

# Report of Reviewable Deaths in 2008 & 2009

Volume 2: Deaths of people with  
disabilities in care

September 2011





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# Ombudsman's Foreword

This is the sixth report I have tabled about reviewable deaths since 2004, and the first since legislative amendments significantly changed my responsibilities in relation to reviewable deaths.

I am tabling this report to Parliament later than has been my practice. This is due to the changes in my jurisdiction for reviewable child deaths and, moreover, the uncertainty that accompanied these changes.

In April 2009, and following on from Justice Wood's Special Commission of Inquiry into Child Protection Services in NSW, the NSW Parliament assented to significant changes to my work in child deaths. Two key changes also applied directly to my work in reviewing the deaths of people with disabilities in care: my report would be tabled every two years, rather than every year, and on a financial year basis.

Reviewable deaths have previously been reported on a calendar year basis, and the change required a significant re-working of our systems. Unfortunately, the change was not sustainable. The Wood Inquiry also resulted in the transfer of the NSW Child Death Review Team to my office, for the purpose of creating an integrated child death review function. The Team reports on a calendar year basis, creating an unworkable anomaly. However, it was not until late 2010 that the original legislation changing reviewable death reporting timeframes was repealed.

While the past two years have presented many challenges for my office in our reviewable deaths role, I am very pleased that we can now move forward with this important work.

In the period since my last report on the deaths of people with disabilities in care, there have been important developments and progress on some of the issues that we

have been pursuing for many years. This includes action to ensure consistent first aid requirements across accommodation services for people with disabilities; improved medication administration requirements in licensed boarding houses; commencement of a specialised clinical service pilot in the Illawarra area for people with intellectual disability; and establishment of an Intellectual Disability Network under the Agency for Clinical Innovation.

I am pleased to see progress in these critical areas. However, this report clearly identifies that much more can, and should, be done to improve health outcomes for people with disabilities in care and to reduce preventable deaths. In particular, my report raises questions about the equitable access of people with disabilities in care to health programs, such as those aimed at providing out-of-hospital clinical support. It also draws attention to the need for improved health support and coordination for people in licensed boarding houses to address significant risk factors; and a greater focus on effective risk management in disability services to reduce preventable deaths. My recommendations are targeted at achieving progress on these issues.

In moving forward with our work in reviewing the deaths of people with disabilities in care, we need to ensure that the key messages from our work are available and accessible to disability support workers, licensed boarding house staff, and their managers. Following release of this report, we will explore strategies for effectively communicating the main messages and areas for action, such as the development of simplified and targeted fact sheets.

It is also timely, as we approach the 10-year mark of my office's jurisdiction over reviewable

disability deaths, that we take a fresh look at this function and the way we undertake this work, in the context of our legislation and intended purpose, available resources, changes in the disability and health sectors, and progress to date.

I would like to take this opportunity to thank the members of the reviewable disability deaths Advisory Committee for their invaluable advice and assistance in my work. I greatly appreciate the Committee's commitment and expertise.

Finally, I want to pay tribute to Anne Slater, who sadly died in May. Anne was a valued member of our reviewable disability deaths Advisory Committee from its beginning in 2003 until she resigned in March this year due to poor health. She was a passionate and tenacious advocate for people with disabilities and their need for better health care and coordinated support. We benefited enormously from her expert advice and her persistent and important focus on strengthening the work to effectively identify and manage respiratory issues to prevent premature deaths.

Anne is greatly missed by our team.

A handwritten signature in black ink, appearing to read 'B. Barbour'.

Bruce Barbour  
Ombudsman

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# Executive summary

Our functions in relation to the deaths of people with disabilities in care are aimed at preventing or reducing deaths that are preventable. We monitor and review the deaths of people living in, or temporarily absent from, residential care authorised or funded under the *Disability Services Act*, and licensed boarding houses.

## Key points from this report

Through our work, we have identified critical issues that require attention to improve the health outcomes of people with disabilities in care, and to reduce preventable deaths. These include the need to:

- Improve the work of disability and health services to identify the risks faced by individuals and to adequately support them to address or minimise the risks. There are serious health risks faced by people in disability accommodation services and licensed boarding houses, and our reviews indicate that the work of services and practitioners to identify and address the risks is often inadequate.
- Increase access to specialists, particularly respiratory specialists, for people with recurrent or chronic illness. There is a role for service staff to canvass the need for possible referral with the person's GP.
- Increase the rate of influenza and pneumococcal vaccination for those at risk.
- Increase access to annual comprehensive health assessments for people in disability accommodation services and licensed boarding houses. This assessment provides a useful prompt to consider

vaccination, the need for specialist assistance, review medications, and to identify emerging health concerns.

- Enable equitable access of people with disabilities in care with chronic health problems to community-based health programs, including the Connecting Care program for people with chronic diseases, and out-of-hospital programs such as Hospital in the Home.
- Review the use of antipsychotic medications for people with disabilities in care to ensure that there is a clear reason for its administration; and that the use of antipsychotic medication to manage behaviour is supported by a clear and regularly reviewed behaviour support plan.

## About the people who died in 2008 and 2009

The deaths of 193 people with disabilities in care in 2008 and 2009 were reviewable, comprising 88 people who died in 2008, and 105 people who died in 2009.

- 92 people lived in accommodation operated by Ageing, Disability and Home Care (ADHC)
- 68 people lived in non-government (ADHC-funded) accommodation
- 33 people lived in licensed boarding houses.

On average, the people who had lived in disability services (ADHC operated or funded accommodation) were 55 years old when they died – nine years younger than people in licensed boarding houses – and around 25 years younger than the general population.

Consistent with previous years:

- Most of the disability services residents who died had multiple impairments, typically intellectual, physical and sensory impairments. They tended to need assistance with key daily activities, including mobility, meals, and communication. Many had health concerns that included swallowing difficulties, recurrent respiratory illness, constipation and gastro-oesophageal reflux disease.
- Most of the licensed boarding house residents who died had a mental illness, and many had some form of cognitive impairment, whether intellectual disability, acquired brain injury, and/or dementia. Many had risk factors for cardiovascular disease, including high blood pressure, obesity, and heavy smoking.

## Key issues identified through our work

### Identifying and managing risks

A critical part of preventing premature deaths involves identifying health and safety risks and taking steps to reduce or remove them. There are clear requirements for disability accommodation services to identify the risks faced by the people in their care, and to take action to support individuals to address or reduce those risks. ADHC has provided risk management policy guidance to services, as well as risk assessment checklists and templates to support this work.

However, our reviews of deaths in 2008 and 2009 revealed significant and continuing problems in how disability services are undertaking this important work. Of concern to us is that:

- At least 15 of the people who lived in NGO services did not have key risk assessments and planning documents, or these had

not been reviewed for an extensive period of time. These included individual plans, nutrition and swallowing risk assessments, and health care plans.

- We found inadequate work on the part of services to identify all of the risks faced by individuals. This included a failure to identify:
  - nutrition, swallowing and respiratory risks – even when prompted in the assessment, the person had been in the care of the service for a long time, and the information was elsewhere identified on file;
  - new risks due to changing support needs, such as increased swallowing and/or mobility problems; and
  - considerable safety risks associated with positioning in bed.
- We also found inadequate action on the part of disability services to address the identified risks. This included staff not taking any action in response to identified nutrition, swallowing or respiratory risks – such as raising issues with the GP or seeking a speech pathology review. It also included staff failing to implement the recommendations of health professionals; including not monitoring weight, and giving food and fluids when the person was not alert.

Greater attention is required to improve disability services staff's understanding of effective risk management and the associated requirements, and to monitor staff practice to ensure compliance.

Our reviews of deaths in 2008 and 2009 also raised concerns about the adequacy of actions to manage the medication risks of people in disability services and licensed boarding houses; and the support for people in licensed boarding houses to reduce the risks associated with smoking.

People in licensed boarding houses face considerable health risks, including those related to heavy smoking, obesity, and lack of

exercise. Greater focus is required by services and practitioners to clearly identify the risks, and provide coordinated support to residents to help them to minimise those risks.

## Health supports for people with disabilities

Our work has indicated that more needs to be done to improve the coordination of support between disability and health services to people with disabilities in care, and to improve their access to certain health supports and programs. Our reviews indicate low rates of access to specialists, chronic disease management programs, and other out-of-hospital programs.

In particular, we found:

- Low rates of specialist involvement in people with complex and chronic health problems. This includes infrequent referral to respiratory specialists for people with recurrent and chronic respiratory issues such as chronic obstructive pulmonary disease (COPD), recurrent aspiration pneumonia, or emphysema.
- None of the 49 people who died in 2008-09 who had chronic disease had been linked to any chronic disease management or other out-of-hospital program, despite meeting the benchmark of 'high risk' or 'very high risk' patients. Almost half of the 49 people had multiple presentations to hospital in relation to their chronic illnesses, which included COPD, coronary artery disease, chronic lung disease, and diabetes.

Our reviews also reinforced the need for clear guidance for health and disability services staff, and agreement between ADHC and NSW Health, on support for people with disabilities in hospital.

## Causes of death of people with disabilities in care 2003 – 2009

Important aspects of our work in reviewing deaths involve monitoring and analysing trends, and undertaking research or other projects for the purpose of formulating strategies to reduce or remove risk factors associated with reviewable deaths that are preventable.

In this context, we have analysed the causes of death of 642 people who died between 2003 and 2009, and undertaken a detailed examination of the main causes of death of a) people in disability services; and b) licensed boarding house residents.

### All people with disabilities in care

Diseases of the circulatory system, such as ischaemic heart disease, were the leading underlying cause of death for all people with disabilities in care between 2003 and 2009. Other main causes of death for the 642 people were cancers, diseases of the nervous system, and respiratory diseases.

### People in disability services

The leading underlying causes of death of people in disability services were nervous system diseases (such as epilepsy); cancers (mainly lung cancer and colon cancer); respiratory diseases (mainly aspiration, pneumonia, and chronic lower respiratory diseases); circulatory diseases; and external causes (mainly choking on food).

However, respiratory diseases were the largest contributory cause of death for disability services residents. Respiratory diseases contributed to half of all deaths in disability services. Key lessons from our reviews of the deaths of people in disability services from respiratory diseases, including aspiration and pneumonia, include:

- The critical importance of comprehensive assessment of aspiration risks to individuals through nutrition and swallowing risk assessments, and ensuring that a clear plan is developed to address the identified risks through a combination of staff actions and the involvement of relevant health practitioners, such as speech pathologists.
- The need for staff to identify people with risks related to respiratory illness, including recurrent respiratory infections and GORD, and to ensure that the person has the involvement of relevant health practitioners.
- The importance of people with respiratory illness being referred to relevant specialists, such as respiratory specialists, and the need for clear prompts for disability staff to discuss referral with the person's GP.
- The need for services to develop strategies to promote staff understanding of, and compliance with, recommendations made in support plans or assessments.
- The need for vigilance in relation to changes in a person's health or behaviour, including increased drowsiness or weight loss; and critical importance of service and medical staff recognising when the person needs urgent medical assistance.

Our reviews of the deaths of licensed boarding house residents from circulatory diseases, such as chronic ischaemic heart disease and heart attack, and lung cancer have emphasised the need for:

- Proactive strategies and support for individuals to address their multiple risk factors – particularly lifestyle factors such as smoking, physical inactivity, and obesity. It was not clear what support was available or offered to individuals to enable them to address risks, or to make an informed choice not to. This includes dietician involvement; changes to the person's diet or the menu at the boarding house; involvement in exercise options through Boarding House Reform Program services; and provision of nicotine replacement therapy.
- Promotion of, and access to, chronic disease management programs for people with disabilities in care with chronic ischaemic heart diseases.
- Vigilance in relation to changes in the person's health or behaviour, including unexplained weight loss, fatigue and falls, and subsequent action, including review of the person's health and support needs.

## People in licensed boarding houses

The leading underlying causes of death of people in licensed boarding houses were circulatory diseases; cancers (mainly lung cancer); respiratory diseases (mainly chronic lower respiratory diseases such as COPD); and external causes (mainly intentional self-harm).

Mental and behavioural disorders, such as mental illness, were the largest contributory cause of death for licensed boarding house residents, contributing to almost one-third of all deaths in licensed boarding houses.

# Recommendations

## Nutrition and swallowing risk management

ADHC's *Nutrition and Swallowing* policy<sup>1</sup>, incorporating the nutrition and swallowing risk checklist, was rolled out to ADHC operated and funded disability accommodation services in 2004. Our previous recommendations have focused on the need to effectively monitor the implementation of the policy, and to evaluate the policy once implemented.

Evaluation of the policy was completed in May 2009, and ADHC accepted all of the recommendations. The recommendations included mandatory regular and refresher competency-based training for staff; clearer guidance for staff; improved use and accessibility of policy resources; increased access to dietitians; data collection on key clinical indicators; and staff survey to check practice. Work on the revised policy is to be completed by the end of 2011.

Our reviews indicate that this work is critical and overdue. We continue to identify compliance and quality problems in the actions of staff to identify and manage nutrition and swallowing risks, particularly in funded services.

**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;**

**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.**

## Monitoring disability services

In our reviews of the deaths of people in 2008 and 2009, we continued to identify individuals for whom key risk assessments and planning documents were not in place, or had not been reviewed for an extensive period of time – particularly people in funded services. These included individual plans; nutrition and swallowing and other risk assessments; and key support documents such as health care and behaviour management plans. Our reviews also raised concerns about the adequacy and quality of the work undertaken by disability services to identify and manage the risks of the people with disabilities in their care.

**2. ADHC should provide detailed advice as to how it currently monitors ADHC-operated and funded services to ensure compliance with ADHC policy requirements.**

1. Formerly known as the *Ensuring Good Nutrition* policy.



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.

## Antipsychotic medication and behaviour management

Analysis of information from our reviews of deaths between 2003 and 2009 has raised questions about the use of antipsychotic medication for some people in disability services. We found 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.

Our reviews also raised questions about the frequency of use of antipsychotic medication as a primary behaviour management strategy. We found 14 people in disability services on antipsychotic medication who had challenging behaviour and no mental illness who did not have a behaviour support plan.

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.

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.

## Implementation of ADHC's Health Care policy

ADHC released its revised *Health Care* policy to ADHC operated and funded accommodation services in July 2007. Our previous recommendations have been focused on the need for ADHC to evaluate implementation of the policy in those services. ADHC plans to review the policy in 2011/12 and, as part of the review, develop a broader health and wellbeing policy framework.

6. ADHC should provide detailed advice to us on the progress of its review of the *Health Care* policy, including advice as to:
  - a) the scope and timeframes of the review
  - b) the aims and scope of the proposed health and wellbeing policy framework.

## Health care and licensed boarding house residents

In 2007, ADHC contracted NSW Health to conduct a review of the health needs of licensed boarding house residents in the inner-west area of Sydney. This review highlighted significant gaps in the assessment and provision of health care to residents, and made seven recommendations to ADHC to improve the health outcomes of people living in licensed boarding houses across NSW. In March 2009, ADHC told us that the findings of the 2007 report would be considered in the broader context of an evaluation of the Primary and Secondary Health Care services.

The evaluation was completed by April 2011, and included recommendations to expand the range of Primary and Secondary Health Care services to include allied health services; develop a statewide model of Primary and Secondary Health Care service provision that reflects consistent and best practice; and develop a framework that ensures that all residents have an individual health plan developed by a community nurse and reviewed annually in conjunction with a GP. The recommendations are to be implemented by 1 July 2012.

Our report has identified a range of concerns about the access of people in licensed boarding houses to health specialists, vaccination, medication reviews, and health programs and initiatives such as chronic disease management and quit smoking programs. Our reviews have also highlighted the need for proactive and cooperative work to support residents in managing weight and nutrition, and increasing physical activity.

**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.**

## Palliative care

We have previously raised concerns about the provision and coordination of palliative care to people with disabilities, including the involvement of the person with a disability in decision-making, and the adequacy of discharge planning for people receiving palliative care. In 2006, ADHC released a *Palliative Care* policy to ADHC operated and funded services; and an independent evaluation of the policy has since been completed.

The evaluation recommendations concern education and training for disability services staff; development of improved guidance and accessible information; provision of clinical

nurse consultant support; and interagency partnerships on palliative care. Work on a revised *Palliative Care* policy and practice guide is to be completed by the end of 2011.

**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.

## People with disabilities who are ageing

Our reviews and consultations with the disability sector have emphasised the need for clear policy guidance on support for people with disabilities as they age. We have heard that the lack of clear guidance tends to result in inconsistent practice across disability services. 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.

ADHC is currently undertaking a project – *Ageing in Place: Impacts on Accommodation Services* – to develop and implement an evidence-based action plan to better meet the needs of people with disabilities who are ageing, with a new policy direction to re-orient services to enable clients to age in place. The project will be completed in September 2011.

**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.

## Access to health services for people with dual diagnosis

Since 2006, we have made recommendations aimed at improving the support for people with dual diagnoses of intellectual disability and mental illness. A Memorandum of Understanding (MOU) and guidelines for the provision of services to people with an intellectual disability and mental illness was released in January 2011. An Intellectual Disability Mental Health Working Group is monitoring the implementation of the MOU and will evaluate it 18 months after the date of commencement. As at July 2011, ADHC and NSW Health mental health services were developing the detailed implementation arrangements for the MOU.

**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.

## Access to NSW Health chronic disease management and out-of-hospital programs

Many of the people whose deaths we have reviewed had chronic illnesses and met the criteria of 'very high risk' and/or 'high risk' patients. However, according to the records we reviewed, none of these people had been involved in NSW Health's chronic disease management programs or the various out-of-hospital programs. This included at least 49 people who died in 2008-09, many of whom had multiple hospital presentations in relation to their chronic illnesses.

In response to our draft report, NSW Health advised that the Connecting Care (chronic disease management) program is investigating ways to best meet the needs of vulnerable communities, and that residents of disability services and licensed boarding houses require specific consideration in the program.

**11. In relation to the Connecting Care and other out-of-hospital programs, NSW Health should take immediate action to improve the access of 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 program.



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.

## Support for people with disabilities in hospital

We have previously reported concerns that had been raised with us by disability services about the support provided to people with disabilities in hospital. Services raised concerns about being asked by treating hospitals to provide staff to support their client for the duration of their hospital stay, and the cost involved to the service.

Since 2009, ADHC and NSW Health have been working on developing a joint statewide guideline on support for people with disabilities in ADHC operated and funded services in NSW public hospitals. Our reviews of deaths in 2008 and 2009 continued to identify similar problems to those previously reported, and have highlighted the need for this work to be completed as soon as possible.

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.

## Health service framework for people with intellectual disability

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

In 2007, NSW Health consulted with key stakeholders about a discussion paper it had developed with ADHC and the NSW Council for Intellectual Disability on a service framework to improve health care for people with an intellectual disability. The draft service framework outlined possible options for developing local area specialist health resources and a statewide specialist centre to provide clinical leadership. Our previous recommendations have been aimed at achieving progress towards implementing the framework.

In the past year, NSW Health has funded a three-year specialised clinical service pilot in the Illawarra area, and the creation of an Intellectual Disability Network to provide and coordinate clinical leadership. This is a small, but important, first step towards the development of a broader service framework to improve the health of people with intellectual disability.

Our reviews continue to highlight the pressing need for the service framework across NSW. Our work in relation to the deaths of people with disabilities who died in 2008 and 2009 raises questions about the equitable access

of people with disabilities in care to relevant specialists, and to health programs, such as chronic disease management and other out-of-hospital programs.

**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.

## **Reporting against our recommendations**

**15. In relation to the recommendations we have directed to their respective agencies, ADHC and NSW Health should:**

- a) provide a response to the recommendations by 30 December 2011; and
- b) provide a progress report on implementation of the recommendations by 27 July 2012.

# Part One

## Deaths in 2008 and 2009



# 1 Introduction

This report is the sixth, and first biennial report of reviewable deaths, and covers the period 1 January 2008 – 31 December 2009. In this period, the deaths of 193 people with disabilities in care were reviewable.

## 1.1 Reviewable deaths

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

- a child in care;
- a child whose death is, or may be, due to abuse or neglect or that occurs in suspicious circumstances;
- a child who, at the time of the child's death, was an inmate of a children's detention centre, a correctional centre or a lock-up (or was temporarily absent from such a place); and
- a person (whether or not a child) who, at the time of the person's death, was living in, or was temporarily absent from, residential care provided by a service provider and authorised or funded under the *Disability Services Act 1993* or a licensed boarding house.

To assist in the identification of deaths that are reviewable, section 37 of CS CRAMA requires particular agencies to notify us of certain deaths within 30 days after receiving the notification:

- a) The Registrar of Births, Deaths and Marriages must provide us with a copy of death registration information relating to a child's death.
- b) Ageing, Disability and Home Care (ADHC) must provide us with copies of any notification received by the Director-General relating to a reviewable death.
- c) The State Coroner must notify us of any reviewable death notified to her.

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

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

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

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

## 1.2 The scope of our work

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

Therefore, our reviews aim to identify any shortcomings in systems and practice that may have contributed to the death of a person who has lived in care, or that may expose others to risks in the future.

Our work includes examining relevant records and information relating to the person who died, such as: coronial records about the person's death; government and non-government agency records about the history of their contact with the individual; and incident reports or internal reviews of the person's death. We may also request specific information from agencies to assist in our review.

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

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

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

issues and whether they are systemic in nature, and take into account any action that an agency may be taking to address the issues.

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

## 1.3 Our work arising from the deaths of people with disabilities in 2008 and 2009

In 2008-09, the deaths of 193 individuals in residential care or licensed boarding houses were reviewable, and we took further action in relation to 36. In some cases, action related to more than one agency. Most of our work focused on the disability service or licensed boarding house that had provided direct support to the individuals, with a number of matters involving area health services and other government agencies.

### Investigations and reports to agencies

We conducted an investigation in relation to the death of a man who died from pneumonia in 2009 (see case study 12).

We made 27 reports to agencies under section 43(3) of CS-CRAMA arising from our reviews of the deaths of 33 people. The reports were directed to:

- ADHC (nine reports about 10 people)
- NGO disability services (13 reports about 20 people)
- NSW Health services (three reports about four people)
- NSW Ambulance Service (one report about one person)
- Community Services (one report about one person)

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.

In relation to 18 of the 33 people, we met with the service providers (eight services) to discuss our concerns prior to making the report. The issues identified through our reviews of deaths in 2008 and 2009, including those raised in our reports to services, are reported in Chapter 3.

## Other action

We made a complaint to the Health Care Complaints Commission (HCCC) regarding issues we identified in our review of the death of a man in 2009 that raised questions about the adequacy of the care provided by his general practitioner.

A previous referral of a GP to the HCCC was resolved in 2009. We made the referral in 2006 in relation to concerns about the potential over-administration of antipsychotic medication to a woman who subsequently committed suicide, and the adequacy of the GPs records relating to treatment of the woman and two other people. Following its inquiry into the matter, the Professional Standards Committee reported that the complaint about administration of the antipsychotic medication was not proven. In relation to record keeping, the Professional Standards Committee issued a reprimand and imposed conditions on the doctor's registration, including auditing of randomly selected records by the NSW Medical Board.

## Advisory committee

We have established an advisory committee to assist us in our work. The committee provides us with valuable advice on complex disability death matters and on relevant policy and practice issues. We obtained advice from

members of our advisory committee in relation to the deaths of 31 people in 2008 and 2009.

A list of the advisory committee members for the deaths of people with disabilities in care is provided in Appendix 2.

## 1.4 This report

This sixth report will be released in two volumes. The first volume concerns the deaths of certain children. This second volume relates to the deaths in 2008 and 2009 of 193 people with disabilities in care.

Of the 193 people who died, seven were children or young people. The reviews of these seven individuals are therefore included in both volumes of this report.

Part One provides information on the deaths of people with disabilities in 2008 and 2009. Chapter 2 details the demographic and other data relating to the people who died, and Chapter 3 reports on the main findings from our reviews of deaths in that 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.

Important aspects of our work in reviewing deaths include analysing data to identify trends and undertaking research or other projects for the purpose of formulating strategies to reduce or remove risk factors associated with reviewable deaths that are preventable. Consistent with these functions, Part Three (Chapter 5) contains analysis of causes of death between 2003 and 2009, and a more detailed examination of the main causes of death for people who were living



in disability services and licensed boarding houses. This work includes consideration of:

- the key data and other information relating to the people who died;
- the known risk factors for those causes of death;
- the existence of those risk factors in relation to the people who died and any actions taken to reduce or remove the risk factors; and
- the major findings from our work in reviewing the deaths of those individuals.

## 1.5 Developments since our last report

Since our last report in November 2008, there have been some notable developments in the disability sector, and considerable progress in addressing issues that have repeatedly featured in our recommendations. Of particular note are developments relating to first aid requirements, licensed boarding houses, and an intellectual disability health service framework.

### First aid

Since our last report, action has been taken to achieve consistent first aid requirements across disability accommodation services and licensed boarding houses. All services are now required to ensure that at least one staff member on each shift has current first aid qualifications. This is a significant development, and is directly relevant to reducing preventable deaths.

### Licensed boarding houses

In 2010, new Youth and Community Services (YACS) regulations were enacted that strengthened the minimum requirements in licensed boarding houses. As a result of the new regulations, all licence conditions are now legally enforceable and additional requirements have been introduced relating to first aid and the administration of regular prescribed medications. Both issues were the subjects of repeated recommendations in our previous reports on the deaths of people with disabilities in care.

In June 2011, the Interdepartmental Committee on Reform of the Private Residential Service Sector submitted a report to government on options for reform of the boarding house sector, following consultation with key stakeholders. In August, we tabled a report in Parliament on our work in relation to licensed boarding houses and the pressing need for reform of the broader sector.

### Health service framework for people with intellectual disability

For many years we have made recommendations relating to the development of a service framework to improve the health care of people with intellectual disability. In the past year, NSW Health has funded a three-year specialised clinical service pilot in the Illawarra area, and the creation of an Intellectual Disability Network to provide and coordinate clinical leadership.

This is a small, but important, first step towards the development of a broader service framework to improve the health of people with intellectual disability. Further information about the progress of ADHC and NSW Health towards meeting our recommendations is outlined in Chapter 4 of this report.



# Deaths of people with disabilities in 2008 and 2009

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 2008 and 31 December 2009.

## 2.1 Reviewable disability deaths in 2008-09

Of the 193 reviewable deaths of people with disabilities in care in 2008-09, 88 people died in 2008, and 105 people died in 2009.

- 92 people (48%) lived in ADHC accommodation
- 68 people (35%) lived in NGO (ADHC-funded) accommodation
- 33 people (17%) 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 2008-09<sup>2</sup>**

Accommodation	Estimated total number of residents 2008-09 <sup>3</sup>	Number of deaths 2008-2009 (Number Total = 193)	Crude Mortality Rate <sup>4</sup>	Percentage of reviewable disability deaths
Group home (funded)	5205	39	7.5	20.21
Group home (ADHC)	2786	32	11.5	16.58
Residential centre (funded)	854	26	30.4	13.47
Residential centre (ADHC)	2342	55	23.5	28.49
Licensed boarding house	1744	33	18.9	17.10

2 Not included in the table are eight people who died in 2008-09 in other accommodation. Six people died in respite care – three in ADHC respite, and three in NGO respite. One young child lived in a host family placement that was funded by an NGO service, and one woman lived in her own home and received overnight support from an NGO service.

3 The total number of people in care in 2008-09 has been estimated based on data provided by ADHC. The data related to the numbers of people in care for the financial years of 2007/08 and 2008/09.

4 Crude Mortality Rate is based per 1000 person-years.

Over one-quarter of the deaths in 2008-09 occurred in ADHC residential centres – accounting for the highest proportion of reviewable deaths in that period.

However, NGO residential centres had the highest crude mortality rate. That is, NGO residential centres had the highest proportion of deaths relative to the number of residents. This has consistently been the case since at least 2004.

## 2.2 Age, gender and cultural status

### Age

The mean age at death of people in disability services was 55 years, ranging from one to 93 years. Licensed boarding house residents were considerably older than disability services residents when they died. The mean age at death of people in licensed boarding houses was 64 years, ranging from 26 to 89 years.

Table 2 provides the mean age at death in 2008-09, by accommodation type. People who died in respite had the youngest mean age, at 16.6 years. Of the main accommodation types, people in group homes had the youngest mean age at death, at 49 years. People in licensed boarding houses had the oldest mean age at death, at 64 years.

Residents of group homes had a significantly lower age at death than residents of licensed boarding houses. People in residential centres did not.<sup>5</sup>

**Table 2: Mean age at death by accommodation type 2008-09**

Type of accommodation	Mean	No.
Respite	16.6	6
Other	24.2	2
Group home	49.0	72
Small residential	58.6	13
Large residential	60.8	67
Licensed BH	64.1	33

Table 3 provides the mean and median ages at death in 2008-09 by accommodation type and service provider. People in ADHC group homes and residential centres had a younger mean and median age at death than people in NGO services. Across all accommodation and service types, people in NGO large residential centres had the oldest mean and median age at death, at 69 years.

**Table 3: Mean and median age at death by accommodation type and service provider 2008-09**

Service provider and accom. type	Mean	Median	No.
<b>NGO</b>			
Respite	12.8	15.5	3
Group home	53.3	53.7	39
Small residential	60.8	63.3	11
Large residential	69.0	69.1	15
<b>ADHC</b>			
Respite	20.4	18.7	3
Group home	44.0	43.8	33
Small residential	46.5	46.5	2
Large residential	58.4	56.5	52
<b>Licensed BH</b>			
Licensed BH	64.1	63.3	33

### Gender

In 2008-09, two-thirds of the people in disability services (107 people) and almost three-quarters of the licensed boarding house residents who died (24 people) were male. The prevalence of males reflects the

<sup>5</sup> Linear model using residence type as factor GH vs BH: beta=-15.4, t[1]=-4.48, p=0.00001; R vs BH: beta=-4.7, t[1]=-1.38, p=0.17

broader population of people with disabilities in care, where males outnumber females in all accommodation and service types.

Data relating to the gender of people who died between 2003 and 2009 is provided in Appendix 1.

## Cultural status

Five people who died were identified as Aboriginal or Torres Strait Islander,<sup>6</sup> and 12 people were from a CALD background.

## 2.3 Care arrangements

### Length of time in care

The people in residential centres who died in 2008-09 had lived in care for longer than people in group homes. The residents of licensed boarding houses who died had spent a lower proportion of their lives in care than residents of disability services.<sup>7</sup>

**Table 4: Length of time in care by accommodation type 2008 and 2009**

Length of time in care - 2008	Mean	Median	No.
Group home	20.54	18	24
Residential centre	38.43	45	35
Licensed BH	17.66	10.5	8

Length of time in care - 2009	Mean	Median	No.
Group home	29.62	25.5	32
Residential centre	39.48	39.5	42
Licensed BH	12.4	9	11

### Years at location

Residents of licensed boarding houses and group homes had resided at their last

accommodation location for a shorter time than people in residential centres.

Residents of group homes had lived at their last accommodation location for the shortest length of time. This was slightly, but not significantly, less than those in licensed boarding houses. Residents of other disability services had lived significantly longer at their last accommodation location.<sup>8</sup>

**Table 5: Number of years at last location 2008 and 2009**

Years at location - 2008	Mean	Median	No.
Group home	6.34	4	31
Residential centre	24.91	25	36
Licensed BH	10.05	10.5	16

Years at location - 2009	Mean	Median	No.
Group home	5.89	5	40
Residential centre	24.48	23	44
Licensed BH	12.06	9	17

## 2.4 Disability

Information relating to disability and impairment for people who died in 2008-09 is largely consistent with previous years.

More than three-quarters of the people in disability services who died in 2008-09 (151) had multiple impairments – typically intellectual, physical and sensory impairments.

As indicated in table 6, the vast majority of disability services residents had a cognitive impairment, whether intellectual disability, dementia, acquired brain injury, and/or developmental delay. Most of the people with intellectual disability had a moderate or severe level of impairment. Physical disability and sensory impairment also featured highly for disability services residents.

6 Aboriginal or Torres Strait Islander status was indicated by services on the Client Death Notification form and recorded in the person's service records.

7 Generalised linear model with 'quasi' link function BH vs GH:  $t[1]=4.38$ ,  $p=0.00002$ ; BH vs R:  $t[1]=5.9$ ,  $p=0.00000002$

8 Generalised linear model with 'quasi' link function BH vs GH:  $t[1]=-1.88$ ,  $p=0.06$ ; BH vs R:  $t[1]=4.98$ ,  $p=0.000001$

Most of the people in licensed boarding houses who died did not have multiple impairments; they tended to have one area of impairment, typically a mental illness.

Two-thirds of the people in licensed boarding houses who died had a mental illness. Many of the boarding house residents had some form of cognitive impairment, whether intellectual disability, acquired brain injury (typically alcohol related brain damage), and/or dementia. Most of the people with intellectual disability had a mild level of impairment.

**Table 6: Number and percentage of people by type of impairment 2008-09**

Impairment	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Intellectual	7	(21)	142	(89)
Physical	0	(0)	116	(73)
Sensory	10	(30)	100	(63)
Psychiatric	22	(67)	54	(34)
Neurological	2	(6)	21	(13)
Acquired brain injury	11	(33)	10	(6)
Developmental delay	0	(0)	9	(6)

## Consent provider

Just over one-third of disability services residents (22) and over three-quarters of licensed boarding house residents (26) provided their own consent to medical or dental treatment.

## 2.5 Support needs

### 2.5.1 Mobility assistance

Three-quarters of the people in disability services who died (119) required assistance with mobility. Over half (92) relied on a wheelchair for mobility.

Only eight licensed boarding house residents needed mobility assistance. Most of these eight people either relied on a walking stick or had no aid.

### 2.5.2 Communication needs

Almost three-quarters of the people in disability services needed assistance to communicate (112); mainly adjusted verbal language or other signing (such as gestures). Few of the people in licensed boarding houses who died required communication support (4).

### 2.5.3 Assistance with meals

Almost three-quarters of the disability services residents (117) needed help with meals. None of the licensed boarding house residents required assistance with meals.

#### *Enteral nutrition*

The majority of the people in disability services who died did not rely on enteral nutrition (tube feeding). Of the 31 people who did, the majority (28) relied on enteral nutrition exclusively, and did not have any oral intake of food, fluids or medication. Most of the people who relied on enteral nutrition (19) lived in ADHC accommodation.

None of the licensed boarding house residents required enteral nutrition.

### *Swallowing difficulties*

Most of the people in disability services (112) were reported to have had swallowing difficulties (also known as dysphagia). Only two licensed boarding house residents were reported to have had swallowing difficulties.

### *Speech pathology review*

The majority of people in disability services with swallowing difficulties (133) had seen a speech pathologist. Neither of the two people in licensed boarding houses with swallowing difficulties who died had seen a speech pathologist.

### *Nutrition and swallowing risk checklist*

Since 2005, all disability accommodation services have been required to identify and address the nutrition and swallowing risks of the individuals in their care using an appropriate checklist. ADHC rolled out the *Ensuring Good Nutrition* policy to ADHC operated and funded services in mid-2004. Now known as the *Nutrition and Swallowing* policy, it includes a nutrition and swallowing risk checklist for services to use.

Since the introduction of the policy, the percentage of people in disability services who died who had a nutrition and swallowing risk assessment has increased. However, the data for 2008-09 indicates that:

- Not everyone in NGO services had a nutrition and swallowing risk assessment – including people with swallowing difficulties. Over 20 percent of people in NGO services who died did not have this risk assessment (15 people). This included five people in NGO services with swallowing difficulties.
- Less than half of the people in NGO services (32) had a completed checklist that identified all of the relevant risks and the actions that were required to address them. Of the people in NGO services with swallowing difficulties who died in 2008-09,

just over half had a comprehensive nutrition and swallowing risk assessment (18).

- In ADHC services, the main problem with the quality of the checklist completion was that not all of the risks for the individuals had been identified. Unrecorded risks included risks relating to recurrent chest infections, recurrent vomiting, missing teeth, and weight status.
- In NGO services, the main problem with the quality of the checklist completion was that staff had not recorded actions that needed to be taken to address the identified risks.

Data relating to the application of the nutrition and swallowing checklist in NGO and ADHC accommodation services since 2005 is provided in Appendix 1.

### *Mealtime support guidance*

In 2008-09, the vast majority of people in disability services who had swallowing difficulties (104) had a mealtime management plan (or similar document) in place at the time of their death.

Data relating to mealtime management plans for people in disability services who died between 2003 and 2009 is provided in Appendix 1.

## **2.5.4 Incontinence**

Three-quarters of the people in disability services (119) had some form of incontinence; mainly double incontinence. The majority of people in licensed boarding houses (22) were continent.

## **2.6 Health needs**

### **2.6.1 Dentition**

As indicated in table 7, less than one-third of the people in disability services (49) and six licensed boarding house residents had all of their teeth.

**Table 7: Dentition status of people who died in 2008 and 2009**

Dentition	Licensed BH				Disability services			
	2008		2009		2008		2009	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
All	3	(19)	3	(18)	23	(32)	26	(30)
Some	6	(38)	6	(35)	33	(46)	26	(30)
Dentures	4	(25)	4	(24)	3	(4)	8	(9)
None	2	(13)	4	(24)	13	(18)	28	(32)
Unknown	1	(6)	0	(0)	0	(0)	0	(0)
<b>Total</b>	<b>16</b>	<b>(100)</b>	<b>17</b>	<b>(100)</b>	<b>72</b>	<b>(100)</b>	<b>88</b>	<b>(100)<sup>9</sup></b>

### Dental review

The majority of the people in disability services (120) and licensed boarding houses who died in 2008-09 (30) had seen a dentist at some stage.

### 2.6.2 Weight

In 2008-09, just under half of the people in disability services who died<sup>10</sup> (65) were in the healthy weight range. One-quarter (37) were underweight, and just under one-third (44) were overweight.

In relation to licensed boarding house residents, less than one-third of the people who died<sup>11</sup> were in the healthy weight range (4). Almost two-thirds (9) were overweight. One licensed boarding house resident who died in 2008 was underweight.

Data relating to the weight status of people who died between 2003 and 2009 is provided in Appendix 1.

### 2.6.3 Respiratory illness

- In 2008-09, 14 people in disability services and six people in licensed boarding houses were reported to have had asthma.
- Over half of the people in disability services who died (82) were reported to have had

recurrent respiratory infections. In licensed boarding houses, six people had recurrent respiratory infections.

- Of the people who died in 2008-09 who had recurrent respiratory infections, just over one-quarter of the people in disability services (21) and one licensed boarding house resident had seen a respiratory specialist at any point.

### 2.6.4 Other key health issues

- Two-thirds of the people in disability services (106) and one-quarter of the people in licensed boarding houses (eight) had constipation.
- More than half of the people in disability services (92) and seven licensed boarding house residents had GORD.
- Just under half of the people in disability services (67) and two licensed boarding house residents had epilepsy.
- Over one-third of the people in disability services (58) and five people in licensed boarding houses had osteoporosis.
- Just under one-quarter of the people in disability services (37) and one-third of the licensed boarding house residents (11) had hypertension (high blood pressure).

<sup>9</sup> In this report, we have rounded the percentages to the nearest whole number. As a result, not all of the totals add to 100 percent.

<sup>10</sup> Weight status information was available for 146 people in disability services (91%). The percentages in this section are based on the 146 people.

<sup>11</sup> Weight status information was available for 14 people in licensed boarding houses (42%). The percentages in this section are based on the 14 people.



- Eighteen people in disability services and seven people in licensed boarding houses had diabetes.

## 2.6.5 Smoking

In 2008-09, 16 people in disability services and two-thirds of the people in licensed boarding houses who died (22) were smokers at the time of their death.

**Table 8: Smoking rates for people who died in 2008-09**

Tobacco use	Licensed BH		Disability services	
	No.	(%)	No.	(%)
No	5	(15)	130	(81)
Ex-smoker	4	(12)	13	(8)
Current ≤ 10/ day	2	(6)	2	(1)
Current 11 to 20/ day	11	(33)	4	(3)
Current > 20/ day	8	(24)	8	(5)
Occasional	1	(3)	2	(1)
Not recorded	2	(6)	1	(1)
<b>Total</b>	<b>33</b>	<b>(100)</b>	<b>160</b>	<b>(100)</b>

This is consistent with data since 2003: the vast majority of people in disability services who died had never smoked, while the majority of people in licensed boarding houses were smokers at the time of their death. More data and information relating to smoking and the people who died between 2003 and 2009 is provided in Appendix 1.

## 2.6.6 Vaccination

All people with severely impaired immunity are at increased risk of morbidity and mortality from influenza and invasive pneumococcal disease.<sup>12</sup>

### *Influenza vaccination*

The Australian Immunisation Handbook states that the administration of influenza vaccine to people at risk of complications of infection is 'the single most important measure in preventing or attenuating influenza infection and preventing mortality.'

Annual influenza vaccination is strongly recommended and should be actively promoted for people at increased risk of complications from influenza infection, including people ≥6 months of age with conditions including:

- **Chronic respiratory conditions** – such as suppurative lung disease and bronchiectasis; chronic obstructive pulmonary disease and chronic emphysema; and severe asthma.
- **Cardiac disease** – including congenital heart disease, coronary artery disease and congestive heart failure.
- **Other chronic illnesses requiring regular medical follow-up or hospitalisation in the preceding year** – including diabetes mellitus, chronic renal failure and impaired immunity.
- **Chronic neurological conditions** – such as multiple sclerosis, spinal cord injuries, and seizure disorders.
- **People with impaired immunity** – including HIV infection, malignancy and chronic steroid use.

<sup>12</sup> The Australian Immunisation Handbook, 9th Edition.

In 2008-09, just under two-thirds of the people in disability services (112) and just under half of the licensed boarding house residents who died (26) had received the influenza vaccination in the year before their death.

Data and information relating to influenza vaccination rates for the people who died between 2003 and 2009 is provided in Appendix 1.

### *Pneumococcal vaccination*

In adults, pneumococcal pneumonia is the most common clinical presentation of invasive pneumococcal disease (IPD). In children, bacteraemia is the major clinical syndrome.<sup>13</sup>

People who are recommended to receive the pneumococcal vaccine include:<sup>14</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 increased risk of IPD due to impaired immunity.
  - Chronic illness associated with increased risk of IPD, including chronic cardiac, renal or pulmonary disease, diabetes, and alcohol-related problems.
- Tobacco smokers.

In 2008-09, less than half of the people in disability services (70) and six licensed boarding house residents had received the pneumococcal vaccination in the five years before their death.

Data and information relating to pneumococcal vaccination rates for the people who died between 2003 and 2009 is provided in Appendix 1.

### **2.6.7 Comprehensive health assessment**

Since 2003, ADHC services have been required to support clients to have an annual GP health assessment. In 2007, the same requirement was extended to NGO accommodation services funded by ADHC.

On 1 July 2007, the Commonwealth Government added to the Medicare Benefits Schedule (MBS) an item for medical practitioners to conduct an annual comprehensive health assessment for people with intellectual disability. The health assessment provides a structured clinical framework for medical practitioners to comprehensively assess a person with intellectual disability and to identify any medical intervention and preventive health care required.

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 (146) and just below two-thirds of the licensed boarding house residents (20) who died in 2008-09 had a comprehensive health assessment in the year before their death.

Data and information relating to comprehensive health assessments for the people who died between 2003 and 2009 is provided in Appendix 1.

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<sup>13</sup> *Op cit*

<sup>14</sup> 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).



# Reviews of deaths in 2008 and 2009

In this chapter, we report our observations from our reviews of the deaths of the 193 people who died in 2008-09.

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:

- the actions taken by services to identify and manage the risks faced by individuals;
- the actions taken by services to effectively coordinate the health needs of individuals;
- the support provided to people with disabilities in hospital; and
- access of people with disabilities in care to appropriate health services and programs.

Deaths in 2008-09 are typically illustrative of systemic issues that we have noted across the seven-year period. As a result, in some areas we have drawn on information and data relating to all deaths during 2003-09, with specific examples and case studies from 2008-09.

## 3.1. Identifying and managing risks

In our previous reports, we have noted that certain deaths of people with disabilities in care may have been prevented if more effective systems were in place to identify and manage risks.

There are a range of assessments and plans that ADHC and NGO disability accommodation services are required to conduct and complete to identify and manage the risks of individual residents, including:

- Assessment of individuals for risks to their lifestyle, health, safety and wellbeing; completion of a risk profile; and, where risks are identified, development of a risk management plan. (*Client Risk policy*)
- Annual GP health assessment and development and review of a health care plan that summarises their health care needs and management interventions. (*Health Care policy*)
- Identification and management of swallowing and nutrition risks through the use of an appropriate checklist; development of individualised health and nutrition plans; and at least annual reviews of the individual's nutritional support needs. (*Nutrition and Swallowing policy*).

The purpose of these assessments and plans is to identify risks to individuals, and to develop and record strategies to manage those risks.

Of concern to us in our reviews of the deaths in 2008 and 2009 was that there were at least 15 people in NGO services for whom key risk assessments and planning documents were not in place, or had not been reviewed for an extensive period of time. These included individual plans; nutrition and swallowing and other risk assessments; and key support documents such as health care and behaviour management plans.

From our reviews, it was not clear to us why these individuals did not have the required assessments and support documents.

In this regard, we met with a number of NGO services and were informed that some were not aware that such requirements existed; others were not aware that their staff were not undertaking the necessary assessments and/or planning; and some considered that they

did not need to as they had nurses on staff. In the main, the services were responsive to our concerns and indicated actions they would take.

Overall, and irrespective of the area of risk or the disability service provider, our reviews of deaths in 2008-09 raised questions about the adequacy of the assessments and planning undertaken by staff to identify and ameliorate the risks. This included where:

- not all of the person's risks had been identified despite the relevant information being on file and the staff member reportedly knowing the person for a long time;
- inaccurate information was recorded on health (such as the Comprehensive Health Assessment Program [CHAP] tool) or other risk assessments, despite the person having lived in the service for a long time; and
- assessments and support plans were not reviewed or updated when the needs of individuals changed.

The issues reported below illustrate the importance of the existing requirements relating to identifying and managing health-related and other risks.

### **3.1.1 Nutrition, swallowing and respiratory risks**

Risks relating to nutrition, swallowing and/or respiratory problems feature highly in the leading causes of death of people with disabilities in care, including deaths due to respiratory diseases, choking, circulatory diseases, and the deaths of people with Down syndrome and cerebral palsy.

In disability services, one of the key assessments to identify these risks is the nutrition and swallowing risk checklist. As noted in Chapter 2, the proportion of people each year who had a nutrition and swallowing risk assessment increased between 2005 and 2009.

However, our reviews of deaths in 2008 and 2009 identified some continuing problems.

#### *ADHC and NGO services*

The nutrition and swallowing risk assessment for 27 people did not identify all of their existing risks, particularly risks relating to missing or no teeth, frequent chest infections, and recurrent vomiting.

We found that identification of nutrition, swallowing or respiratory risks did not always result in staff taking action to address the risks, such as raising the issues with the person's GP or seeking a speech pathology review. In some instances, risks were clearly identified in the assessment and in support plans, but staff actions did not address those risks.

For example, our review of the death of a 54-year-old woman from pneumonia found that the service had clearly identified her swallowing and aspiration risks. However, we noted that staff gave her food and fluid at times when she was not alert or oriented, which increases the risks of aspiration and respiratory illness.

Our reviews also raised questions about the adequacy of actions by staff and health practitioners to proactively address the person's risks of aspiration. This included a lack of evident action to investigate the cause of recurrent vomiting, or referral to an appropriate specialist.

#### *NGO services*

Specifically in relation to NGO services, we found that 15 people did not have any nutrition and swallowing risk assessment. This included three women whose swallowing function had deteriorated due to ageing, cancer, and dementia.

#### *Licensed boarding houses*

In relation to people in licensed boarding houses, we found that identifying and managing nutrition, swallowing and respiratory

risks appears to rest solely with the person's GP. While we noted that some GPs identified and discussed risks such as obesity and smoking with individuals, we rarely noted a management plan or coordinated approach to assisting the person to reduce the risks. The active involvement of Primary and Secondary Health Care services was not often evident.

### Previous recommendations and relevant actions

Each of our previous five reports has included recommendations aimed at improving service practice in identifying and managing nutrition and swallowing risks. The recommendations have focused on the need to monitor and evaluate the *Nutrition and Swallowing* policy and checklist and its implementation by staff in disability services.

An evaluation of the policy and its implementation has been completed since our 2008 report on reviewable deaths. The evaluation found that there was a need for: mandatory and regular training and clearer guidance for staff in the policy, tools, and provision of appropriate nutrition and swallowing support; redesign and simplification of the resources; and collection of data on key clinical indicators of nutritional health.

ADHC has advised that it has redesigned and simplified the policy and related resources, including strengthening the nutrition and swallowing risk checklist to create a clearer action pathway to respond to identified risks. The agency has also indicated that it will integrate training on the policy and resources into the existing learning and development strategy for ADHC staff. It is not clear what training will be provided to staff in NGO services, or how implementation of the revised policy and tools will be monitored.

More information about ADHCs current work on the *Nutrition and Swallowing* policy and related resources is reported in Chapter 4. We

have made further recommendations to ADHC in this report, directed at this work.

### 3.1.2 Health care planning

Health care plans are the key means by which disability services identify and manage the health care risks for the individuals they support. The plans are intended to provide a comprehensive summary of the person's health issues – identified through GP and other health practitioner assessments – and to outline the actions that staff need to take to support those health needs and manage the risks.

Important components of effective health care planning – and management of health risks – include coordinating services to meet the person's identified health needs, and implementing the recommendations of health professionals in a timely way.

Our reviews of deaths in 2008 and 2009 highlighted the importance of comprehensive health care planning. We identified people in disability services for whom:

- there was no health care plan (or similar);
- the health care plan was not recent, was not updated when their needs changed, and/or provided inadequate guidance to staff;
- there was no action, or inadequate action, taken by staff to implement the recommendations of health professionals; and
- the health care planning stopped when they moved accommodation – even where the service provider had not changed.

For example, we reviewed the death of a 54-year-old woman from an aortic dissection.<sup>15</sup> She had chronic schizophrenia, oesophagitis, constipation and several allergies. Our review identified that her health care plan was basic, did not include all of her health concerns, and was not updated or reviewed when her health needs changed. In the eight months before

15 An aortic dissection is a rare condition in which blood passes through the inner lining and between the layers of the aorta.

her death there were recommendations for the woman to be reviewed by a cardiologist, a gastroenterologist, and a dietician, but there was no indication that these were followed-up. We met with the service to discuss our concerns, and received information about the changes it had implemented to its health care management processes, including improved coordination of referrals.

Our review of the death of a man from aspiration pneumonia in 2009 also provides a useful illustration of the importance of effective health care planning (case study 1).

### **Case study 1**

A 72-year-old man who lived in a regional group home died from aspiration pneumonia.

Six months before his death he was involved in a motor vehicle accident as a pedestrian, which resulted in around three months of hospitalisation and rehabilitation. Prior to the accident he was very independent, frequently accessed the community, and visited his family without support. After he was discharged from hospital, the man's support needs were much higher. He had reduced mobility and had increased swallowing problems that necessitated changes to the consistency of his food and drink.

Our review identified that, while the man's eating requirements had changed, staff had not reviewed his nutrition and swallowing risk checklist, and did not develop a mealtime management plan to provide guidance to staff in his changed needs. As a result, it was not clear what guidance was available to staff to ensure that his swallowing needs were met and risks addressed.

We also found that the main risk assessment for him was incomplete, and had not been reviewed by staff following his discharge from rehabilitation and significant changes in his support needs. The existing risk assessment did not highlight to staff the increased risks in relation to swallowing and falls, or outline what

action was to be taken to address or minimise those risks.

The man had significant health concerns, including ischaemic heart disease, hypertension, severe rheumatoid arthritis, pulmonary fibrosis, and anaemia. He had regular access to his GP and was prescribed multiple medications to treat his health issues. However, we found that it had been over two years since the last comprehensive health assessment with his GP, and he did not have a current health care plan. As a result, there did not appear to be a document available to staff that provided a comprehensive picture of his health needs, what action they needed to take to meet those needs, and what progress had been made.

We raised our concerns with the service. In response, the service advised that its health policies included requirements relating to identifying and managing risks and reviewing key assessments and support plans in response to health changes, but those requirements had not been met for this man. Since the man's death, staff had received additional training in the requirements in order to achieve stricter adherence to the existing policies.

### **Previous recommendations and relevant actions**

Our previous recommendations in relation to health care planning have included the need to provide clear policy guidance to disability services in meeting client health needs and specific areas of support such as enteral nutrition and epilepsy; and to evaluate ADHC's *Health Care* policy and its implementation in disability services.

In the period since our recommendations, the *Health Care* and *Epilepsy* policies have been rolled out to all disability services, and clinical nurse specialist positions have been reinstated in ADHC Community Support Teams.

ADHC has advised that it will review its *Health Care* policy this year, and that issues around coordinated health care management will be examined during the review. ADHC has told us that, as part of that review, a broader health and wellbeing policy framework will be developed. Identifying the need for, and improving access to, mainstream and specialist health support services for people in supported accommodation will be explored as part of that framework.

### 3.1.3 Safety risks

Risks are highly individual and can frequently change, depending on factors such as the environment the person is in and changes in their health. As a result, it is important that risk assessments are comprehensive, and that they are reviewed and updated in response to any changes. The deaths of two people in 2008 and 2009 illustrate the importance of this.

#### Case study 2

In relation to the death of a 46-year-old woman, our review found problems with the adequacy of the actions of the disability service to manage her risks when in the community and in new environments. The woman died after falling down a flight of stairs at the home of a staff member. She was taken to hospital with extensive facial injuries, including a broken jaw, and died two days later from bronchopneumonia and aspiration.

The woman had a severe cognitive impairment as well as hearing and vision impairments. She regularly visited the homes of staff members and their families as part of her community access activities. The service had identified a number of risks, including that she was vulnerable to falls, had deteriorating vision, and required assistance with stairs.

However, our review found that the service had not conducted a comprehensive assessment of the woman's risks, including her specific mobility needs. Beyond

supervision, there were no documented strategies to guide staff in how to minimise the risks that she faced. We also found that she did not have an Individual Plan, and there was no reference in her file to any individual planning for the two years before her death.

We wrote to the service with our concerns and sought further information. We found that the service's policies required risk assessment and management as part of community access support planning, but staff had not complied with the requirements. Following the woman's death, the service implemented improved risk assessment and individual planning tools to assist staff, and developed improved policy guidance regarding community access.

Effective identification and management of risk may reduce the likelihood of fatal incidents such as those illustrated by the case study above, and case study 3.

#### Case study 3

We reviewed the death of a 65-year-old man who lived in a group home. While the final cause of the man's death is not yet known, information indicates that the weight of his body on the bed controller caused his bed to decline at a 45° angle, and his face became pressed into the mattress.

The man had cerebral palsy and was reliant on a wheelchair for mobility. While he had some upper-body strength, he required the full assistance of staff with mobility and transfers. The man was unable to speak verbally, but communicated through the use of a communication board, noises, and by banging on his bedroom wall.

At approximately 5am on the morning of the man's death, a staff member entered his room and the man used a spelling chart to indicate that he wanted to have his breakfast. The staff member told him that he would need to wait until 6am.



At 7am, staff heard the man moaning, but continued with their duties, noting that he often moaned. At 10am, a staff member went into the man's room to take his breakfast order. They found that the head of the man's bed was down at a 45° angle, the man was lying on his stomach, face down, and the top of his head was against the bed head. The man was deceased by the time he was found by staff.

The service conducted a root cause analysis of the man's death, which identified a range of concerns, including that:

- the existing risk identification system failed to provide an adequate communication system for the man to communicate his needs, particularly in an emergency;
- there were unclear strategies for staff to ensure adequate observations of the man, particular given his risky positioning in bed; and
- both staff members working that morning were agency staff who did not have the training to safely manage the situation.

Our review also noted a lack of risk assessments in relation to the man's bed remote and position, despite a previous incident with the remote control and changes to his positioning needs related to pressure areas. We also identified gaps in health care planning and support for the man. While the man experienced changes in his health and support needs, his health care plan and nutrition and swallowing risk checklist were not reviewed, and he had no Individual Plan.

We met with the service to discuss our concerns, and to get an update on its progress in implementing the recommendations from the root cause analysis report. The service provided advice and written information regarding a range of actions taken since the man's death to improve the service's capacity to manage risk, including:

- strengthening its client risk management system, including regular review and

analysis of risks, and actions to improve communication of client risk information to all staff;

- increasing staff competency-based training;
- improving training and support for agency staff and the strategic placement of staff to ensure appropriate support and supervision of clients; and
- using Registered Nurses in the community group homes to assist in health care planning and liaison with medical practitioners.

### Previous recommendations and relevant actions

Our recommendations in this area have focused on the need to improve guidance for both ADHC and NGO disability accommodation services in identifying and managing client risks. In 2008, the *Client Risk* policy was rolled out to all disability services, including templates for client risk assessments and profiles.

#### 3.1.4 Medication risks

We have previously reported on the risks faced by people with disabilities in care related to medication, such as medication toxicity due to a particular drug or the interaction between different medications.

Our reviews of the deaths of people in 2008 and 2009 again highlighted medication risks, including:

- hospitalisations due to the side effects of antipsychotic medication and toxic levels of anticonvulsant medication;
- instances of staff not administering major medications when they should have; and
- a death of a woman in a licensed boarding house due to Olanzapine (antipsychotic medication) toxicity – see case study 4.

#### **Case study 4**

A 60-year-old woman who lived in a licensed boarding house died from Olanzapine toxicity. She was prescribed two antipsychotic medications, including Olanzapine, to treat schizophrenia. She also had chronic obstructive pulmonary disease, was a heavy smoker, and was underweight.

She was noted to decline some interventions, including women's health screening and involvement in community activities. There was no indication that the cause of her underweight status was explored.

Monitoring of the woman's mental health and prescription of the antipsychotic medications was undertaken by her GP, who she saw on a fortnightly basis. She last saw a psychiatrist four years before her death.

The available records indicate that on the morning of the day before her death, the woman was unable to stand up from a sitting position, and required the assistance of a co-resident. Her roommate last saw her alive at 8:30pm, sleeping on her bed. She was found deceased at 7am the next morning by a Home Care worker.

We sought expert forensic medical advice on how the antipsychotic medication reached fatal levels. We were advised that it could not be stated on the available information whether the woman's toxic levels of Olanzapine were caused by taking excessive amounts of the drug on multiple occasions, or by taking a large single dose – in the region of 500mg (25 or more 20mg tablets).

We also obtained expert advice from a psychiatrist. We were advised that the woman should have been seen at least annually by a community mental health team with expertise in long-term care of people with schizophrenia. We were also told that her low body weight should have prompted a review of the woman's dose of antipsychotic medications.

We are continuing to review this woman's death as part of a group review of deaths in the licensed boarding house.

#### *Use of antipsychotic medication*

Antipsychotic medications are major medications that can have a significant impact on the people for whom they are prescribed. This can include side effects, such as weight gain, involuntary repetitive body movements, drowsiness and dry mouth; adverse interactions with other medications; and risks of adverse medication events such as toxicity. Our reviews have found that a high proportion of people who died from choking on food were taking antipsychotic medication at the time of their death (see page 102).

Between 2003 and 2009, our work has identified that over two-thirds of the licensed boarding house residents who died (84 people) and one-third of people in disability services (180 people) took antipsychotic medication.

While antipsychotic medications are typically used to treat some forms of mental illness, they are also sometimes prescribed for people with disabilities in care who have challenging behaviour. Across the seven years, we found that 39 people had been prescribed antipsychotic medication without a clear reason for it, including 10 licensed boarding house residents and 29 people in disability services.

#### **Case study 5**

A 70-year-old man who lived in a regional group home died from pneumonia. He had a moderate intellectual disability, swallowing difficulties, recurrent respiratory infections, and deep vein thrombosis.

The man took antipsychotic medication on a daily basis, and had done so for at least two years before his death. There was no information to indicate why the medication had been initially prescribed, or why it continued to be administered. The man did not have a mental illness, had no identified behaviour

management issues, and did not see a psychiatrist.

The man's health declined markedly in the six months before his death, with multiple admissions to hospital for community-acquired pneumonia. While consideration was given to changing the antipsychotic medication to syrup rather than tablet form to take into account his declining swallowing function, there was no indication that the need for continued prescription of the psychotropic medication was reviewed.

### *Antipsychotic medication and behaviour management*

Analysis of information from our reviews of deaths between 2003 and 2009 raises questions about the frequency of use of antipsychotic medication as a primary behaviour management strategy.

In relation to people in disability services, ADHC policies state that psychotropic medication must not be the primary behaviour support strategy used for a person with intellectual disability.<sup>16</sup> In addition, while medication prescribed to manage challenging behaviours does not constitute a restrictive practice as defined by the Guardianship Tribunal, 'consent to such use of medication must be conditional on its use in the context of a Behaviour Support Plan.'<sup>17</sup>

In our reviews of deaths between 2003 and 2009, we found that 44 people in disability services on antipsychotic medication had challenging behaviour and no mental illness. Almost one-third of these people did not have a behaviour support plan (14 people).

Our reviews of deaths in this period also identified that four licensed boarding house residents on antipsychotic medication had challenging behaviour and no mental illness. We did not identify any other action to support the individuals to manage the behaviour.

## **Case study 6**

A 51-year-old man who lived in a group home died from renal failure. He had a mild cognitive impairment and complex health issues, including chronic renal failure, asthma, type 2 diabetes, recurrent respiratory infections, chronic lower leg ulceration and ischaemic heart disease.

The man took antipsychotic and antidepressant medications in addition to a range of other medications for his health issues. He did not have a mental illness and records indicated that he was prescribed the medications for behaviour management purposes. The service recorded that the man had a history of assaulting staff, however there was no record of any assaults in the 12 months before his death. Incident reports for that period recorded that he yelled and/or swore at staff and co-residents on 10 occasions.

Service records indicated that staff were encouraged to redirect the man and give him space to reduce his agitation, and to ensure that he took his medications. The man was reviewed by a psychiatrist six months before his death. However, there was no behaviour support plan and no indication that he had the involvement of behaviour clinicians.

## **Previous recommendations and relevant actions**

Our previous recommendations in relation to medication risks have focused on the need to promote Domiciliary Medication Management Reviews (DMMR) with disability accommodation services and GPs, and to improve standards relating to medication administration in licensed boarding houses.

There are prompts for medication reviews in the Medicare item for GP comprehensive health assessments, and in the Comprehensive Health Assessment Program (CHAP) tool used by ADHC and some funded services. In 2009,

<sup>16</sup> ADHC (January 2009) *Behaviour Support policy*

<sup>17</sup> ADHC (January 2009) *Behaviour Support: Policy and Practice Manual*



we met with GP NSW and the Pharmacy Guild of NSW in relation to increasing awareness amongst GPs and pharmacists of DMMR for people with disabilities in care. The Pharmacy Guild subsequently promoted the use of DMMR for people with disabilities in care through its newsletter.

In relation to licensed boarding houses, a new Youth and Community Services Regulation commenced in September 2010. This regulation ensures that the licence conditions are enforceable by ADHC, and includes an additional requirement relating to administration of all prescribed medications. The requirement includes packaging of medications by a registered pharmacist into individual doses in a blister pack (if it is practicable to do so), direct administration of the medication to the resident, and maintenance of records relating to all medication administration. This is a considerable improvement on the previous requirements, which related only to *prn* (as needed) medication.

### 3.1.5 Smoking risks and licensed boarding house residents

Smoking is a significant risk factor for deaths due to chronic lower respiratory diseases, ischaemic heart diseases, lung cancer and colon cancer. Overall, a high proportion (almost 70%) of the people in licensed boarding houses who died between 2003 and 2009 were smokers.

Despite the high rates of smoking, our reviews of the deaths of licensed boarding house residents in 2008-09 found few references to the use of proactive strategies, such as the provision of nicotine replacement therapy, or evidence of cooperative and partnership approaches between health practitioners, boarding house staff, and Boarding House Reform Program staff (such as Primary and

Secondary Health Care workers). This is consistent with our findings for deaths in 2003-09.

We previously raised concerns about the high prevalence of smokers in licensed boarding houses in our 2006 report of reviewable deaths. We reported that some licensed boarding houses had introduced smoking cessation programs, and that some Primary and Secondary Health Care caseworkers provided nicotine patches out of the program funds. In that report, we noted the importance of monitoring and evaluating any activities or programs introduced to address the continued high smoking rates in licensed boarding houses. We saw this as critical to determining their effectiveness and the possibility of broader application of successful models across the boarding house sector.<sup>18</sup>

### Previous recommendations and relevant actions

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

ADHC has advised that the role of Primary and Secondary Health Care providers includes promoting health care education and awareness in licensed boarding houses, providing individual case management services, and coordinating support services to improve outcomes for licensed boarding house residents.

Since our last report, ADHC has completed an evaluation of Primary and Secondary Health Care services. Recommendations from the evaluation include expanding the range of services to include allied health services; and developing a statewide model of Primary and Secondary Health Care service provision that reflects best practice and is consistent across the state.

<sup>18</sup> NSW Ombudsman (November 2006) *Report of Reviewable Deaths in 2005, Volume 1: Deaths of people with disabilities in care*, pp18-19.

ADHC has advised that it intends to have all recommendations in the evaluation report implemented by 1 July 2012. More information about the Primary and Secondary Health Care evaluation is reported in Chapter 4. We have made further recommendations to ADHC in this report, directed at this work.

## 3.2 Health supports for people with disabilities

Our reviews of deaths in 2008-09 have raised questions about the adequacy and coordination of support between disability and health services to people with disabilities in care, and about their access to certain health supports and programs. In this regard, our reviews indicate low rates of access to specialists and chronic disease management and other out-of-hospital programs. Information from our reviews of deaths between 2003 and 2009 reinforces the need for attention in these areas.

### 3.2.1 Access to specialists

Our reviews of deaths in 2008 and 2009 identified low rates of specialist involvement in people with disabilities in care with complex and chronic health problems. This is consistent with previous years.

In particular, our reviews found infrequent referral to respiratory specialists for people with recurrent and chronic respiratory issues, including chronic obstructive pulmonary disease, recurrent aspiration pneumonia, or emphysema.

We have previously reported on the low level of involvement of respiratory specialists, following a group review of 27 people who died from respiratory disease in 2005. It is not clear from our reviews why people with disabilities in care with recurrent or chronic

respiratory issues are not typically being referred to respiratory specialists.

In considering strategies to improve access of individuals to relevant specialists, we need to consult more broadly with GP and specialist group representatives, and explore the potential overlap with access to chronic disease management and other out-of-hospital programs.

Access to specialists is also considered in Chapter 5 of this report, in our examination of particular causes of death.

### 3.2.2 Support for people with chronic disease

Chronic disease is a condition that is long term and persistent and leads to progressive deterioration of health.<sup>19</sup> Chronic diseases include coronary heart disease, stroke, lung cancer, depression, diabetes, asthma, chronic obstructive pulmonary disease, chronic kidney disease, oral diseases, arthritis and osteoporosis.

Chronic disease is the most common and leading cause of premature mortality, and patients with complex chronic disease are among the heaviest users of health and community services.<sup>20</sup> A significant proportion of the chronic disease burden in NSW is represented by patients who are either 'very high risk' or 'high risk':

**Very high risk** patients include those who have four or more active long term conditions, are classified as 'frail elderly', are cognitively impaired, living alone, medically unstable, or have high intensity social care needs.

**High risk** patients include those who have one or more chronic conditions, who recently experienced a major health event or often need pain management, or those who frequently attend the Emergency Department for care.

19 Commissioner Peter Garling SC (July 2008) *Final Report of the Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals*.

20 *Op cit*

Effective chronic disease management depends on early detection and treatment of conditions to avoid deterioration and emergency hospitalisation; focus during hospitalisation on well organised management of long-term health rather than just fixing immediate symptoms; and effective partnerships between GPs, community-based teams, hospitals and specialist services.<sup>21</sup>

It is generally recognised that people with chronic disease 'are best managed in the community with all necessary support services, unless they are acutely ill.'<sup>22</sup>

Since 2000, NSW Health has had a chronic care program to improve services for people with chronic illness. There are a number of community-based chronic disease management programs that focus on specific diseases, including respiratory programs operating out of St George, Westmead-Auburn-Blacktown, Prince of Wales, Royal Prince Alfred, Sutherland, Bathurst and Orange Hospitals.<sup>23</sup>

There are also other out-of-hospital programs, including Community Acute/ Post Acute Care (CAPAC), Hospital in the Home, and Healthy at Home. The CAPAC and Hospital in the Home programs have been operating since the 1980s and provide patients with acute or post-acute care services in their home rather than in hospital.<sup>24</sup> The Healthy at Home program provides integrated community care for people aged over 65 years (over 45 years for Aboriginal people) with emerging acute care needs.<sup>25</sup>

## Access of people with disabilities in care to chronic disease management programs

Many of the people whose deaths we have reviewed had chronic illnesses and met the criteria of 'very high risk' and/or 'high risk' patients. However, our reviews have not identified anyone that had been involved in NSW Health's chronic disease management programs or the various out-of-hospital programs.

Of the people who died in 2008 or 2009, at least 49 people had chronic disease but were not linked to any chronic disease management or other out-of-hospital program. This included 10 licensed boarding house residents, and 39 people who lived in disability services. All of them met the benchmark of 'high risk' patients, and all but one of them met the 'very high risk' benchmark.

Most of the licensed boarding house residents (eight people) were 65 years of age and older and had chronic diseases that included diabetes, COPD, coronary artery disease, high blood pressure, and congestive cardiac failure. Two people were younger than 65 years.

Most of the disability services residents with chronic disease were younger than 65 years (24 people).<sup>26</sup> They tended to have chronic diseases that included lung disease, GORD, asthma, renal disease, and recurrent respiratory illness.

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<sup>21</sup> *Op cit.*

<sup>22</sup> *Op cit.*

<sup>23</sup> Agency for Clinical Innovation (July 2010) *Improved Management of Patients with Severe Chronic Respiratory Disease and Severe Chronic Cardiac Disease in the Community*

<sup>24</sup> The patients considered for inclusion in CAPAC/ Hospital in the Home are medically stable, not requiring very high clinical support but may include multi-morbid patients with complex needs. Referrals can come from a variety of sources, including Emergency Departments, GPs, specialists, and hospital inpatient or outpatient units. The conditions treated under these programs include pneumonia and acute exacerbation of COPD, urosepsis, cellulitis, septicaemia, osteomyelitis, pulmonary embolism, and post-orthopaedic rehabilitation and post-operative treatment for some surgical patients. The treatments dispensed include IV antibiotics, anticoagulation, transfusions, nebulisers, home oxygen, chest physiotherapy, and rehabilitation.

<sup>25</sup> Healthy at Home provides a combined assessment by a health clinician and a case manager within 48 hours of referral, fast tracking of diagnostics and assessment, and up to six weeks of case management to set up access to long-term patient and carer support. The program includes a telephone referral service staffed by nurses and other clinicians to out-of-hospital care services.

<sup>26</sup> Of these 24 people, half were aged 45-64 years, and half were younger than 45 years.

From our assessment, all of the 45 people with chronic disease had conditions that may have made them eligible for out-of-hospital programs like Hospital in the Home. These conditions included pneumonia, COPD, cellulitis, and osteomyelitis.

## Multiple hospital presentations

Almost half of the 49 people (24) had multiple presentations to hospital in relation to their chronic illnesses.

The five boarding house residents who had multiple presentations to hospital included one man who had seven presentations in seven months, with three of those presentations occurring less than two weeks after discharge.

### Case study 7

An 89-year-old man who lived in a licensed boarding house in a rural area died from ischaemic heart disease. He did not have a disability, but had multiple chronic illnesses, including emphysema/ COPD, hypertension, peripheral vascular disease, and numerous known cardiac problems such as ischaemic heart disease, angina and congestive cardiac failure.

He had experienced a heart attack nine years before his death, and had had a coronary artery bypass graft and repair of an abdominal aortic aneurysm. He received the assistance of Home Care for showering, and used oxygen therapy intermittently at the boarding house.

The man saw his GP regularly, but had also presented to hospital seven times in the seven months before his death, mainly due to chest and/or stomach pain. After the last hospital admission, the man was assessed by the local Aged Care Assessment Team as he had increased care needs, and increased pain from arthritis in his back. He was approved for hostel accommodation, but died before an alternative placement could be located.

Nineteen of the disability services residents had multiple presentations to hospital in relation to their chronic illnesses. They included:

- A woman who presented to hospital four times in 2.5 months – one of the admissions occurred on the same day as her previous presentation.
- A man who presented to hospital six times in 2.5 months.
- A man who presented to hospital five times in six months – two of the presentations were within six days of discharge.
- A man who presented to hospital 10 times in seven months – on four occasions, he re-presented to hospital within three days of the date he was discharged.

The man who presented 10 times in seven months lived in a regional group home and died from gastrointestinal haemorrhage as a result of a gastric ulcer. He had multiple chronic health problems that included diabetes, colon cancer, chronic osteomyelitis, epilepsy, high blood pressure and GORD. He was 55 years old.

The man's 10 hospital presentations included four admissions. The main reason he presented to hospital was for management of his diabetes, with repeated episodes of hyperglycaemia and seizure activity. He had regular GP contact, and was reviewed by a diabetes nurse. However, it does not appear that he was reviewed by an endocrinologist.

## Changes to the chronic disease management programs

The Garling Inquiry report of November 2008 noted the need for a statewide approach to supporting patients with chronic disease. The report included recommendations to NSW Health to:

- implement and expand its Severe Chronic Disease Management Program to include

all 'very high risk' and 'high risk' patients over the age of 18; and

- consider and develop a comprehensive plan for the expansion of Hospital in the Home programs of care for chronic and complex patients.

In March 2009, NSW Health accepted the recommendation regarding the Severe Chronic Disease Management Program, but indicated that it would initially target very high risk and high risk persons over the age of 65 years (over 45 years for the Indigenous community) for five chronic diseases: diabetes, congestive cardiac failure, coronary artery disease, chronic obstructive pulmonary disease, and high blood pressure.

NSW Health has since stated that enrolment to the Severe Chronic Disease Management Program<sup>27</sup> will initially only be offered to people (over 16 years) who are diagnosed with one of the five major chronic diseases and who are experiencing repeated episodes in hospital.<sup>28</sup>

In relation to the Hospital in the Home programs, NSW Health indicated in 2009 that it would roll out programs across the state to provide home-based care for more patients over the next five years, including for patients with chronic and complex conditions.

The increased focus on chronic disease management and other out-of-hospital programs is positive. Access to these programs has the potential to provide improved support to people with disabilities in care with chronic diseases – including reduced hospital admissions, access to specialist assistance, and improved coordination of health care. However, our reviews have found that there are significant problems in gaining access to the programs.

Our information indicates that:

- The primary means by which individuals have accessed specialist assistance and management of their chronic diseases has been through repeated presentation and admission to hospital. Community-based and out-of-hospital chronic disease support does not appear to have been identified or offered as an option.
- Many people in disability services with chronic diseases will be excluded from access to the Severe Chronic Disease Management Program due to the focus on five chronic diseases only.

In response to our draft report, NSW Health advised that the program is investigating ways to best meet the needs of vulnerable communities and that residents of disability services and licensed boarding houses with chronic diseases 'require specific consideration' in the program.

## Chronic respiratory disease management

Respiratory disease including recurrent respiratory illness is a major factor in the deaths of people with disabilities in care – both as underlying and contributory causes.

Many of the people with recurrent respiratory illness whose deaths we have reviewed had multiple and frequent hospital admissions for treatment of the acute condition, but few had specialist respiratory input, and none had been involved in programs aimed at improving the coordination and management of their conditions in the community. While chronic obstructive pulmonary disease is one of the target diseases under the Severe Chronic Disease Management Program, other chronic respiratory diseases are not included.

We note that one of the Agency for Clinical Innovation (ACI)<sup>29</sup> Respiratory Network

<sup>27</sup> Now known as the Connecting Care (SCDM) Program.

<sup>28</sup> NSW Health has indicated that in the future the Program 'will expand and be offered to people with these conditions even if they are not being admitted to hospital frequently to prevent their deterioration.'

<sup>29</sup> The ACI is a board-governed statutory health corporation that reports to the NSW Minister for Health and the Director-General of NSW Health. Established by the NSW Government in direct response to the Garling Inquiry into Acute Care Services in NSW Public Hospitals, the ACI has replaced the Greater Metropolitan Clinical Taskforce (GMCT).



projects is targeted at developing coordinated care of chronic respiratory patients in the community, and includes the development of a dedicated 'Respiratory Hospital in the Home' program.

To this end, in July 2010, the Network submitted a proposal to NSW Health for the development of a Severe Chronic Respiratory & Cardiac Care Program, to deliver community-based coordinated patient-centred care to people with chronic and complex respiratory disease.<sup>30</sup> There is no information to indicate whether NSW Health has responded to this proposal.

### 3.2.3 Support for people with disabilities in hospital

In 2005 and 2006 we reported concerns that had been raised with us by disability services through two separate projects about the support provided to people with disabilities in hospital. Services raised concerns about being asked by treating hospitals to provide staff to support their clients for the duration of their hospital stay, and the cost involved to the service.

In addition, our reviews of deaths in 2004 identified problems with the quantity and quality of information provided to hospital staff by services when clients are admitted.

Our reviews of deaths in 2008-09 have identified similar problems, as illustrated by case study 8.

#### Case study 8

A 49-year-old man who lived in a group home died in 2009 as a result of complications of diabetes.

The man was taken to hospital four times in the four months before his death, including three admissions. Our review identified some problems relating to support for the man while in hospital.

During an unplanned hospital admission due to bilateral pneumonia, the man was noted to have frequently refused interventions, including medication; displayed challenging behaviour and was aggressive towards hospital staff; and had an unwitnessed fall. Information provided by the disability service to hospital staff on the man's admission included his health care plan and a seven-month old letter from his psychiatrist stating that he had not had any aggressive behaviour in the previous three months. No information appeared to be provided regarding behaviour management strategies or other support needs.

Two months after discharge from this admission, the man returned to hospital to have a planned overnight dental extraction. During this admission, hospital records noted that he refused all medications, including insulin; was aggressive towards hospital staff; and repeatedly said that he wanted to go home. On discharge, he was prescribed a penicillin he had been noted to be allergic to during a previous admission to the same hospital. He returned to the hospital again the next day, with an allergic reaction to the penicillin.

In our review, we considered that the support provided to the man in hospital did not appear to be well coordinated, and that this had the potential to adversely affect his health. The information provided by the service to hospital staff did not provide a complete picture of the man's support needs or provide any guidance about the strategies required to support the man's behaviour and other needs. There did not appear to be active communication between service and hospital staff.

We met with the service to discuss the issues identified through our review of the man's death. We were advised that the service now provides a package of information to hospital staff when sending a client to hospital, which includes behaviour management plans and specific support information. The service also

<sup>30</sup> ACI (July 2010) *Improved Management of Patients with Severe Chronic Respiratory Disease & Severe Chronic Cardiac Disease in the Community*.

advised that it was in the process of working with NSW Health to establish some local protocols about support for clients in hospital, including who pays if a support person is provided.

### **Our recommendations relating to support for people with disabilities in hospital**

In October 2005, NSW Health released the *People with Disabilities: Responding to their needs during hospitalisation* policy directive, which is to be used in the development of local-level protocols. Our recommendations have focused on evaluation of the policy directive and its implementation.

Following evaluation, NSW Health re-issued the revised policy directive in February 2008. Amendments to the policy included greater emphasis on local protocols/ agreement between hospitals and disability service providers and the engagement of consumers and advocates.

However, disability services have continued to raise concerns and make complaints to us about the inadequate support for people with disabilities in hospital, and the unresolved problems relating to which agency pays for the support person when required. In October 2009, we met with ADHC, NSW Health and National Disability Services (NDS) to discuss the concerns that have been raised with us, and were advised that ADHC and NSW Health had commenced work towards developing a joint statewide protocol for support of people with disabilities in hospital. The work was also to include development of a template for use at the local level (between hospitals and disability services) to assist with the development of local protocols. The anticipated timeframe for this work was June 2010. In July 2010, NSW Health advised that consultations had occurred and stakeholders had noted concerns that required escalation to senior officers and other branches to resolve.

In July 2011, we received a draft of the *NSW Health and ADHC Joint Guideline to support residents of ADHC operated and funded accommodation support services who attend or are admitted to a NSW public hospital* that has been released for targeted stakeholder consultation. The guideline has been developed to provide best practice guidance for health and disability staff to work collaboratively to identify areas of risk for individuals in hospital; agree on what additional supports are required to reduce the risks; and negotiate responsibility and resources for the provision of the agreed additional support.

It is important that this work is completed as soon as possible, and that there is a clear plan for:

- supporting health and disability services to implement the guideline and related policies; and
- monitoring the implementation of the guideline and evaluating its effectiveness.





# Part Two

## Monitoring our recommendations



# Agency progress against recommendations in our last report

## First aid

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

## Progress

ADHC has amended its *Health Care* policy to include a requirement that all ADHC operated and funded services have at least one person on each shift with a current first aid qualification. Compliance with the policy is a condition of the funding agreement between ADHC and the funded providers.

To help with compliance, ADHC made one-off payments to funded service providers to provide first aid training for staff and required them to be fully compliant with the first aid requirement within 18 months of 1 July 2009.

## Our comments

ADHC has taken significant action to ensure that there are consistent first aid requirements in ADHC operated and funded disability accommodation services. All accommodation services for people with disabilities are now required to have at least one person on each shift with a current first aid qualification – including licensed boarding houses.

The Youth and Community Services Regulation 2005 was amended on 1 September 2010. Under the 2010 Regulation, at least one staff member on duty must hold first aid qualifications.

Recommendations relating to the need for consistent first aid requirements have featured in our last four reports. We are pleased that this issue has now been addressed, and will continue to monitor first aid practice through our reviews.

## Swallowing and nutrition

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

## Progress

The *Ensuring Good Nutrition* policy is now known as the *Nutrition and Swallowing* policy. Evaluation of the policy was completed in May 2009, and ADHC has accepted all of the recommendations from the evaluation, in principle. Key findings included that:

- Training should be formalised, provided regularly, and have a practical focus, including 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.

- 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.
- Clearer guidance is required for staff about the relationship between the checklist and the manual and how to use the two resources to develop and review nutrition action plans, monitor client nutritional health, and respond to changes in height or weight.
- The use and accessibility of policy resources needs to be improved, including through redesign and location of the policy and its tools and resources in one document.
- Access to dietitians should be increased through the employment of additional dietitians by ADHC, and work with NSW Health and the Dietitians Association to increase capacity of dietitians in the mainstream health system.
- ADHC should collect data on key clinical indicators of nutritional health from supported accommodation and respite services, such as the number of choking incidents, hospitalisations for aspiration pneumonia, and number of people with diabetes.
- A survey of staff should be conducted to identify current practice, knowledge and use of resources for meal preparation and planning.

ADHC told us that it has revised the *Nutrition and Swallowing* policy and its tools, including the nutrition and swallowing checklist, and is in the process of updating and redesigning the *Nutrition in Practice* manual as a practice guide. The policy, tools and practice guide have been streamlined to make them easy to use by staff, and refocused to reflect a person-centred approach. The nutrition and swallowing checklist has been strengthened to create a clearer action pathway to respond to identified risks. ADHC has advised that the

final consultation of the revised policy will be completed by the end of 2011.

ADHC will integrate learning and development initiatives to support implementation of the policy, practice guide, and tools into the existing training strategy for ADHC operated accommodation and respite services.

In January 2009, through *Stronger Together*, ADHC engaged dietician services in each of its Regions to assist clients in accommodation services and the community to gain improved access to specialist clinical support regarding nutrition.

In relation to the chest care checklist, ADHC told us that the review of the *Health Care* policy in 2006-07 determined that a specific chest care checklist was unnecessary as both the nutrition and swallowing checklist and the CHAP tool include indicators of risk and symptoms checks related to chest care, and allow the client to be referred to a specialist, if required.

## Our comments

Advice from ADHC about the implementation and training strategy appears to apply only to ADHC operated accommodation and respite services, not funded services. Our reviews continue to identify compliance and quality problems with the *Nutrition and Swallowing* policy and use of the nutrition and swallowing risk checklist – particularly for people with disabilities living in funded services.

We are pleased to see a strong emphasis in the recommendations on staff training, and guidance on the relationship between the nutrition and swallowing risk checklist and the *Nutrition in Practice* manual. However, we have not seen draft versions of the revised documents, and it is not yet clear to us whether the proposed actions will address the issues consistently identified in our reviews.

We will continue to monitor this work.

# Licensed boarding houses

## Screening tool for entry

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

## Progress

The review of the screening tool has resulted in a revised tool and guidelines. Until 31 March 2010, Aged Care Assessment Teams (ACATs) conducted the screenings. On 1 April 2010, Home Care Referral and Assessment Centre (RAC) took over responsibility for conducting the screening tool for entry to licensed boarding houses.

The role of Home Care RAC staff is to screen people and then make appropriate recommendations. They are not expected to fill vacancies in licensed boarding houses or to take on the responsibility of finding accommodation for a person who has been screened and found not suitable for entry.

In April 2010, ADHC released 'A user's guide to the Screening Tool for Entry to Licensed Residential Centres' fact sheet. The fact sheet makes it clear that all new entrants to licensed residential centres must be screened to avoid inappropriate entry of people with high complex needs, and that there are no exceptions.

ADHC advised that it has made submissions to the Anti-Discrimination Board and Australian Human Rights Commission to amend the screening tool to allow anyone under the age of 18 years to be deemed unsuitable for entry into a licensed boarding house. In June 2011, ADHC also introduced new screening tool questions on nutrition and swallowing, to prevent the inappropriate entry of people who

have swallowing issues and are at risk of choking.

ADHC told us that reports of how many people have been assessed by the Home Care RAC, the numbers deemed eligible and not eligible, and reasons for decisions are maintained on a database.

## Our comments

Since 2005 we have recommended that ADHC undertake a review of the current application of the screening tool. There has been significant progress over that time, with review and revision of the tool and change in assessors.

We consider that moving responsibility for undertaking the screening to the Home Care RAC has the potential to improve the accuracy and consistency of the assessments.

This recommendation has been met. We will continue to monitor the application of the screening tool through our reviews.

## Identifying and addressing health needs and risks

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

## Progress

In March 2009, ADHC told us that the findings of the 2007 report would be considered in the broader context of an evaluation of the Primary and Secondary Health Care services.

By April 2011, Primary and Secondary Health Care services had been evaluated. ADHC indicated that the evaluation found that services are meeting their objectives and many clients are accessing services at a higher rate than the general population. ADHC told us that findings in the report include that:

- all residents are accessing GP services and most residents are also accessing psychiatric services and mental health teams on a regular basis;
- Primary and Secondary Health Care services are effective in reducing financial barriers for residents to access health services;
- there are some variations in service provision across and within ADHC regions;
- GPs were often reluctant to use all Medicare Enhanced Primary Care item numbers fully, perhaps because of a perception of over servicing, lack of practice nurses or lack of available time; and
- transport is a potential barrier for access to health services for some areas.

Recommendations include:

- expanding the range of Primary and Secondary Health Care services provided to include allied health services outside traditional GP and psychiatric/ mental health services;
- developing a statewide model of Primary and Secondary Health Care service provision that reflects best practice service provision and is consistent across the state;
- developing a reporting system for all Primary and Secondary Health Care funding that provides ADHC with feedback on expenditure by service type; and
- developing a framework that ensures that all residents have an individual health plan developed by a community nurse, which is reviewed annually in conjunction with a GP to ensure that all services provided are in response to the individual's identified needs.

ADHC told us that implementing the recommendations from the evaluation will substantially address the findings and recommendations of the 2007 review of the health needs of licensed boarding house residents in the inner west area of Sydney.

A consultant is expected to commence the work in August 2011, with the aim to have all recommendations in the report implemented by 1 July 2012, when the current funding arrangements are due to expire.

## Our comments

The 2007 review of the health needs of licensed boarding house residents in the inner west area of Sydney highlighted significant gaps in the assessment and provision of health care to residents in that region, and made seven recommendations to ADHC to improve health outcomes. The recommendations included:

- developing an ongoing process to implement health care plans;
- developing a system to provide a comprehensive health assessment and follow-up to new residents;
- developing a systematic approach to recurrent health screening; and
- undertaking health promotion activities that respond to the lifestyle issues of licensed boarding house residents, including smoking cessation, medication management, dental health, asthma medication, exercise and good nutrition, and sun protection.

Our report has identified a range of concerns about access of people in licensed boarding houses to health specialists, vaccination, medication reviews, and health programs and initiatives such as chronic disease management and smoking cessation programs. Our reviews have highlighted the need for proactive and cooperative work to support residents in managing weight and nutrition, and increasing physical activity.

We consider that implementation of the recommendations from the Primary and Secondary Health Care services evaluation has the potential to address the issues and recommendations from the 2007 review and the



concerns noted in our report. Given the potential significance of this work in improving the health outcomes for people living in licensed boarding houses, it is important that we continue to monitor ADHC's actions in this regard.

## Administration of regular prescribed medication

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

## Progress

One of the key changes in the 2010 YACS Regulation is the additional provision relating to the administration of prescribed medications. Section 11(4) of the regulation requires that:

*'any prescription medication of a resident:*

- a) *must, if it is practicable to do so, be separated by a registered pharmacist into individual doses in a blister pack and be clearly marked so as to identify the resident, and*
- b) *must be administered directly to the resident and a record of that administration be retained.'*

To promote good practice standards within licensed boarding houses in the administration of regular medication, ADHC has also:

- revised the Licensed Residential Centre Licensing and Monitoring policy manual, clarifying the requirements of administration of medication; and
- developed a Compliance Practice Guide to support licensing officers and licensed boarding house staff in interpreting the 2010 YACS Regulation, including

the administration and recording of prescription medications.

In June 2011, ADHC provided a two-day training workshop for ADHC licensing officers and case managers to ensure a consistent approach to the monitoring of licensed boarding houses for compliance with the licence conditions and YACS regulations. A module provided at this workshop covered best practice in administering medications.

## Our comments

The introduction of the new regulation effectively addresses our recommendation. There are now requirements relating to the administration and recording of both regular and PRN prescription medications.

We will monitor the implementation of this requirement through our reviews.

## Record keeping and guidance

### 6. ADHC should report on progress towards:

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

## Progress

ADHC has advised that the licence conditions relating to record keeping have been substantially transferred to the 2010 regulation. As a result of the introduction of new regulations, the licence conditions are now legally enforceable.

In January 2011, ADHC released a Compliance Practice Guide for the YACS Regulation 2010. In relation to record keeping, the practice guide provides templates for proprietors to use to record medication administration, the register of resident information, and contact details.

## Our comments

The record keeping requirements of licensed boarding house operators are now enforceable by ADHC, and the Compliance Practice Guide provides templates for operators to fulfil the requirements. Changes to the requirements have been minimal – with the exception of the additional requirement to record administration of regular prescription medications.

We will monitor compliance with the record keeping requirements through our reviews.

## Review of the *Youth and Community Services Act 1973*

### 7. ADHC should provide detailed advice regarding action taken by the Interdepartmental Committee on Reform of the Private Residential Services Sector to:

- a) develop a work plan to progress the reforms;
- b) progress the review of the *Youth and Community Services Act 1973*; and
- c) develop a policy framework.

## Progress

ADHC has told us that the Interdepartmental Committee (IDC) has explored a range of options for reform of the industry, from introducing new and comprehensive legislation for the boarding house industry with either a system of accreditation or registration through to a 'no change' option.

In December 2010, Cabinet considered a Cabinet Minute and high level Options Paper, and asked the IDC to undertake targeted consultations with key stakeholders to test the options, with a view to developing a direction for reform of the sector for consideration by government. In 2011, ADHC engaged a consultant to undertake the stakeholder consultations.

To assist the consultations, the IDC released a discussion paper on boarding house reform, seeking comment and potential solutions to a range of issues it has identified, including the complex legislative framework, the lack of occupancy rights and responsibilities, and access to support for residents who need extra assistance.

The discussion paper indicates that the IDC's preferred option is to have:

- a consistent regulatory framework in the form of new legislation;
- a differential registration system for boarding houses that takes into account the differing needs of clients;
- the introduction of a legislative requirement for a principles-based approach to occupancy rights and responsibilities for all boarding houses;
- accommodation and operational standards for all boarding houses contained in one key piece of legislation specific to boarding houses where this is appropriate and feasible;
- service standards for proprietors providing accommodation services to vulnerable residents;
- appropriate incentives to assist boarding house proprietors to remain viable; and
- greater engagement from the non-government sector in providing services to boarding house residents.

In June 2011, the IDC submitted a report to government relating to the consultations.

## Our comments

We are pleased to see progress in relation to potential reform of the broader boarding house sector. However, we are aware that consultations have previously been undertaken on reform of the sector, and this work did not progress beyond a report. It is critical that, this time, broad ranging reform

is achieved to deliver real and improved outcomes for people living in licensed and unlicensed boarding houses.

Against this background, in August 2011 we tabled a special report in Parliament on this topic, titled: *More than board and lodging: the need for boarding house reform*. The report is available for download on our website.

Given the importance of legislative change and broader reform in improving outcomes for people with disabilities living in licensed boarding houses, we will continue to monitor the progress of the work of ADHC and the IDC in this area.

## Palliative care

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

### Progress

ADHC's action plan from the revision of the *Palliative Care* policy indicates that the agency will:

- develop an education and training plan for operated and funded services;
- explore options for providing formal clinical nurse consultant support to ADHC operated group homes;
- examine recommendations in relation to interagency roles and responsibilities regarding effective development and implementation of Palliative Care Plans, with particular reference to formal partnerships, and links to the NSW Health *People with a Disability: Responding to Needs During Hospitalisation* policy;
- develop an information kit regarding death and dying and palliative care in formats that are appropriate for clients, families and carers, other residents, and staff; and

- develop guidelines that clarify policy requirements relating to end-of-life decisions, not-for-resuscitation orders, and advance care planning.

ADHC told us that, overall, the evaluation findings indicate that the policy is consistent with the NSW Health Palliative Care Framework. Following the evaluation, the policy is being revised to align with *Standards for Providing Quality Palliative Care for all Australians* developed by the Council of Palliative Care Australia.

In addition to the Palliative Care Plan, the revised policy will include a tool to help staff identify and manage pain. The practice guide will include resources to support the dying and bereavement process for clients and their families. The final policy and practice guide will be repositioned under the broader health and wellbeing policy framework that is being developed as part of the *Health Care* policy review. The final consultations on the revised policy will be completed by the end of 2011.

ADHC is liaising with staff from the Program of Experience in the Palliative Approach (PEPA) to arrange education workshops for Regional staff in 2011. The workshops aim to:

- raise awareness of the palliative approach;
- increase knowledge and skills; and
- build and develop professional local networks between specialist palliative care providers and other service sectors including disability.

PEPA will also be liaising with National Disability Services to set up similar workshops for funded accommodation support services.

### Our comments

There has been considerable progress in relation to this recommendation, including the development of improved guidance for staff. As many of the actions are still in train, we will continue to monitor ADHC's work in this area.

## Implementation of ADHC's Health Care policy

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

### Progress

ADHC has advised that it plans to review the *Health Care* policy in 2011/12 and will draft a discussion paper by the end of August 2011 to inform the scope of the review. ADHC told us that issues around coordinated health care management, including referral pathways, clinical management pathways, and information management between and within the health and disability sectors will be examined during the review.

As part of the *Health Care* policy review, a broader health and wellbeing policy framework will be developed. Identifying the need for, and improving access to, mainstream and specialist health support services for people in supported accommodation will be explored as part of that framework.

### Our comments

ADHC has met the recommendation. We will monitor ADHC's actions to review the policy.

## People with disabilities who are ageing

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

making and the delivery of services when working with ageing people with disabilities.

### Progress

In July 2009, ADHC told us that it was developing an overarching statement/ position on ageing, within a person-centred planning framework. Further operational policy needs were to be assessed once this statement was finalised. The draft statement was expected to be completed by the end of July 2009.

In May 2010, ADHC commissioned a major project, *Ageing in Place: Impacts on Accommodation Services*, to develop and implement an evidence-based action plan to better meet the needs of people with a disability who are ageing. The initiative includes extensive consultation across the sector to get recommendations on how services provided by ADHC can be improved for people with disability who are ageing.

Findings from this work will inform the future development of the accommodation support system to ensure that supports specifically suited for people with a disability who are ageing are developed.

The project will be completed in September 2011, and will inform future planning and service development under *Stronger Together: The second phase*. The resultant recommendations will be developed into an Action Plan with a clear justification and outline of new policy direction to re-orient services to allow clients to age in place.

ADHC has told us that, while this research will inform a formal policy position, the agency currently supports people with a disability who are ageing to stay in their most appropriate accommodation option, using generic community supports where appropriate.

ADHC has also advised that there are two pilot projects planned through the *Stronger Together: the second phase* accommodation program that

have an ageing in place component, involving RASAIID and Macleay Options.

## Our comments

The recommendation has not yet been met, but ADHC has commenced key work to inform a formal policy position. We will continue to monitor ADHC's actions in this area.

## Access to health services for people with dual diagnosis

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

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

## Progress

ADHC funds and oversees the University Chair and the Advanced Psychiatric Fellowships in Intellectual Disability Mental Health. Associate Professor Julian Trollor has held the Chair at the University of NSW since February 2009.

During 2010, Associate Professor Trollor led a series of two-day training workshops in one (former) Area Health Service, providing mental health staff with a comprehensive introduction to Intellectual Disability Mental Health (IDMH). Five training modules each for the introductory and advanced IDMH workshops were developed. NSW Health has advised that this project, and its evaluation, continues to

provide the basis for further staff development in IDMH for mental health clinicians across the NSW Health system.

Three Fellowships have been awarded, including one that has been completed. The process is overseen by a committee that is chaired by the Executive Director, Office of the Senior Practitioner in ADHC, and includes Associate Professor Trollor and a number of other psychiatrists, representing the Institute of Psychiatry, Child and Adolescent Psychiatry and Forensic Mental Health.

The Memorandum of Understanding (MOU) and guidelines for the provision of services to people with an intellectual disability and a mental illness was released in January 2011. The MOU commits both NSW Health and ADHC to work in cooperation to promote a safe and coordinated system of care for people with intellectual disability and a mental illness.

The policy directive sets out operational requirements in each Local Health District and all Mental Health Services are required to work in collaboration with ADHC staff to:

- establish local area/ regional joint forums to assist in the implementation and ongoing facilitation of the MOU;
- develop local protocols detailing the precise mechanisms by which each agency will request the involvement of the other for acute care and immediate response; and
- provide resolution to any dispute that may arise and identifies the mechanism for escalation on issues that cannot be resolved via the local forum.

NSW Health has advised that an Intellectual Disability Mental Health Working Group was instrumental in developing the MOU, and monitors its implementation. The working group will also evaluate the MOU 18 months after the date of commencement. ADHC and NSW Health mental health services are currently developing the detailed implementation arrangements for the MOU.



## Our comments

NSW Health has met this recommendation. However, given the longstanding issues for people with an intellectual disability and mental illness relating to access to appropriate and coordinated support, we will continue to monitor the work of NSW Health and ADHC in this area.

We note that, while the MOU was released in January 2011, the arrangements to support implementation of the MOU by ADHC and Health staff are not yet clear.

## Health service framework for people with intellectual disability

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

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

### Progress

NSW Health has advised that it is in the early stages of development of Tiers 4 and 5 of the service framework.

Tier 4 refers to the provision of specialised health services capable of better assessing, treating and managing the health needs of people with intellectual disability and is being implemented through a small Specialised Clinical Service Pilot based in the Illawarra area.

Tier 5 refers in part to the establishment of an Agency for Clinical Innovation (ACI) Network on Intellectual Disability that will develop links

to, and collaborate with, relevant individuals and organisations to achieve:

- a coordinated statewide approach in clinical leadership to improve health service delivery for people with intellectual disability;
- the development of specific initiatives to implement change in areas such as standardised treatment protocols, models of care and service benchmarks;
- a forum for clinical leadership in which clinicians, relevant government and non-government groups and consumers determine future directions for health care for people with intellectual disability across the age span through interagency agreements and partnerships; and
- improvements in education, research, and the safety and quality of service provision.

NSW Health has advised that the Network will work closely with the Tier 4 Pilot Clinical Service in undertaking and fostering collaborative research to enhance the evidence base for best practice.

In 2010/11, recurrent funding of \$0.5M per annum was allocated to NSW Health to implement the two projects (Tier 4 and Tier 5).

The Illawarra Shoalhaven Intellectual Disability Health Pilot proposal by the South Eastern Sydney Local Health District was approved. NSW Health has told us that two other EOI proposals have been placed on a ranked eligibility list to pilot additional Clinical Services, should further funding become available. NSW Health has advised that it has made a submission for further funding for additional pilot services.

NSW Health has advised that an independent evaluation of the effectiveness of the Pilot Clinical Service will occur at the end of 2013 and, if determined a success, further services are expected to be established across the State.



A Network Manager has been appointed to the ACI Network on Intellectual Disability, and a Network Steering Committee has been established to oversee this strategy.

## **Our comments**

There has been significant progress in relation to the service framework to improve health care for people with intellectual disabilities. The pilot Specialised Clinical Service and the ACI Network on Intellectual Disability have been awarded, and are in the early stages of commencement.

NSW Health's website includes information about the Network, and limited information on the Specialised Clinical Service pilot. However, the overall service framework to improve the health care of people with intellectual disabilities is not available on the department's website. It is important that the framework underpinning the pilot clinical service and the Network is publicly available.

While NSW Health has indicated that it has made a submission for further funding for additional pilot services, it is not clear how many additional pilot services this relates to, and whether it is aimed at replicating or changing the model and size of the pilot currently underway in the Illawarra area.

The implementation of parts of the service framework to improve the health care of people with intellectual disabilities is in its early stages. Given the significance of this work, we will continue to monitor.



# Part Three

## Analysis of causes of deaths 2003 – 2009

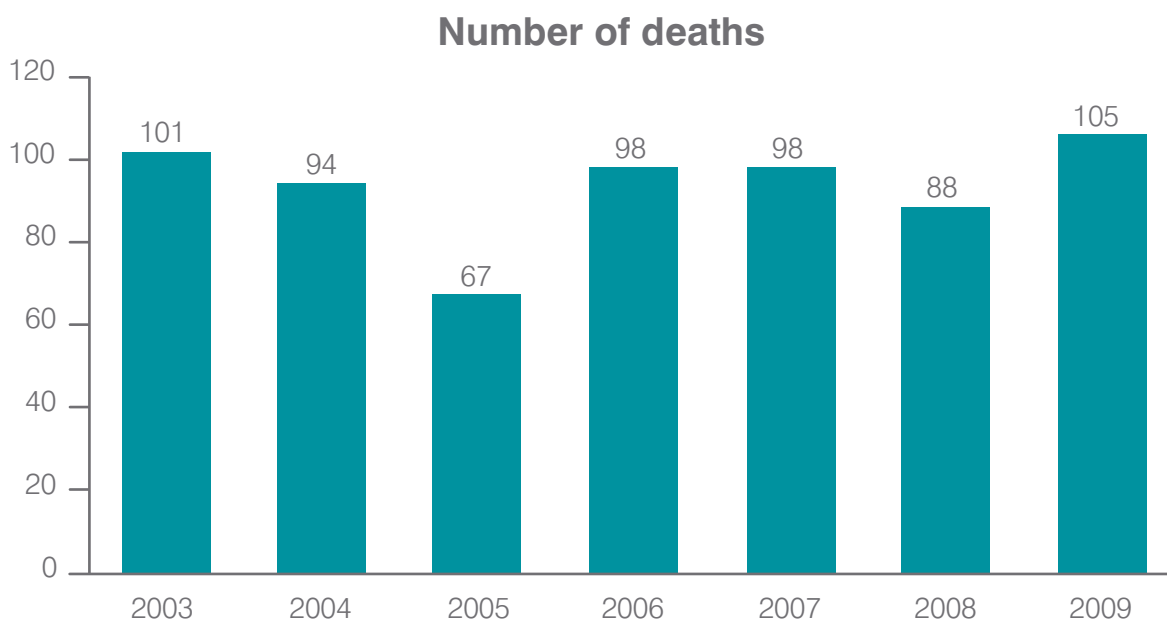


# 5 Causes of death 2003 – 2009

## 5.1 Introduction

Between 2003 and 2009, the deaths of 651 people with disabilities in care were reviewable. At the time of writing this report, we had the final cause of death for 642 people.

**Table 9: Reviewable deaths per year 2003-09**



In 2010, we engaged the National Centre for Health Information Research and Training (NCHIRT), based in the Queensland University of Technology, to analyse underlying causes of death for all deaths of people with disabilities in care in NSW from 2003 to 2009.

The main reason we sought this analysis was to gain a better understanding of the range of factors that may contribute to particular causes of death, to inform our future work and to identify issues that warrant specific focus.

We have used the initial analysis and data reports provided by the NCHIRT and undertaken further analysis of the leading causes of death of people in disability services and licensed boarding houses.

## 5.2 Underlying causes of death

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>31</sup>

<sup>31</sup> 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.

## Broad underlying causes of death

- The vast majority of people with disabilities in care (569 people; 89%) died from natural causes.
- Sixty-six people (10%) died from unnatural unintentional or undetermined causes.<sup>32</sup> This included 55 people in disability services (11%) and 11 people in licensed boarding houses (9%).
- Seven people (1%) died from unnatural intentional causes, such as suicide. The majority of those (6) were licensed boarding house residents.

## 5.3 Leading underlying causes of death

### 5.3.1 Leading underlying causes of death of people with disabilities in care

As indicated in table 10, the leading cause of the deaths in 2003-09 of people with disabilities in care was circulatory system disease (122 people; 19%). Other main causes of death were cancers (101 people; 16%); nervous system diseases (99 people; 15%); and respiratory diseases (92 people; 14%).

**Table 10: Service type and gender by underlying cause of death ICD Chapter**

UCOD	Licensed BH				Disability services							
	Female		Male		Total		Female		Male		Total	
Infectious (A00-B99)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>	6	(3.0)	7	(2.2)	<b>13</b>	<b>(2.5)</b>
Neoplasms (C00-D48)	5	(20.0)	15	(15.6)	<b>20</b>	<b>(16.5)</b>	28	(13.9)	53	(16.6)	<b>81</b>	<b>(15.5)</b>
Blood (D50-D89)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>	1	(0.5)	1	(0.3)	<b>2</b>	<b>(0.4)</b>
Endocrine (E00-E90)	0	(0.0)	1	(1.0)	<b>1</b>	<b>(0.8)</b>	3	(1.5)	5	(1.6)	<b>8</b>	<b>(1.5)</b>
Mental (F00-F99)	0	(0.0)	3	(3.1)	<b>3</b>	<b>(2.5)</b>	4	(2.0)	1	(0.3)	<b>5</b>	<b>(1.0)</b>
Nervous system (G00-G99)	0	(0.0)	3	(3.1)	<b>3</b>	<b>(2.5)</b>	39	(19.4)	57	(17.8)	<b>96</b>	<b>(18.4)</b>
Circulatory (I00-I99)	10	(40.0)	40	(41.7)	<b>50</b>	<b>(41.3)</b>	24	(11.9)	48	(15.0)	<b>72</b>	<b>(13.8)</b>
Respiratory (J00-J99)	6	(24.0)	11	(11.5)	<b>17</b>	<b>(14.0)</b>	27	(13.4)	48	(15.0)	<b>75</b>	<b>(14.4)</b>
Digestive (K00-K93)	1	(4.0)	5	(5.2)	<b>6</b>	<b>(5.0)</b>	13	(6.5)	23	(7.2)	<b>36</b>	<b>(6.9)</b>
Skin (L00-L99)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>	1	(0.5)	0	(0.0)	<b>1</b>	<b>(0.2)</b>
Muscle (M00-M99)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>	1	(0.5)	0	(0.0)	<b>1</b>	<b>(0.2)</b>
Genitourinary (N00-N99)	0	(0.0)	2	(2.1)	<b>2</b>	<b>(1.7)</b>	5	(2.5)	8	(2.5)	<b>13</b>	<b>(2.5)</b>
Perinatal (P00-P96)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>	2	(1.0)	1	(0.3)	<b>3</b>	<b>(0.6)</b>
Congenital (Q00-Q99)	0	(0.0)	1	(1.0)	<b>1</b>	<b>(0.8)</b>	23	(11.4)	31	(9.7)	<b>54</b>	<b>(10.4)</b>
Unclassified (R00-R99)	0	(0.0)	1	(1.0)	<b>1</b>	<b>(0.8)</b>	2	(1.0)	2	(0.6)	<b>4</b>	<b>(0.8)</b>
Injury (S00-T98)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>	0	(0.0)	1	(0.3)	<b>1</b>	<b>(0.2)</b>
External causes (V01-Y98)	3	(12.0)	14	(14.6)	<b>17</b>	<b>(14.0)</b>	22	(10.9)	34	(10.6)	<b>56</b>	<b>(10.7)</b>
<b>Total</b>	<b>25</b>	<b>(100)</b>	<b>96</b>	<b>(100)</b>	<b>121</b>	<b>(100)</b>	<b>201</b>	<b>(100)</b>	<b>320</b>	<b>(100)</b>	<b>521</b>	<b>(100)</b>

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.

<sup>32</sup> Deaths from unnatural unintentional causes are those due to unintentional external causes such as accidents and complications of medical and surgical care.

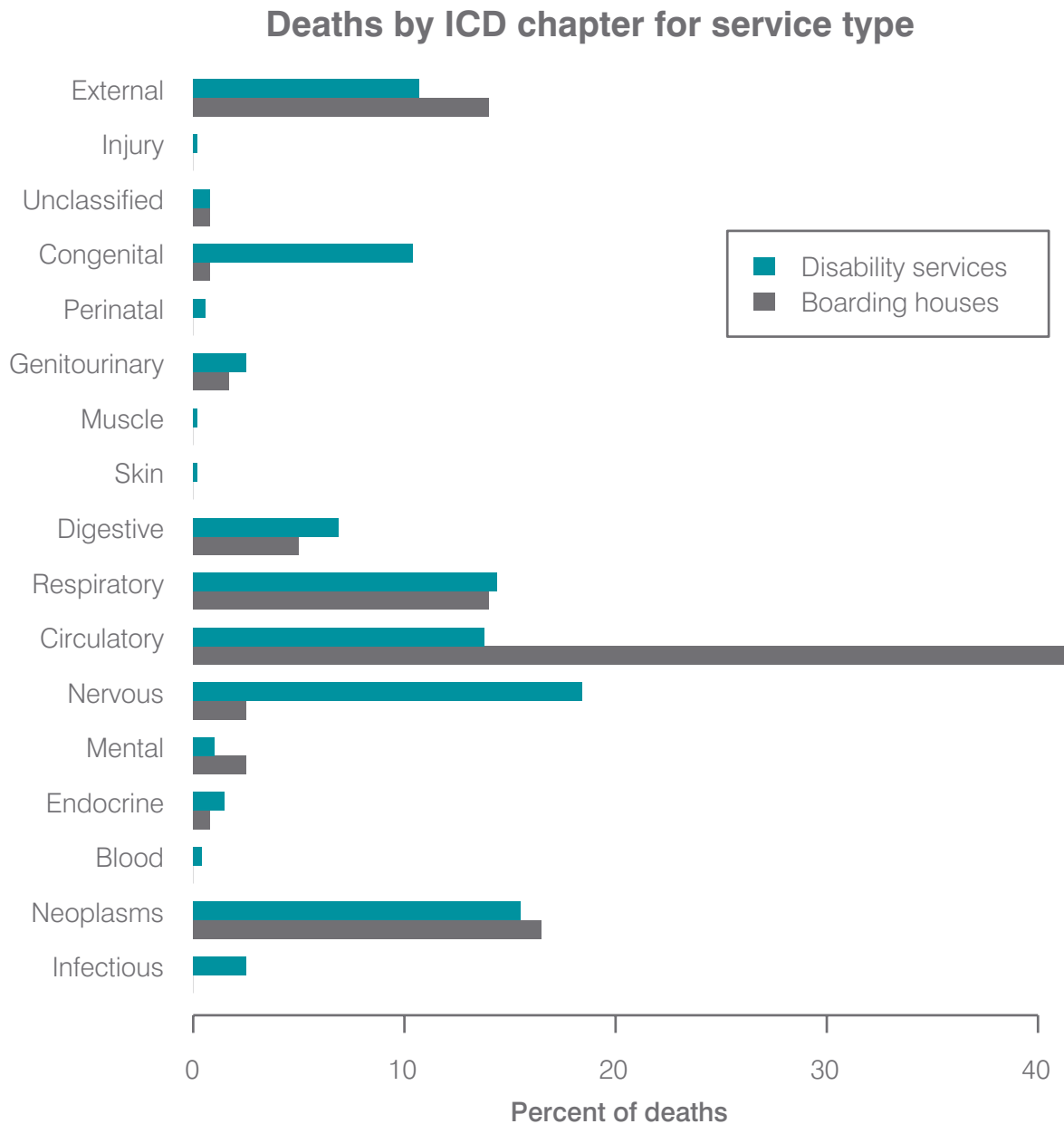


### 5.3.2 Leading underlying causes of death of people in disability services

The leading underlying causes of death of people in disability services in 2003-09 were:

1. **Nervous system diseases** (96 people; 18%) – primarily epilepsy (38 people; 7%) and cerebral palsy (34 people; 7%);
2. **Neoplasms** (81 people; 16%) – mainly cancer of the trachea, bronchus and lung (17 people; 3%) and colon cancer (11 people; 2%);
3. **Respiratory diseases** (75 people; 14%) – mainly aspiration (29 people; 6%), pneumonia (23 people; 4%) and chronic lower respiratory diseases (16 people; 3%);
4. **Circulatory diseases** (72 people; 14%) – primarily ischaemic heart disease (32 people; 6%);
5. **External causes** (56 people; 11%) – mainly choking (12 people; 2%); and
6. **Congenital causes** (54 people; 10%) – primarily Down syndrome (26 people; 5%).

**Table 11: Underlying causes of death of people with disabilities in care 2003-09**



### 5.3.3 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** (50 people; 41%) – primarily ischaemic heart diseases (33 people; 27%);
2. **Neoplasms** (20 people; 17%) – mainly cancer of the trachea, bronchus and lung (6 people; 5%);
3. **Respiratory diseases** (17 people; 14%) – primarily chronic lower respiratory diseases

(9 people; 7%); and

4. **External causes** (17 people; 14%) – mainly intentional self-harm (5 people; 4%).

## 5.4 Underlying cause of death and gender

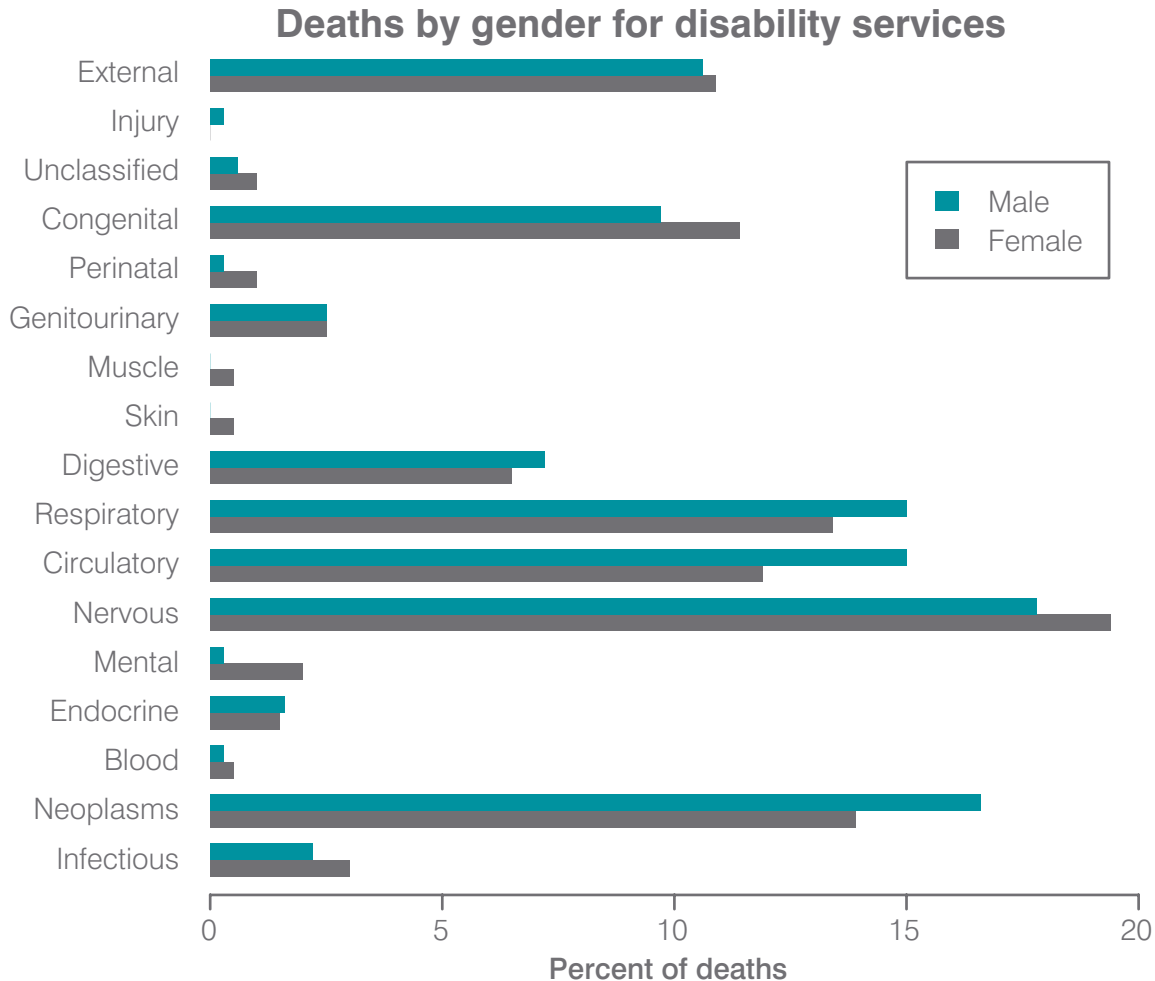
Table 10 also outlines the underlying causes of death, by gender. The leading causes of death of females were largely consistent with the leading causes for males, particularly in disability services.

### 5.4.1 People in disability services

The leading causes of death for both females and males in disability services were diseases of the nervous system, followed by cancers and respiratory diseases. For males in disability services, circulatory diseases were the equal third leading underlying cause of death.

As indicated in table 12, in disability services, a greater proportion of males than females died from cancer, respiratory diseases and circulatory diseases. A higher proportion of females were represented in deaths from nervous system diseases and congenital factors.

**Table 12: Underlying causes of death of people in disability services by gender**

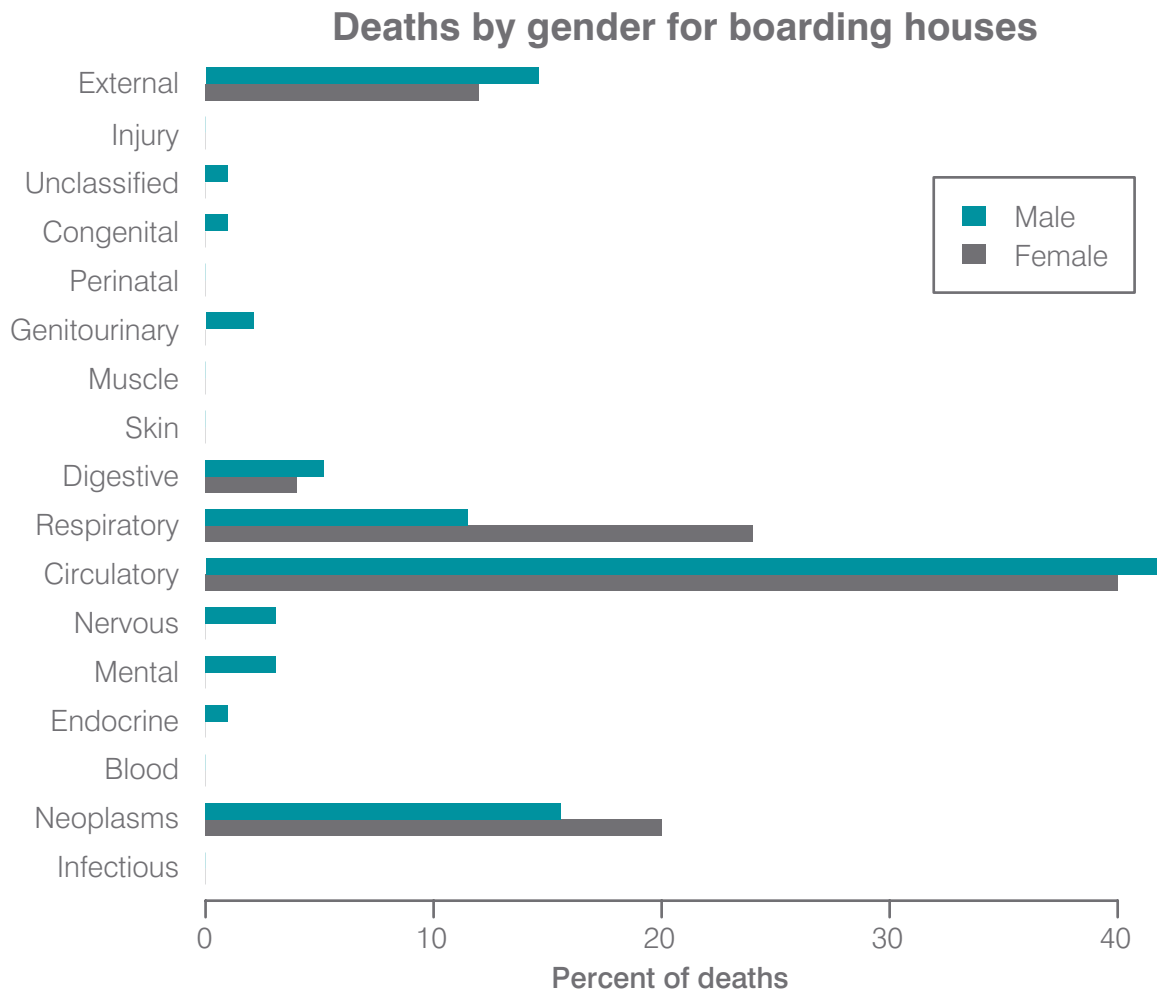


## 5.4.2 People in licensed boarding houses

The leading cause of death for both females and males in licensed boarding houses was circulatory system disease. For females, the other main underlying causes of death were respiratory diseases and cancers. For males, the other main causes of death were cancers and external causes.

As indicated in table 13, a higher proportion of males were represented in all causes except for respiratory diseases and cancer.

**Table 13: Underlying cause of death of licensed boarding house residents by gender**



## 5.5 Age and cause of death

In both disability services and licensed boarding houses, circulatory diseases were the leading underlying cause of death for people over 65 years of age. Below 65 years, there were key differences in the main causes of death between the two populations.

### 5.5.1 People in disability services

As indicated in table 14, nervous system diseases were the leading cause of death of people in disability services up to the age of 44 years. Between 45 and 64 years of age, cancer was the leading cause of death. Circulatory disease was the leading cause of death for people in disability services aged over 65 years.

Of the leading causes of death, people in disability services had a younger median age at death from diseases of the nervous system (42 years) and congenital factors (44 years). People who died from circulatory disease had the oldest median age at death – 64.5 years.

**Table 14: Underlying causes of death of people in disability services by age group**

Disability services	≤ 14 years		15-24 years		25-44 years		45-54 years		55-64 years		≥ 65 years		Total	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Infectious (A00-B99)	0	(0.0)	1	(2.9)	3	(2.3)	5	(4.2)	2	(2.0)	2	(1.5)	13	(2.5)
Neoplasms (C00-D48)	0	(0.0)	0	(0.0)	11	(8.6)	21	(17.8)	23	(23.5)	26	(19.1)	81	(15.6)
Blood (D50-D89)	0	(0.0)	0	(0.0)	2	(1.6)	0	(0.0)	0	(0.0)	0	(0.0)	2	(0.4)
Endocrine (E00-E90)	1	(16.7)	0	(0.0)	1	(0.8)	2	(1.7)	2	(2.0)	2	(1.5)	8	(1.5)
Mental (F00-F99)	0	(0.0)	1	(2.9)	0	(0.0)	2	(1.7)	1	(1.0)	1	(0.7)	5	(0.9)
Nervous system (G00-G99)	3	(50.0)	17	(48.6)	35	(27.3)	20	(16.9)	11	(11.2)	10	(7.4)	96	(18.4)
Circulatory (I00-I99)	0	(0.0)	2	(5.7)	9	(7.0)	15	(12.7)	10	(10.2)	36	(26.5)	72	(13.8)
Respiratory (J00-J99)	0	(0.0)	6	(17.1)	14	(10.9)	15	(12.7)	13	(13.3)	27	(19.9)	75	(14.4)
Digestive (K00-K93)	0	(0.0)	1	(2.9)	8	(6.3)	14	(11.9)	8	(8.2)	5	(3.7)	36	(6.9)
Skin (L00-L99)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	1	(0.7)	1	(0.2)
Muscle (M00-M99)	0	(0.0)	1	(2.9)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	1	(0.2)
Genitourinary (N00-N99)	0	(0.0)	0	(0.0)	4	(3.1)	4	(3.4)	1	(1.0)	4	(2.9)	13	(2.5)
Perinatal (P00-P96)	0	(0.0)	0	(0.0)	2	(1.6)	0	(0.0)	1	(1.0)	0	(0.0)	3	(0.6)
Congenital (Q00-Q99)	2	(33.3)	4	(11.4)	23	(17.9)	11	(9.3)	11	(11.2)	3	(2.2)	54	(10.4)
Unclassified (R00-R99)	0	(0.0)	0	(0.0)	0	(0.0)	2	(1.7)	0	(0.0)	2	(1.5)	4	(0.8)
Injury (S00-T98)	0	(0.0)	1	(2.9)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	1	(0.2)
External causes (V01-Y98)	0	(0.0)	1	(2.9)	16	(12.5)	7	(5.9)	15	(15.3)	17	(12.5)	56	(10.8)
<b>Total</b>	<b>6</b>	<b>(100)</b>	<b>35</b>	<b>(100)</b>	<b>128</b>	<b>(100)</b>	<b>118</b>	<b>(100)</b>	<b>98</b>	<b>(100)</b>	<b>136</b>	<b>(100)</b>	<b>521</b>	<b>(100)</b>

### 5.5.2 People in licensed boarding houses

As indicated in table 15, for people in licensed boarding houses, circulatory disease was the leading cause of death across all age groups.

Deaths due to external causes occurred most often between 25 and 54 years of age. Licensed boarding house residents who died

from cancer or respiratory disease tended to be 55 years of age and older.

Of the leading causes of death, people in licensed boarding houses had a younger median age at death from diseases of the nervous system (47 years) and external causes (54 years) than other causes. People who died from respiratory diseases had the oldest median age at death – 72 years.

**Table 15: Underlying causes of death of people in licensed boarding houses by age group**

Licensed BH	25-44 years		45-54 years		55-64 years		Over 65 years		Total	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Infectious (A00-B99)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>
Neoplasms (C00-D48)	1	(9.1)	3	(13.6)	9	(30.0)	7	(12.1)	<b>20</b>	<b>(16.5)</b>
Blood (D50-D89)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>
Endocrine (E00-E90)	0	(0.0)	0	(0.0)	0	(0.0)	1	(1.7)	<b>1</b>	<b>(0.8)</b>
Mental (F00-F99)	0	(0.0)	2	(9.1)	1	(3.3)	1	(1.7)	<b>4</b>	<b>(3.3)</b>
Nervous system (G00-G99)	1	(9.1)	1	(4.6)	0	(0.0)	1	(1.7)	<b>3</b>	<b>(2.5)</b>
Circulatory (I00-I99)	4	(36.4)	8	(36.4)	12	(40.0)	26	(44.8)	<b>50</b>	<b>(41.3)</b>
Respiratory (J00-J99)	1	(9.1)	0	(0.0)	4	(13.3)	12	(20.7)	<b>17</b>	<b>(14.1)</b>
Digestive (K00-K93)	1	(9.1)	1	(4.6)	1	(3.3)	3	(5.2)	<b>6</b>	<b>(4.9)</b>
Skin (L00-L99)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>
Muscle (M00-M99)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>
Genitourinary (N00-N99)	0	(0.0)	0	(0.0)	1	(3.3)	1	(1.7)	<b>2</b>	<b>(1.7)</b>
Perinatal (P00-P96)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>
Congenital (Q00-Q99)	0	(0.0)	0	(0.0)	0	(0.0)	1	(1.7)	<b>1</b>	<b>(0.8)</b>
Unclassified (R00-R99)	0	(0.0)	1	(4.6)	0	(0.0)	0	(0.0)	<b>1</b>	<b>(0.8)</b>
Injury (S00-T98)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	<b>0</b>	<b>(0.0)</b>
External causes (V01-Y98)	3	(27.3)	6	(27.3)	2	(6.7)	5	(8.6)	<b>16</b>	<b>(13.2)</b>
<b>Total</b>	<b>11</b>	<b>(100)</b>	<b>22</b>	<b>(100)</b>	<b>30</b>	<b>(100)</b>	<b>58</b>	<b>(100)</b>	<b>121</b>	<b>(100)</b>

## 5.6 Cause of death comparison with general population

### 5.6.1 Comparison of leading causes of death

In the general population, the majority of people who die are 65 years of age and older. For example, in Australia in 2008, 81.6 per cent of people who died were aged 65 years and older.<sup>33</sup>

This was not the case for the people with disabilities in care who died between 2003 and 2009. Almost three-quarters of the people in disability services who died (391 people) and more than half of the people in licensed boarding houses (64 people) were younger than 65 years of age. More than half of the

people in disability services were younger than 55 years of age.

Table 16 provides a comparison of the main causes of death by age group of people in licensed boarding houses, disability services, and the general population.

The greatest similarity in the leading causes of death between people with disabilities in care and the general population occurred in the 65 years and older age bracket, where diseases of the circulatory system were the leading cause of death.

Respiratory disease featured as a leading cause of death of people in disability services from an early age. In the general population, respiratory diseases did not feature as a leading cause of death until 65 years of age and above.

<sup>33</sup> Australian Bureau of Statistics (2010) 3303.0 – Causes of Death, Australia, 2008

**Table 16: Leading causes of death of people with disabilities in care and general population by age group 2003-09**

Age	Licensed BH	Disability services	General population <sup>34</sup>
0-14 years		7 deaths (1%): <ul style="list-style-type: none"> <li>Nervous (n=3 – 43%)</li> <li>Congenital (n=2 – 29%)</li> <li>Endocrine (n=1 – 14%)</li> </ul>	<ul style="list-style-type: none"> <li>Perinatal conditions 33%</li> <li>Congenital 15%</li> <li>External causes 9%</li> </ul>
15-24 years		35 deaths (7%): <ul style="list-style-type: none"> <li>Nervous (n=17 – 49%)</li> <li>Respiratory (n=6 – 17%)</li> <li>Congenital (n=4 – 11%)</li> </ul>	<ul style="list-style-type: none"> <li>External causes 65%</li> <li>Neoplasms 5%</li> </ul>
25-44 years	11 deaths (9%): <ul style="list-style-type: none"> <li>Circulatory (n=4, 36%)</li> <li>External causes (n=3 – 27%)</li> </ul>	130 deaths (25%): <ul style="list-style-type: none"> <li>Nervous (n=35 – 27%)</li> <li>Congenital (n=22 – 17%)</li> <li>External causes (n=16 – 12%)</li> <li>Respiratory (n=14 – 11%)</li> </ul>	<ul style="list-style-type: none"> <li>External causes 40%</li> <li>Neoplasms 16%</li> <li>Circulatory 11%</li> </ul>
45-54 years	22 deaths (18%): <ul style="list-style-type: none"> <li>Circulatory (n=8 – 36%)</li> <li>External causes (n=6 – 27%)</li> <li>Neoplasms (n=2 – 9%) / Mental and behavioural</li> </ul>	119 deaths (23%): <ul style="list-style-type: none"> <li>Neoplasms (n=21 – 18%)</li> <li>Nervous (n=19 – 16%)</li> <li>Respiratory (n=16 – 13%)</li> <li>Circulatory (n=15 – 13%)</li> </ul>	<ul style="list-style-type: none"> <li>Neoplasms 33%</li> <li>Circulatory 19%</li> <li>External causes 11%</li> </ul>
55-64 years	31 deaths (25%): <ul style="list-style-type: none"> <li>Circulatory (n=12 – 39%)</li> <li>Neoplasms (n=9 – 29%)</li> <li>Respiratory (n=4 – 13%)</li> <li>External causes (n=2 – 7%)</li> </ul>	100 deaths (19%): <ul style="list-style-type: none"> <li>Neoplasms (n=23 – 23%)</li> <li>External causes (n=14 – 14%)</li> <li>Respiratory (n=13 – 13%)</li> <li>Congenital (n=11 – 11%)</li> </ul>	<ul style="list-style-type: none"> <li>Neoplasms 43%</li> <li>Circulatory 22%</li> </ul>
65+ years	58 deaths (48%): <ul style="list-style-type: none"> <li>Circulatory (n=26 – 45%)</li> <li>Respiratory (n=12 – 21%)</li> <li>Neoplasms (n=7 – 13%)</li> <li>External causes (n=5 – 7%)</li> </ul>	138 deaths (26%): <ul style="list-style-type: none"> <li>Circulatory (n=36 – 26%)</li> <li>Respiratory (n=26 – 19%)</li> <li>Neoplasms (n=24 – 17%)</li> <li>External causes (n=16 – 12%)</li> </ul>	<ul style="list-style-type: none"> <li>Circulatory 37%</li> <li>Neoplasms 21%</li> <li>Respiratory 7%</li> </ul>

## 5.6.2 Mortality rate comparison of deaths in disability services with the general population 2003-2005

Mortality data for 2003-2005 for the population of NSW was available for comparison to the data for deaths of people with a disability in care for the same time period. Table 17 shows the average number of deaths and average population size over 2003-2005 for disability services residents compared to the NSW population.

<sup>34</sup> The leading causes of death in the general population between 2003 and 2009 have been calculated by taking the average between the ABS cause of death data for the first year (2003) and the last year (2009).

The age standardised mortality rate<sup>35</sup> for people in disability services<sup>36</sup> on average each year for 2003-2005 was 18.28 per 1000, while the average mortality rate for the general population of NSW for the same time period was 6.75 per 1000. The mortality rate for people in disability services was two to three times that of the general population.

People in disability services had a higher age standardised mortality rate than the general population in every age group. The difference in mortality rate was greatest in the 15-24 years age group, where the mortality rate for people in disability services was 25 times that of the general population.

**Table 17: Mortality rates for people in disability services and the general population in 2003-05**

Age	Average number of disability services deaths 2003-05	Average 2003-05 disability services resident population	Age specific rates per 1000	Average deaths in NSW population 2003-05	Average NSW resident population 2003-05	Age specific rates per 1000
0-14	1	285	2.34	573	1325138	0.43
15-24	5	484	11.03	386	907115	0.43
25-34	7	924	7.22	621	970987	0.64
35-44	13	1321	10.10	1080	998165	1.08
45-54	11	1091	10.39	2137	911767	2.34
55-64	12	651	17.92	4088	704469	5.80
65-74	9	196	46.00	7572	475049	15.94
75+	8	71	112.68	28931	433008	66.81
<b>Total</b>	<b>66</b>	<b>5022</b>		<b>45389</b>	<b>6725698</b>	

## 5.7 Contributory causes of death

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

Single underlying cause of death analysis does not provide complete information about conditions that frequently appear as a multiple cause of death, but which rarely appear as an underlying cause. Multiple cause of death data can provide a more comprehensive view of mortality patterns.<sup>37</sup>

The tables on pages 58 and 59 show the multiple causes of death at the ICD-10 chapter level overall, for disability services and licensed boarding house residents.

<sup>35</sup> To enable the calculation of age specific mortality rates and an age standardised rate for the population of people with disabilities in care, we obtained data from ADHC regarding the numbers of people in disability services. These data were provided for 2003/04, 2004/05, and 2005/06 financial years. Estimated resident population data was accessed for NSW from the ABS for 2003, 2004 and 2005 calendar years to provide data for the NSW state mortality data. The data provides a close approximation to enable the examination of differences in age structure and patterns of mortality between the two groups.

<sup>36</sup> No age specific data was available for the boarding house residents, so the age specific rate comparisons are limited to people in disability services.

<sup>37</sup> Australian Bureau of Statistics (2003) 3319.0.55.001 – Multiple Cause of Death Analysis 1997-2001



### 5.7.1 Multiple causes of death of people in disability services

As indicated in table 18, respiratory diseases were the largest contributory cause of death for disability services residents. They contributed to half of all deaths in disability services (263 people) as either an underlying (75 people) or multiple cause (188 people).

Respiratory diseases were associated most often with deaths due to diseases of the nervous system, congenital factors, circulatory disease, and cancers. Respiratory diseases, such as pneumonia, are often the end-point of other illnesses and palliative care, and consequently feature highly as the direct cause of death.

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

- Nervous system diseases – contributed to 35 percent of deaths in disability services (181 people) as either an underlying (96 people) or multiple cause (85 people). Diseases of the nervous system were associated most often with deaths due to congenital factors, respiratory diseases, and cancers.
- Circulatory diseases – contributed to 30 percent of deaths (156 people) as either an underlying (72 people) or multiple cause (84 people). Circulatory diseases were associated most often with deaths due to respiratory diseases, diseases of the nervous system, cancers, and congenital factors.
- Congenital and chromosomal factors – contributed to 20 percent of deaths (102 people) as either an underlying (54 people) or multiple cause (48 people). Congenital factors were associated most often with deaths due to diseases of the circulatory system and respiratory diseases.
- Mental and behavioural disorders<sup>38</sup> – contributed to 18 percent of deaths (95 people) as either an underlying (5 people)

or multiple cause (90 people). Mental and behavioural disorders were associated most often with deaths due to respiratory diseases, diseases of the nervous system, congenital factors and external causes.

### 5.7.2 Multiple causes of death of people in licensed boarding houses

As indicated in table 19, circulatory diseases contributed to more than half of all deaths (64 people) as either an underlying (50 people) or multiple cause (14 people).

The other key multiple causes of death for people in licensed boarding houses were:

- Respiratory diseases – contributed to over one-third of deaths (45 people) as either an underlying (17 people) or multiple cause (28 people). Respiratory diseases were associated most often with deaths due to diseases of the circulatory system and cancers.
- Mental and behavioural disorders – contributed to almost one-third of all deaths in licensed boarding houses (37 people) as either an underlying (three people) or multiple cause (34 people). Mental and behavioural disorders were associated most often with deaths due to diseases of the circulatory system and respiratory diseases.

In the following sections we report on the work we have undertaken to examine some of the main causes of death of people with disabilities in care in more detail. Our analysis includes consideration of:

- the key data relating to the people who died, including demographic information;
- the known risk factors for those causes of death in the general population, and any additional risk factors for people with disabilities;

<sup>38</sup> Mental and behavioural disorders include dementia, mental illness, intellectual disability, and developmental disorders such as autism.

- the existence of those risk factors in relation to the people who died and any actions taken to reduce or remove the risks; and
- the key findings from our work in reviewing the deaths of those individuals.

Our selection of the particular underlying causes of death to examine in this chapter is based primarily on the main causes for people in disability services and people in licensed boarding houses (as identified in section 5.3). There are seven sections:

## **5.8 Deaths due to respiratory diseases**

- 5.8.1 Aspiration
- 5.8.2 Pneumonia
- 5.8.3 Chronic lower respiratory diseases

## **5.9 Deaths due to nervous system diseases**

- 5.9.1 Epilepsy
- 5.9.2 Cerebral palsy

## **5.10 Deaths due to congenital and chromosomal factors**

- 5.10.1 Down syndrome

## **5.11 Deaths due to circulatory system diseases**

- 5.11.1 Chronic ischaemic heart disease
- 5.11.2 Heart attack

## **5.12 Deaths due to neoplasms**

- 5.12.1 Lung cancer
- 5.12.2 Colon cancer

## **5.13 Deaths due to digestive system diseases**

- 5.13.1 Other diseases of the intestines

## **5.14 Deaths due to external causes**

- 5.14.1 Choking

**Table 18: Multiple causes of death of people in disability services**

UCOD Chapters	MCCOD Chapters											TOTAL UCODs
	Infectious	Endocrine	Mental	Nervous	Circulatory	Respiratory	Digestive	Genitourinary	Congenital	Symptoms	Injuries	
Certain infectious and parasitic diseases (A00-B99)	0	0	1	7	0	5	2	4	1	2	0	13
Neoplasms (C00-D48)	3	7	8	10	13	21	11	2	4	3	1	81
Disease of the blood and blood-forming organs and certain disorders involving the immune mechanism (D50-D89)	0	0	0	1	1	1	0	0	1	1	0	2
Endocrine, nutritional & metabolic diseases (E00-E90)	1	0	1	0	3	4	0	2	0	0	0	8
Mental and behavioural disorders (F00-F99)	0	1	0	3	1	3	1	0	1	2	0	5
Diseases of the nervous system (G00-G99)	8	5	17	0	14	61	3	2	7	10	11	96
Diseases of the circulatory system (I00-I99)	3	8	10	10	0	21	7	6	12	8	2	72
Diseases of the respiratory system (J00-J99)	10	4	17	15	17	0	4	6	10	7	3	75
Diseases of the digestive system (K00-K93)	9	5	9	9	7	11	0	3	1	9	4	36
Diseases of the skin and subcutaneous tissue (L00-L99)	1	0	0	0	0	0	0	0	0	0	0	1
Diseases of the musculoskeletal system and connective tissue (M00-M99)	0	0	1	0	1	2	0	1	2	0	0	1
Diseases of the genitourinary system (N00-N99)	5	4	1	2	2	5	0	0	5	3	0	13
Certain conditions originating in the perinatal period (P00-P96)	0	0	1	1	0	1	0	0	0	0	0	3
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	4	3	11	16	15	33	5	2	0	11	0	54
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	0	0	0	0	0	0	0	0	0	0	0	4
External causes of morbidity and mortality (V01-Y98)	3	2	13	11	10	20	8	3	4	13	50	56
<b>TOTAL MCCODs</b>	<b>47</b>	<b>39</b>	<b>90</b>	<b>85</b>	<b>84</b>	<b>188</b>	<b>41</b>	<b>31</b>	<b>48</b>	<b>69</b>	<b>71</b>	<b>521</b>

**Table 19: Multiple causes of death of people in licensed boarding houses**

UCOD Chapters	MCOD Chapters										TOTAL UCODs	
	Infectious	Endocrine	Mental	Nervous	Circulatory	Respiratory	Digestive	Genitourinary	Congenital	Symptoms		Injuries
Certain infectious and parasitic diseases (A00-B99)	0	0	0	0	0	0	0	0	0	0	0	0
Neoplasms (C00-D48)	1	2	4	0	4	7	1	2	0	2	0	20
Disease of the blood and blood-forming organs and certain disorders involving the immune mechanism (D50-D89)	0	0	0	0	0	0	0	0	0	0	0	0
Endocrine, nutritional & metabolic diseases (E00-E90)	0	0	0	0	0	1	0	0	0	0	0	1
Mental and behavioural disorders (F00-F99)	0	0	0	0	2	0	0	0	0	0	0	3
Diseases of the nervous system (G00-G99)	0	0	1	0	1	2	0	0	0	0	0	3
Diseases of the circulatory system (I00-I99)	0	6	16	1	0	13	0	2	0	1	3	50
Diseases of the respiratory system (J00-J99)	1	0	7	1	2	0	0	1	0	1	0	17
Diseases of the digestive system (K00-K93)	1	0	2	0	1	3	0	1	0	1	0	6
Diseases of the skin and subcutaneous tissue (L00-L99)	0	0	0	0	0	0	0	0	0	0	0	0
Diseases of the musculoskeletal system and connective tissue (M00-M99)	0	0	0	0	0	0	0	0	0	0	0	0
Diseases of the genitourinary system (N00-N99)	1	0	0	0	2	1	1	0	0	0	0	2
Certain conditions originating in the perinatal period (P00-P96)	0	0	0	0	0	0	0	0	0	0	0	0
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	0	0	0	1	1	0	1	0	0	0	0	1
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	0	0	0	0	0	0	0	0	0	0	0	0
External causes of morbidity and mortality (V01-Y98)	0	1	4	0	1	1	3	0	0	1	16	17
<b>TOTAL MCODES</b>	<b>4</b>	<b>9</b>	<b>34</b>	<b>3</b>	<b>14</b>	<b>28</b>	<b>6</b>	<b>6</b>	<b>0</b>	<b>6</b>	<b>19</b>	<b>121</b>

## 5.8 Deaths from diseases of the respiratory system

In the general population, diseases of the respiratory system generally account for a relatively small number of deaths each year (less than 8%) – predominantly older age people. For example, in Australia in 2008, the median age at death from respiratory diseases was 82.5 years.<sup>39</sup>

Diseases of the respiratory system were the third most common underlying cause of death for people in disability services (75 people; 15%) and people in licensed boarding houses (17 people; 14%). Respiratory diseases are also a major contributing factor in the overall deaths of people with disabilities in care, with strong links to deaths such as those from epilepsy, cerebral palsy and Down syndrome.

People in disability services died from respiratory diseases at a much younger age than people in the general population. The median age at death was 56 years – over 25 years younger than the general population. The majority of the disability services residents whose underlying cause of death was respiratory disease were under 65 years of age (49 people; 65%), the opposite of what occurs in the general population.

The most common forms of respiratory disease that caused the deaths of people in disability services were aspiration, pneumonia, and chronic lower respiratory diseases.

People in licensed boarding houses also died from respiratory diseases at a younger median age than the general population, at 72 years. The most common respiratory diseases that caused the deaths of people

in licensed boarding houses were chronic lower respiratory diseases, such as chronic obstructive pulmonary disease (COPD) and emphysema.

### 5.8.1 Aspiration (Pneumonitis)

Aspiration, also known as pneumonitis, refers to the entry of food, liquid or saliva into the trachea and lungs. It can be caused by food and/or oral secretions entering the lungs while eating, or caused by stomach contents moving back up the oesophagus and spilling into the lungs. Aspiration can cause inflammation and injury of lung tissue. If the lungs become infected as a result of aspiration, the condition is called 'aspiration pneumonia'. Chronic aspiration can cause irreversible lung damage.

Risk factors for aspiration include:<sup>40</sup>

- feeding and swallowing problems, such as dependence on being fed by others; difficulty sitting upright and holding head up; swallowing difficulties; eating problems (such as a reduced rate of chewing, fast eating, and swallowing large mouthfuls of food); and a history of choking;
- limited mobility;
- gastrointestinal problems, including GORD and recurrent vomiting/ regurgitation;
- recurrent respiratory infections;
- neurological and neuromuscular conditions such as cerebral palsy or epilepsy;
- drowsiness and reduced alertness;
- poor oral hygiene, including gum disease; and
- some medications such as antipsychotics, anticonvulsants, sedatives and muscle relaxants.

39 Australian Bureau of Statistics (2010) 3303.0 – *Causes of Death, Australia, 2008*

40 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, SE et al 'Predictors of Aspiration Pneumonia. How important is dysphagia?' in *Dysphagia*, Vol 13, No 2, February, 1998, 69-81; Stewart, JT '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.

Many people in disability services are at high risk of aspiration as they have multiple risk factors.

### Case study 9

A 73-year-old man who lived in a large residential centre died from aspiration pneumonia in 2009. He had a profound intellectual disability and multiple chronic health issues that included severe swallowing difficulties, GORD, recurrent respiratory infections, osteoporosis, asthma, osteoarthritis, anaemia and hiatus hernia.

He had received vaccination against influenza and H1N1, but not for pneumococcus. In the year before his death he had six respiratory tract infections, which were reviewed by the centre's medical officers and treated with antibiotics. He did not see a respiratory specialist.

Five months before his death, staff noted that he was refusing to eat and drink with increasing frequency, and had lost four kilograms in the previous month. He was reviewed by a dietician and a speech pathologist, was weighed weekly, and was on a weight gaining diet. However, at the time of his death he was underweight. A psychologist assessed that the man's food refusal was not behavioural, but there did not appear to be further investigation of the possible cause of his refusal. The man also had recurrent vomiting but the cause did not appear to be investigated, and there was no gastroenterology involvement.

He died the day after being admitted to hospital. A chest x-ray noted that he had aspiration pneumonia and lung scarring.

### Case study 10

A 20-year-old man who lived in a group home died from aspiration pneumonia in 2009. He had a severe intellectual disability due to contracting meningitis when he was three months old. He also had cerebral palsy with spastic quadriplegia, and chronic health issues that included epilepsy, GORD, and recurrent respiratory infections.

The man received all of his food and fluids via a feeding tube (PEG<sup>41</sup>), which had been inserted when he was 11 years old. To try to further prevent aspiration, he had a fundoplication<sup>42</sup> procedure two years later. Despite these measures, the man continued to aspirate – linked to saliva and continued vomiting.

The man was reviewed regularly by his GP, and had the involvement of medical specialists and other health professionals, including specialist disability health clinics, a respiratory specialist, neurologist, gastroenterologist, and allied health staff. The service had clear and comprehensive plans in place to guide staff in how to meet the man's needs, including identification and management of respiratory infections, PEG care, epilepsy management, and oral care.

He had four admissions to hospital in the year before his death – once for an upper respiratory tract infection and three times for aspiration pneumonia. In his second to last hospital admission, he had a gastroscopy, which indicated that there were no issues with his fundoplication and no significant reflux disease.

Three months after this admission, the man returned to hospital with fever, shortness of breath and recurrent vomiting. He was noted to have aspiration pneumonia, but the cause of the vomiting was not found. The man died three days after admission, following agreement between his family and his treating clinicians that he should receive palliative care.

<sup>41</sup> A percutaneous endoscopic gastrostomy (PEG) tube feeds directly into the stomach.

<sup>42</sup> Nissen fundoplication surgery involves wrapping a part of the stomach known as the gastric fundus around the lower oesophagus. This prevents the flow of acids from the stomach into the oesophagus and strengthens the valve between the oesophagus and the stomach, which stops acid from backing up into the oesophagus as easily. ([http://www.umm.edu/general\\_surgery/nissen\\_fundo.htm](http://www.umm.edu/general_surgery/nissen_fundo.htm)).



In the general population, aspiration accounts for a very small number of deaths each year (less than 1%), although the number of deaths from aspiration has increased substantially over time – mainly in the 60 years and over age group.<sup>43</sup>

### Deaths from aspiration in disability services 2003 – 2009

In disability services, aspiration was the underlying cause of death for 29 people (6%) between 2003 and 2009. It was a factor in the deaths<sup>44</sup> of another 21 individuals – mainly people whose underlying cause of death was cerebral palsy, epilepsy, or a congenital condition – and a significant condition relating to the deaths of a further three people. Taken together, aspiration was a contributing factor in the deaths of 53 people in disability services (10%).

The following relates to the 29 people for whom aspiration was the underlying cause of death.

### Age, gender and cultural background

The median age at death of the 29 people who died from aspiration pneumonia was 53 years. Almost three-quarters of the people who died from aspiration were male (20).

Two people were from a CALD background. None of the people who died from aspiration were Aboriginal or Torres Strait Islander.

### Accommodation

Most of the 29 people who died from aspiration lived in ADHC accommodation (16), and in large residential centres (15).

**Table 20: Number of deaths from aspiration by service and accommodation type**

NGO	No.	(%)
Group home	6	(46)
Large residential	5	(39)
Small residential	2	(15)
<b>Total</b>	<b>13</b>	<b>(100)</b>

ADHC	No.	(%)
Group home	5	(31)
Large residential	10	(63)
Respite	1	(6)
<b>Total</b>	<b>16</b>	<b>(100)</b>

### Disability, health issues and support needs

People who died from aspiration tended to have a high degree of cognitive impairment (18 people had a severe or profound intellectual disability), and a physical impairment (such as scoliosis).

Six people had cerebral palsy, and five people had Down syndrome.

Of the 29 people who died from aspiration in 2003-09:

- The majority had recurrent respiratory infections (22) and swallowing difficulties (25).
- The majority had limited mobility (26), required assistance with meals (25), and required help to communicate (23).
- Common health issues included constipation (18); epilepsy (17); GORD (14); osteoporosis (11); and asthma (7).
- Eight people were exclusively reliant on enteral nutrition; all via a PEG.

<sup>43</sup> Australian Bureau of Statistics (2011) 3303.0 – *Causes of Death, Australia, 2009*.

<sup>44</sup> That is, the Coroner listed aspiration pneumonia as one of the factors that led to the person's death, but it was not identified as the underlying cause of death. We have excluded those deaths in which aspiration was only the final cause of death following a terminal illness or palliative care.

Weight status information was available for 24 of the 29 people who died from aspiration. Most of these individuals (15) were in the healthy weight range. Seven people were underweight and two people were overweight.

All of the people who were underweight had seen a dietician. Neither of the people who were overweight had seen a dietician at any point.

## Managing aspiration risks

### *Vaccination*

Just over two-thirds (20) had received the influenza vaccination, and less than half (13) had received the pneumococcal vaccination.

### *Health assessments and supports*

In terms of access to allied health or medical specialists:

- All 29 people who died from aspiration had seen a GP. Just over two-thirds (20) had had a comprehensive assessment of their health at some point; most of whom (17) had a comprehensive health assessment in the year before their death.
- Over three-quarters of the 25 people who had swallowing difficulties (20) had seen a speech pathologist or attended a dysphagia clinic at some time. Most had been reviewed in the 12 months before their death.
- Six of the 22 people who had recurrent respiratory infections had seen a respiratory specialist.
- Five of the 14 people who had GORD, had seen a gastroenterologist – four in the year before their death.
- Half of the people who died from aspiration (15) had seen a dentist, mainly within the previous year (11).
- Seventeen people had seen a physiotherapist, and 20 people had seen an occupational therapist.

Since 2005, all disability accommodation services have been required to identify and address the nutrition and swallowing risks of the individuals in their care using an appropriate checklist.<sup>45</sup> Twenty-four of the 29 people who died from aspiration died between 2005 and 2009.

Our reviews identified that less than half (10) had a completed nutrition and swallowing checklist that identified all of the relevant risks and the actions that were required to address them. Seven of these people lived in ADHC services, and three in NGO services.

Four people had not had a swallowing and nutrition risk assessment at all; all of whom lived in NGO services. For the remaining seven people, services had identified some – but not all – risks, or had identified the risks but had not identified the actions to be taken to address them.

### *Support plans*

All of the people who died from aspiration had a health care plan. However, nine people did not have a mealtime management (or similar) plan in place to guide staff. Most of these people were living in NGO services (7) and two lived in ADHC accommodation.

## Our reviews

Our reviews of the deaths of the 29 people who died as a result of aspiration found that all had a number of risk factors that increased the likelihood of aspiration, including swallowing and mobility problems, epilepsy with ongoing seizures, recurrent vomiting, and multiple medications that affect functioning in key areas.

In the main, we found that services had identified these risks, but this was not the case for all people. Some of our reviews identified practices that did not lead to risks being minimised. This was primarily where aspiration risks were identified, but the service had not acted comprehensively to address the risks

<sup>45</sup> ADHC *Ensuring Good Nutrition* policy (2002) – the policy and associated Nutrition in Practice Manual includes a nutrition and swallowing risk checklist for services to use.

through identifying actions to be taken; or staff had not complied with recommendations in plans; or individuals were not referred for specialist assessment or treatment when this was indicated.

### Key lessons from our work include:

- The critical importance of comprehensive assessment of aspiration risks to individuals through nutrition and swallowing risk assessments, and ensuring that a clear plan is developed to address the identified risks through staff actions and the involvement of relevant health practitioners, such as speech pathologists.
- The need for services to develop strategies to promote staff understanding of, and compliance with, recommendations made in assessments and support plans.
- The importance of appropriate referral for specialist input, particularly where there is evidence of aspiration risk factors, including recurrent respiratory infections and recurrent vomiting.
- The need for vigilance in relation to changes in a person's health or behaviour, including increased drowsiness or weight loss; and

the subsequent need for review of the person's support needs, revision of support plans, and consideration of the need for allied health and/or medical review.

## 5.8.2 Pneumonia

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 *Streptococcus pneumoniae*, or pneumococcus), viruses, myoplasmas, other infectious agents such as fungi, and various chemicals.

Lobar pneumonia affects a section (lobe) of a lung. Bronchial pneumonia (or bronchopneumonia) affects patches throughout both lungs.

Between 2003 and 2009, pneumonia was the underlying cause of death for 23 people in disability services (4%). It was a contributing factor in the deaths of another 104 people in disability services, although for 80 of these individuals, it was recorded as the direct cause of death only. Pneumonia was most often a contributing factor in the deaths of people from cerebral palsy, Down syndrome or epilepsy.

**Table 21: Number of deaths from pneumonia 2003-09**

		Licensed BH		Disability services	
		No.	(%)	No.	(%)
J10.0	Influenza with pneumonia, influenza virus identified	0	(0)	1	(4)
J12.9	Viral pneumonia, unspecified	0	(0)	1	(4)
J13	Pneumonia due to <i>Streptococcus pneumoniae</i>	1	(20)	0	(0)
J18.0	Bronchopneumonia, unspecified	2	(40)	5	(22)
J18.1	Lobar pneumonia, unspecified	0	(0)	2	(9)
J18.9	Pneumonia, unspecified	2	(40)	14	(61)
<b>Total</b>		<b>5</b>	<b>(100)</b>	<b>23</b>	<b>(100)</b>

Pneumonia was also the underlying cause of death for five people in licensed boarding houses (4%), and a contributory factor in the deaths of another 13 people, including eight people for whom it was the direct cause of death only.

Our analysis of deaths from pneumonia in this section focuses on the 23 people in disability services.

## Risk factors

In the general community, pneumonia tends to be more serious for infants and young children, older adults (aged 65 years and older), people who have other chronic health problems, and people who have weak immune systems as a result of diseases or other factors.

Other risk factors in the general community for pneumonia include:<sup>46</sup>

- smoking;
- swallowing difficulties – such as due to stroke, dementia, Parkinson’s disease or other neurological conditions;
- crowded living conditions;
- hospitalisation – people who are hospitalised have a much higher risk of developing pneumonia than do non-hospitalised individuals (this risk is even higher for patients who have recently undergone major surgery or who are on ventilators);
- alcohol and drug abuse; and
- impaired consciousness.

There are additional factors that increase the risks for some people with disabilities, 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/ gum disease.

## Case study 11

A 54-year-old woman who lived in an ADHC large residential centre died from pneumonia in 2009. She had a moderate intellectual disability and spastic quadriplegia. She had a rare condition that made it difficult for her to regulate her temperature, as well as epilepsy, recurrent respiratory infections, severe swallowing difficulties and intermittent asthma.

The woman’s swallowing ability fluctuated from mild to severe dysphagia from day to day. The last review by a speech pathologist organised by the disability service was almost two years prior to her death, despite staff recording in the nutrition and swallowing risk assessment that a speech pathology review was needed. While the service was responsive to the woman’s changing swallowing function, we found that staff sometimes gave her food and fluids when she was not alert or oriented.

In the year before her death, she had increased seizure activity and drowsiness. She also had three episodes of respiratory illness including aspiration pneumonia, and a persistent wheeze, but was not seen by a respiratory specialist.

Eleven days before her death, the woman developed symptoms of respiratory illness, and commenced antibiotics two days later. The next day she was noted to be hypoxemic on oxygen saturation, and continued to have low oxygen saturation and widespread crepitations over the following days. At the time that she was admitted to hospital, a week after she displayed symptoms of respiratory illness, her oxygen saturation was down to 80%. She died four days after being admitted to hospital.

A medical specialist on our advisory committee reviewed the woman’s death and advised that she had acute respiratory failure at the time that she was first noted to be hypoxemic, and should have been admitted to hospital urgently. The committee member recommended that:

46 Shepard, JJ, *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)*.

- a. ADHC establish clear criteria whereby residents with respiratory illness such as pneumonia and asthma are rapidly referred for assessment and/or admission. The committee member indicated that the criteria should include airway threat, oxygen saturation of less than 90%, and a respiratory rate higher than 35.
- b. ADHC establish cardiac criteria, such as a heart rate of less than 60 or higher than 130, or hypotension.
- c. Any person with a documented episode of aspiration pneumonia should be assessed by both a speech pathologist and a respiratory physician.

We referred this advice to ADHC for its consideration and action. ADHC subsequently told us that it intends to review its *Health Care* policy in 2011, and issues regarding coordinated health care management, including referral and clinical management pathways, would be examined during the review.

### **Case study 12**

We investigated the conduct of ADHC in relation to the death in February 2009 of a 58-year-old man who lived in a large residential centre. He had a severe level of cognitive impairment, communication difficulties, and relied on a wheelchair for mobility. He also had significant health concerns that required ongoing management and regular review, including epilepsy and GORD.

The man was booked in to have a colonography, and he received bowel preparation medications in the days leading up to the test. The evening before he was due to have the colonography, nursing staff at the residential centre received a copy of the man's pathology results. These indicated that he had electrolyte imbalance, with elevated sodium levels and low potassium levels. Staff called an after hours medical service and were advised over the telephone to administer

Gastrolyte, an electrolyte replacement to prevent dehydration.

That evening and the following morning, staff recorded that the man was accepting very little fluid. They had tried to syringe thickened fluids into his mouth, but he was swallowing only a small amount. The man went to the colonography appointment, but when he returned he refused all food and accepted only a small amount of fluid. In the late afternoon, staff noted that the man's condition had deteriorated. He had become listless and lethargic and was no longer sitting upright in his wheelchair. Staff put him in bed and noted an hour later that he had started dribbling and had a fixed stare.

Staff contacted the after-hours nurse manager, and called for an ambulance 17 minutes later. On arrival at hospital, the man was found to be extremely dehydrated and had a number of life-threatening electrolyte abnormalities, including acute kidney failure. His condition did not improve and he died the following morning from pneumonia.

We found that the actions of ADHC staff in response to the man's critical health issues were inadequate because they:

- did not call for a review of his condition by the centre's medical officer at any point, despite significant health risks and numerous triggers to do so;
- did not clearly identify the risk of dehydration or take adequate action to address the risk; and
- were not responsive to the change in the man's health needs the evening before his death and did not identify that his condition was critical and required immediate medical attention.

We also found that staff had withheld the man's anticonvulsant and anti-reflux medications on two consecutive occasions during this period, without medical authority to do so.



We made a number of recommendations to ADHC to address the issues in our report. These are targeted at improving practice in the large residential centre and ensuring that nursing staff across ADHC's residential centres have the skills and knowledge to adequately fulfil their responsibilities. ADHC accepted all of the recommendations and we are monitoring their implementation.

## Deaths from pneumonia in disability services 2003 – 2009

### Age, gender and cultural background

In the general population, people who die from pneumonia tend to be of older age. For example, in Australia in 2008, the median age at death from pneumonia was 84.8 years for males and 90.3 years for females.<sup>47</sup>

The people in disability services who died from pneumonia in 2003-09 were much younger. The median age at death was 58 years – more than 25 years younger than the general population.

More females (13) died from pneumonia than males (10). None of the people in disability services who died from pneumonia were from a CALD background or were Aboriginal or Torres Strait Islander.

### Accommodation

Just over half (12) lived in NGO services. Most of the people who died from pneumonia (16) lived in large residential centres.

**Table 22: Deaths from pneumonia in disability services by service and accommodation type**

NGO	No.	(%)
Group home	6	(50)
Large residential	4	(33)
Small residential	2	(17)
<b>Total</b>	<b>12</b>	<b>(100)</b>

ADHC	No.	(%)
Group home	1	(9)
Large residential	10	(91)
<b>Total</b>	<b>11</b>	<b>(100)</b>

### Disability, health issues and support needs

All of the people who died from pneumonia had an intellectual disability, mainly at a moderate (12) or severe (6) level. Of the 23 people who died from pneumonia in 2003-09:

- the majority had limited mobility (20), swallowing difficulties (18) and required assistance with meals (17);
- common health issues included GORD (16), recurrent respiratory infections (14), osteoporosis (14), and epilepsy (13); and
- less than half needed help to communicate (11) and few people relied on enteral feeding (3).

Height and weight information was available for 22 of the 23 people in disability services who died from pneumonia. Half were in the healthy weight range. Seven people were overweight, including three people who were obese. Four people were underweight, including two people who were very underweight.

Nine of the 11 people who were outside of the healthy weight range had seen a dietician at some point, generally in the year before their death. This included all of the people who were underweight.

Smoking was not a significant factor for the disability services residents who died from pneumonia. Only three people had smoked, and none were current smokers at the time of their death.

<sup>47</sup> Australian Bureau of Statistics (2010) *3303.0 Causes of Death, Australia, 2008*.



## Managing pneumonia risks

### *Vaccination*

22 of the 23 people in disability services who died from pneumonia had received the influenza vaccination. Ten people had received the pneumococcal vaccination.

### *Health assessments and supports*

In terms of access to allied health or medical specialists:

- All but one person had seen a GP in the year before their death. Fourteen people had had a comprehensive health assessment at some point.
- Of the 18 people who had swallowing difficulties, just over three-quarters (14) had seen a speech pathologist or attended a dysphagia clinic at some time, and most had been reviewed in the year before their death.
- Six of the 14 people who had recurrent respiratory infections had seen a respiratory specialist.
- Of the 16 people who had GORD, seven had seen a gastroenterologist – three in the year before their death. Each of the three people who received enteral feeding had seen a gastroenterologist.
- Just over half of the people in disability services who died from pneumonia (13) had seen a dentist, mainly in the year before their death.

Seventeen of the 23 people died after the introduction of nutrition and swallowing risk assessment requirements. Our reviews identified that two-thirds of the individuals (11) had a completed nutrition and swallowing checklist that identified all of the relevant risks and the actions that were required to address them. Six of these people lived in ADHC services, and five in NGO services.

One person who lived in an NGO service did not have any nutrition and swallowing risk assessment. For two people in NGO services, not all of their risks had been identified. For three people, the risks had been identified, but services had not identified action that needed to be taken to address them. Two of the three people lived in ADHC accommodation.

### *Support plans*

Twenty-two of the 23 people in disability services who died from pneumonia had a health care plan, including all of the people who lived in ADHC accommodation. However, 13 people did not have a mealtime management (or similar) plan to guide staff. This included three people in ADHC accommodation and seven people in NGO services.

## Our reviews

The issues identified in our reviews have primarily related to actions to identify and address the health risks faced by the individuals, including respiratory risks.

### **Key lessons from our work include:**

- The need for staff to identify people with risks related to respiratory illness, including recurrent respiratory infections and GORD; and to ensure that the person has the involvement of relevant health practitioners.
- The importance of people with respiratory illness being referred to relevant specialists, such as respiratory specialists; and the need for clear prompts for disability staff to discuss referral with the person's GP.
- The critical importance of staff responding quickly to changes in health and seeking medical assistance; and of service and medical staff recognising when the person needs urgent medical assistance. For many of the people who died from pneumonia, there was a matter of days between displaying symptoms (such as fever, cough and not eating or drinking) and their death.

### 5.8.3 Chronic lower respiratory diseases

Between 2003 and 2009, chronic lower respiratory diseases were the underlying cause of death for 16 people in disability services (3%) and a contributing factor in the deaths of another 21 people.

It was also the underlying cause of death of nine people in licensed boarding houses (7%), and a contributing factor in the deaths of another 21 people.

For both disability services and licensed boarding house residents, chronic lower respiratory diseases were most often associated with deaths due to circulatory diseases.

**Table 23: Deaths from chronic lower respiratory diseases 2003-09**

	Licensed BH		Disability services	
	No.	(%)	No.	(%)
J43.9 Emphysema, unspecified	1	(11)	0	(0)
J44.0 Chronic obstructive pulmonary disease with acute lower respiratory infection	1	(11)	1	(6)
J44.1 Other chronic obstructive pulmonary disease with acute exacerbation, unspecified	0	(0)	1	(6)
J44.8 Other specified chronic obstructive pulmonary disease	0	(0)	1	(6)
J44.9 Chronic obstructive pulmonary disease, unspecified	5	(56)	9	(56)
J45.9 Asthma, unspecified	1	(11)	4	(25)
J46 Status asthmaticus	1	(11)	0	(0)
<b>Total</b>	<b>9</b>	<b>(100)</b>	<b>16</b>	<b>(100)</b>

Chronic obstructive pulmonary disease (COPD) was the main chronic lower respiratory disease reported. Smoking is the leading cause of COPD.

#### Case study 13

A 75-year-old man who lived in a licensed boarding house in a regional area died from complications of chronic airways limitation in 2009. He had brain damage due to alcohol and an assault 10 years earlier. He also had significant chronic diseases, including chronic airways limitation, asbestosis, hypertension and GORD.

The man saw a GP on a regular basis, and had all necessary vaccinations. The GP Management Plan included goals that related to smoking cessation via encouragement, and annual chest x-rays for lung disease management. The GP regularly spoke with the man about smoking cessation, but at the time

of his death he was continuing to smoke up to 20 cigarettes a day. The local boarding house team noted that the man had refused quit smoking patches.

There was no indication that the man was referred to a respiratory specialist despite chronic airways limitation, asbestosis, and recurrent chest infections. Four days before his death, the man saw his GP for a chest infection and commenced antibiotics. The day before his death he was reported to have felt better, but died suddenly after collapsing in his bedroom. Boarding house staff provided CPR but the man was unable to be resuscitated.

#### Case study 14

A 73-year-old man who lived in a regional licensed boarding house died from asthma and chronic airways limitation in 2009. He had alcohol related brain damage and multiple chronic health issues that included

emphysema, cardiomegaly, osteomyelitis, and recurrent respiratory infections. He was also a heavy smoker.

The last comprehensive health assessment by the man's GP seven months before his death noted that spirometry had been attempted and there was a poor result. At the same time, a community nurse recorded that the man slept on the lounge at the boarding house as he considered that his bedroom did not have enough ventilation, and his health care plan noted that he was using his Ventolin/ spiriva puffers without regard to time or frequency of use. There was no indication that he was referred to a respiratory specialist at any point.

Two months before his death, the man was admitted to hospital following a fall in his bathroom and chest pain. When ambulance officers arrived, his oxygen saturation was only 45%. He was assessed as having type 2 respiratory failure and a pneumothorax, and was discharged to an aged care hostel.

Two days before his death, the man returned to the licensed boarding house as his daughter reported that he was unhappy at the aged care hostel. The boarding house proprietor accepted the man back on condition that he would only get tobacco every second day, he would not have alcohol, and he would receive showering assistance from Home Care. On the morning of his death, staff called for an ambulance after the man appeared with puffy eyes and reported that he did not feel well. On arrival at hospital he was unconscious and in acute respiratory distress. His condition continued to deteriorate and he died later that evening.

## Deaths from chronic lower respiratory diseases in disability services 2003 – 2009

### Age, gender and cultural background

In the general population, deaths from chronic lower respiratory diseases tend to occur at an older age. For example, in Australia in 2008,

the median age at death was 80.4 years for males and 81.5 years for females.<sup>48</sup>

The deaths of people with disabilities in care from chronic lower respiratory diseases tended to occur at a younger age. This was particularly the case for people in disability services, where the median age at death was 61 years – 20 years younger than the general population. The median age at death from chronic lower respiratory diseases for licensed boarding houses residents was 73 years.

More males than females died from chronic lower respiratory diseases, consistent with the broader population of people with disabilities in care, and deaths from this cause in the general population.

Two people in licensed boarding houses and one disability services resident were from a CALD background. None of the people who died from chronic lower respiratory diseases were Aboriginal or Torres Strait Islander.

### Accommodation

Just over half of the 16 people in disability services who died from chronic lower respiratory disease (9) lived in NGO services. The same number lived in large residential accommodation.

**Table 24: Deaths from chronic lower respiratory diseases by service and accommodation type**

NGO	No.	(%)
Group home	6	(67)
Large residential	3	(33)
<b>Total</b>	<b>19</b>	<b>(100)</b>

ADHC	No.	(%)
Group home	1	(14)
Large residential	6	(86)
<b>Total</b>	<b>7</b>	<b>(100)</b>

<sup>48</sup> Australian Bureau of Statistics (2010) 3303.0 Causes of Death, Australia, 2008.

## Disability, health issues and support needs

### People in disability services

Of the 16 people in disability services who died from chronic lower respiratory disease in 2003-09:

- The majority (13) had an intellectual disability, mainly at a mild (5) or severe (4) level. Eleven people had multiple impairments, including six people with a physical or sensory impairment.
- The majority had limited mobility (13), but only seven people relied on a wheelchair.
- Half required help with meals, and less than half needed help to communicate (7).
- Health issues included recurrent respiratory infections (14), and asthma (6).

Height and weight information was available for 15 people. Seven people were in the healthy weight range, and seven people were overweight. One person was underweight.

Half of the eight people outside of the healthy weight range had seen a dietician, including the person who was underweight.

### Licensed boarding houses

Four of the nine licensed boarding house residents who died from chronic lower respiratory diseases had alcohol related brain damage, and two people had a mild intellectual disability. Less than half (4) had a mental illness.

Of the nine people in licensed boarding houses who died from chronic lower respiratory diseases in 2003-09:

- More than half had recurrent respiratory infections (6) and asthma (5).
- Just over half had limited mobility (5).

Weight status information was available for five of the nine people in licensed boarding houses who died from chronic

lower respiratory diseases. Two people were overweight, two people were underweight, and one person was in the healthy weight range.

One person who was overweight had seen a dietician.

## Smoking

Most of the people with disabilities in care who died from chronic lower respiratory diseases had smoked, including half of the 16 disability services residents and all of the licensed boarding house residents. Eight of the nine people in licensed boarding houses were current smokers at the time of their death.

Of the 11 current smokers, more than half smoked over 20 cigarettes per day.

**Table 25: Smoking rates of people who died from chronic lower respiratory diseases 2003-09**

Tobacco	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Yes	8	(89)	3	(19)
Ex-smoker	1	(11)	5	(31)
No	0	(0)	8	(50)
<b>Total</b>	<b>9</b>	<b>(100)</b>	<b>16</b>	<b>(100)</b>

Tobacco – yes	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Occasional	0	(0)	0	(0)
Up to 10/ day	2	(25)	0	(0)
11-20/ day	2	(25)	1	(33)
>20/ day	4	(50)	2	(67)
<b>Total</b>	<b>8</b>	<b>(100)</b>	<b>3</b>	<b>100%</b>

## Managing risks

### Vaccination

Three-quarters of the 16 people in disability services who died from chronic lower respiratory diseases had received the

influenza vaccination (12). Seven people had received the pneumococcal vaccination.

Two-thirds of the nine people in licensed boarding houses who died from chronic lower respiratory diseases had received the influenza vaccination (6). Only one person had received the pneumococcal vaccination.

### *Health assessments and supports*

All of the people who died from chronic lower respiratory diseases had seen a GP. Less than two-thirds of the people in disability services (10) and less than half of the people in licensed boarding houses (4) had ever had a comprehensive health assessment.

Of the 14 people in disability services who had recurrent respiratory infections, less than half (6) had seen a respiratory specialist. None of the six licensed boarding house residents who had recurrent respiratory infections and died from chronic lower respiratory disease had seen a respiratory specialist.

Just under half of the disability services residents (7) and licensed boarding house residents (4) had seen a physiotherapist.

## **Our reviews**

### **Key lessons from our reviews:**

Our reviews of the deaths of people from chronic lower respiratory diseases have highlighted the importance of improving the access of people with disabilities in care to:

- quit smoking strategies or programs;
- respiratory specialists; and
- chronic disease management programs.

### *Smoking cessation*

Our reviews identified a small number of people who had been given nicotine patches while in hospital or had otherwise had discussions with staff, their GP or psychiatrist about the ramifications of smoking for their lower respiratory disease and the need to quit.

However, in the main, our reviews did not find any indication that people with chronic lower respiratory disease who were current (and generally heavy) smokers had been informed about the risks associated with continuing to smoke or offered any assistance to quit. This was particularly the case for licensed boarding house residents.

### *Access to respiratory specialists*

Our reviews found that few people with chronic lower respiratory diseases had seen a respiratory specialist. In particular, none of the people in licensed boarding houses who had chronic lower respiratory diseases – and had recurrent respiratory infections – had been referred to a respiratory specialist. This included people whose respiratory health worsened in the period leading up to their death. For some individuals, the referral to a respiratory specialist came too late (see case study 15).

### **Case study 15**

A 75-year-old man who lived in a group home in a regional area died from chronic lung disease and asthma in 2009. He had a mild cognitive impairment, bipolar affective disorder, and significant chronic health issues, including epilepsy, COPD, recurrent respiratory infections, and asthma. He had a history of smoking 20 cigarettes a day, but had successfully quit smoking three years before his death.

The man had regular reviews with his GP, primarily for recurrent respiratory infections and deterioration in his lung function. In the two years before his death, he had at least 11 episodes of chest infections including pneumonia, and nine instances of exacerbation of asthma and/or COPD. While the man was treated with antibiotics and multiple other medications, there is no indication that he saw a respiratory specialist at any time.



One month before he died, the man saw a different GP regarding infective exacerbation of his COPD that had not improved with antibiotics. The GP immediately referred the man to hospital for x-rays and oxygen. The man was seen in the emergency department and discharged with antibiotics, other medications, and for follow-up with his GP. His regular GP reviewed him three days later and made a referral to a thoracic physician. Staff at the disability service were advised that there was a two-month wait to see the specialist unless it was an emergency. The man died before he could attend the appointment.

*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.

## 5.9 Deaths from diseases of the nervous system

In the general population, deaths from diseases of the nervous system tend to occur in older age. For example, in Australia in 2008 the median age at death was 82.3 years. The

leading causes of these deaths in the general population include Alzheimer’s disease and Parkinson’s disease.<sup>49</sup>

For people in disability services, diseases of the nervous system were the largest cause of death in 2003-09, accounting for the deaths of 96 people (18%). The median age at death was 42.5 years – 40 years younger than the general population.

The main causes of deaths from nervous system diseases of people in disability services in 2003-09 were epilepsy and cerebral palsy.

### 5.9.1 Epilepsy

#### Deaths of people with disabilities in care with epilepsy 2003 – 2009

More than one-third of the 651 people with disabilities in care who died between 2003 and 2009 had epilepsy (247 people). Twelve people lived in licensed boarding houses, and 235 people lived in disability services.

The leading causes of death for people who had epilepsy who died in 2003-09 related to diseases of the nervous system (76 people), including epilepsy, cerebral palsy and muscular dystrophy.

Other key causes of death related to respiratory illness (45 people), including aspiration, pneumonia, COPD and asthma; and congenital factors (24 people), mainly Down syndrome.

**Table 26: Leading underlying causes of death of people with epilepsy 2003-09<sup>50</sup>**

UCOD	No.	(%)
G40.90 Epilepsy, unspecified	29	(12)
G80.9 Cerebral palsy, unspecified	17	(7)
J69.0 Pneumonitis due to food and vomit	17	(7)
Q90.9 Down syndrome, unspecified	12	(5)
J18.9 Pneumonia, unspecified	8	(3)
G41.9 Status epilepticus, unspecified	5	(2)
J44.9 Chronic obstructive pulmonary disease, unspecified	5	(2)
W79 Inhalation and ingestion of food causing obstruction of respiratory tract	5	(2)

49 Australian Bureau of Statistics (2010) 3303.0 Causes of Death, Australia, 2008.

50 We have only included the causes for which there was over two percent of deaths.



## Deaths from epilepsy in disability services 2003 – 2009

Epilepsy was the underlying cause of death of 38 people in disability services (7%). The number of deaths each year has been variable, including 10 people in 2003 and one person in 2009.

**Table 27: Deaths due to epilepsy 2003-09**

		Licensed BH		Disability services	
		No.	(%)	No.	(%)
G40.40	Other generalized epilepsy and epileptic syndromes	0	(0)	1	(3)
G40.60	Grand mal seizures, unspecified (with or without petit mal)	0	(0)	2	(5)
G40.80	Other epilepsy	0	(0)	1	(3)
G40.90	Epilepsy, unspecified	1	(50)	29	(76)
G41.0	Grand mal status epilepticus	0	(0)	1	(3)
G41.9	Status epilepticus, unspecified	1	(50)	4	(11)
<b>Total</b>		<b>2</b>	<b>(100)</b>	<b>38</b>	<b>(100)</b>

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>51</sup> In Australia, about 300 people die from epilepsy each year. Of these, approximately half are attributed to SUDEP.<sup>52</sup>

Other causes of seizure related deaths include accidents such as drowning, burns or head injury, status epilepticus, respiratory illness and cardio-respiratory arrest.

Of the 38 people in disability services whose deaths in 2003-09 were due to epilepsy:

- eleven people aspirated or inhaled vomitus during a seizure;
- the deaths of nine people were linked to SUDEP;
- five deaths were due to status epilepticus;<sup>53</sup>
- the deaths of five people were linked to pneumonia;
- three people drowned while having a seizure (one person in a pool in 2003; one in a bath in 2003; and one in a spa in 2008);
- one person died from head injury sustained during a seizure;

- one person choked on food during a seizure; and
- the manner of the deaths of three people is not clear – two people appeared to aspirate during seizure activity and one man was found face down in bed.

### Case study 16

A 23-year-old man with epilepsy who lived in a group home died after drowning in a spa. The man experienced tonic clonic seizures that tended to occur in the afternoon without identifiable warning signs or triggers.

In the year before his death, the man was noted to have drop attacks that occurred without apparent warning, involving him falling forwards and hitting his face. Two months before his death, he was taken to hospital following a series of seizures. Hospital staff recorded that his anticonvulsant levels were low. The man had regular neurology reviews, including a review five days before his death. At this review, the neurologist reviewed the man's low medication levels, noted that he appeared to have rapid transit for the tablets, and altered the dose.

<sup>51</sup> Epilepsy Australia website, [www.epilepsyaustralia.net](http://www.epilepsyaustralia.net).

<sup>52</sup> Australian Institute of Health and Welfare (2004), *Annex Table 2: Deaths by cause, sex and mortality stratum in WHO regions, estimates for 2002, World Health Report*, Canberra.

<sup>53</sup> Status epilepticus refers to a continuous state of seizure.

The man's support plans, including his epilepsy management plan and health care plan clearly identified the risks that he faced in relation to water, and indicated that he needed to have 1:1 support when in the spa to ensure his safety.

On the afternoon of the day of the critical incident, the man was squatting on the edge of the spa in the backyard, playing with the water. Two staff members were on shift, supporting four residents. One staff member was monitoring the man through the kitchen window, but left to open the front door to the mother of another resident. The staff member spoke with the mother about issues affecting that resident, and then walked back towards the spa. The staff member found the man face down in the spa. The staff called 000 and commenced CPR, which was continued by the ambulance officers. He died before he arrived at hospital.

Following the man's death, the service contracted an external agency to undertake a full review of its existing guidelines and supports in relation to epilepsy management, and to provide staff training across its services. We monitored the progress of the service's actions to address the issues identified in relation to the man's death, and to prevent recurrence of such events.

### Risk factors<sup>54</sup>

Very little is known about the causes and mechanisms of SUDEP. Research indicates that it is most likely to occur during sleep and the cause of death probably involves a number of factors resulting in interruptions to respiratory and cardiac function. Although the cause of SUDEP is unknown, research has indicated some common risk factors, including:

- 20-40 years of age;
- male
- early onset seizures;
- chronic epilepsy and poor seizure control;
- intellectual disability;
- generalised tonic clonic<sup>55</sup> seizures;
- multiple anticonvulsant medications;
- non-therapeutic levels of anticonvulsant medications in bloodstream; and
- sudden or drastic changes in the anticonvulsant medication regime.

In relation to epilepsy more broadly, there are certain factors that can trigger seizures, including:<sup>56</sup>

- fatigue and lack of sleep;
- illness and stress;
- missed medications;
- startle, such as a loud noise;
- patterns of light (such as flashing lights or a flickering TV screen);
- alcohol;
- excessive caffeine intake, including coffee and soft drinks;
- low blood sugar; and
- hormonal changes in some females.

Our reviews found that factors that appeared to trigger seizures in some of the people in disability services whose underlying cause of death was epilepsy included illness (including fever) and deterioration in health, excessive diet cola consumption, and lack of sleep.

<sup>54</sup> Nilsson, L., Farahmand, B., Persson, P., Thiblin, I., and Tomson, T. 'Risk factors for sudden unexpected death in epilepsy: a case control study' in *The Lancet* Vol 353, March 13, 1999: 888-893; Hughes, J, 'A review of sudden unexpected death in epilepsy: prediction of patients at risk', in *Epilepsy & Behavior*, 2009 February, 14(2): 280-7; and McKee, J and Bodfish, J, 'Sudden Unexpected Death in Epilepsy in Adults with Mental Retardation', in *American Journal on Mental Retardation*, 2000, Vol 105, No 4, 229-235.

<sup>55</sup> A generalised tonic clonic seizure involves the whole brain and entails loss of consciousness, stiffening of the body, and then jerking of the limbs.

<sup>56</sup> Epilepsy Action Australia website, [www.epilepsy.org.au](http://www.epilepsy.org.au).

## Age, gender and cultural background

The median age at death from epilepsy was 44 years. Almost two-thirds of the 38 people who died from epilepsy were male.

One person was Aboriginal or Torres Strait Islander. None of the people who died from epilepsy were from a CALD background.

## Accommodation

Over half of the people who died from epilepsy lived in ADHC accommodation (23), mainly in large residential centres.

**Table 28: Deaths from epilepsy in disability services by service and accommodation type**

NGO	No.	(%)
Group home	11	(73)
Large residential	3	(20)
Small residential	1	(7)
<b>Total</b>	<b>15</b>	<b>(100)</b>

ADHC	No.	(%)
Group home	6	(26)
Large residential	17	(74)
<b>Total</b>	<b>23</b>	<b>(100)</b>

## Disability and support needs

All but one of the 38 people whose underlying cause of death was epilepsy had an intellectual disability. More than half had a severe or profound degree of cognitive impairment (21). The people who died from epilepsy in 2003-09 did not tend to have other types of impairment. Other than epilepsy, they also did not tend to have many other health issues.

Eighteen people were overweight, and 17 people were in the healthy weight range. Three people were underweight.

## Epilepsy management

Thirty of the 38 people had epilepsy with ongoing seizures,<sup>57</sup> despite medication. More than half of these individuals had experienced increased seizure activity in the months before their death (16). This included seven of the nine people who died from SUDEP, and five of the 11 people whose deaths were linked to aspiration.

Four people had not had seizures for more than two years before their death, including two people who drowned. Two people only started having seizures shortly before their death.

### *Medical reviews*

All of the 38 people had seen a GP in the year prior to their death. Less than half (15 people) had ever had a comprehensive health assessment.

Most of the people whose underlying cause of death was epilepsy (32 people) had been reviewed by a neurologist. The neurology review for most of these individuals had been in the 12 months before their death. Some of these people had more regular reviews, including three or six monthly.

## Case study 17

In 2005, the deaths of a man and a woman in one service (different group homes) were due to SUDEP. Our reviews found that both individuals had epilepsy with ongoing seizures, and had experienced an increase in seizure activity in the months before their death. While both were reviewed regularly by their GPs, there was no indication that either person had been reviewed by a neurologist.

In relation to the woman who died, we found that there was a lack of clarity about whether the falls or 'drop attacks' she experienced on a regular basis were seizure related, faints, or behaviour related. Her records indicated that she received a very low dose of anticonvulsant

<sup>57</sup> 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'.

medication, and there were numerous instances where her medication was not administered at the scheduled times, or was missed altogether.

We obtained expert advice that the best chance of preventing these deaths would have been more active neurological management. The specialist we consulted advised that review by a neurologist was warranted given the woman's drop attacks, the increase in seizure activity for both people, and the fact that both were on very low doses of anticonvulsant medication and had continuing seizures. We provided this feedback to the service to inform their support of other people with epilepsy.

#### *Risk assessment and management*

All disability accommodation services provided or funded by ADHC are required to ensure that all clients with epilepsy have an epilepsy management plan. The epilepsy management plan is a risk management tool that is designed to ensure that there is clear information regarding the person's seizures; the risks for them and how they will be managed; medications; and actions to take in response to a seizure.

ADHC services have been required to develop epilepsy management plans since 2004. In May 2007, ADHC released a revised *Epilepsy* policy, which applies to both ADHC operated and funded services.

Of the 16 people who lived in ADHC accommodation and died from epilepsy between 2004 and 2009, all but one person had an epilepsy management plan. Only one person in funded services died from epilepsy in 2008/09, and they had an epilepsy management plan.

## Our reviews

### Our reviews have highlighted the importance of:

- Clearly identifying the risks for individuals relating to their epilepsy and taking comprehensive action to minimise the risks. Our reviews emphasised the importance of providing supervision in risky situations (including around water, following a seizure, and when restrained); and consistently administering the person's required medications.
- Providing clear guidance to staff about the support required by the individual, including the use of PRN medication.
- Consistently and accurately recording the person's seizure activity and providing comprehensive information to the person's GP and neurologist.

## 5.9.2 Cerebral palsy

### Deaths of people with disabilities in care with cerebral palsy 2003 - 2009

Cerebral palsy is a physical condition that primarily affects movement. The impairments associated with cerebral palsy are permanent but not progressive.<sup>58</sup> The most common form is spastic cerebral palsy, in which symptoms include muscles that are very tight and do not stretch; tight joints that do not open up all the way (joint contracture); and muscle weakness or loss of movement in a group of muscles.

Symptoms of cerebral palsy can vary considerably from person to person. The symptoms can range from mild to very severe; involve one or both sides of the body; and be more pronounced in either the arms or legs, or involve both the arms and legs.

Of the 651 people with disabilities in care who died in 2003-09, 122 people had cerebral palsy. One person lived in a licensed boarding house, and 121 people lived in disability services.

<sup>58</sup> Cerebral Palsy Australia website: [www.cerebralpalsyaustralia.com](http://www.cerebralpalsyaustralia.com).

The leading causes of death for people with cerebral palsy related to diseases of the nervous system (45 people), including cerebral palsy itself and epilepsy. Other key causes of death related to respiratory illness (18 people), mainly aspiration and pneumonia; and cancers (14 people), primarily colon cancer and breast cancer.

**Table 29: Leading underlying causes of death of people with cerebral palsy 2003-09<sup>59</sup>**

UCOD	No.	(%)
G80.9 Cerebral palsy, unspecified	23	(19)
J69.0 Pneumonitis due to food and vomit	6	(5)
J18.9 Pneumonia, unspecified	5	(4)
G40.90 Epilepsy, unspecified	4	(3)
G80.03 Spastic quadriplegic cerebral palsy	4	(3)
G80.8 Other infantile cerebral palsy	4	(3)
C18.9 Malignant neoplasm of colon, unspecified	3	(3)
C50.9 Malignant neoplasm of breast, central portion of breast	3	(3)
J18.0 Bronchopneumonia, unspecified	3	(3)
W79 Inhalation and ingestion of food causing obstruction of respiratory tract	3	(3)

### Deaths of people with disabilities in care with cerebral palsy 2003 – 2009

Cerebral palsy was the underlying cause of death of 34 people with disabilities in care in 2003-09 (7%), all of whom lived in disability services.

**Table 30: Deaths due to cerebral palsy 2003-09**

	Disability services	
	No.	(%)
G80.9 Cerebral palsy, unspecified	23	(68)
G80.03 Spastic quadriplegic cerebral palsy	5	(15)
G80.8 Other infantile cerebral palsy	4	(12)
G80.3 Dyskinetic cerebral palsy	2	(6)
<b>Total</b>	<b>34</b>	<b>(100)</b>

Respiratory illness was a key factor in the majority of the deaths. Overall, the deaths of the 34 people were related to:

- aspiration pneumonia or inhalation of food or gastric contents (17 people);

- pneumonia/ bronchopneumonia/chest infection (11);
- seizures due to epilepsy (2);
- malnutrition (1);
- congenital heart disease (1);
- acute on chronic renal failure (1); and
- cerebral atrophy (1).

### Case study 18

A 13-year-old girl who lived in a group home died in 2009, two months after starting to receive palliative care. She had cerebral palsy, a cognitive impairment, and multiple chronic health problems, including chronic lung disease, asthma, epilepsy, GORD, recurrent respiratory infections, and swallowing difficulties. She received all of her food and fluids via PEG and PEJ<sup>60</sup> tubes.

In the 12-18 months before her death, the girl's condition deteriorated, with more frequent illnesses requiring more hospital admissions and slower recovery times. In the year before her death, she presented to hospital 15 times

<sup>59</sup> We have only included causes for which there was more than two percent of deaths.

<sup>60</sup> A percutaneous endoscopic jejunostomy (PEJ) tube feeds directly into the jejunum (part of the small intestine).



due to repeated problems with blockages and migration of her enteral feeding tubes, vomiting, and respiratory infections. Her breathing was highly compromised by her progressive lung disease, to the extent that she could only tolerate sitting up in her wheelchair for less than an hour at a time.

The girl saw a GP on a regular basis, and had the involvement of many health professionals, including allied health, a respiratory specialist, a stoma therapist, and a dysphagia clinic.

Two months before her death, the girl's family, treating clinicians and disability services staff identified that her deterioration was not reversible and continuation of active treatment was no longer appropriate. Palliative care planning was comprehensive and involved her family, palliative care professionals, disability service staff, and Community Services.

### Age, gender and cultural background

The median age at death was 32 years. Cerebral palsy was the underlying cause of death of just as many females as males.

One person was from a CALD background, and three people were Aboriginal or Torres Strait Islander.

### Accommodation

Half of the people whose underlying cause of death was cerebral palsy lived in ADHC accommodation, and half lived with NGO services.

**Table 31: People with underlying cause of death of cerebral palsy by service and accommodation type**

NGO	No.	(%)
Group home	8	(47)
Large residential	6	(35)
Respite	2	(12)
Small residential	1	(6)
<b>Total</b>	<b>17</b>	<b>(100)</b>

ADHC	No.	(%)
Group home	8	(47)
Large residential	9	(53)
<b>Total</b>	<b>17</b>	<b>(100)</b>

### Disability, health issues and support needs

Of the 34 people whose underlying cause of death was cerebral palsy, all but one person had an intellectual disability, mainly in the severe (10) or profound (16) range of impairment. Almost half (16) had a sensory impairment, mainly visual impairment.

Overall, the people whose underlying cause of death was cerebral palsy had high support needs and multiple chronic health issues:

- The majority had swallowing difficulties (29) and required assistance with meals (33). Almost half relied on enteral feeding (16), mainly via PEG.
- Only four people did not require some form of support to communicate.
- All had limited mobility, and all but two people relied on a wheelchair.
- Common health issues included epilepsy (25), constipation (24), GORD (22), and recurrent respiratory infections (20).
- Nine people had osteoporosis and six people had asthma.

Many people with cerebral palsy have problems gaining or maintaining weight. Weight status information was available for 33 people whose underlying cause of death was cerebral palsy. Just over half (18) were underweight. Nine people were in the healthy weight range, and six people were overweight.

Nineteen of the 24 people who were outside of the healthy weight range had seen a dietician or attended a dysphagia clinic at some point – all in the 12 months before their death. Of the six people for whom there was no information regarding dietician involvement, we noted



that one person died while on respite, and the other people died in 2003 or 2004.

## Health assessments and supports

Just over three-quarters of the people whose underlying cause of death was cerebral palsy had received the influenza vaccination (26). Less than half (14) had received the pneumococcal vaccination.

In terms of access to allied health and medical specialists:

- All but one person had seen a GP. Less than half (15) had had a comprehensive health assessment; most of whom (13) had the assessment in the year before their death.
- Of the 29 people who had swallowing difficulties, most (24) had seen a speech pathologist or attended a dysphagia clinic, mainly in the year before their death.
- Five of the 20 people who had recurrent respiratory infections had seen a respiratory specialist.
- Less than two-thirds had seen a dentist (21); most of whom (18) had seen a dentist in the year before their death.
- Most of the 16 people who relied on enteral feeding (14) had seen a dietician in the year before they died, and seven people had seen a gastroenterologist. Nine of the 22 people with GORD had seen a gastroenterologist.
- All of the people whose underlying cause of death was cerebral palsy had limited mobility. Fifteen people had seen a physiotherapist, all in the year before their death. The same number had seen an occupational therapist.

Twenty-three people died after the introduction of nutrition and swallowing risk assessment requirements. Our reviews identified that just under two-thirds (15) had a completed nutrition and swallowing risk checklist that

identified all of the relevant risks and the actions that were required to address them. Nine of these people lived in NGO services, and six in ADHC accommodation.

Two people had had no nutrition and swallowing risk assessment at all. Both people lived in NGO services. For the remaining six people, services had identified some – but not all – risks, or had identified the risks but not identified the actions required to address them.

## Our reviews

The issues we have identified in our reviews of the deaths of people whose underlying cause of death was cerebral palsy mainly related to the identification and management of nutrition, swallowing and respiratory risks.

### Our reviews have identified:

- The need to provide clear guidance for staff about the person's support needs, including positioning during and after meals and in bed; and to update support plans following changes in the person's needs.
- The importance of staff actions to identify nutrition, swallowing and respiratory risks through risk assessments and referral to appropriate health practitioners.
- The need for services to develop strategies to promote staff understanding of, and compliance with, recommendations made in assessment and support plans. Our reviews found instances where staff actions did not assist the person to manage their risks, including provision of fluids in a reclined position; provision of food and fluids that were not consistent with recommendations; lack of referral to speech pathology assistance despite swallowing problems; and medication administration errors.

## 5.10 Deaths from congenital malformations and chromosomal abnormalities

Deaths due to congenital and chromosomal factors are not common in the general population, and they typically occur at a very young age – often within the first year of life.

Congenital and chromosomal factors feature more highly as a cause of death of people in disability services. It was the sixth leading cause of death of disability services residents in 2003-09, accounting for the deaths of 54 people (10%). The median age at death was 44 years.

The most common congenital or chromosomal factor in these deaths was Down syndrome.

### 5.10.1 Down syndrome

#### Deaths of people with disabilities in care with Down syndrome 2003-2009

Of the 651 people with disabilities in care who died in 2003-09, 80 people (12%) had Down syndrome. All lived in the care of disability services.

The main underlying cause of death for people with Down syndrome was congenital and chromosomal factors (29 people), mainly Down syndrome itself (26 people).

Other leading underlying causes of death for people with Down syndrome were respiratory diseases (14 people), mainly aspiration or other pneumonia; and circulatory diseases (12 people), mainly cerebrovascular diseases.

**Table 32: Leading causes of death of people with Down syndrome 2003-09<sup>61</sup>**

No. = 80		Disability services	
		No.	(%)
Q90.9	Trisomy 21	23	(29)
J69.0	Pneumonitis due to food and vomit	5	(6)
J18.9	Pneumonia, unspecified	4	(5)
G40.90	Epilepsy, unspecified	3	(4)
Q21.8	Other congenital malformations of cardiac septa	3	(4)
I21.9	Acute myocardial infarction, unspecified	2	(3)
I61.9	Intracerebral haemorrhage, unspecified	2	(3)
J44.9	Chronic obstructive pulmonary disease, unspecified	2	(3)

#### Deaths from Down syndrome in disability services 2003-2009

Of the 26 people whose underlying cause of death was Down syndrome, the key contributory causes of death were:

- Respiratory diseases (17 people), including:
  - eight people with pneumonia;
  - five people with pneumonia and dementia/Alzheimer's disease; and

- four people with aspiration pneumonia.

- Congenital heart disease (four people)

Dementia was a contributory factor in the deaths of another three people.

#### Age, gender and cultural background

The median age at death from Down syndrome was 50 years, and over half of the people whose deaths were due to Down syndrome were male (15).

<sup>61</sup> We have only included causes for which there was over two percent of deaths.

One person was from a CALD background. None of the people whose underlying cause of death was Down syndrome were Aboriginal or Torres Strait Islander.

## Accommodation

Over half of the people (15) lived in NGO accommodation. Most lived in group homes (16).

**Table 33: People with underlying cause of death of Down syndrome by service and accommodation type**

NGO	No.	(%)
Group home	15	(100)
<b>Total</b>	<b>15</b>	<b>(100)</b>

ADHC	No.	(%)
Group home	1	(9)
Large residential	10	(91)
<b>Total</b>	<b>11</b>	<b>(100)</b>

## Disability, health issues and support needs

All people with Down syndrome have some degree of intellectual impairment. Most of the people whose underlying cause of death was Down syndrome had a moderate (10) to severe (11) intellectual disability.

Of the 26 people whose underlying cause of death in 2003-09 was Down syndrome:

- the majority had multiple impairments (23), including dementia (13) and sensory impairments (17);
- the majority needed help with meals (19), had limited mobility (20), and needed support to communicate (23); and
- key health issues included swallowing difficulties (18), recurrent respiratory infections (14), epilepsy (12), GORD (12) and osteoporosis (9).

Other common health issues included constipation (11); heart problems, such as

congenital heart disease (8); hypothyroidism (7) and arthritis/ osteoarthritis (6).

Weight status information was available for 25 of the 26 people whose underlying cause of death was Down syndrome. Less than half of the people (11) were in the healthy weight range. Ten people were overweight, and four people were underweight.

Half of the 14 people who were outside the healthy weight range had seen a dietician, including six of the 10 people who were overweight.

## Case study 19

A 35-year-old man with Down syndrome who lived in a group home in a regional area died in 2009 from acute bronchopneumonia. Prior to developing pneumonia, the man worked part-time and had a busy social life.

He had a mild intellectual disability and severe obesity. He was on a weight reduction diet and had an exercise program. Three months before his death, his GP made a referral to a dietician but the appointment was cancelled when he developed pneumonia.

One month before his death, the man developed a cough and chest infection. He saw his GP the next day and started antibiotics. Despite treatment, the man's condition failed to improve. Eight days after the start of his symptoms, the man was admitted to hospital with community-acquired pneumonia. Two other residents of the group home and some staff were also reported to have pneumonia at the time.

While the man's respiratory function initially improved and the pneumonia showed signs of resolving, during the admission he contracted Vancomycin Resistant Enterococci (VRE), and was moved to a single room. He was subsequently transferred to the intensive care unit and put on life support after going into respiratory arrest.

A subsequent health service review of the man's death found that his care had been compromised during admission due to factors such as inadequate monitoring of his oxygen levels and lack of thorough ongoing clinical assessments.

## Health assessments and supports

Two-thirds (17) had received the influenza vaccine in the year before their death. Just over one-third (9) had received the pneumococcal vaccination.

In terms of access to allied health and medical specialists:

- All of the 26 people whose underlying cause of death was Down syndrome had seen a GP. Less than half (11) had ever had a comprehensive health assessment.
- Three of the 14 people who had recurrent respiratory infections had seen a respiratory specialist at some time.
- Less than one-third of people (7) had seen a dentist.
- Almost three-quarters of the 18 people who had swallowing difficulties (13) had been reviewed by a speech pathologist and/or attend a dysphagia clinic at some point.

Seventeen people died after the introduction of nutrition and swallowing risk assessment requirements. Almost two-thirds (11) had a nutrition and swallowing assessment that identified all of their risks and the actions that would be taken to address them. Six of these people lived in NGO services, and five in ADHC accommodation.

Two people in NGO services did not have a nutrition and swallowing risk assessment at all. For the remaining four people, services had identified some – but not all – risks, or had identified the risks but had not identified the actions to be taken to address them.

Five of the 26 people had a mealtime management plan to provide guidance to staff.

## Case study 20

A 58-year-old woman who lived in a regional group home died in 2009. She had Down syndrome and dementia, and her health declined in the year before her death due to progression of dementia and the effects of ageing.

She had significant health risks and support needs that required ongoing and intensive staff support, including mobility, pressure areas, swallowing and nutrition. We found that the service was responsive to her increasing needs, assisted by additional support provided through a disability aged care pilot.

The woman had regular reviews with her GP, access to community nurses for wound management, and the involvement of relevant allied health and specialist medical staff, including a gerontologist.

Three weeks before her death, she was admitted to hospital with a chest infection and shortness of breath. She did not improve with active treatment, and subsequently died after receiving palliative care.

## Our reviews

Overall, our reviews of the deaths of the 26 people found that the disability services provided good support, including links to developmental disability health clinic reviews.

The majority experienced a decline in their health and increased support needs in the six to 12 months before their death, and in the main we noted provision by disability services of additional support, and actions on the part of health professionals to identify the cause.

All of the people whose deaths were due to their congenital heart condition had had regular cardiology reviews and proactive treatment as much as possible.

## 5.11 Deaths from diseases of the circulatory system

Diseases of the circulatory system are the leading cause of death in Australia, accounting for around one-third of all deaths. In the general population, deaths from this cause tend to occur in older age. For example, the median age at death in Australia in 2008 was 84.6 years.<sup>62</sup>

Diseases of the circulatory system are also the leading cause of death of people in licensed boarding houses, across all age groups. Between 2003 and 2009, the deaths of 50 people in licensed boarding houses (41%) were due to diseases of the circulatory system, primarily ischaemic heart diseases. Diseases of the circulatory system were also contributory factors in the deaths of another 14 people.

Circulatory system diseases were the third largest underlying cause of death of people in disability services, and were the leading cause of death of disability services residents over 65 years of age. The deaths of 72 people in disability services (14%) were due to diseases of the circulatory system, primarily ischaemic heart diseases and cerebrovascular diseases. Diseases of the circulatory system were contributory factors in the deaths of another 80 people in disability services.<sup>63</sup>

### 5.11.1 Ischaemic heart diseases

Ischaemic heart diseases, including angina, heart attacks, and chronic ischaemic heart disease have been the leading cause of death for all Australians since 2000.<sup>64</sup>

Ischaemic heart diseases were also a leading cause of death of people with disabilities in care between 2003 and 2009, accounting for the deaths of 32 people in licensed boarding houses and 32 people in disability services.

The main ischaemic heart diseases that caused the deaths of people with disabilities in care were chronic ischaemic heart disease and acute myocardial infarction (heart attack).

#### Chronic ischaemic heart disease

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.

For people in disability services, chronic ischaemic heart disease was the underlying cause of death of 17 people, and a contributory factor in the death of another 30 people.

For people in licensed boarding houses, chronic ischaemic heart disease was the underlying cause of death of 14 people, and a contributory factor in the death of another 14 people.

**Table 34: Deaths from chronic ischaemic heart disease 2003-09**

		Licensed BH		Disability services	
		No.	(%)	No.	(%)
I25.11	Atherosclerotic heart disease of native coronary artery	9	(64)	10	(59)
I25.9	Chronic ischaemic heart disease, unspecified	4	(29)	7	(41)
I25.5	Ischaemic cardiomyopathy	1	(7)	0	(0)
<b>Total</b>		<b>14</b>	<b>(100)</b>	<b>17</b>	<b>(100)</b>

62 Australian Bureau of Statistics (2010) 3303.0 Causes of Death, Australia, 2008.

63 This includes people for whom circulatory disease was only the direct cause of death.

64 Australian Bureau of Statistics (2011) 3303.0 Causes of Death, Australia, 2009.



## Risk factors

The risk of ischaemic heart disease increases with age. Other risk factors include:

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

Chronic ischaemic heart disease is more common in men and those who have close relatives with the condition. Men in their 40s have a higher risk of chronic ischaemic heart disease than women. However, as women get older, their risk increases so that it is almost equal to that for men.

### Case study 21

A 54-year-old woman who lived in a group home died from coronary artery atheroma and ischaemic heart disease in 2009. The woman died shortly after collapsing in the street while out buying dinner.

She had schizophrenia and alcohol related brain damage, as well as chronic health issues that included diabetes, hepatitis C, and a gastric ulcer. She smoked up to 20 cigarettes a day. Disability service staff encouraged the woman to stop smoking, but were unsuccessful.

The woman was overweight, but saw a dietician regularly and was encouraged by staff to make healthy food choices that were in line with a diabetic diet. She resided in a separate flat adjoining the group home and was very independent.

Ischaemic heart disease was not identified prior to the woman's death, and on a day-to-

day basis she presented with no symptoms. However, she had numerous risk factors for development of the disease – including smoking, diabetes, and being overweight. In addition, shortly before her death, a blood test indicated that she had slightly elevated cholesterol.

### Case study 22

A 42-year-old man who lived in a regional licensed boarding house died in 2007 from coronary artery disease.

The man had chronic schizophrenia and multiple risk factors for ischaemic heart disease, including obesity, heavy smoking, high blood pressure, and type II diabetes. He was also prescribed an antipsychotic medication that carried risks of myocarditis and cardiomyopathy.

The man had monthly reviews with his GP in relation to his overall health and monitoring of the antipsychotic medication, including blood testing and weight monitoring. The GP had regular discussions with him about the need to address the risks associated with his smoking and obesity, but the man was reluctant to change his lifestyle.

Other than a psychiatric review, he did not appear to have other specialist reviews in the year before his death. At his last cardiology review, conducted over two years before his death, he was found to have trivial pulmonary regurgitation, but no abnormalities.

## Deaths from chronic ischaemic heart disease 2003-2009

### Age, gender and cultural background

Overall, people with disabilities in care died from chronic ischaemic heart disease approximately 20 years younger than the general population. The median age at death was 68 years for people in disability services, and 61 years for licensed boarding house residents.



More males than females died from chronic ischaemic heart disease. Males accounted for 11 of the 17 people in disability services who died from this condition, and 12 of the 14 people in licensed boarding houses.

One licensed boarding house resident was from a CALD background. One disability services resident was Aboriginal.

## Smoking

Seven people in disability services who died from chronic ischaemic heart disease had smoked; four of whom were smokers at the time of their death.

More than three-quarters of the licensed boarding house residents who died from chronic ischaemic heart disease had smoked (11). Most smoked more than 11 cigarettes a day at the time of their death.

**Table 35: Tobacco use by people who died from ischaemic heart disease**

Tobacco	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Yes	9	(64)	4	(24)
Ex-smoker	2	(14)	3	(18)
No	3	(21)	10	(59)
<b>Total</b>	<b>14</b>	<b>(100)</b>	<b>17</b>	<b>(100)</b>

Tobacco – yes	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Occasional	2	(22)	1	(25)
Up to 10/ day	1	(11)	0	(0)
11-20/ day	3	(33)	3	(75)
>20/ day	3	(33)	0	(0)
<b>Total</b>	<b>9</b>	<b>(100)</b>	<b>4</b>	<b>(100)</b>

## Weight

Most of the 17 people in disability services who died from chronic ischaemic heart disease (10) were overweight. Half of these

individuals had seen a dietician in the year before their death.

Weight status information was available for 11 of the 14 licensed boarding house residents. Most of these individuals (8) were overweight or obese. None of these people had seen a dietician.

## Mobility

Just over half of the 17 people in disability services who died from chronic ischaemic heart disease (10) had limited mobility, including six people who relied on a wheelchair.

Five people in licensed boarding houses who died from this condition had mobility problems – three relied on a walking stick and two people used no mobility aide.

## Health issues

The key health issues for the people who died from chronic ischaemic heart disease, in both licensed boarding houses and disability services, were hypertension, diabetes and constipation:

- Of the 17 people in disability services who died from chronic ischaemic heart disease, 10 had constipation, eight had hypertension, and seven had diabetes.
- Of the 14 licensed boarding house residents who died from this condition, five had diabetes, five had hypertension, and five had constipation.

## Health supports

All of the people had seen a GP. Less than half of the disability services residents (8) and one licensed boarding house resident had had a comprehensive health assessment in the year before they died.

Of the 17 people in disability services who died from chronic ischaemic heart disease, at least nine people had known heart problems (such as congenital heart disease or

cardiomegaly). Three people had numerous risk factors and were on relevant medications. Six people had seen a cardiologist.

Of the 14 people in licensed boarding houses who died from chronic ischaemic heart disease, at least three people had known heart problems (such as congestive cardiac failure or ischaemic heart disease). Five people had numerous risk factors and were on relevant medications such as antihypertensives). Three people had seen a cardiologist.

### Acute myocardial infarction

An acute myocardial infarction is also known as a heart attack. It occurs when there is a sudden, complete blockage of an artery that supplies blood to a part of the heart. Some of the heart muscle begins to die, and without early medical treatment the damage can be permanent.

Most heart attacks are caused by coronary heart disease – where the build-up of fatty deposits (plaque) on the inner wall of the arteries that supply the heart muscle with blood gradually clogs and narrows the inside channel of the arteries. A heart attack usually begins when an area of plaque cracks and triggers a blood clot to form, which suddenly and completely blocks the blood flow to the heart muscle.

Heart attack was the underlying cause of death for 19 people in licensed boarding houses, and a contributing factor in the death of one other person.

It was also the underlying cause of death of 15 people in disability services, and the contributing factor in the death of another two people.

**Table 36: Deaths from heart attack 2003-09**

		Licensed BH		Disability services	
		No.	(%)	No.	(%)
I21.9	Acute myocardial infarction, unspecified	18	(95)	15	(100)
I21.4	Acute subendocardial myocardial infarction	1	(5)	0	(0)
<b>Total</b>		<b>19</b>	<b>(100)</b>	<b>15</b>	<b>(100)</b>

### Risk factors for coronary heart disease and heart attack<sup>65</sup>

There is no single cause of coronary heart disease, but there are risk factors that increase a person’s chance of developing it. There are risk factors that cannot be changed, such as being male, having a family history of coronary heart disease, and increasing age. There are also modifiable risk factors, including:

- smoking;
- high blood cholesterol;
- high blood pressure;
- diabetes;
- physical inactivity;
- too much fat in the diet;

- being overweight; and
- depression.

These are the same risk factors that exist for chronic ischaemic heart disease.

### Case study 22

A 61-year-old woman who lived in a regional licensed boarding house died in 2009 from a heart attack. She had schizophrenia and chronic health problems that included type II diabetes, hypothyroidism, hypertension, cardiomegaly, recurrent respiratory infections and chronic renal failure.

She had multiple risk factors for heart attack, including hypertension, diabetes, and smoking (up to 10 per day).

<sup>65</sup> Heart Foundation of Australia website, [www.heartfoundation.org.au](http://www.heartfoundation.org.au).

The woman was admitted to hospital four times in the 12 months before her death. In three of the four instances, she presented with facial swelling/ swollen tongue. During one of the hospital admissions, 10 months before her death, she was noted to have mild mitral regurgitation and mild to moderate pulmonary hypertension.

The woman did not receive the pneumococcal vaccine despite her chronic health issues and risk from smoking.

### Case study 23

A 61-year-old man who lived in a licensed boarding house died from a heart attack. He had schizophrenia and was a heavy smoker. Less than three weeks before his death, the man was admitted to hospital with chest pain, excessive sweating, pain in the right shoulder, and vomiting. Hospital staff recorded that the man did not have a history of chest pain, but did have multiple cardiac risks.

After assessment of the man in hospital, the treating specialists proposed bypass surgery. The surgery did not proceed, and there was insufficient information in the records to ascertain why this was the case. He was discharged to the boarding house 11 days after being admitted, for a follow-up cardiology appointment and review by his GP. Eight days after discharge, the man collapsed at the boarding house and was unable to be revived.

## Deaths from heart attack 2003-2009

### Age, gender and cultural background

The median age at death from heart attack was 76 years for people in disability services and 68 years for people in licensed boarding houses.

More males died from heart attack than females in both licensed boarding houses and disability services. Males accounted for two-thirds of the 15 people in disability services who died from heart attack (10), and 16 of the

19 licensed boarding house residents who died from that condition.

Two people in licensed boarding houses and one disability services resident were from a CALD background. One licensed boarding house resident who died from a heart attack was Aboriginal.

### Accommodation

Most of the 15 people in disability services who died from heart attack (11) lived in NGO services. Just over half lived in group homes.

**Table 37: Deaths from heart attack by service and accommodation type**

ADHC	No.	(%)
Group home	2	(50)
Large residential	2	(50)
<b>Total</b>	<b>11</b>	<b>(100)</b>

NGO	No.	(%)
Group home	6	(55)
Large residential	5	(46)
<b>Total</b>	<b>11</b>	<b>(100)</b>

### Disability

Ten disability services residents had an intellectual disability, mainly at a mild (2) or moderate (6) level of impairment. Six people had a mental illness.

Most of the licensed boarding house residents who died from heart attack (14) had a mental illness, and nine people had an intellectual disability and/or alcohol related brain damage.

### Smoking

Three people in disability services who died from heart attack had smoked, and only one person was a current smoker at the time of their death.

All but one of the 19 people in licensed boarding houses who died from heart attack had smoked, including 16 people who were current smokers at the time of their death.

Most of the 16 people smoked more than 10 cigarettes a day, including five people who smoked more than 20 cigarettes a day.

**Table 38: Tobacco use by people who died from heart attack**

Tobacco	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Yes	16	(84)	1	(7)
Ex-smoker	2	(11)	2	(13)
No	1	(5)	12	(80)
<b>Total</b>	<b>19</b>	<b>(100)</b>	<b>15</b>	<b>(100)</b>

Tobacco - Current	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Occasional	0	(0)	0	(0)
Up to 10/ day	3	(19)	1	(100)
11-20/ day	8	(50)	0	(0)
>20/ day	5	(31)	0	(0)
<b>Total</b>	<b>16</b>	<b>(100)</b>	<b>1</b>	<b>(100)</b>

## Weight

Weight status information was available for 11 of the 15 disability services residents. Just over half of those individuals (6) were overweight. Three people were in the healthy weight range, and two people were underweight.

The weight status of six of the 16 licensed boarding house residents was recorded. Five of the six people were overweight, and one person was in the healthy weight range.

Both of the people who were underweight had seen a dietician. Only two of the 11 people who were overweight had seen a dietician – one licensed boarding house resident and one person in a disability service.

## Mobility

Most of the people in disability services who died from heart attack (12) had limited mobility. Only three licensed boarding house

residents had limited mobility, and none of them used a mobility aide.

## Health issues

More than half of the 15 people in disability services who died from heart attack had hypertension (8), and five people had diabetes. Nine disability services residents had known heart problems, including congestive cardiac failure, atrial fibrillation, congenital heart disease, and ischaemic heart disease. Two of the nine people had a pacemaker.

Eight of the 19 people in licensed boarding houses who died from heart attack had hypertension. Seven people had known heart problems, including angina, cardiomegaly, arteriosclerosis, and ischaemic heart disease.

## Health supports

Five licensed boarding house residents and five people in disability services had seen a cardiologist.

All of the people who died from heart attack had seen a GP. Less than one-third of the 15 people in disability services (4) and just over one-quarter of the 19 people in licensed boarding houses (5) had ever had a comprehensive health assessment.

## Our reviews of deaths from chronic ischaemic heart disease and heart attack

Our reviews of the deaths of people from chronic ischaemic heart disease or heart attack in 2003-09 identified examples of good practice in identifying and managing the key risks, particularly by disability services.

This included people who had regular GP and cardiology reviews, links to dieticians and regular weight checks to target obesity, and regular discussions with staff and/or health practitioners about the implications of continuing to smoke.

However, our reviews also identified the need for:

- Proactive strategies and support of individuals to address their multiple risk factors for ischaemic heart diseases – particularly lifestyle factors such as smoking, physical inactivity, and obesity. It was not clear what support was available or offered to the individuals to enable them to address the risks, or to make an informed choice not to. This includes dietician involvement; changes to the person's diet or the menu at the boarding house; involvement in exercise options through ALI activities; and provision of nicotine replacement therapy.
- Promotion of regular physical activity or exercise to people in disability services and licensed boarding houses.
- Promotion of, and access to, chronic disease management programs for people with disabilities in care with chronic ischaemic heart diseases.

## 5.12 Deaths from neoplasms (cancer)

Cancer was the second leading cause of death of people in disability services in 2003-09, accounting for the deaths of 81 people (16%). The median age at death was 58 years.

It was also the second leading cause of death of people in licensed boarding houses, accounting for the deaths of 20 people (17%). The median age at death was 61.5 years.

The main forms of cancer that caused the deaths of people with disabilities in care were lung cancer and colon (or bowel) cancer.

### 5.12.1 Lung cancer

Between 2003 and 2009, lung cancer accounted for the deaths of 17 people in disability services and six people in licensed boarding houses. It was also a contributing factor in the deaths of another two disability services residents.

**Table 39: Deaths due to lung cancer 2003-09**

	Licensed BH		Disability services	
	No.	(%)	No.	(%)
C34.9 Malignant neoplasm of bronchus or lung, unspecified	4	(67)	15	(88)
C34.3 Malignant neoplasm of lower lobe, bronchus or lung	1	(17)	1	(6)
C34.0 Malignant neoplasm of main bronchus	0	(0)	1	(6)
C34.1 Malignant neoplasm of upper lobe, bronchus or lung	1	(17)	0	(0)
<b>Total</b>	<b>6</b>	<b>(100)</b>	<b>17</b>	<b>(100)</b>

### Risk factors<sup>66</sup>

Cigarette smoking is the leading cause of lung cancer. The more cigarettes a person smokes per day, and the earlier they start smoking, the greater their risk of lung cancer. However, lung cancer has occurred in people who have never smoked. Second-hand smoke increases the risk of lung cancer. Other risk factors include a family history of lung cancer; asbestos; high levels of air pollution; and radiation therapy to the lungs.

### Case study 24

A 64-year-old woman who lived in a licensed boarding house for 15 years died from lung cancer in 2009. She had schizophrenia, and chronic health issues that included asthma, COPD, congestive cardiac failure, GORD, sciatica and osteoarthritis.

She was a heavy smoker despite her chronic breathing problems. Records indicated that her psychiatrist and GP both spoke with her about the risks associated with continued smoking, and the GP Management Plan

<sup>66</sup> Cancer Council Australia website, [www.cancer.org.au](http://www.cancer.org.au).



included a goal of smoking cessation. The woman had regular access to her GP, psychiatrist, the local ADHC boarding house team, and the community.

She saw a GP on a regular basis, and a chest x-ray taken 10 months before death had not indicated any mass. Nineteen days before her death, the woman was reviewed by a GP after the boarding house manager noted that she had a bad cough, was tired, and had blue lips. She had a chest x-ray the same day and a CT scan five days later, which indicated that she had lung cancer. On being told of the cancer diagnosis by her GP, the woman reportedly stated that she did not want surgery. The GP referred her to a specialist for an opinion and advice regarding cancer management.

Six days before her death, and before she could see the specialist, the woman was admitted to hospital due to a sustained period of shortness of breath, increasing drowsiness and jaundice. Discussions took place between the hospital's discharge planner, the woman and her step-daughter regarding possible discharge options, noting that she would not be able to return to the boarding house with her current support needs. She died in hospital four days later.

## Deaths from lung cancer 2003-2009

### Age, gender and cultural background

The median age at death from lung cancer was 65 years for people in disability services and 60 years for people in licensed boarding houses.

The majority of people who died from lung cancer were male. Males accounted for 14 of the 17 people in disability services and five of the six licensed boarding house residents who died from lung cancer.

One of the six licensed boarding house residents who died from lung cancer was from a CALD background. None of the people who died from this condition were Aboriginal or Torres Strait Islander.

## Accommodation

Just over half of the 17 people in disability services who died from lung cancer (10) lived in ADHC accommodation, mainly large residential centres.

**Table 40: Deaths due to lung cancer by service and accommodation type**

NGO	Disability services	
	No.	(%)
Group home	4	(57)
Large residential	2	(29)
Small residential	1	(14)
<b>Total</b>	<b>7</b>	<b>(100)</b>

ADHC	Disability services	
	No.	(%)
Group home	3	(30)
Large residential	7	(70)
<b>Total</b>	<b>10</b>	<b>(100)</b>

## Disability

Most of the people in disability services who died from lung cancer had an intellectual disability (13) and/or acquired brain injury (3), including two people with alcohol related brain damage. Just over half (9) had a mental illness.

Two-thirds of the licensed boarding house residents who died from lung cancer had an intellectual disability and/or alcohol related brain damage. Half of the six people had a mental illness.

## Length of time between diagnosis and death

Our reviews found that there tended to be a short period of time between individuals being diagnosed with lung cancer and their death from the condition. Of the six people who died from lung cancer in 2008 or 2009, one person was diagnosed six months before death, four people were diagnosed approximately two weeks before their death, and the person in the following case study died two days after the lung cancer was diagnosed.



## Case study 25

A 64-year-old man who lived in a large residential centre died from lung cancer, two days after being diagnosed with the condition. He was a heavy smoker, and had not attempted to quit despite disability service staff regularly discussing it with him, and offering assistance.

Twelve days before his death, the man was reviewed by a GP due to fever and a continuing cough. The GP diagnosed bronchitis and prescribed antibiotics. Four days later he had increased shortness of breath, was admitted to hospital, and diagnosed with bilateral pneumonia. While in hospital, the man complained of stomach pain. Further tests indicated that he had cancer in his liver and lung.

The diagnosis was discussed with the man, his friends, and disability service staff. A referral was made for an oncology consultation, but he died the following day.

## Smoking

The majority of the people with disabilities in care who died from lung cancer had smoked. Fourteen of the 17 people in disability services had smoked, including eight people who were smokers at the time of their death.

Five of the six licensed boarding house residents were current smokers at the time of their death. Most of these people smoked more than 10 cigarettes a day.

**Table 41: Tobacco use by people who died from lung cancer**

Tobacco	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Current	5	(83)	8	(47)
Ex-smoker	0	(0)	6	(35)
No	1	(17)	3	(18)
<b>Total</b>	<b>6</b>	<b>(100)</b>	<b>17</b>	<b>(100)</b>

Tobacco - Current	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Occasional	1	(20)	0	(0)
Up to 10/ day	0	(0)	3	(38)
11-20/ day	2	(40)	3	(38)
>20/ day	2	(40)	2	(25)
<b>Total</b>	<b>5</b>	<b>(100)</b>	<b>8</b>	<b>(100)</b>

## Health support

All of the licensed boarding house residents and all but one of the disability services residents had seen a GP in the year before they died. One-third of the 23 people who died from lung cancer (8) had had a comprehensive health assessment in the year before their death.

Nine of the 17 people in disability services and one of the six licensed boarding house residents who died from lung cancer had seen an oncologist. In some cases, this was because there was a very short period of time between the person being diagnosed with the condition and their death.

Most of the people with disabilities in care who died from lung cancer (16) had the involvement of palliative care professionals, including 11 of the 17 people in disability services.

## Our reviews

We found that for the majority of the people who died from lung cancer, there was a very short period of time between being diagnosed with the condition and their death from it – generally two months. Few people had radiotherapy or chemotherapy – for some people the cancer was considered too advanced, and for others further investigations were being conducted to ascertain the treatment options when they died.

### Our reviews have highlighted:

- The need for vigilance in relation to changes in a person's health or behaviour, including unexplained weight loss, fatigue and falls, and subsequent action, including review of the person's health and support needs.
- The importance of access to smoking cessation strategies and programs. We found that a few people had been encouraged to quit smoking by health practitioners and/or staff, and some had managed to do so. However, for the majority of people who died from lung cancer and who were smokers at the time

of their death, there was no indication that they had been provided with information and support to stop smoking.

### 5.12.2 Colon cancer

Colon cancer is also known as colorectal or bowel cancer.

Between 2003 and 2009, colon cancer accounted for the deaths of 11 people in disability services and three people in licensed boarding houses. It was also a contributing factor in the death of another disability services resident.

**Table 42: Deaths due to colon cancer 2003-09**

		Licensed BH		Disability services	
		No.	(%)	No.	(%)
C18.9	Colon, unspecified	1	(33)	5	(46)
C18.7	Sigmoid colon	0	(0)	3	(28)
C20	Malignant neoplasm of rectum	1	(33)	1	(9)
C18.6	Malignant neoplasm: descending colon	0	(0)	1	(9)
C19	Malignant neoplasm of rectosigmoid junction	1	(33)	0	(0)
C21.0	Anus, unspecified	0	(0)	1	(9)
<b>Total</b>		<b>3</b>	<b>(100)</b>	<b>11</b>	<b>(100)</b>

### Risk factors<sup>67</sup>

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

- are 50 years and over;
- smoke cigarettes;
- are obese;
- have low fruit and vegetable consumption;
- have colorectal polyps;
- have inflammatory bowel disease (Crohn's disease or ulcerative colitis);
- have inherited genetic risk, including a family history of colon cancer, or certain hereditary conditions such as Lynch syndrome or familial adenomatous polyposis; and

- have a personal history of cancer of the colon, rectum, ovary, endometrium or breast cancer.

Symptoms of colon 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;
- weight loss with no known reason.

Colon cancer can develop without any warning signs. The cancer can grow on the inside wall of the bowel for several years before spreading to other parts of the body.

<sup>67</sup> Bowel Cancer Australia website, [www.bowelcanceraustralia.org/bca/](http://www.bowelcanceraustralia.org/bca/)

Often very small amounts of blood leak from these growths and pass into the bowel motion before any symptoms are noticed. A faecal occult blood test (FOBT) can detect these small amounts of blood.

Screening for bowel cancer using a FOBT is a simple, non-invasive process. People aged 50 years and older are currently recommended to have a FOBT every two years. Having a FOBT every two years can reduce the risk of dying from bowel cancer by up to one-third.

### **Case study 26**

A 67-year-old man who lived in a licensed boarding house died from bowel cancer in 2008. He was a heavy smoker and had schizophrenia. While he saw a GP and the community mental health team on a regular basis and took medications as required, he had a consistent history of refusing a range of medical interventions, such as some diagnostic tests and examination in hospital. Our review found that there was liaison between the man's GP, his niece (private guardian), the community mental health team, and boarding house staff to support him to accept greater medical intervention.

Eight months before the man's death, his GP referred him to a urologist for opinion regarding possible prostate cancer. The urologist confirmed that the man was likely to have prostate cancer, and made arrangements for him to have an anaesthetic review to determine whether he would be appropriate for surgery.

Before the anaesthetic review could occur, the man was admitted to hospital with bilateral leg oedema and found to have a bowel obstruction and likely bowel cancer. The man died the following day, after having a cardiac arrest.

### **Case study 27**

A 73-year-old woman with cerebral palsy who lived in a group home died from complications of colon cancer in 2008. She had no cognitive impairment, and provided her own consent to treatment.

The woman had a history of bowel cancer, but refused to undergo colonoscopies or have tests to detect cancer markers.

Two months before her death, the woman was admitted to hospital with acute cholecystitis. She was found to have multiple gallstones, but with no evidence of perforation. She was discharged for follow-up with her gastroenterologist. She was readmitted to hospital the next day with a distended abdomen. A CT scan queried a bowel mass, but a subsequent colonoscopy did not identify an obstruction or lesion. The radiographer noted that the woman was difficult to examine.

A subsequent CT scan, conducted during the woman's final hospital admission two weeks before her death, identified colorectal cancer. She underwent surgery to remove the tumour, but developed pneumonia and sepsis and died in hospital.

## **Deaths from colon cancer 2003-2009**

### **Age, gender and cultural background**

The median age at death from colon cancer was 61 years for people in disability services and 67 years for people in licensed boarding houses. All but one person who lived in disability services were aged 50 years or older. All of the licensed boarding house residents were 55 years or older when they died.

More males (8) than females (6) died from colon cancer. None of the people who died from colon cancer were from a CALD background or were Aboriginal or Torres Strait Islander.

## Accommodation

Most of the disability services residents who died from colon cancer (8) lived in large residential centres, and in ADHC accommodation.

**Table 43: Deaths due to colon cancer by service and accommodation type**

ADHC	Disability services	
	No.	(%)
Group home	1	(14)
Large residential	6	(86)
<b>Total</b>	<b>7</b>	<b>(100)</b>

NGO	Disability services	
	No.	(%)
Group home	2	(50)
Large residential	2	(50)
<b>Total</b>	<b>4</b>	<b>(100)</b>

## Disability

The majority of people in disability services who died from colon cancer (9) had an intellectual disability, most of whom (7) had a moderate or severe level of impairment. Seven people had a sensory impairment, mainly vision. Five people had cerebral palsy.

All of the three licensed boarding house residents had a mental illness. One person also had a moderate intellectual disability.

## Mobility

The people who died from colon cancer tended to have limited mobility. Only two people in disability services and one licensed boarding house resident who died from colon cancer did not have mobility problems.

## Weight

The risk factor of obesity was not a common factor for the people with disabilities in care who died from colon cancer.

Most of the disability services residents who died from colon cancer (6) were in the healthy

weight range. Three people were underweight, and two people were overweight, including one person who was obese.

Weight status information was available for two of the three licensed boarding house residents. One person was overweight, and one was underweight.

## Constipation

Constipation was a health issue for three people in disability services, and one licensed boarding house resident.

## Smoking

The vast majority of the disability services residents had never smoked (10). Two of the three people in licensed boarding houses who died from colon cancer were current smokers at the time of their death, and smoked more than 20 cigarettes a day.

**Table 44: Smoking rates of people who died from colon cancer**

Tobacco	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Yes	2	(67)	1	(9)
Ex-smoker	0	(0)	0	(0)
No	1	(33)	10	(91)
<b>Total</b>	<b>3</b>	<b>(100)</b>	<b>11</b>	<b>(100)</b>

Tobacco – yes	Licensed BH		Disability services	
	No.	(%)	No.	(%)
Occasional	0	(0)	0	(0)
Up to 10/ day	0	(0)	1	(100)
11-20/ day	0	(0)	0	(0)
>20/ day	2	(100)	0	(0)
<b>Total</b>	<b>2</b>	<b>(100)</b>	<b>1</b>	<b>(100)</b>

## Health supports

All of the people who died from colon cancer had seen a GP in the year before their deaths. Just over half of the people in

disability services (6) and one of the three licensed boarding house residents had had a comprehensive health assessment in the year before their death.

Just over one-quarter of the people in disability services who died from colon cancer (3) had seen an oncologist. None of the three people in licensed boarding houses had seen an oncologist.

Seven of the 11 people in disability services and one of the three licensed boarding house residents who died from colon cancer had had the involvement of palliative care professionals.

## Our reviews

We found that the length of time between diagnosis of colon cancer and the person's death was variable. For some people, the length of time was very short – from one day to eight months. Others had been diagnosed years previously, had received treatment and remained stable, but died after the cancer returned. Many of the people who died from colon cancer had received treatment for it, including surgery and radiotherapy.

For people in disability services, our reviews identified examples of good palliative care planning. This included comprehensive

consideration of the person's needs, involvement of the person, family, staff and health practitioners, and provision of coordinated care.

## 5.13 Diseases of the digestive system

Between 2003 and 2009, diseases of the digestive system accounted for the deaths of 36 people in disability services (7%) and six people in licensed boarding houses (5%).

The median age at death from diseases of the digestive system was 53 years for people in disability services and 61 years for people in licensed boarding houses.

The main digestive system diseases that caused the deaths of people with disabilities in care were 'other diseases of the intestines'. These include intestinal obstruction, intestinal vascular disorders, diverticular diseases, and constipation.

### 5.13.1 Other diseases of the intestines

Other diseases of the intestines were the underlying cause of death for 16 people in disability services.

**Table 45: Deaths due to other diseases of the intestines 2003-09**

	No.	(%)
K56.2 Volvulus	4	(25)
K55.0 Acute vascular disorders of intestine	3	(19)
K56.6 Other and unspecified intestinal obstruction	3	(19)
K59.3 Megacolon, not elsewhere classified	2	(13)
K56.4 Other impaction of intestine	1	(6)
K56.5 Intestinal adhesions (bands) with obstruction	1	(6)
K59.0 Constipation	1	(6)
K63.1 Perforation of intestine (non traumatic)	1	(6)
<b>Total</b>	<b>16</b>	<b>(100)</b>



## Volvulus

Nine deaths were related to paralytic ileus<sup>68</sup> (also known as pseudo-obstruction) and intestinal obstruction, including four deaths due to volvulus.

Volvulus is an abnormal twisting of the intestine that can impair the blood flow and lead to gangrene and death of that segment of the gastrointestinal tract, intestinal obstruction, perforation of the intestine, and peritonitis. The stomach, small intestine, caecum,<sup>69</sup> and sigmoid colon can all be subject to volvulus. The most common volvulus occurs in the sigmoid.<sup>70</sup>

Of the four people in disability services who died from volvulus, three people had sigmoid and one person had caecal volvulus.

Volvulus often has a sudden onset. The symptoms and signs may include abdominal pain, nausea, vomiting, and blood in the stool. The treatment is emergency surgery to free the obstruction and ensure normal blood flow to the bowel.

Risk factors that can make a person more likely to have sigmoid volvulus<sup>71</sup> are Hirschsprung's disease, intestinal pseudo-obstructions and megacolon (an enlarged colon). It is more common in men than women, possibly because men have long sigmoid colons. It is also more common in people over age 60 years, and people who are on antipsychotic medications. Antipsychotic medications often have an anti-cholinergic constipatory effect. Common to all people with sigmoid volvulus is chronic constipation. Other common symptoms are severe abdominal pain and a distended abdomen.

Prevention of volvulus is essentially a matter of preventing chronic constipation.

## Case study 28

A 70-year-old man who lived in a large residential centre died in 2007 from bowel volvulus. He had a severe cognitive impairment and multiple chronic health issues, including constipation, hiatus hernia, epilepsy, swallowing difficulties and GORD. He was reliant on a wheelchair for mobility, and had limited verbal communication.

The man had a history of chronic constipation and sigmoid volvulus since at least 1977, and had a sigmoid colectomy 10 months before his death. Following the colectomy, the frequency of his bowel complaints reduced. He had the involvement of relevant health professionals, including allied health and specialists.

Two days before his death, he was taken to hospital following a seizure and vomiting of coffee ground fluids. Tests found that he had gastrointestinal haemorrhage, volvulus and aspiration pneumonia. He was treated with fluids, antibiotics and suctioning but his condition continued to deteriorate. He died shortly after a decision by his family to cease active treatment.

## Case study 29

A 49-year-old woman who lived in a large residential centre died in 2006 from sigmoid volvulus complicated by an infarcted colon (dead bowel secondary to loss of blood supply related to the twist).

The woman had a history of gulping air, which occasionally led to distension of her abdomen. This was typically managed through staff providing peppermint water and monitoring her girth measurements.

Six years before her death, she had a significant episode of abdominal distension that required admission to hospital. A CT scan

68 Paralytic ileus refers to obstruction of the intestine due to paralysis of the intestinal muscles.

69 The caecum is the first part of the large intestine.

70 The sigmoid is the S-shaped curve of the large intestine where the colon joins the rectum.

71 [www.abdopain.com/sigmoid-volvulus.html](http://www.abdopain.com/sigmoid-volvulus.html).



indicated that she had a dilated colon and a suspicious area in the region of the sigmoid, but did not identify a specific obstruction. A subsequently sigmoidoscopy decompressed the colon, and no obstruction was identified.

A barium enema was organised but it was cancelled at the last minute because the woman refused to take the bowel preparation. During the admission she experienced watery diarrhoea and refractory hyperkalemia, suggesting ongoing bowel dysfunction despite decompression. She was discharged with a diagnosis of intestinal pseudo-obstruction. No arrangements were made for gastrointestinal follow-up.

On the morning of her death, she complained of abdominal pain and staff noted that she was much more distended than usual. Symptoms continued throughout the day and she was taken to hospital in the afternoon. Medical staff commenced investigations to identify a potential cause of bowel obstruction, but she experienced a respiratory arrest shortly after admission. She was resuscitated but had a prolonged period of hypoxia, and aspirated during the arrest. Treatment was subsequently withdrawn following discussion between her family and the treating clinicians.

We obtained expert advice in relation to the woman's death. A specialist member of our advisory committee told us that intestinal pseudo-obstruction usually implies a chronic medical condition with potentially severe complications, and gastrointestinal follow-up should have been organised. The specialist told us that the original diagnosis of pseudo-obstruction was incorrect, and the diagnostic confusion was likely confounded by the woman's inability to communicate with medical staff. The specialist advised that earlier expert review may have prevented the woman's death.

## Deaths due to other diseases of the intestines in disability services 2003-2009

### Age, gender and cultural background

The median age at death from other diseases of the intestines was 54 years, and more males (10) than females (6) died from this cause.

One person was from a CALD background. None of the people who died from other diseases of the intestines was Aboriginal or Torres Strait Islander.

### Accommodation

Half of the 16 people lived in ADHC accommodation and half lived with NGO services. Most of the people in NGO services lived in group homes, and most of the people in ADHC accommodation lived in large residential centres.

**Table 46: Deaths due to other diseases of the intestines by service and accommodation type**

NGO	No.	(%)
Group home	5	(63)
Large residential	3	(37)
<b>Total</b>	<b>8</b>	<b>(100)</b>

ADHC	No.	(%)
Group home	2	(25)
Large residential	6	(75)
<b>Total</b>	<b>8</b>	<b>(100)</b>

### Disability

The majority of people who died from other diseases of the intestines (14) had an intellectual disability, mainly at a moderate (6) or severe (6) level of impairment. Six people had cerebral palsy (4), paraplegia or quadriplegia.

Three people had a mental illness, and seven people were taking antipsychotic medication.

Most of the 16 people required communication support (10).

## Weight

Weight status information was available for 15 people. Six people were underweight; five people were in the healthy weight range; and four people were overweight.

Of the 10 people who were outside of the healthy weight range, four people had seen a dietician. This included half of the six people who were underweight, and one person who was overweight.

## Health issues

Constipation was a health issue for 14 of the 16 people who died from other diseases of the intestines. Ten people had used laxatives.

Half of the 16 people had other gastrointestinal health issues, such as hernia, dilation of the large and small bowel, recurrent bowel obstructions, and bowel overload. At least three people who died from volvulus had had previous episodes of the condition that had been rectified with surgery.

Eleven people were incontinent, including six people who were doubly incontinent.

## Mobility

The majority of the people who died from other diseases of the intestines had limited mobility (13). Just over one-third relied on a wheelchair for mobility.

Five people had seen an occupational therapist in the year before their deaths. Five people had seen a physiotherapist – four in the year before their death.

## Health supports

All of the people who died from other diseases of the intestines had seen a GP in the year before they died. Half had had a comprehensive health assessment in that period.

Seven people who died from other diseases of intestines had seen a dietician or dysphagia

clinic at any point. Three people had seen a gastroenterologist.

The questions in the nutrition and swallowing risk checklist are aimed at identifying nutrition, swallowing and respiratory problems, including issues relating to constipation. The *Nutrition in Practice* manual provides guidance to staff as to actions to take in response to identified problems, including changes to diet, referral to a dietician, and involvement of a doctor.

Ten people in disability services died after the nutrition and swallowing risk assessment requirements were introduced. Less than half (four people) had a completed assessment that identified all of the relevant nutrition and swallowing risks and the actions that were required to address them.

One person in an NGO service did not have a nutrition and swallowing risk assessment. For four people, services had identified the risks but had not indicated what actions needed to be taken to address them. For one person, the service had not identified all of their risks.

## Our reviews

Our reviews of the deaths of people from other diseases of the intestines have identified examples of comprehensive health coordination by services and responsiveness to bowel problems. However, this was not always the case.

### Key lessons from our work include the importance of:

- appropriate referral for specialist input, particularly where there is evidence of ongoing bowel problems;
- provision of clear guidance to staff regarding the person's support needs and signs/ symptoms of constipation or bowel obstruction where required; and
- provision of adequate information by disability services staff to hospital staff on

admission regarding the person's support needs and previous investigations into bowel issues.

## 5.14 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 2003-09, external causes accounted for the deaths of 56 people (11%) in disability services and 17 people (14%) in licensed boarding houses.

The median age at death from external causes was 57.5 years for people in disability services and 54 years for people in licensed boarding houses.

The main external cause of death of people in licensed boarding houses was suicide (5 people). The leading external causes of death of people in disability services were accidental threats to breathing (19), falls (8), and complications of medical and surgical care (7).

Between 2003 and 2009, accidental threats to breathing – due to inhalation of gastric contents or inhalation/ ingestion of food or other objects causing obstruction of the respiratory tract – accounted for the deaths of 19 people in disability services and two people in licensed boarding houses. Most of the individuals choked on food.

### 5.14.1 Choking on food

#### Deaths due to choking on food 2003-2009

Between 2003 and 2009, 13 people died as a result of choking on food, including 11 people in disability services and two licensed boarding house residents.<sup>72</sup>

<sup>72</sup> Choking on food (W79) was recorded as the underlying cause of death of one licensed boarding house resident and 12 people in disability services. However, our reviews of the deaths identified that two of the people in disability services actually aspirated. We identified two other people for whom choking on food was a contributory factor in their death but was not recorded as the underlying cause. In this section, our examination of deaths due to choking has included these two individuals but excluded the two people who aspirated.

### Age, gender and cultural background

The median age at death was 59 years for people in disability services and 64 years for people in licensed boarding houses.

Just over half of the 11 people in disability services who choked on food were female (6). Of the two licensed boarding house residents, one was male and one was female.

One person in disability services was from a CALD background. None of the people who died due to choking on food were Aboriginal or Torres Strait Islander.

### Accommodation

Most of the disability services residents who choked on food lived in ADHC accommodation (7). Six people lived in group homes, and five people lived in residential centres.

**Table 47: Deaths due to choking in disability services by service and accommodation type**

ADHC	No.	(%)
Group home	5	(71)
Large residential	2	(29)
<b>Total</b>	<b>7</b>	<b>(100)</b>

NGO	No.	(%)
Group home	1	(25)
Large residential	3	(75)
<b>Total</b>	<b>4</b>	<b>(100)</b>

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

For all but one of the 11 people in disability services, the service had identified that they were at risk of choking. The risks were related to swallowing problems and/or the person's tendency to eat fast, overfill their mouth, and swallow without adequately chewing.

Three of the people who died acted against their meal requirements and restrictions. This included taking food off another resident, swapping their meal for someone else's, and taking food that was not suitable for them from common areas. Supervision was an issue in one of these deaths.

For eight of the individuals, staff had not complied with the person's mealtime management plan or had otherwise not taken adequate action to manage the person's choking risks. This included where staff had:

- Provided food that was not in line with the person's mealtime management plan. This included the provision of pork to a woman on a soft food diet, and a whole hot cross bun to a man who required food to be cut into small pieces.
- Identified the risks but had not taken adequate action to address or minimise those risks. This included where:
  - Assessments, such as the nutrition and swallowing risk checklist and the client risk profile, identified choking risks but no actions had been recorded to manage the risks. For one woman, no mealtime management or other support plan had been developed to provide guidance to staff in what they needed to do to minimise her choking risks.
  - Support plans for one woman indicated that her rapid eating behaviour put her at acute risk of choking and she needed annual speech pathology and nutrition reviews. However, at the time of her death she had not been reviewed by a speech pathologist or dietician for over six years.
- Not provided adequate supervision, despite known risks and against specific recommendations in the person's mealtime management or other support plan.

In at least six of the deaths, the individuals had previously experienced episodes of

choking on food. In two of these matters, the services had taken appropriate subsequent action to try to minimise the risks, such as making a referral to a speech pathologist, or developing a behaviour management plan and counselling the person about the risks.

In the other four matters, we had concerns about the adequacy of the action taken by the services to minimise the chance of the person choking again. This included where:

- Staff provided a man with a whole hot cross bun, against the requirements in his mealtime management plan. The man's previous episode of choking, 11 months earlier, had involved the same food.
- A man had two instances of gagging on food in the year before his death – involving a piece of apple and a large piece of roast meat. There was no indication that the service had completed incident reports following either event, or otherwise identified means for minimising the chance of recurrence. There was no mealtime management plan or other document that advised staff that he needed food to be cut up; his nutrition and swallowing checklist was not reviewed; and staff did not provide adequate supervision at the time of his fatal choking incident.

### **Case study 30**

A 37-year-old man who lived in a group home died in 2008 after choking on a sandwich. The man had experienced two prior choking incidents in the year before his death. On both occasions, the service considered that the choking events were due to staff not following the man's mealtime management and other support requirements.

After the second incident, group home managers made entries in the house communication book instructing all staff to comply with the man's mealtime management plan and to monitor him at all times while eating and drinking, without exception. A

group home manager also spoke directly with the staff member who had been on shift to remind them of their obligation to follow the man's mealtime management requirements.

Six months after this incident, the man fatally choked on food. The Coroner held an inquest into the man's death, which identified concerns about the first aid response of the agency staff that were providing support to the man. The inquest heard that the staff sought resuscitation advice from 000 operators rather than relying on their training.

Staff reliance on emergency telephone operators for first aid and resuscitation instructions also featured in the death of another person in a disability service who choked on food. We note that, since these deaths, first aid requirements for staff in disability services have been strengthened. From 1 January 2011, at least one person on each shift in both ADHC and NGO disability accommodation services must have current first aid qualifications.

### **Factors in the deaths of people in licensed boarding houses who choked on food**

Of the two people in licensed boarding houses who choked on food, one person ate a peanut butter sandwich too fast, and one person choked on a sausage.

The man who choked on the sandwich did not appear to have had swallowing difficulties or previous instances of choking or gagging on food, although he did have tardive dyskinesia.<sup>73</sup> In our review of the man's death, we found that

the first aid response was inadequate, with no evident CPR provided by staff.

We note that, since these deaths, the first aid requirements have been strengthened in licensed boarding houses. On 1 September 2010, a new Youth and Community Services Regulation was enacted. The new regulation requires that at least one staff member on duty must hold first aid qualifications.

The woman who choked on a sausage had tardive dyskinesia and risk factors for choking that included no teeth (and refusal to wear her dentures), and decline in her swallowing ability when she was mentally unwell and/or had urinary tract infections. She had previously had a choking episode when she was mentally unwell. Our review identified that sausage was not appropriate for her given her lack of teeth, and the first aid response had been delayed due to the woman eating alone in her room.

### **Use of psychotropic medication and deaths from choking on food**

A number of studies have found that mental illness is a risk factor for deaths from choking.<sup>74</sup> The presence of mental health issues, and the use of psychotropic medications, featured highly in the people with disabilities in care who choked on food in 2003-09 – in both licensed boarding houses and disability services:

- Nine of the 13 people who choked on food had an identified mental illness, mainly schizophrenia or psychosis.
- Twelve people were taking antipsychotic medication. Four of these individuals

<sup>73</sup> 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).

<sup>74</sup> For example, Kuschna D., Mullen PE., Palmer S., Burgess P., Corder SM., Drummer OH., Wallace C., and Barry-Walsh J, 'Choking deaths: the role of antipsychotic medication' in *Br J Psychiatry*, 2003, Nov; 183: 446-50, found that the 70 people in their study who choked to death were over 20 times more likely to have been treated previously for schizophrenia. PHW Yim and CSY Chong 'Choking in Psychiatric Patients: Associations and Outcomes' in *Hong Kong J Psychiatry* 2009; 19: 145-9, found that in psychiatric inpatients, the mortality rate due to choking was eight-fold higher than that of the general population. Medication side-effects and poor eating habits were implicated as contributing causes.



were taking two or more antipsychotic medications.

- More than three-quarters (10) were taking two or more psychotropic medications, such as antipsychotic, antidepressant, sedative or anti-anxiety medication.

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.

## Our reviews

Key lessons from our reviews of the deaths of people from choking on food are largely consistent with those relating to deaths from aspiration.

### Our reviews have identified:

- the importance of comprehensive assessment of swallowing and choking risks to individuals through nutrition and swallowing risk assessments, and ensuring that a clear plan is developed to address the identified risks through staff actions and the involvement of relevant health practitioners, such as speech pathologists;
- the need for services to develop strategies to promote staff understanding of, and compliance with, requirements and recommendations made in support plans or assessments; and
- the importance of regular medication reviews and consideration of medication side-effects, and access to appropriate mental health support.





# Appendix 1: Additional data 2003-09

## Deaths 2003-09 by gender

Table 48 provides the data relating to the gender of people who died in 2003-09. In all seven years, more males than females died – in both disability services and licensed boarding houses. The prevalence of males reflects the broader population of people with disabilities in care, where males outnumber females in all accommodation and service types.

**Table 48: Deaths in 2003-09 by gender**

	Licensed BH						Disability services					
	Male		Female		Total		Male		Female		Total	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
2003	16	(76)	5	(24)	<b>21</b>	<b>(100)</b>	44	(55)	36	(45)	<b>80</b>	<b>(100)</b>
2004	20	(83)	4	(17)	<b>24</b>	<b>(100)</b>	43	(61)	27	(39)	<b>70</b>	<b>(100)</b>
2005	11	(85)	2	(15)	<b>13</b>	<b>(100)</b>	33	(61)	21	(39)	<b>54</b>	<b>(100)</b>
2006	15	(94)	1	(6)	<b>16</b>	<b>(100)</b>	52	(63)	30	(37)	<b>82</b>	<b>(100)</b>
2007	10	(67)	5	(33)	<b>15</b>	<b>(100)</b>	48	(58)	35	(42)	<b>83</b>	<b>(100)</b>
2008	14	(88)	2	(12)	<b>16</b>	<b>(100)</b>	43	(60)	29	(40)	<b>72</b>	<b>(100)</b>
2009	10	(59)	7	(41)	<b>17</b>	<b>(100)</b>	64	(73)	24	(27)	<b>88</b>	<b>(100)</b>
<b>Total</b>	<b>96</b>	<b>(79)</b>	<b>26</b>	<b>(21)</b>	<b>122</b>	<b>(100)</b>	<b>327</b>	<b>(62)</b>	<b>202</b>	<b>(38)</b>	<b>529</b>	<b>(100)</b>

## Application of the nutrition and swallowing checklist 2005-09

Table 49 provides data regarding the application of the nutrition and swallowing risk checklist for all people in disability services who died in 2005-09. It indicates the percentage of people who had an assessment that identified all of their risks and the actions to be taken to address them ('risk assessment complete'); an assessment that did not identify all of their risks; an assessment that identified the risks but did not outline the actions to be taken to address them; or no risk assessment. The percentage of people who did not have a risk assessment has declined. However, there are continuing problems with the quality of the assessment, as indicated in Chapter 2.

**Table 49: Nutrition and swallowing checklist for all people in disability services who died by year**

Nutrition and swallowing risk checklist	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)
No risk assessment	20	21	16	11	9
Not all risks identified	11	4	2	18	16
Risks identified but no/ incomplete action plan	22	30	14	13	14
Risk assessment complete	46	45	67	58	61

Table 50 provides the same information, but for people in disability services who had swallowing difficulties who died in 2005-09.

**Table 50: Nutrition and swallowing checklist for all people in disability services with swallowing difficulties who died by year**

Nutrition and swallowing risk checklist	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)
No risk assessment	7	18	9	4	5
Not all risks identified	14	4	0	24	17
Risks identified but no/ incomplete action plan	24	32	9	8	16
Risk assessment complete	55	46	83	63	62

## Mealtime management guidance 2003-09

A mealtime management plan is intended to be an easy to understand record of how to best assist a person to eat and drink. It may provide details on positioning and seating, equipment, assistance required, food and drink preferences and consistencies, and suggested food items and quantities.

Table 51 provides the number and percentage of people in disability services with swallowing difficulties who died in 2003-09 who had a mealtime management plan. Since 2003, the percentage of people in disability services who died who had a mealtime management plan increased.

**Table 51: Number and percentage of people in disability services with swallowing difficulties with a mealtime management plan 2003-09 by year**

Disability services	Yes		No		Total	
	No.	(%)	No.	(%)	No.	(%)
2003	8	(21)	31	(80)	<b>39</b>	<b>(100)</b>
2004	10	(23)	34	(77)	<b>44</b>	<b>(100)</b>
2005	10	(35)	19	(66)	<b>29</b>	<b>(100)</b>
2006	38	(76)	12	(24)	<b>50</b>	<b>(100)</b>
2007	29	(62)	18	(38)	<b>47</b>	<b>(100)</b>
2008	45	(92)	4	(8)	<b>49</b>	<b>(100)</b>
2009	59	(94)	4	(6)	<b>63</b>	<b>(100)</b>

## Weight 2003-09

Table 52 provides the number and percentage of people in disability services who died in 2003-09, by weight category. The percentage of people who died who were in the healthy weight range has increased, and the percentage who were in the overweight range has declined.

**Table 52: Number of people in disability services by weight status and year**

Disability services	2003		2004		2005		2006		2007		2008		2009	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Underweight	12	(17)	10	(19)	10	(21)	12	(17)	15	(21)	16	(24)	21	(26)
Healthy weight	26	(38)	18	(35)	17	(36)	28	(39)	33	(46)	28	(42)	37	(46)
Overweight	31	(45)	24	(46)	20	(43)	31	(44)	23	(32)	22	(33)	22	(28)
<b>Total</b>	<b>69</b>	<b>(100)</b>	<b>52</b>	<b>(100)</b>	<b>47</b>	<b>(100)</b>	<b>71</b>	<b>(100)</b>	<b>71</b>	<b>(100)</b>	<b>66</b>	<b>(100)</b>	<b>80</b>	<b>(100)</b>

Across the seven years, the weight status has been known for few people in licensed boarding houses. The absence of this information also raises questions about the adequacy of actions to identify and support the health needs of the individuals.

## Smoking 2003-09

Smoking rates in the Australian population are between 17 and 21 percent, but rates for disadvantaged populations are higher. Smoking rates among people with mental illness range from 60 to 80 percent.<sup>75</sup>

Overall, 69 percent of the licensed boarding house residents who died between 2003 and 2009 were current smokers. In four of the seven years, at least half of the licensed boarding house residents who were current smokers at the time of their death smoked more than 20 cigarettes a day.

Tables 53 and 54 provide data on the smoking rates and frequency of disability services residents who died in 2003-09.

**Table 53: Smoking rates for disability services residents by year**

Disability services	Smoker		Non-smoker		Ex-smoker		Total	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
2003	4	(5)	68	(85)	8	(10)	<b>80</b>	<b>(100)</b>
2004	6	(9)	56	(80)	8	(11)	<b>70</b>	<b>(100)</b>
2005	4	(7)	44	(81)	6	(11)	<b>54</b>	<b>(100)</b>
2006	8	(10)	65	(79)	9	(11)	<b>82</b>	<b>(100)</b>
2007	7	(8)	71	(86)	5	(6)	<b>83</b>	<b>(100)</b>
2008	3	(4)	65	(90)	4	(6)	<b>72</b>	<b>(100)</b>
2009	13	(15)	66	(75)	9	(10)	<b>88</b>	<b>(100)</b>

**Table 54: Smoking frequency of current smokers in disability services by year**

Disability services	2003		2004		2005		2006		2007		2008		2009	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Current ≤ 10/ day	3	(75)	4	(67)	1	(25)	1	(13)	1	(14)	0	(0)	2	(15)
Current 11-20/ day	1	(25)	1	(17)	0	(0)	5	(63)	4	(57)	0	(0)	4	(25)
Current >20/ day	0	(0)	1	(17)	2	(50)	1	(13)	2	(29)	2	(67)	6	(46)
Occasional	0	(0)	0	(0)	1	(25)	1	(13)	0	(0)	1	(33)	1	(8)
<b>Total</b>	<b>4</b>	<b>(100)</b>	<b>6</b>	<b>(100)</b>	<b>4</b>	<b>(100)</b>	<b>8</b>	<b>(100)</b>	<b>7</b>	<b>(100)</b>	<b>3</b>	<b>(100)</b>	<b>13</b>	<b>(100)</b>

<sup>75</sup> The Cancer Council of NSW and NCOSS *Lifting the Burden: Tobacco Control and Social Equity Strategy July 2006 to June 2011*.

Tables 55 and 56 provide data on the smoking rates and frequency of licensed boarding house residents who died in 2003-09.

**Table 55: Smoking rates for licensed boarding house residents by year**

Licensed BH	Smoker		Non-smoker		Ex-smoker		Total	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
2003	10	(48)	7	(33)	4	(19)	<b>21</b>	<b>(100)</b>
2004	18	(75)	5	(22)	1	(4)	<b>24</b>	<b>(100)</b>
2005	11	(79)	2	(15)	0	(0)	<b>13</b>	<b>(100)</b>
2006	10	(63)	3	(19)	3	(19)	<b>16</b>	<b>(100)</b>
2007	12	(80)	2	(13)	1	(7)	<b>15</b>	<b>(100)</b>
2008	10	(63)	5	(31)	1	(6)	<b>16</b>	<b>(100)</b>
2009	12	(71)	2	(12)	3	(18)	<b>17</b>	<b>(100)</b>

**Table 56: Smoking frequency of current smokers in licensed boarding houses by year**

Licensed BH	2003		2004		2005		2006		2007		2008		2009	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Occasional	0	(0)	1	(6)	0	(0)	2	(20)	1	(8)	0	(0)	1	(8)
Current ≤ 10/ day	0	(0)	4	(22)	5	(46)	3	(30)	0	(0)	1	(10)	1	(8)
Current 11-20/ day	4	(40)	4	(22)	5	(46)	3	(30)	4	(33)	4	(40)	7	(58)
Current >20/ day	6	(60)	9	(50)	1	(9)	2	(20)	7	(58)	5	(50)	3	(25)
<b>Total</b>	<b>10</b>	<b>(100)</b>	<b>18</b>	<b>(100)</b>	<b>11</b>	<b>(100)</b>	<b>10</b>	<b>(100)</b>	<b>12</b>	<b>(100)</b>	<b>10</b>	<b>(100)</b>	<b>12</b>	<b>(100)</b>

## Vaccination 2003-09

### Influenza vaccination

Just over three-quarters of people in disability services who died between 2003 and 2009 had been vaccinated against influenza in the year before their death.

**Table 57: Influenza vaccination of disability services residents by year**

Disability services	Yes		No		Total	
	No.	(%)	No.	(%)	No.	(%)
2003	63	(79)	17	(21)	<b>80</b>	<b>(100)</b>
2004	59	(84)	11	(16)	<b>70</b>	<b>(100)</b>
2005	40	(74)	14	(26)	<b>54</b>	<b>(100)</b>
2006	62	(76)	20	(24)	<b>82</b>	<b>(100)</b>
2007	70	(84)	13	(16)	<b>83</b>	<b>(100)</b>
2008	50	(69)	22	(31)	<b>72</b>	<b>(100)</b>
2009	62	(71)	26	(29)	<b>88</b>	<b>(100)</b>

Two-thirds of people in licensed boarding houses who died between 2003 and 2009 had been vaccinated against influenza in the year before their death.

**Table 58: Influenza vaccination of licensed boarding house residents by year**

Licensed BH	Yes		No		Total	
	No.	(%)	No.	(%)	No.	(%)
2003	14	(67)	7	(33)	21	(100)
2004	15	(63)	9	(37)	24	(100)
2005	6	(46)	7	(54)	13	(100)
2006	11	(69)	5	(31)	16	(100)
2007	7	(47)	8	(53)	15	(100)
2008	10	(63)	6	(37)	16	(100)
2009	16	(94)	1	(6)	17	(100)

## Pneumococcal vaccination

Just over one-third of the disability services residents and less than 20 percent of the people in licensed boarding houses who died between 2003 and 2009 had received the pneumococcal vaccination in the five years before their death.

**Table 59: Pneumococcal vaccination of disability services residents by year**

Disability services	Yes		No		Total	
	No.	(%)	No.	(%)	No.	(%)
2003	18	(23)	62	(77)	80	(100)
2004	23	(33)	47	(67)	70	(100)
2005	13	(24)	41	(76)	54	(100)
2006	32	(39)	50	(61)	82	(100)
2007	36	(43)	47	(57)	83	(100)
2008	28	(39)	44	(61)	72	(100)
2009	42	(48)	46	(52)	88	(100)

**Table 60: Pneumococcal vaccination of licensed boarding residents by year**

Licensed BH	Yes		No		Total	
	No.	(%)	No.	(%)	No.	(%)
2003	5	(24)	16	(76)	21	(100)
2004	3	(12)	21	(88)	24	(100)
2005	1	(8)	12	(92)	13	(100)
2006	3	(19)	13	(81)	16	(100)
2007	4	(27)	11	(73)	15	(100)
2008	1	(6)	15	(94)	16	(100)
2009	5	(29)	12	(71)	17	(100)



## Comprehensive health assessment 2003-09

Tables 61 and 62 provide the number and percentage of people in licensed boarding houses and disability services who were recorded as having had a comprehensive health assessment at any time.

**Table 61: Number and percentage of people in licensed boarding houses with a comprehensive health assessment 2003-09**

Licensed BH	Yes		No		Total	
	No.	(%)	No.	(%)	No.	(%)
2003	0	(0)	21	(100)	<b>21</b>	<b>(100)</b>
2004	0	(0)	24	(100)	<b>24</b>	<b>(100)</b>
2005	0	(0)	13	(100)	<b>13</b>	<b>(100)</b>
2006	2	(12)	14	(88)	<b>16</b>	<b>(100)</b>
2007	6	(40)	9	(60)	<b>15</b>	<b>(100)</b>
2008	9	(56)	7	(44)	<b>16</b>	<b>(100)</b>
2009	11	(65)	6	(35)	<b>17</b>	<b>(100)</b>

**Table 62: Number and percentage of people in disability services with a comprehensive health assessment 2003-09**

Disability services	Yes		No		Total	
	No.	(%)	No.	(%)	No.	(%)
2003	0	(0)	80	(100)	<b>80</b>	<b>(100)</b>
2004	0	(0)	70	(100)	<b>70</b>	<b>(100)</b>
2005	1	(2)	53	(98)	<b>54</b>	<b>(100)</b>
2006	54	(66)	28	(34)	<b>82</b>	<b>(100)</b>
2007	63	(76)	20	(24)	<b>83</b>	<b>(100)</b>
2008	65	(90)	7	(10)	<b>72</b>	<b>(100)</b>
2009	81	(92)	7	(8)	<b>88</b>	<b>(100)</b>

# Appendix 2: Reviewable disability deaths advisory committee: members

Mr Bruce Barbour	Ombudsman (chair)
Mr Steve Kinmond	Deputy Ombudsman and Community and Disability Services Commissioner
Ms Margaret Bail	Human services consultant
Professor Helen Beange 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 District
Ms Anne Slater	Physiotherapist, Allowah Children's Hospital (resigned March 2011)
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







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Telephone Interpreter Service (TIS): 131 450

We can arrange an interpreter through TIS or you can contact TIS yourself before speaking to us.