to Armidale conjointly with ADHC, NGOs, a local Paediatrician and GPs.

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Our reviews continue to point to the importance of the service framework in providing specialised services and, critically, providing assistance to mainstream health services to build their knowledge and skills in supporting people with intellectual disability to improve health outcomes for this population.

The quarterly reporting and independent evaluation provide valuable opportunities to identify both key strategies and best practice initiatives for advancing this work.

Importantly, our reviews emphasise the need for improved services and support for people with disabilities across all tiers of the service framework: including primary health and community health care (tier 2) and acute health care services (tier 3). We note that the NSW Implementation Plan for the National Disability Framework includes actions to implement the service framework in 2012-14 that involve:

- developing enhanced models of care for people with intellectual disability through clarifying clinical roles and responsibilities

- improving referral pathways with particular emphasis on aspects of care related to challenging behaviours
- instigating the establishment of a state-wide patient/client database to improve client outcomes
- mapping health services catering for people with intellectual disability, across the different age ranges, and linking with services provided by other agencies such as ADHC, Community Services and DEC, and
- working with key education providers to enhance the curriculum and teaching resources related to healthcare for people with intellectual disability.

Given the significance of these actions and the broader service framework to addressing many of the issues identified through our reviews of the deaths of people with disabilities in care, we will monitor this work.

## Appendix 1

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### Reviewable Disability Deaths Expert Panel: members

Mr Bruce Barbour	Ombudsman (chair)
Mr Steve Kinmond	Deputy Ombudsman and Community and Disability Services Commissioner
Ms Margaret Bail	Human services consultant
Professor Helen Beange AM	Clinical Professor, Faculty of Medicine, University of Sydney
Ms Linda Goddard	Acting Undergraduate Courses Director, Senior Lecturer: Intellectual Disability, Chronic Care and Mental Health, School of Nursing, Midwifery & Indigenous Health, Charles Sturt University
Assoc Prof Alvin Ing	Senior Staff Specialist, Respiratory Medicine, Bankstown-Lidcombe Hospital and Senior Visiting Respiratory Physician, Concord Hospital
Dr Cheryl McIntyre	General practitioner, Obstetrician (Inverell)
Dr Ted O'Loughlin	Senior staff specialist, Gastroenterology, The Children's Hospital at Westmead
Dr Rosemary Sheehy	Geriatrician/Endocrinologist, Sydney Local Health Network
Assoc Prof Ernest Somerville	Director, Comprehensive Epilepsy Service, Prince of Wales Hospital
Assoc Prof Julian Trollor	Chair, Intellectual Disability Mental Health, School of Psychiatry, Head, Department of Developmental Disability Neuropsychiatry, University of New South Wales

## Appendix 2

### Additional data

Table 13: Key demographics of reviewable disability deaths in 2010<sup>77</sup>

	2010 Deaths in Disability Services	2010 Estimated Disability Services Population	Age Specific Rates per 1000	95%LCI	95%UCI
<b>Gender</b>					
Female	40	2,454	16.3	12.0	22.2
Male	49	3,720	13.2	10.0	17.4
<b>Age</b>					
0-14	2	7	285.7	71.5	1,142.4
15-24	7	436	16.1	7.7	33.7
25-34	5	918	5.4	2.3	13.1
35-44	15	1,467	10.2	6.2	17.0
45-54	18	1,641	11.0	6.9	17.4
55-64	23	1,197	19.2	12.8	28.9
65-74	10	401	24.9	13.4	46.3
75-84	6	94	63.8	28.7	142.1
85+	3	13	230.8	74.4	715.5
<b>ATSI status</b>					
ATSI	1	205	4.9	0.7	34.6
Non-ATSI	88	5,969	14.7	12.0	18.2
<b>Accommodation</b>					
Disability services	89	6,174	14.4	11.7	17.7
Licensed BH	11	697	15.8	8.7	28.5
<b>Total</b>	<b>89</b>	<b>6,174</b>	<b>14.4</b>	<b>11.7</b>	<b>17.7</b>

77. Gender, age and ATSI status population characteristics were only available for the disability services population. Therefore, deaths/populations reported for these rows are only for disability services, not licensed boarding houses.

**Table 14: Key demographics of reviewable disability deaths in 2011<sup>78</sup>**

	2011 DS Deaths	2011 Estimated DS Population	Age Specific Rates per 1000	95%LCI	95%UCI
<b>Gender</b>					
Female	40	2,536	15.8	11.6	21.5
Male	66	3,857	17.1	13.4	21.8
<b>Age</b>					
0-14	0	7	0.0	na	na
15-24	6	451	13.3	6.0	29.6
25-34	10	951	10.5	5.7	19.6
35-44	16	1,519	10.5	6.5	17.2
45-54	22	1,699	12.9	8.5	19.7
55-64	23	1,239	18.6	12.3	27.9
65-74	17	415	40.9	25.5	65.9
75-84	9	97	92.5	48.1	177.7
85+	3	13	222.9	71.9	691.0
<b>ATSI status</b>					
ATSI	4	212	18.8	7.1	50.2
Non-ATSI	102	6,181	16.5	13.6	20.0
<b>Accommodation</b>					
Disability services	106	6,393	16.6	13.7	20.1
Boarding homes	14	636	22.0	13.0	37.2
<b>Total</b>	<b>106</b>	<b>6,393</b>	<b>16.6</b>	<b>13.7</b>	<b>20.1</b>

**Table 15: Deaths of people in disability services in 2003-11 by age group**

	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Under 15	2	0	0	1	1	1	2	2	0	9
15-24	5	6	4	3	6	6	5	7	6	48
25-34	11	4	7	9	4	5	8	5	10	63
35-44	13	12	15	13	12	8	9	15	16	113
45-54	17	14	7	20	21	25	15	18	22	159
55-64	13	10	13	17	18	15	15	23	23	147
65-74	10	13	4	10	8	8	16	10	17	96
75-84	8	8	3	5	9	2	16	6	9	66
85-94	1	3	1	4	4	2	2	3	3	23
<b>Total</b>	<b>80</b>	<b>70</b>	<b>54</b>	<b>82</b>	<b>83</b>	<b>72</b>	<b>88</b>	<b>89</b>	<b>106</b>	<b>724</b>

78. Gender, age and ATSI status population characteristics were only available for the disability services population. Therefore, deaths/populations reported for these rows are only for disability services, not licensed boarding houses.

**Table 16: Deaths of people in licensed boarding houses in 2003-11 by age group**

	2003	2004	2005	2006	2007	2008	2009	2010	2011	Total
Under 15	0	0	0	0	0	0	0	0	0	0
15-24	0	0	0	0	0	0	0	0	0	0
25-34	1	0	0	0	0	1	1	0	0	3
35-44	1	2	1	2	2	0	0	0	0	8
45-54	3	3	2	4	3	4	3	1	1	24
55-64	5	6	5	2	4	4	5	2	7	40
65-74	9	7	3	5	4	4	5	6	3	46
75-84	2	5	1	2	1	3	1	2	3	20
85-94	0	1	1	1	1	0	2	0	0	6
<b>Total</b>	<b>21</b>	<b>24</b>	<b>13</b>	<b>16</b>	<b>15</b>	<b>16</b>	<b>17</b>	<b>11</b>	<b>14</b>	<b>147</b>



**Table 17: Deaths of people with disabilities in care in 2003-11 by service type and gender**

		Disability services			Boarding houses		
		Number	Mean	Median	Number	Mean	Median
<b>Male</b>	2003	44	51.7	53	16	61.0	65
	2004	43	55.8	53	20	66.1	68
	2005	33	49.8	48	11	63.6	61
	2006	52	53.8	55	15	62.7	59
	2007	48	53.8	54	10	56.8	60
	2008	43	49.3	49	14	60.1	62
	2009	63	56.4	61	10	65.9	72
	2010	49	48.4	51	9	67.6	67
	2011	66	52.2	53	12	63.8	62
	<b>Total</b>		<b>441</b>	<b>52.6</b>	<b>53</b>	<b>117</b>	<b>63.1</b>
<b>Female</b>	2003	36	48.7	45	5	62.6	63
	2004	27	53.0	52	4	63.8	69
	2005	21	46.8	44	2	59.5	60
	2006	30	51.0	51	1	71.0	71
	2007	35	54.7	54	5	72.0	74
	2008	29	48.9	49	2	73.0	73
	2009	25	53.8	54	7	64.7	62
	2010	40	54.3	56	2	65.5	66
	2011	40	55.1	55	2	67.5	68
	<b>Total</b>		<b>283</b>	<b>52.1</b>	<b>52</b>	<b>30</b>	<b>66.1</b>
<b>Total</b>	2003	80	50.3	49	21	61.4	65
	2004	70	54.7	53	24	65.7	69
	2005	54	48.6	47	13	63.0	60
	2006	82	52.8	52	16	63.2	64
	2007	83	54.1	54	15	61.9	61
	2008	72	49.1	49	16	61.8	63
	2009	88	55.7	58	17	65.4	63
	2010	89	51.0	53	11	67.2	67
	2011	106	53.3	53	14	64.4	62
	<b>Total</b>		<b>724</b>	<b>52.4</b>	<b>53</b>	<b>147</b>	<b>63.7</b>

**Table 18: Consent provider for people in disability services in 2010 and 2011**

	2010		2011		Total	
	N	%	N	%	N	%
Family	62	69.7	72	67.9	134	68.7
Person themselves	9	10.1	18	17	27	13.8
Guardianship Public	13	14.6	10	9.4	23	11.8
Guardianship Private	3	3.4	3	2.8	6	3.1
None identified	2	2.2	2	1.9	4	2.1
Other	0	0	1	0.9	1	0.5
<b>Total</b>	<b>89</b>	<b>100%</b>	<b>106</b>	<b>100%</b>	<b>195</b>	<b>100%</b>

**Table 19: Consent provider for people in licensed boarding houses in 2010 and 2011**

	2010		2011		Total	
	N	%	N	%	N	%
Person themselves	9	81.8	12	85.7	21	84
Family	1	9.1	2	14.3	3	12
Guardianship Private	1	9.1	0	0	1	4
Guardianship Public	0	0	0	0	0	0
None identified	0	0	0	0	0	0
Other	0	0	0	0	0	0
<b>Total</b>	<b>11</b>	<b>100%</b>	<b>14</b>	<b>100%</b>	<b>25</b>	<b>100%</b>

**Table 20: Length of time in care of people with disabilities who died in 2010 and 2011<sup>79</sup>**

	Mean	Median	N
All	26.4	24	189
Disability services	27.5	26.5	176
Licensed BH	11.2	9	13

**Table 21: Length of time at current residence of people with disabilities who died in 2010 and 2011**

	Mean	Median	N
All	13.7	8.75	220
Disability services	14.3	9	195
Licensed BH	9.7	6	25

79. Information on the length of time in care was available for 189 people (86%).

**Table 22: Place of death of people with disabilities in care in 2010 and 2011 by provider**

	ADHC		Licensed BH		NGO		Total	
	N	%	N	%	N	%	N	%
Community	0	0	0	0	2	2	2	0.9
Family home	1	1	0	0	1	1	2	0.9
Hospital	47	48.5	13	52	67	68.4	127	57.7
Non-residential service	1	1	0	0	1	1	2	0.9
Other	1	1	0	0	0	0	1	0.5
Service	47	48.5	12	48	27	27.6	86	39.1
<b>Total</b>	<b>97</b>	<b>100.0%</b>	<b>25</b>	<b>100.0%</b>	<b>98</b>	<b>100.0%</b>	<b>220</b>	<b>100.0%</b>

**Table 23: Mobility status of people who died in 2010 and 2011, by residence type**

	Disability services		Licensed BH		Total	
	N	%	N	%	N	%
Wheelchair	90	46.2	0	0	90	40.9
No mobility issues	62	31.8	20	80.0	82	37.3
Walking frame	19	9.7	2	8.0	21	9.5
Limited mobility – no aid	17	8.7	0	0	17	7.7
Other aid	5	2.6	0	0	5	2.3
Walking stick	2	1.0	3	12.0	5	2.3
<b>Total</b>	<b>195</b>	<b>100.0%</b>	<b>25</b>	<b>100.0%</b>	<b>220</b>	<b>100.0%</b>

**Table 24: Communication support required by people who died in 2010 and 2011, by residence type**

	Disability services		Licensed BH		Total	
	N	%	N	%	N	%
No	62	31.8	25	100.0	87	39.55
Other signing	66	33.9	0	0	66	30
Adjusted verbal	45	23.1	0	0	45	20.45
Hearing aids	8	4.1	0	0	8	3.64
Picture	8	4.1	0	0	8	3.64
Sign language	5	2.6	0	0	5	2.27
Electronic	1	0.5	0	0	1	0.45
<b>Total</b>	<b>195</b>	<b>100.0%</b>	<b>25</b>	<b>100.0%</b>	<b>220</b>	<b>100.00%</b>

**Table 25: Incontinence status of people who died in 2010 and 2011, by residence type**

	Disability services		Licensed BH		Total	
	N	%	N	%	N	%
Doubly	106	54.4	1	4	107	48.6
No	44	22.6	17	68	61	27.7
Urinary	40	20.5	7	28	47	21.4
Faecal	5	2.6	0	0	5	2.3
<b>Total</b>	<b>195</b>	<b>100%</b>	<b>25</b>	<b>100%</b>	<b>220</b>	<b>100%</b>

**Table 26: Top 10 underlying causes of death of people with disabilities in care 2003-11**

	N	%	Crude mortality rate per 1000	95%LCI	95%UCI
Ischaemic heart diseases	75	8.70	1.29	0.65	2.53
Epilepsy	49	5.68	0.84	0.36	1.94
Cerebral palsy	47	5.45	0.81	0.34	1.90
Pneumonitis due to solids and liquids	43	4.99	0.74	0.30	1.81
Pneumonia	37	4.29	0.63	0.24	1.67
Other heart diseases	35	4.06	0.60	0.22	1.62
Down syndrome	33	3.83	0.57	0.20	1.57
Chronic lower respiratory diseases	32	3.71	0.55	0.19	1.55
Cerebrovascular diseases	29	3.36	0.50	0.17	1.48
Malignant neoplasm of trachea, bronchus and lung	25	2.90	0.43	0.13	1.39
<b>Total top 10 underlying causes overall</b>	<b>405</b>	<b>46.98%</b>			

Estimated disability services and licensed boarding house population average 2003-11: **6,484**

**Table 27: Top 10 underlying causes of death of people in disability services 2003-11**

	N	%	Crude mortality rate per 1000	95%LCI	95%UCI
Epilepsy	48	6.71	0.95	0.41	2.23
Cerebral palsy	47	6.57	0.93	0.40	2.20
Pneumonitis due to solids and liquids	42	5.87	0.84	0.34	2.07
Ischaemic heart diseases	38	5.31	0.76	0.29	1.96
Down Syndrome	33	4.62	0.66	0.24	1.83
Pneumonia	29	4.06	0.58	0.19	1.72
Other heart diseases	26	3.64	0.52	0.16	1.64
Cerebrovascular diseases	24	3.36	0.48	0.14	1.58
Chronic lower respiratory diseases	20	2.80	0.40	0.11	1.48
Inhalation and ingestion of food causing obstruction of respiratory tract	18	2.52	0.36	0.09	1.43
<b>Total top 10 underlying causes in disability services</b>	<b>325</b>	<b>45.45%</b>			

Estimated disability services population average 2003-11: **5,588**

**Table 28: Top 10 underlying causes of death of people in licensed boarding houses in 2003-11**

	N	%	Crude mortality rate per 1000	95%LCI	95%UCI
Ischaemic heart diseases	37	25.17	4.57	1.74	12.01
Chronic lower respiratory diseases	12	8.16	1.48	0.27	8.09
Other heart diseases	9	6.12	1.11	0.16	7.89
Pneumonia	8	5.44	0.99	0.12	7.90
Malignant neoplasm of trachea, bronchus and lung	8	5.44	0.99	0.12	7.90
Cerebrovascular diseases	5	3.40	0.62	0.04	8.56
Intentional self-harm	5	3.40	0.62	0.04	8.56
Inhalation and ingestion of food causing obstruction of respiratory tract	4	2.72	0.49	0.03	9.34
Malignant neoplasm of colon, rectum and anus	3	2.04	0.37	0.01	11.04
Mental and behavioural disorders due to psychoactive substance use	3	2.04	0.37	0.01	11.04
<b>Total top 10 underlying causes in licensed boarding houses</b>	<b>94</b>	<b>63.95%</b>			

Estimated licensed boarding house population average 2003-11: **900**

**Table 29: Top 10 underlying causes of death of people with disabilities in care in 2003-11 compared with all deaths in NSW**

Cause of death and ICD-10 code	All disability deaths		NSW deaths	
	Number of Deaths 2003-2011	Average Crude Mortality Rate 2003-2011	Number of Deaths 2002-2010	Average Crude Mortality Rate 2002-2010
Ischaemic heart diseases	75	1.285	73,671	1.191
Epilepsy	49	0.840	773	0.012
Cerebral palsy	47	0.805	198	0.003
Pneumonitis due to solids and liquids	43	0.737	3,618	0.058
Pneumonia	37	0.634	7,805	0.126
Other heart diseases	35	0.600	23,834	0.385
Down syndrome	33	0.565	158	0.003
Chronic lower respiratory diseases	32	0.548	17,873	0.289
Cerebrovascular diseases	29	0.497	39,110	0.632
Malignant neoplasm of trachea, bronchus, lung	25	0.428	22,672	0.366

**Table 30: Top 10 underlying causes of death of people in disability services in 2003-11 compared with all deaths in NSW**

Cause of death and ICD-10 code	Disabilities services deaths		NSW deaths	
	Number of Deaths 2003-2011	Average Crude Mortality Rate 2003-2011	Number of Deaths 2002-2010	Average Crude Mortality Rate 2002-2010
Epilepsy	48	0.954	773	0.012
Cerebral palsy	47	0.935	198	0.003
Pneumonitis due to solids and liquids	42	0.835	3,618	0.058
Ischaemic heart diseases	38	0.756	73,671	1.191
Down syndrome	33	0.656	158	0.003
Pneumonia	29	0.577	7,805	0.126
Other heart diseases	26	0.517	23,834	0.385
Cerebrovascular diseases	24	0.477	39,110	0.632
Chronic lower respiratory diseases	20	0.398	17,873	0.289
Inhalation and ingestion of food causing obstruction of respiratory tract	18	0.358	137	0.002

**Table 31: Top 10 underlying causes of death of people in licensed boarding houses in 2003-11 compared with all deaths in NSW**

Cause of death and ICD-10 code	Boarding house deaths		NSW deaths	
	Number of Deaths 2003-2011	Average Crude Mortality Rate 2003-2011	Number of Deaths 2002-2010	Average Crude Mortality Rate 2002-2010
Ischaemic heart diseases	37	4.568	73,671	1.191
Chronic lower respiratory diseases	12	1.481	17,873	0.289
Other heart diseases	9	1.111	23,834	0.385
Pneumonia	8	0.988	7,805	0.126
Malignant neoplasm of trachea, bronchus, lung	8	0.988	22,672	0.366
Cerebrovascular diseases	5	0.617	39,110	0.632
Intentional self-harm	5	0.617	5,467	0.088
Inhalation and ingestion of food causing obstruction of respiratory tract	4	0.494	137	0.002
Malignant neoplasm of colon, rectum and anus	3	0.370	12,103	0.196
Mental and behavioural disorders due to psychoactive substance use	3	0.370	1,373	0.022



NSW Ombudsman  
Level 24, 580 George Street  
Sydney NSW 2000

General enquiries: 02 9286 1000  
Toll free (outside Sydney Metro Area, NSW only): 1800 451 524  
Tel. typewriter (TTY): 02 9264 8050  
Facsimile: 02 9283 2911  
Email: [nswombo@ombo.nsw.gov.au](mailto:nswombo@ombo.nsw.gov.au)

[www.ombo.nsw.gov.au](http://www.ombo.nsw.gov.au)

