

Report of Reviewable Deaths in 2012 and 2013

**Volume 2:
Deaths of people with
disability in residential care**

June 2015

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NSW Ombudsman
Level 24, 580 George Street
Sydney NSW 2000

Phone 02 9286 1000
Toll free (outside Sydney Metro Area): 1800 451 524
Facsimile: 02 9283 2911
Website: www.ombo.nsw.gov.au
Email: nswombo@ombo.nsw.gov.au

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Foreword

This is my eighth report on the deaths of people with disability in residential care, and my last as the NSW Ombudsman.

This report identifies significant issues arising from our reviews of the deaths in 2012 and 2013 of 239 people with disability who lived in residential care – including opportunities for reducing preventable deaths associated with, for example, choking on food; falls and fractures; and delayed diagnosis of life-threatening conditions. Our recommendations are targeted at ensuring, as much as possible, that there is appropriate support for people in residential care (and the staff who support them) to improve and maximise their health outcomes.

Importantly, this report also includes a specific focus on the concerted planning and related work that is required in NSW ahead of the full transition to the National Disability Insurance Scheme (NDIS) in July 2018. The NDIS introduces unprecedented reform, and presents substantial opportunity to people with disability to obtain the support they need, in the way they want it. The reforms are aimed at changing not just specialist disability supports, but also improving the access and inclusion of people with disability to mainstream services.

While we welcome and support the introduction and broader roll out of the NDIS, my office's unique role in reviewing the deaths of people with disability in residential care has enabled us to clearly identify the significant health challenges and risks faced by this population, and the disadvantage and adversity they tend to experience in their contact with mainstream health services. From over 12 years working in this area, it is evident that there are considerable risks for people with disability if mainstream health services are not ready at the point of transition to the NDIS and the associated withdrawal of NSW Government-funded specialist disability supports. Noting the very short timeframe ahead of the full NDIS roll out, it is imperative that the necessary planning and other actions are undertaken as a matter of priority. We will actively monitor and publicly report on the progress of this work.

Finally, the information in this report highlights the vital role that the reviews of the deaths of people with disability play in shining a light on the current experience of this population, the support they require to maximise their health outcomes and life expectancy, and the considerable existing gaps in the service system. It has been my privilege to be involved in this work, and to have responsibility for bringing this information to public attention.



Bruce Barbour
Ombudsman.

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Executive summary

We review the deaths of people with disability in residential care in NSW, and make recommendations to reduce preventable deaths. This is our eighth report to Parliament on reviewable deaths, and focuses on deaths in 2012 and 2013.

About the people who died in 2012 and 2013 (Chapters 2 and 3)

In 2012 and 2013, the deaths of 239 people with disability in residential care were reviewable:

- 121 people (51%) lived in Department of Family and Community Services: Ageing, Disability and Home Care (ADHC) accommodation
- 101 people (42%) lived in non-government (ADHC-funded) accommodation
- 14 people (6%) lived in assisted boarding houses, and
- three people (1%) were living in private or community housing with ADHC or NGO support.

The average age at death of people with disability in residential care in 2012 and 2013 was around 25 years younger than the average of the general population in Australia. On average, the people who had lived in 'disability services' (ADHC or NGO accommodation) were 55 years old when they died, and the assisted boarding house residents were 59 years old.

Main causes of death

People in disability services

In 2012 and 2013, the leading underlying causes of death of people in disability services were:

- Respiratory diseases (24%) – mainly pneumonia and aspiration pneumonia
- Nervous system diseases (17%) – mainly epilepsy and cerebral palsy
- Neoplasms (16%) – mainly lung and breast cancer, and
- Circulatory diseases (11%) – primarily ischaemic heart diseases.

Most of the deaths of people with disability in residential care are due to natural causes, such as those referred to above. In 2012 and 2013, the deaths of 7% of the people in disability services who died were due to external (or unnatural) causes, mainly choking on food.

Respiratory diseases always feature highly in the deaths of people in disability services because they tend to have multiple risk factors for developing respiratory illness (such as swallowing difficulties; reliance on others for assistance with meals; and mobility problems). However, respiratory diseases accounted for a higher proportion of deaths in 2012 and 2013 than recent years.

People in assisted boarding houses

In 2012 and 2013, the leading underlying causes of death of people in assisted boarding houses were:

- Circulatory system diseases (43%) – mainly ischaemic and other heart diseases
- Neoplasms (21%) – mainly liver cancer, and
- Respiratory diseases (14%) – mainly chronic lower respiratory diseases and pneumonia.

Heart diseases have consistently been the primary cause of death of people in assisted boarding houses, as they tend to have many of the relevant risk factors, including smoking, hypertension, and obesity.

Key issues identified through our reviews (Chapter 4)

Recognising and responding to critical situations

Identifying illness and taking action

Our reviews have continued to highlight the very short period of time for some people with disability in residential care between showing symptoms of illness or critical health changes and their death. This has particularly been the case for people who have died as a result of respiratory illness.

The deaths of people with disability in residential care in 2012 and 2013 have pointed to the vital need for all disability support staff to be alert to notable changes in the person's health and/or behaviour, and to get urgent help. In some cases, staff noted obvious changes in the person's health before their death (such as vomiting over an extended period of time) but did not take adequate action to obtain medical assistance. In other cases, staff recognised that the person's behaviour had changed and that something was not right, but were not sure whether it warranted immediate action.

Our work has shown that staff do not need to make a professional or clinical judgement about a person's health – if they have any concerns or any doubt, they should get urgent medical help.

Critical incident response

While there are mandatory first aid requirements in all residential care environments (disability services and assisted boarding houses), our reviews of deaths in 2012 and 2013 identified instances where staff called their manager in the first instance rather than emergency services; were not aware how to check for signs of life; and were heavily reliant on the instructions of 000 operators.

Our reviews of deaths in 2012 and 2013 have emphasised the importance of staff receiving regular refresher training to support them to take appropriate action at the time of a critical health event. There is also a need for services to identify and address any factors that may impede an effective response (such as a lack of cordless or mobile phones).

Recommendations:

1. FACS and NDS should consider the information in this report regarding identifying illness and taking action, and provide advice to this office as to what action they will take to ensure that:
 - a) disability residential care staff are issued with clear instructions that they need to call for emergency medical help as early as possible where they have any doubt as to the seriousness of a person's presenting health condition, and
 - b) these instructions are reinforced with direct care staff through team meetings (or via other appropriate mechanisms).
2. FACS and NDS should consider the information in this report regarding critical incident responses, and provide advice to this office as to what action they will take to ensure that:
 - a) disability residential care staff receive regular refresher information on what to do in response to critical health events, and
 - b) disability residential care providers take steps to identify any factors that may impede an effective response (such as no cordless or mobile phone).

Effectively managing individual risks

Managing choking risks

Deaths associated with choking have increased in recent years. The majority (18) of the 25 people who died from choking in the decade to 2013 died in the last four years – including 10 people in 2012 and 2013.

Most of the 10 people had known risk factors for choking, including eating problems; behaviour-related issues with food (such as taking food off others); dental problems; mental illness; and swallowing difficulties.

The most common factors in the choking deaths in 2012 and 2013 were a combination of eating and/or food-related behaviour problems and inadequate supervision. We found that it only took momentary lapses in supervision – due to staff being involved in other activities or responding to other residents – to result in fatal choking events.

Our reviews have highlighted the importance of:

- **providing active supervision** of people with swallowing and/or choking risks around food
- ensuring that staff have **clear guidance about the person's choking risks** and what they need to do, and
- staff being alert to the choking risks of individuals and **always following support plans and other guidance to manage the risks.**

Managing respiratory risks

Many of the people with disability who died from respiratory illness did so despite active and early treatment, highlighting the difficulty for some people in residential care of overcoming respiratory illness once it develops. As a result, preventative action to manage respiratory risk factors is crucial, including work to identify and (as much as possible) manage risks associated with:

- swallowing and eating difficulties
- falls and fractures (with heightened risk of respiratory illness following surgery and due to limited mobility)
- seizures (with the risk of aspirating during a seizure), and
- medications (with risks of aspiration due to the effects of some psychotropic medications, such as antipsychotics and sedatives).

We also found that the access of people with recurrent or chronic respiratory illness to respiratory specialists was low. Only 27 of the 103 people (26%) in disability services, and none of the assisted boarding house residents with recurrent respiratory illness, had seen a respiratory specialist. In particular, **we found that none of the five people who died in 2012 and 2013 from chronic obstructive pulmonary disease (COPD) had seen a respiratory specialist.**

Managing fracture risks

At least nine people with disability in residential care who died in 2012 and 2013 experienced fractures ahead of their death, mainly as a result of a fall. In all but one case, the fracture was a factor in their death – including development of respiratory illness, sepsis, or deep vein thrombosis following the fracture.

Our reviews of the deaths of people with disability that were associated with fractures have emphasised the importance of:

- **support staff and practitioners identifying, and taking appropriate action to minimise, the risks faced by people with disability in residential care associated with osteoporosis, falls and fractures**
- **support staff and practitioners taking timely action in response to falls to prevent recurrence, and**

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- **support staff being alert to any bruising or injury on a person with disability in residential care, and taking timely action to:**
 - **report the injury**
 - **identify the likely cause, and**
 - **identify and implement strategies to manage the risk to the person (and any other people with disability in the accommodation).**

Recommendation:

3. **FACS and NDS should consider the information in this report regarding the management of individual risks and access to preventative health support, and provide advice to this office as to what action they will take to ensure that:**
 - a) **as part of staff induction processes, all direct care staff in disability residential care services are required to read and certify that they have understood the information in the NSW Ombudsman’s fact sheets on:**
 - (i) **Preventing deaths of people with disabilities in care: Breathing, swallowing and choking risks (factsheet 4), and**
 - (ii) **Preventing deaths of people with disabilities in care: Smoking, obesity and other lifestyle risks (factsheet 5), and**
 - b) **the information in the above fact sheets is reinforced with direct care staff through supervision and support mechanisms, such as team meetings.**

Internal reviews by services

Our reviews of deaths in 2012 and 2013 have emphasised the need for disability service providers to conduct an internal review following the death of a person in their care. In particular, our work has demonstrated the need for action by disability services (and clear guidance for staff) in relation to:

1. **Incident reporting by direct care staff** – it is vital that there is a clear record of the chain of events and relevant details. However, in many instances we have found no incident report completed by any of the staff who were supporting the person at the time of the critical event.
2. **Internal review** – the death of any person with disability in the care of a service provider should prompt an internal review by the service, including consideration of: the person’s death and their broader care and circumstances; any deficits relating to service practice or internal controls; whether the issues have larger implications for the service (and other people in care); and what action will be taken in response.

Recommendation:

4. **As part of FACS’ review of its *Client death* policy and procedures, the agency should take into account the issues identified in the ‘Internal reviews by services’ section of this report, and provide clear guidance to improve the actions of services following the death of a client in relation to:**
 - a) **incident reporting by staff, and**
 - b) **internal reviews.**

Care coordination between health and disability services

Support to access medical treatment and support in hospital

Consistent with previous years, our reviews of deaths in 2012 and 2013 identified multiple people whose behaviour or decisions adversely affected their health and medical treatment (including people who refused medical interventions, or were unable to remain still during medical tests). **The impact on the individuals was significant, including seven people who died from cancer whose resistance or non-compliance delayed the diagnosis and/or affected decisions about treatment of the condition.**

Unless the person has made an informed decision to forego examination and treatment, every effort should be made to make it easier for them to access the necessary health care. The substantial and adverse impact of the behaviour of some people with disability on their access to appropriate health and medical care emphasises the importance of:

- **person-centred and coordinated support to help to minimise the individual's aversion to health services and treatment, and**
- ensuring that individuals have **access to appropriate behaviour support in relation to these issues**, including positive behaviour support strategies that provide clear guidance for supporting staff.

In relation to support in hospital, it is important that health and disability support staff make every effort to work together – and with the person with disability (and their supporters, where appropriate) – to facilitate appropriate and person-centred support in hospital. This includes implementing the NSW Health and ADHC Joint Guideline on supporting disability services residents in public hospitals to ensure that support is coordinated, and health and disability services staff are clear about their respective responsibilities.

Access to preventative health support

Our reviews of deaths in 2012 and 2013 continued to identify the substantial health risks faced by people with disability in residential care associated with:

- **Smoking** – unlike the general population, in which the rates of daily smoking have dropped to around 16%, the smoking rates of the people in assisted boarding houses who have died have remained consistently high, with a 10-year average of 83%. Smoking was a prevalent factor in deaths from lung cancer, COPD, ischaemic heart disease and heart attack.
- **Obesity, poor diet and lack of physical activity** – obesity featured highly among the people with disability in residential care who died, including over one-third of the people in disability services who died, and over half of the people in assisted boarding houses who died. The physical activity of people with disability in residential care also tends to be low, sometimes complicated by mobility difficulties, drowsiness from medications, and the limitations of their physical environment.

Our work highlights the need for:

- **people with disability to be identified as a priority group in population health strategies aimed at helping people to make healthy choices, including reducing smoking rates and addressing obesity, and**
- **disability support staff and health practitioners to work together, and with the person with disability, to make it easier for them to improve their health prospects.**

The advantage of the current residential care support arrangements for people with disability is that the population is known, including the health risks faced by individuals. This presents significant opportunities for developing and implementing targeted strategies that are able to be tracked and evaluated.

Support for people in assisted boarding houses

The deaths of people with disability in assisted boarding houses in 2012 and 2013 have underscored the importance of the legislative changes that have been introduced to improve the standard of care and safeguards for residents. Among other things, our reviews identified low rates of access to comprehensive health assessments, recommended vaccinations, and dental reviews; and high rates of obesity.

Our work has consistently shown the substantial risks faced by many people with disability in assisted boarding houses, and the importance of maintaining the existing legislative requirements and the associated compliance regime. However, with the withdrawal of ADHC from the disability landscape from July 2016, it is not currently clear where responsibility for monitoring, compliance and coordination activities relating to assisted boarding houses will be located.

As part of the planning in NSW for transition to the NDIS, it is important that specific consideration is given to the needs of people with disability in assisted boarding houses, and the existing effective safeguarding arrangements.

Planning for the health needs of people with disability in the transition to the NDIS (Chapter 5)

Our reviews of the deaths of people with disability in residential care in NSW over the past 12 years have highlighted significant problems in the mainstream health system – and with the interface between disability and health services – that adversely affect the health outcomes of people with disability. For example, we have found:

- inadequate support to facilitate access to health services and treatment
- substantial gaps in health care planning and coordination
- inadequate support in hospital
- poor coordination and transfer of care from hospital to home
- the need for an improved health response to people with complex needs (including people with intellectual disability and mental illness; challenging behaviour; disability and ageing needs; and complex health conditions)
- poor access to community-based health care and programs – including chronic disease management and other out-of-hospital programs; and preventative health programs, and
- end-of-life decision-making that has not met policy requirements.

As it stands, the rights of people with disability – including the right to be provided with the same range, quality and standard of health care and programs as other people; to be provided with care of the same quality as other people; and to be free from discriminatory health care practice – are not consistently upheld. **It is critical that action is taken as a matter of priority to address this situation, and to close the gap and improve health outcomes for people with disability in NSW ahead of the transition to the NDIS.**

The current disability and health reforms – and the NDIS launch sites – provide a valuable opportunity to address cross-sector communication and cooperation, and the longstanding problems and deficits in mainstream health services that have adversely and inequitably affected people with disability. However, our work has underscored the considerable risks that exist for people with disability – in residential care and more broadly – if mainstream services are not ready at the point of transition to the NDIS and the associated withdrawal of NSW Government-funded specialist disability supports. Among other things, there is a need for:

- clarity in relation to funding responsibilities between NDIS and mainstream health services
- clarity in relation to the future arrangements of the health-related services that are currently funded by FACS

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- work to ensure that people with disability (and particularly people with intellectual disability) are actively considered – and consulted – in the development and review of all health policies
 - public reporting on the actions of health services in implementing policies and meeting the needs of people with disability, against clear performance indicators and outcome measures
 - clear guidance to mainstream health services about reasonable adjustment principles and practical examples and options for adapting the supports
 - key positions in health services with lead responsibility for disability inclusion, and
 - the creation and roll out of a health data identifier(s) for people with disability to assist health staff to identify and best support their needs; enable mainstream health services to clearly measure and report on the adequacy of support; and facilitate data analysis to inform broader service planning.

Recommendations:

- 5. The Department of Premier and Cabinet (DPC) should:**
 - a) provide this office with a copy of the NSW Government NDIS transition plan, and**
 - b) ensure that the transition plan includes identification of system improvements to support transition and/or embed service delivery that is responsive to the needs of people with disability.**
- 6. NSW Health, FACS and the NDIA should use the Hunter NDIS launch site to trial and evaluate key initiatives and actions to address known problems and barriers for people with disability in relation to mainstream health services, by:**
 - a) Developing integrated and coordinated care initiatives between Hunter New England LHD (HNELHD) and Hunter Primary Health Network, such as:**
 - (i) developing HNELHD as an integrated care demonstrator site, and**
 - (ii) considering opportunities to integrate and coordinate care through the HealthOne NSW Service locations in HNELHD.**
 - b) Implementing mechanisms in HNELHD to coordinate access and care for people with disability.**
 - c) Developing mechanisms to facilitate the provision of timely, coordinated and multidisciplinary health support to people with disability transitioning from Hunter institutions¹ to community-based accommodation.**
 - d) Creating a minimum dataset for people with disability.**
 - e) Developing and trialling a ‘reasonable adjustments toolkit’ for Hunter health services.**
 - f) In line with the *Disability Inclusion Act 2014*, developing and implementing strategies to develop a culture of inclusion of people with disability in Hunter health services.**
 - g) Working with Hunter General Practitioners to improve written health guidance for people with disability and their carers/support staff.**
 - h) Working with Hunter Primary Health Network to establish clinical pathways with local providers and nurses.**
 - i) Developing key performance indicators and outcomes measures in Hunter health services for people with disability. This work should take into account the NDIS evaluation by the National Institute of Labour Studies, and NSW Health’s Monitoring and Evaluation Framework for measuring the transition to, and impact of, the NDIS in HNELHD.**

¹ Including ADHC large residential centres (Stockton, Kanangra, Tomaree); and HNELHD mental health facilities (Morisset).

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7. In addition to HNELHD, NSW Health should use the HealthNet lead sites and the LHDs that have documented actions in their disability action plans relating to developing data identifiers/flags for people with disability, to establish and trial a minimum dataset for people with disability in electronic medical records.
 8. In addition to work in relation to the NDIS Hunter launch site, and as part of transition planning, NSW Health, FACS and the NDIA should identify and progress actions more broadly in NSW to improve health outcomes for people with disability in their contact with mainstream health services, by:
 - a) Developing integrated and coordinated care initiatives between LHDs and Primary Health Networks. This work should be informed by the evaluations of the Integrated Care and *HealthPathways* trial sites.
 - b) Developing mechanisms in LHDs to coordinate access and care for people with disability.
 - c) Developing mechanisms to facilitate the provision of timely, coordinated and multidisciplinary health support to people with disability transitioning from institutions to community-based accommodation.
 - d) Creating a minimum dataset for people with disability.
 - e) Developing and implementing 'reasonable adjustments' guidance for health services.
 - f) Through the Health Education and Training Institute (HETI), developing and implementing training materials to up-skill health services staff.
 - g) In line with the *Disability Inclusion Act 2014*, developing and implementing strategies to develop a culture of inclusion for people with disability.
 - h) Working with General Practitioners to improve written health guidance for people with disability and their carers/support staff.
 - i) Developing key performance indicators and outcomes measures for health services in relation to people with disability, starting with NDIS participants.
 9. As a matter of priority, DPC (with FACS and Health) should discuss the future arrangements for the provision of FACS-funded health-related supports with the NDIA/Commonwealth Government and report to this office on the outcomes and intended actions.
 10. As part of transition planning, Health and FACS should:
 - a) Establish joint disability/health committees in each district to promote and oversee capacity building in relation to mainstream health services. In this regard, we note that the district NDIS governance arrangements that are in design provide a useful mechanism to deliver leadership and oversight capacity-building in all areas of mainstream service provision for people with disability, including health services.
 - b) Review the implementation and effectiveness of the *NSW Health and ADHC Joint Guideline: Supporting residents of ADHC operated and funded accommodation support services who present to a NSW Public Hospital* and provide advice to this office as to the arrangements that are intended to be put in place with NGO disability providers by the time of full NDIS transition.

Recommendations

Recognising and responding to critical situations

Recommendation 1

FACS and NDS should consider the information in this report regarding identifying illness and taking action, and provide advice to this office as to what action they will take to ensure that:

- a) disability residential care staff are issued with clear instructions that they need to call for emergency medical help as early as possible where they have any doubt as to the seriousness of a person's presenting health condition, and
- b) these instructions are reinforced with direct care staff through team meetings (or other appropriate mechanisms).

Recommendation 2

FACS and NDS should consider the information in this report regarding critical incident responses, and provide advice to this office as to what action they will take to ensure that:

- a) disability residential care staff receive regular refresher information on what to do in response to critical health events, and
- b) disability residential care providers take steps to identify any factors that may impede an effective response (such as no cordless or mobile phone).

Effectively managing individual risks

Recommendation 3

FACS and NDS should consider the information in this report regarding the management of individual risks and access to preventative health support, and provide advice to this office as to what action they will take to ensure that:

- a) as part of staff induction processes, all direct care staff in disability residential care services are required to read and certify that they have understood the information in the NSW Ombudsman's fact sheets on:
 - (i) Preventing deaths of people with disabilities in care: Breathing, swallowing and choking risks (factsheet 4), and
 - (ii) Preventing deaths of people with disabilities in care: Smoking, obesity and other lifestyle risks (factsheet 5), and
- b) the information in the above factsheets is reinforced with direct care staff through supervision and support mechanisms, such as team meetings.

Internal reviews by services

Recommendation 4

As part of FACS' review of its *Client death* policy and procedures, the agency should take into account the issues identified in the 'Internal reviews by services' section of this report, and provide clear guidance to improve the actions of services following the death of a client in relation to:

- a) incident reporting by staff, and
- b) internal reviews.

Planning to meet health needs in the transition to the NDIS

Recommendation 5

The Department of Premier and Cabinet (DPC) should:

- a) provide this office with a copy of the NSW Government NDIS transition plan, and
- b) ensure that the transition plan includes identification of system improvements to support transition and/or embed service delivery that is responsive to the needs of people with disability.

Recommendation 6

NSW Health, FACS and the NDIA should use the Hunter NDIS launch site to trial and evaluate key initiatives and actions to address known problems and barriers for people with disability in relation to mainstream health services, by:

- a) Developing integrated and coordinated care initiatives between Hunter New England LHD (HNELHD) and Hunter Primary Health Network, such as:
 - (i) developing HNELHD as an integrated care demonstrator site, and
 - (ii) considering opportunities to integrate and coordinate care through the HealthOne NSW Service locations in HNELHD.
- b) Implementing mechanisms in HNELHD to coordinate access and care for people with disability.
- c) Developing mechanisms to facilitate the provision of timely, coordinated and multidisciplinary health support to people with disability transitioning from Hunter institutions² to community-based accommodation.
- d) Creating a minimum dataset for people with disability.
- e) Developing and trialling a 'reasonable adjustments toolkit' for Hunter health services.
- f) In line with the *Disability Inclusion Act 2014*, developing and implementing strategies to develop a culture of inclusion of people with disability in Hunter health services.
- g) Working with Hunter General Practitioners to improve written health guidance for people with disability and their carers/support staff.
- h) Working with Hunter Primary Health Network to establish clinical pathways with local providers and nurses.
- i) Developing key performance indicators and outcomes measures in Hunter health services for people with disability. This work should take into account the NDIS evaluation by the National Institute of Labour Studies, and NSW Health's Monitoring and Evaluation Framework for measuring the transition to and impact of the NDIS in HNELHD.

Recommendation 7

In addition to HNELHD, NSW Health should use the HealthNet lead sites and the LHDs that have documented actions in their disability action plans relating to developing data identifiers/flags for people with disability, to establish and trial a minimum dataset for people with disability in electronic medical records.

² Including ADHC large residential centres (Stockton, Kanangra, Tomaree); and HNELHD mental health facilities (Morisset).

Recommendation 8

In addition to work in relation to the NDIS Hunter launch site, and as part of transition planning, NSW Health, FACS and the NDIA should identify and progress actions more broadly in NSW to improve health outcomes for people with disability in their contact with mainstream health services, by:

- a) Developing integrated and coordinated care initiatives between LHDs and Primary Health Networks. This work should be informed by the evaluations of the Integrated Care and *HealthPathways* trial sites.
- b) Developing mechanisms in LHDs to coordinate access and care for people with disability.
- c) Developing mechanisms to facilitate the provision of timely, coordinated and multidisciplinary health support to people with disability transitioning from institutions to community-based accommodation.
- d) Creating a minimum dataset for people with disability.
- e) Developing and implementing 'reasonable adjustments' guidance for health services.
- f) Through the Health Education and Training Institute (HETI), developing and implementing training materials to up-skill health services staff.
- g) In line with the *Disability Inclusion Act 2014*, developing and implementing strategies to develop a culture of inclusion for people with disability.
- h) Working with General Practitioners to improve written health guidance for people with disability and their carers/support staff.
- i) Developing key performance indicators and outcomes measures for health services in relation to people with disability, starting with NDIS participants.

Recommendation 9

As a matter of priority, DPC (with FACS and Health) should discuss the future arrangements for the provision of FACS-funded health-related supports with the NDIA/Commonwealth Government and report to this office on the outcomes and intended actions.

Recommendation 10

As part of transition planning, Health and FACS should:

- a) Establish joint disability/health committees in each district to promote and oversee capacity building in relation to mainstream health services. In this regard, we note that the district NDIS governance arrangements that are in design provide a useful mechanism to deliver leadership and oversight capacity-building in all areas of mainstream service provision for people with disability, including health services.
- b) Review the implementation and effectiveness of the *NSW Health and ADHC Joint Guideline: Supporting residents of ADHC operated and funded accommodation support services who present to a NSW Public Hospital* and provide advice to this office as to the arrangements that are intended to be put in place with NGO disability providers by the time of full NDIS transition.

Part One: Deaths in 2012 and 2013

Chapter 1. Introduction

The NSW Ombudsman has had responsibility for reviewing the deaths of people with disability in residential care and certain children since December 2002.

This report is the eighth report of reviewable deaths, and covers the period 1 January 2012 to 31 December 2013. In this two-year period, the deaths of 239 people with disability in residential care were reviewable.

1.1. Our role in reviewing the deaths of people with disability

Our reviewable deaths functions are detailed in Part 6 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CS CRAMA). In addition to reviewing the deaths of certain children, CS CRAMA requires the Ombudsman to review the death of any person living in, or temporarily absent from, residential care provided by a service provider³ or an assisted boarding house.

The focus of our reviews is on identifying practice and systems issues that may contribute to deaths or affect the safety and wellbeing of people with disability in residential care. Our aim is to recommend relevant changes or new strategies that may ultimately help to prevent avoidable deaths. In part, we do this by considering how agencies and services have acted, and can act, to promote the health and wellbeing of people with disability in residential care.

Our work involves examining relevant records and information relating to the people with disability who died. We may also request specific information from agencies to assist our review.

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

1. the Registrar of Births, Deaths and Marriages must provide the Ombudsman with a copy of death registration information relating to a child's death not later than 30 days after receiving the information
2. the Chief Executive of Ageing, Disability and Home Care (ADHC) must provide the Ombudsman with copies of any notification received by the Chief Executive relating to a reviewable death not later than 30 days after receiving the notification, and
3. it is the duty of the State Coroner to notify the Ombudsman of any reviewable death notified to the State Coroner not later than 30 days after receiving the notification.

1.2. Developments since our last report

We tabled our last biennial report in May 2013. Since that time, there have been significant and continuing reforms to disability support arrangements in NSW and nationally, and notable changes to our reviewable deaths functions.

NDIS

In 2013, legislation⁴ was introduced to enable the start of the National Disability Insurance Scheme (NDIS) in Australia. On 1 July 2013, the NDIS began in the Hunter region of NSW. All of the functions of the Ombudsman's office in NSW – including our reviewable deaths functions – apply to the NDIS launch sites.

3 For the purposes of CS CRAMA, 'service provider' means the Department of Family and Community Services; an implementation company under the *National Disability Insurance Scheme (NSW Enabling) Act 2013*; a person or organisation funded, authorised or licensed by the Minister for Family and Community Services, the Minister for Ageing or the Minister for Disability Services to provide a service; the Home Care Service of NSW or a person or organisation funded by the Home Care Service to provide a service; a person or organisation that is covered by an arrangement made after 7 April 1994 between a Minister of NSW and a State or Commonwealth Minister, under which arrangement that State or Commonwealth Minister agrees to the person or organisation being a service provider for the purposes of this Act; an authorised carer or designated agency within the meaning of the *Children and Young Persons (Care and Protection) Act 1998*; or the proprietor or occupier of premises that consist of an assisted boarding house.

4 *National Disability Insurance Scheme Act 2013*.

The next stage of transition to the NDIS commences on 1 July 2016, with full roll out of the scheme scheduled for 1 July 2018. In Chapter 5 of this report, and against the background of our reviews of the deaths of people with disability in residential care over the past 12 years, we discuss the planning we consider needs to be undertaken as a matter of priority in NSW to meet the health needs of people with disability in the transition to the NDIS.

In March 2015, the Australian Government Department of Social Services commenced consultations on options for the development of an NDIS Quality and Safeguarding Framework. In partnership with other Disability Complaints Commissioners from across Australia, our office has issued a paper on Safeguards and the NDIS, which outlines the minimum safeguards the Commissioners consider need to be in place for people with disability as part of the NDIS.⁵

New disability legislation in NSW

On 3 December 2014, the NSW Government introduced the *Disability Inclusion Act 2014*, replacing the *Disability Services Act 1993* after extensive consultation. The new legislation sets out how the Department of Family and Community Services (FACS) will provide disability supports until the full roll out of the NDIS; and commits the NSW Government to making communities more inclusive and accessible for people with disability now and post-transition to the NDIS. It includes increased disability action planning requirements, including the development and implementation of a State Disability Inclusion Plan.

The Disability Inclusion Act also amended the *Ombudsman Act 1974*, to include Part 3C 'Protection of people with disability' – the disability reportable incidents scheme. Part 3C is the first – and only – legislated scheme in Australia for the reporting and independent oversight of serious incidents involving people with disability in supported accommodation.

Part 3C requires our office to keep under scrutiny the systems of FACS and funded providers for preventing, handling, and responding to reportable incidents in disability 'supported group accommodation'.⁶ Reportable incidents include **employee to client incidents** (physical assault; sexual offence; sexual misconduct; fraud; neglect and ill-treatment); **client to client incidents** (sexual offence; physical assault resulting in serious injury, involving the use of a weapon, or part of a pattern of abuse); **contravention of an Apprehended Violence Order** taken out in relation to a person with disability in supported group accommodation; and **unexplained serious injury**.

Amendments to CS CRAMA

In June 2014, changes were introduced to CS CRAMA to better support our reviewable deaths functions and facilitate enhanced public reporting on systemic issues, as required. The amendments enable the Ombudsman to:

- publicly report on, and make recommendations about, any systemic issues relating to the provision of community services by service providers as he thinks fit,⁷ and

5 The safeguards include 1) Independent oversight, including complaint handling and investigative powers; legislative responsibilities to conduct ongoing reviews into the effectiveness of aspects of the NDIS; and responsibility for promoting access to advocacy and supported decision-making; 2) Safeguards to prevent and effectively respond to abuse, neglect and exploitation, including the reporting and independent oversight of the handling of critical incidents; a comprehensive national screening system for prospective employees; and regulation and oversight of the use of restrictive interventions; 3) Community Visitors; 4) Public Guardian/ Public Advocate; and Disability Advisory Council(s). The paper is available on our website, at: <https://www.ombo.nsw.gov.au/news-and-publications/publications/fact-sheets/community-and-disability-services/safeguards-and-the-ndis>.

6 Section 22(1) of the Disability Inclusion Act defines supported group accommodation as: 'premises in which:
a) a person with disability is living in a shared living arrangement (whether short-term or permanently) with at least one other person with disability, other than an arrangement in which one or more of the persons with disability is living with a guardian of the person or a member of the person's family who is responsible for the care of the person, and
b) support is provided on-site:
(i) for a fee, or
(ii) whether or not for a fee if the support is provided as respite care.'

7 CS CRAMA, section 14A.

-
- more effectively undertake research to prevent or reduce the likelihood of the deaths of children and people with disability in residential care, through provisions to:
 - work in partnership with others on research or other projects to find ways to reduce or remove risk factors associated with reviewable deaths that are preventable,⁸ and
 - provide information to others, where appropriate, to facilitate such research.⁹

Simplified information about reducing preventable deaths

Following our last report, we released a series of factsheets on the key findings and messages from our reviews of the deaths of people with disability in residential care, targeted at direct care staff in disability services and assisted boarding houses, and GPs:

- 1) Preventing deaths of people with disabilities in care - Information for staff of disability services
- 2) Preventing deaths of people with disabilities in care - Information for licensed boarding house staff and services
- 3) Preventing deaths of people with disabilities in care: Information for General Practitioners
- 4) Preventing deaths of people with disabilities in care: Breathing, swallowing and choking risks, and
- 5) Preventing deaths of people with disabilities in care: Smoking, obesity and other lifestyle risks.

The factsheets were disseminated to all disability services, assisted boarding houses, Boarding House Reform Program services, Primary Health Networks and Official Community Visitors, and have been distributed at disability forums and our community education and training sessions.

ADHC has also incorporated the factsheets into its online training tool for direct care staff, and we discussed the factsheets and the key messages relating to assisted boarding house residents in ADHC's training sessions for its new boarding house compliance officers.

It is important that the simple but essential messages are both communicated to, and reinforced with, direct care staff and other services supporting people with disability in residential care.

1.3. This report

This eighth report on reviewable deaths has been released in two volumes. The first volume concerns the deaths of certain children. This second volume relates to the deaths in 2012 and 2013 of 239 people with disability in residential care.

This two-year period marks the first time in the history of reviewable deaths that there were no deaths of children or young people with disability in residential care. Consequently, there is no duplication of the individuals discussed in the two reports.

Part One provides information on the deaths of people with disability in 2012 and 2013:

- **Chapter 2** outlines the demographic and other data relating to the people who died
- **Chapter 3** details data and other information relating to the main causes of deaths, and
- **Chapter 4** reports on the main findings from our reviews of deaths in the two-year period.

Part Two (Chapter 5) discusses the key issues arising from our reviews of the deaths of people with disability in residential care over the past 12 years that need to be taken into account, and addressed, in the planning in NSW (and nationally) to meet the health needs of people with disability in the transition to the NDIS.

Part Three (Chapter 6) details the recommendations we made in our last report and the progress of ADHC, NSW Health, and the Department of Education and Communities in implementing them.

Note: percentages in this report are rounded up, so may not equal 100.

8 CS CRAMA, section 36(1)(d).

9 CS CRAMA, section 39(2).

Chapter 2. Deaths of people with disability in 2012 and 2013

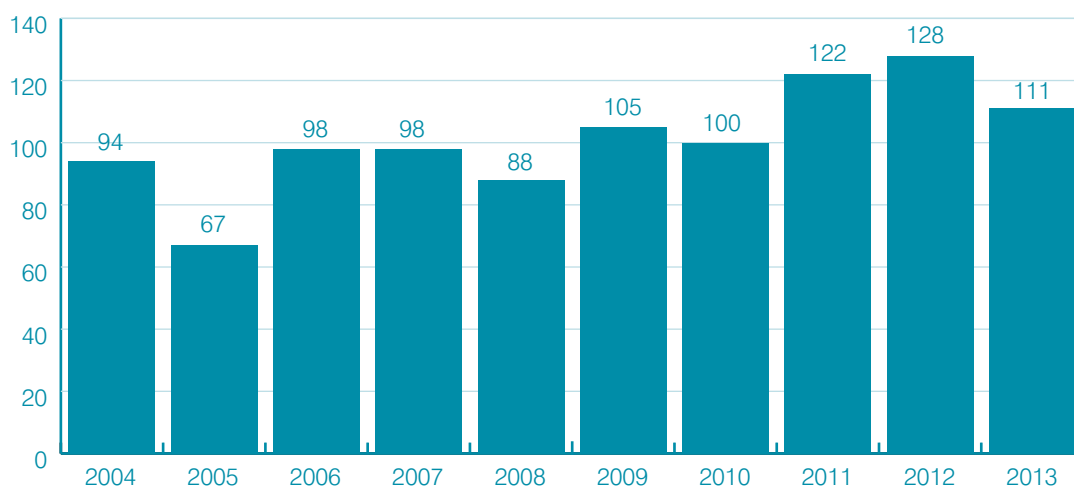
Our responsibilities include reporting on data and information relating to deaths in each two-year period, as well as analysing data relating to all deaths to identify patterns and trends.

In this section we report demographic and other information relating to the people who died between 1 January 2012 and 31 December 2013. Where relevant, we have compared deaths in this period to those that occurred across the 10 years between 2004 and 2013 and noted differences, where they exist.

2.1. Reviewable disability deaths in 2012 and 2013

In 2012 and 2013, 239 people with disability in residential care died. Residential care includes group homes, residential centres, assisted boarding houses,¹⁰ and other accommodation for people with disability, such as centre-based respite.

Figure 1: Number of deaths of people with disability in residential care, 2004-2013¹¹



Of the 239 reviewable deaths of people with disability in residential care in 2012 and 2013:

- 121 (51%) people lived in ADHC accommodation
- 101 (42%) people lived in NGO (ADHC-funded) accommodation
- 14 (6%) people lived in assisted boarding houses, and
- three people (1%) were residing in private or community housing with ADHC or NGO support.

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

¹⁰ Assisted boarding houses used to be known as 'licensed boarding houses'.

¹¹ In our previous biennial report, we indicated that 120 people with disability in residential care died in 2011. Since that report, we have been notified of the deaths of two additional people in 2011.

Table 1: Deaths of people with disability in residential care in 2012 and 2013

Accommodation	Estimated total no. of residents 2012-2013	No. of deaths 2012-2013	Percentage of population who died in 2012-2013	Percentage of reviewable disability deaths
Group home (funded)	3532	70	2.0	29.3
Group home (ADHC)	1632	44	2.7	18.4
Residential centre (funded)	324	27	8.3	11.3
Residential centre (ADHC)	889	77	8.7	32.2
Assisted boarding house	679	14	2.1	5.9
Other ¹²	–	7	–	2.9
Total	7,056	239		100

As shown in the table above, while the largest proportion of people with disability in residential care (50%) reside in NGO group homes, ADHC residential centres accounted for the highest proportion of reviewable deaths in 2012 and 2013.

The 77 people in ADHC residential centres who died in 2012 and 2013 represented a 40% increase on deaths in those facilities in the previous two-year period. On average, people in ADHC residential centres die at a slightly older age than the broader population in disability accommodation services – in 2012 and 2013, the average age at death of people in ADHC residential centres was 61 years, compared with 55 years in disability services.

2.2. Age, gender and cultural status

Age

The age at death of people in disability services ranged from 18 to 87 years. The mean age was 55 years, slightly higher than the 10-year average (53 years).

The age at death of people in assisted boarding houses ranged from 46 to 87 years. The mean age at death of people in assisted boarding houses was 59 years, four years younger than the 10-year average (63 years).

Gender

Consistent with previous years, most (56%) of the people with disability in residential care who died in 2012 and 2013 were male – including just over half of the people in disability services (124) and over three-quarters (11) of the people in assisted boarding houses who died. The prevalence of males reflects the broader population of people with disability in residential care, where males outnumber females in all accommodation and service types.

Cultural status

Two people who died in disability services were identified as Aboriginal and/or Torres Strait Islander. Thirteen people in disability services and two people in assisted boarding houses had a culturally and linguistically diverse background.

¹² The seven people in 'other' accommodation included four people who lived in independent accommodation with ADHC or NGO support; and three people who lived alone in NGO accommodation (such as in a bedsitter or a unit).

2.3. Disability and support needs

Information relating to the disability and support needs of people who died in 2012 and 2013 is largely consistent with previous years.

Disability

As shown in the table below, the vast majority of the people in disability services who died had a cognitive impairment (including intellectual disability, dementia, and acquired brain injury). Many also had other impairments, including sensory, physical and psychosocial disability.

Most of the residents of assisted boarding houses who died had a psychosocial disability (93%). Many also had a cognitive impairment, including intellectual disability and alcohol-related brain damage, and a sensory impairment.

Table 2: Number and percentage of people with disability in residential care who died in 2012 and 2013, by impairment and service type

	Disability services (N=225)		Assisted boarding houses (N=14)		Total (N=239)	
	N	%	N	%	N	%
Intellectual ¹³	198	88.0	4	28.6	202	84.5
Sensory ¹⁴	136	60.4	5	35.7	141	59.0
Physical ¹⁵	118	52.4	0	0.0	118	49.4
Psychosocial ¹⁶	91	40.4	13	92.9	104	43.5
Neurological ¹⁷	32	14.2	1	7.1	33	13.8
Acquired Brain Injury ¹⁸	18	8.0	5	35.7	23	9.6
Autism	13	5.8	0	0.0	13	5.4

Consent to treatment

For the majority of disability services residents, other people provided consent to medical and dental treatment on their behalf, mainly family members (151; 67%). Thirty-four people in disability services provided their own consent.

Just over half of the assisted boarding house residents (8) provided their own consent to medical and dental treatment. The proportion of people in assisted boarding houses who provided their own consent was lower than previous years (for example, 84% of boarding house residents who died in 2010 and 2011 had provided their own consent to medical and dental treatment).

- 13 Consistent with previous years, most of the people in disability services with an intellectual disability had a moderate or severe level of cognitive impairment. The four people in assisted boarding houses with an intellectual disability had a mild level of cognitive impairment.
- 14 The primary sensory impairment for people in disability services and assisted boarding houses was vision impairment.
- 15 The people with physical disability most commonly had cerebral palsy, scoliosis, and/or ataxia.
- 16 All of the assisted boarding house residents who had a mental illness had schizophrenia or schizoaffective disorder. Most of the people in disability services who had a mental illness had a mood disorder, such as depression or bipolar disorder; schizophrenia or other psychotic disorder; and/or an anxiety disorder.
- 17 Dementia, including Alzheimer's disease, was the primary neurological impairment of the people who died in 2012 and 2013.
- 18 The brain injuries were acquired via a range of means, including alcohol-related brain damage, brain tumours, infection, and as a result of an accident.

Mobility and communication support

Almost three-quarters (166) of the people in disability services who died required help with mobility, and 50% required wheelchair support. Two-thirds (147) needed assistance to communicate, using mainly adjusted verbal language or other signing (such as gestures).

One assisted boarding house resident needed mobility assistance and used a walking stick. Three were reported to need communication support, including two who required adjusted verbal support, and one who required a hearing aid.

Assistance with meals

Almost three-quarters of the disability service residents (167) required assistance with meals. No residents of assisted boarding houses needed help with meals.

Enteral nutrition

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

None of the assisted boarding house residents required enteral nutrition.

Swallowing difficulties and review

Two-thirds (148) of the people in disability services who died were reported to have swallowing difficulties (also known as dysphagia). The swallowing function of the majority of these individuals (124; 84%) had been reviewed by a speech pathologist and/or dysphagia clinic at some point. For most (107; 72%), the swallowing review occurred in the year before their death.

None of the assisted boarding house residents who died were reported to have had swallowing difficulties.

Nutrition and swallowing checklist

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

Of the 52 people in NGO services with swallowing difficulties who died in 2012 and 2013:

- six people did not have a risk assessment, and
- only 18 people had a comprehensive assessment.

Of the 96 people in ADHC services with swallowing difficulties who died in 2012 and 2013:

- the majority had a comprehensive nutrition and swallowing risk assessment (66), but
- for almost one-third, staff had either not identified all of the person's risks (22), or had not recorded sufficient actions that needed to be taken to address the risks (6), and
- one person did not have a risk assessment.¹⁹

Mealtime support guidance

Mealtime support guidance (such as a mealtime management plan or eating and drinking plan) was recorded for the majority (128; 86%) of the people with swallowing difficulties in disability services who died. For 20 people with swallowing difficulties, there was no written guidance to indicate to staff (or other services) what support the individuals required to minimise their swallowing risks.

¹⁹ Nutrition and swallowing risk assessment information was not sought for one individual.

2.4. Health needs

Dentition

As indicated in the table below, and consistent with previous years, only one-quarter of the people in disability services (53) and four assisted boarding house residents had all of their teeth.

Table 3: Dentition status of people with disability in care who died in 2012 and 2013

Dentition	Disability services (N=225)		Assisted boarding houses (N=14)		Total (N=239)	
	N	%	N	%	N	%
None	62	27.6	1	7.1	63	26.4
Some	98	43.6	6	42.9	104	43.5
All	53	23.6	4	28.6	57	23.8
Dental aid	11	4.9	3	21.4	14	5.9
Don't know	1	0.4	0	0.0	1	0.4
Total	225	100	14	100	239	100

Dental review

Most (178; 79%) of the people in disability services who died in 2012 and 2013 had seen a dentist. Just under two-thirds (144) had seen a dentist in the year before their death.

Less than half of the assisted boarding house residents (6) had seen a dentist at any time. All of the six people had seen a dentist in the year before they died.

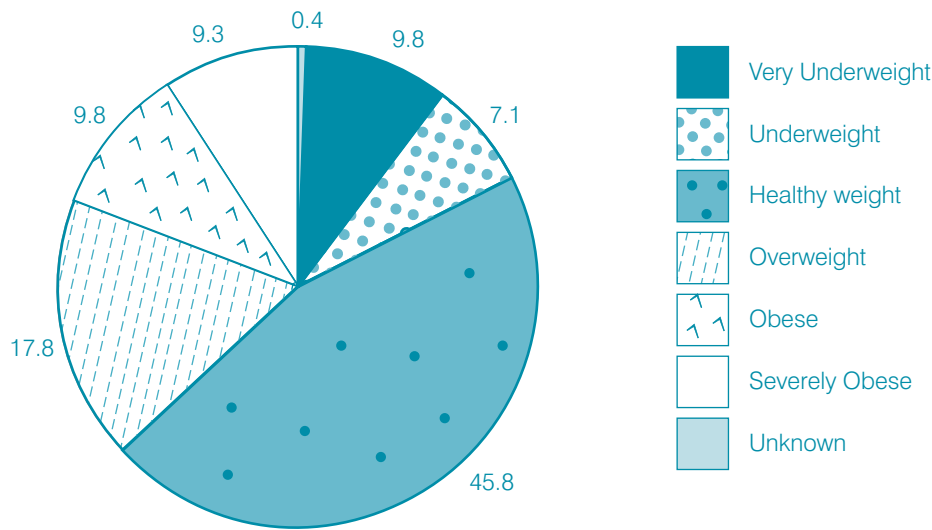
Weight

In 2012 and 2013, less than half (107; 44.8%) of the people with disability in residential care who died were in the healthy weight range. As shown in the figures below, in both disability services and assisted boarding houses, most of the people who were outside of the healthy weight range were overweight to severely obese.

In disability services, over one-third (83) of the people who died were overweight, obese or severely obese. Thirty-eight people (17%) were underweight or very underweight.

Of the 121 people in disability services who were outside of the healthy weight range, just over half (63) had been recorded as ever having seen a dietician; 52 (44%) had seen the dietician in the year before their death.

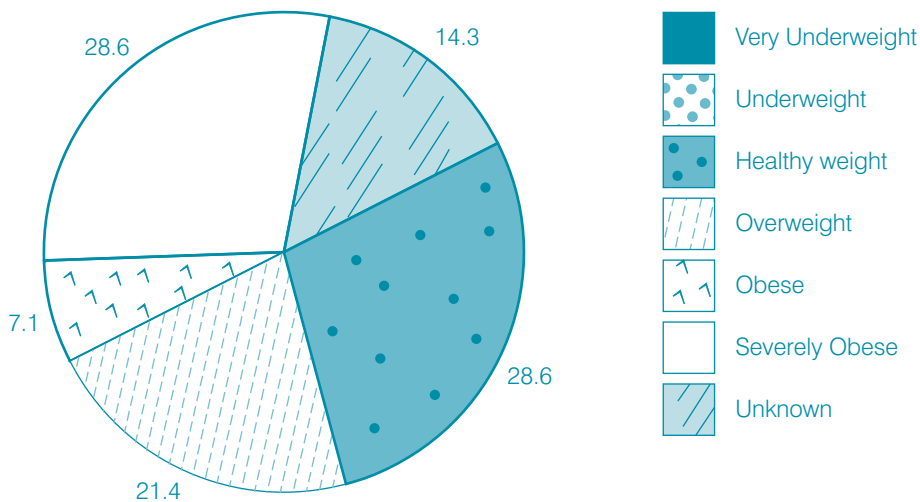
Figure 2: Weight status of people in disability services who died in 2012 and 2013



Consistent with the previous two-year period, less than one-third of the assisted boarding house residents who died in 2012 and 2013 were in the healthy weight range. Eight people (57.1%) were overweight, obese or severely obese. None of the assisted boarding house residents who died were underweight.

Of the eight people in assisted boarding houses who were outside of the healthy weight range, only one person had seen a dietician. The person had seen the dietician in the year before they died.

Figure 3: Weight status of people in assisted boarding houses who died in 2012 and 2013



Other key health issues

Most people in disability services whose deaths we reviewed had health conditions that required either treatment or support. Over half of the 225 people whose deaths we reviewed were reported to have had some level of incontinence, constipation and/or gastro-oesophageal reflux disease. Over one-third (81) had osteoporosis.

Table 4: Main health issues of people in disability services who died in 2012 and 2013

Health issue	N	%
Incontinence ²⁰	160	71
Constipation	155	69
Gastro-oesophageal reflux disease	140	62
Epilepsy	107	48
Recurrent respiratory infections	103	46
Osteoporosis	81	36
Hypertension	66	29
High cholesterol	46	20
Hypothyroidism	42	19
Heart problems ²¹	42	19
Arthritis	41	18
Urinary tract infections	41	18
Asthma	37	16
Diabetes	33	15

As Table 5 illustrates, over one-third of the people in assisted boarding houses who died were reported to have had health issues related to the cardiovascular system, such as hypertension or high cholesterol.

Table 5: Main health issues of people in assisted boarding houses who died in 2012 and 2013

Health issue	N	%
Hypertension	6	40
High cholesterol	6	40
Constipation	5	33
Gastro-oesophageal reflux disease	5	33
Asthma	5	33
Diabetes	4	27
Chronic obstructive pulmonary disease	4	27

20 Mostly double incontinence

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

Respiratory review

Of the 103 people in disability services who had recurrent respiratory illness, 27 had seen a respiratory specialist, including 25 people who had seen a specialist in the year before their death.

Two assisted boarding house residents had recurrent respiratory illness. There was no indication that they had seen a respiratory specialist.

Smoking

The vast majority (12; 86%) of assisted boarding house residents who died in 2012 and 2013 had smoked, and most (11) were still smokers at the time of their death.

Thirty-three people (15%) in disability services who died in 2012 and 2013 had smoked, and 21 were still smokers at the time of their death.

The smoking rates among the people with disability in residential care who have died have been highly consistent over the past decade. Between 2004 and 2013, 83% of the boarding house residents and 17% of the disability services residents who died had smoked.

Vaccination

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

Influenza vaccination

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

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

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

In 2012 and 2013, just below three-quarters of the people in disability services (165) and the vast majority (12) of the 14 assisted boarding house residents who died had received the influenza vaccine in the year before their death.

22 Australian Technical Advisory Group on Immunisation. *The Australian Immunisation Handbook*. 10th ed. Canberra: Australian Government Department of Health, 2013 4.7.3.

23 *Ibid*, 4.7.4.

Pneumococcal vaccination

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

People who are recommended to receive pneumococcal vaccine include:

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

In 2012 and 2013, just over one-third of the people in disability services (83) and less than one-quarter of the assisted boarding house residents who died (3) had received the pneumococcal vaccine in the five years before their death.

Comprehensive health assessment

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

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

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

Just over three-quarters of the people in disability services (173) and just under one-third of the assisted boarding house residents (5) who died in 2012 and 2013 had a comprehensive health assessment in the year before their death.

24 Ibid., 4.13.1.

Chapter 3. Causes of death

Most of the 239 people died from natural causes (illnesses and diseases). A small number of people died from other causes, mainly from choking on food.

The information in this chapter is primarily focused on the 'underlying cause of death'. The underlying cause of death refers to the disease or injury that started the chain of events that led directly to the person's death.²⁵

3.1. Broad underlying causes of death

As has consistently been the case, the vast majority (212; 89%) of the 239 deaths of people with disability in residential care in 2012 and 2013 were due to natural causes (illnesses and diseases). Natural causes accounted for the deaths of most of the people who resided in disability services (199; 88%) and assisted boarding houses (13; 93%).

Seventeen people (7%) died from external (unnatural) causes. All of these deaths were due to unintentional or accidental causes, mainly associated with choking on food (9). The vast majority (16) of the 17 people who died from unintentional external causes resided in disability services; one person lived in an assisted boarding house.

There were no deaths due to intentional causes (such as suicide or assault) in 2012 and 2013.

For 10 people, the cause of death was unable to be determined.

3.2. Leading underlying causes of death

Leading underlying causes of death of all people with disability in residential care in 2012 and 2013

Respiratory diseases (such as pneumonia) were the overall leading cause of death in 2012 and 2013 of people with disability in residential care, accounting for almost one-quarter (56) of all deaths in that period. This is a change from previous years, where nervous system diseases (such as epilepsy and cerebral palsy) have been the leading underlying cause of death.

As indicated in the table below, other main underlying causes of death were:

- neoplasms (39 people; 16%) – mainly lung and breast cancer
- nervous system diseases (38 people; 16%) – mainly cerebral palsy and epilepsy
- circulatory diseases (31 people; 13%) – mainly ischaemic heart diseases
- congenital and chromosomal abnormalities (25 people; 10%) – mainly Down syndrome, and
- external causes (17 people; 7%) – mainly choking on food.

²⁵ 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 for health classification published by the World Health Organisation (WHO) for coding diseases for statistical aggregation and reporting purposes. The ICD provides structured rules for guiding how the underlying cause of death is determined. Use of these rules assists with the standardization of coded data and facilitates comparability with other collections of mortality data.

Table 6: Underlying causes of death in 2012 and 2013 of people with disability in residential care at ICD chapter level

ICD chapter	Disability services						Assisted boarding houses					
	Male		Female		Total		Male		Female		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Infectious and parasitic diseases (A00-B99)	2	1.6	1	1.0	3	1.3	0	0	0	0	0	0
Neoplasms (C00-D48)	19	15.3	17	16.8	36	16.0	2	18.2	1	33.3	3	21.4
Endocrine, nutritional & metabolic disorders (E00-E90)	1	0.8	2	2.0	3	1.3	0	0	0	0	0	0
Mental & behavioural disorders (F00-F99)	0	0	0	0	0	0	1	9.1	0	0	1	7.1
Diseases of the nervous system (G00-G99)	22	17.7	16	15.8	38	16.9	0	0	0	0	0	0
Diseases of the circulatory system (I00-I99)	17	13.7	8	7.9	25	11.1	4	36.4	2	66.7	6	42.9
Diseases of the respiratory system (J00-J99)	30	24.2	24	23.8	54	24.0	2	18.2	0	0	2	14.3
Diseases of the digestive system (K00-K93)	4	3.2	4	4.0	8	3.6	1	9.1	0	0	1	7.1
Musculoskeletal and connective tissue (M00-M99)	0	0	1	1.0	1	0.4	0	0	0	0	0	0
Diseases of the genitourinary system (N00-N99)	2	1.6	4	4.0	6	2.7	0	0	0	0	0	0
Congenital and chromosomal conditions (Q00-Q99)	12	9.7	13	12.9	25	11.1	0	0	0	0	0	0
Symptoms and signs NEC (R00-R99)	4	3.2	6	5.9	10	4.4	0	0	0	0	0	0
External causes (V00-Y98)	11	8.9	5	5.0	16	7.1	1	9.1	0	0	1	7.1
Total	124	100	101	100	225	100	11	100	3	100	14	100

Table 7 below shows the top 11 leading causes of death for people with disability in residential care in 2012 and 2013. These causes accounted for over half of all deaths. In comparison with the 10-year trend over 2004-2013 (as shown in table 8):

- a higher proportion of people died in 2012 and 2013 from pneumonia; pneumonitis due to solids and liquids (aspiration); inhalation and ingestion of food causing obstruction of the respiratory tract (choking); and cerebral palsy, and
- a lower proportion died in 2012 and 2013 from ischaemic heart diseases; chronic lower respiratory diseases; and malignant neoplasm of the trachea, bronchus and lung.

Table 7: Top 11 leading causes of death of people with disability in residential care, 2012-2013

Underlying cause of death	N	%
Pneumonitis due to solids and liquids	22	9.2
Pneumonia	21	8.8
Cerebral palsy	16	6.7
Epilepsy	13	5.4
Ischaemic heart diseases	11	4.6
Inhalation and ingestion of food causing obstruction of respiratory tract	9	3.8
Other heart diseases	9	3.8
Down syndrome	8	3.3
Malignant neoplasm of trachea, bronchus and lung	5	2.1
Cerebrovascular diseases	5	2.1
Chronic lower respiratory diseases	5	2.1
Total top 11 underlying causes overall	124	51.9

Table 8: Top 10 leading causes of death of people with disability in residential care, 2004-2013

Underlying cause of death	N	%	Crude mortality rate per 1,000	95% Confidence Interval
Ischaemic heart diseases	77	7.62	1.18	0.93 - 1.48
Pneumonitis due to solids and liquids	62	6.13	0.95	0.73 - 1.22
Epilepsy	59	5.84	0.91	0.69 - 1.17
Cerebral palsy	59	5.84	0.91	0.69 - 1.17
Pneumonia	51	5.04	0.78	0.58 - 1.03
Down syndrome	40	3.96	0.61	0.44 - 0.84
Other heart diseases	40	3.96	0.61	0.44 - 0.84
Chronic lower respiratory diseases	35	3.46	0.54	0.37 - 0.75
Malignant neoplasm of trachea, bronchus and lung	29	2.87	0.45	0.30 - 0.64
Inhalation and ingestion of food causing obstruction of respiratory tract	29	2.87	0.45	0.30 - 0.64
Total top 10 underlying causes overall	481	47.59		

Consistent with our previous reports, and to gain an accurate picture of the main causes of death, we have examined the underlying causes of death of people in disability services separate from people in assisted boarding houses. As shown in table 6 and the following information, there are notable differences in the main causes of death of the two populations.

Leading causes of death of people in disability services

Respiratory diseases – primarily aspiration and pneumonia – were the leading underlying cause of death of people in disability services in 2012 and 2013, accounting for almost one-quarter of all deaths in this population. While respiratory diseases always feature highly in the deaths of people in disability services, they accounted for a higher proportion of deaths in 2012 and 2013 than recent years.

Respiratory diseases were the leading cause of death of both males and females in disability services.

Figure 4: Leading underlying causes of death of people in disability services in 2012-2013, by ICD chapter

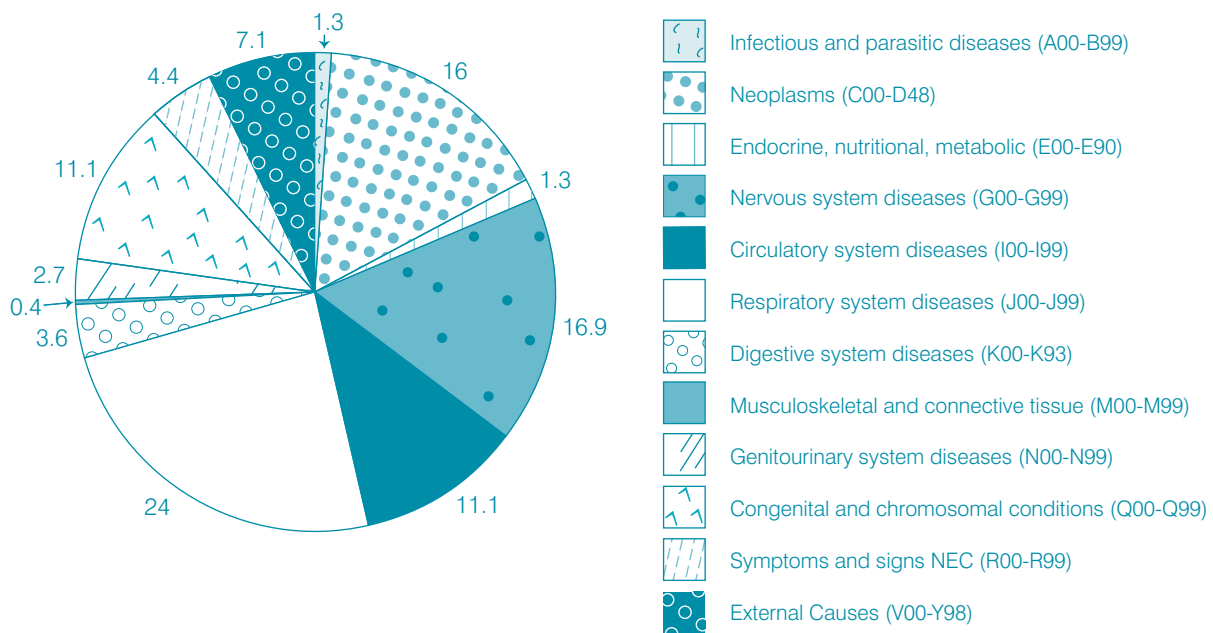


Table 9 below shows the top 10 leading underlying causes of death of people in disability services in 2012 and 2013. These causes accounted for half of all deaths in this population. In comparison with the 10-year trend over 2004-2013 (as shown in table 11):

- a higher proportion of people in disability services died in 2012 and 2013 from pneumonia; pneumonitis due to solids and liquids (aspiration); inhalation and ingestion of food causing obstruction of the respiratory tract (choking); and cerebral palsy, and
- a lower proportion died in 2012 and 2013 from epilepsy; chronic lower respiratory diseases; and Down syndrome.

Table 9: Top 10 leading underlying causes of death of people in disability services, 2012-2013

Underlying cause of death	N	%
Pneumonitis due to solids and liquids	22	9.8
Pneumonia	20	8.9
Cerebral palsy	16	7.1
Epilepsy	13	5.8
Inhalation and ingestion of food causing obstruction of respiratory tract	9	4.0
Ischaemic heart diseases	9	4.0
Down syndrome	8	3.6
Other heart diseases	6	2.7
Malignant neoplasm of trachea, bronchus and lung	5	2.2
Cerebrovascular diseases	5	2.2
Total top 10 underlying causes in disability services	113	50.3

Table 10: Top 10 underlying causes of death of people in disability services, 2004-2013

Underlying cause of death	N	%	Crude mortality rate per 1,000	95% Confidence Interval
Pneumonitis due to solids and liquids	62	7.12	1.09	0.84 - 1.40
Cerebral palsy	59	6.77	1.04	0.79 - 1.34
Epilepsy	58	6.66	1.02	0.78 - 1.32
Pneumonia	45	5.17	0.79	0.58 - 1.06
Ischaemic heart diseases	42	4.82	0.74	0.53 - 1.00
Down syndrome	40	4.59	0.71	0.50 - 0.96
Other heart diseases	28	3.21	0.49	0.33 - 0.71
Cerebrovascular diseases	25	2.87	0.44	0.29 - 0.65
Inhalation and ingestion of food causing obstruction of respiratory tract	25	2.87	0.44	0.29 - 0.65
Chronic lower respiratory diseases	23	2.64	0.41	0.26 - 0.61
Total top 10 underlying causes in disability services	407	46.72		

Leading causes of death of people in assisted boarding houses

Circulatory system diseases comprised the greatest proportion (42.9%) of the deaths of people in assisted boarding houses in 2012 and 2013. Heart diseases – mainly ischaemic heart disease – have consistently been the primary cause of death of assisted boarding house residents.

Figure 5: Leading underlying causes of death of people in assisted boarding houses in 2012-2013, by ICD chapter

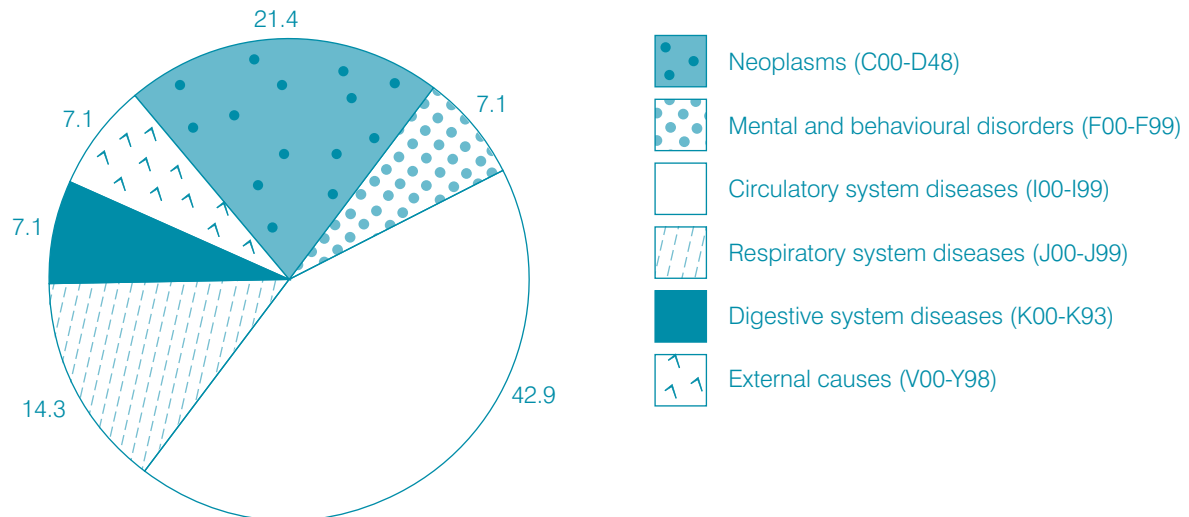


Table 11 below shows the top 4 leading underlying causes of death of people in assisted boarding houses in 2012 and 2013. These causes accounted for half of all deaths. In comparison with the 10-year trend over 2004-2013 (as shown in table 12):

- a higher proportion of people died in 2012 and 2013 from other heart diseases, and
- a lower proportion died in 2012 and 2013 from ischaemic heart diseases and chronic lower respiratory diseases.

Table 11: Top 4 leading causes of death of people in assisted boarding houses, 2012-2013

Underlying cause of death	N	%
Other heart diseases	3	21.4
Ischaemic heart diseases	2	14.3
Chronic lower respiratory diseases	1	7.1
Pneumonia	1	7.1
Total	7	50

Table 12: Top 10 underlying causes of death of people in assisted boarding houses, 2004-2013

	N	%	Crude mortality rate per 1,000	95% Confidence Interval
Ischaemic heart diseases	35	25.00	4.11	2.87 - 5.72
Chronic lower respiratory diseases	12	8.57	1.41	0.73 - 2.46
Other heart diseases	12	8.57	1.41	0.73 - 2.46
Malignant neoplasm of trachea, bronchus and lung	8	5.71	0.94	0.41 - 1.85
Pneumonia	6	4.29	0.71	0.26 - 1.54
Intentional self-harm	5	3.57	0.59	0.19 - 1.37
Inhalation and ingestion of food causing obstruction of respiratory tract	4	2.86	0.47	0.13 - 1.20
Other ill-defined and unspecified cause mortality	4	2.86	0.47	0.13 - 1.20
Malignant neoplasm breast part unspecified	3	2.14	0.35	0.07 - 1.03
Malignant neoplasm without site specification	3	2.14	0.35	0.07 - 1.03
Total top 10 underlying causes in assisted boarding houses	92	65.71		

3.3. Age and cause of death

People in disability services

Up to the age of 45 years, nervous system diseases were the leading cause of death of people in disability services in 2012 and 2013. Between 45 and 74 years, respiratory diseases were the leading cause of death. Circulatory diseases were the leading underlying cause of death for people over 75 years of age in disability services – similar to the general population.

People in assisted boarding houses

All of the assisted boarding house residents who died in 2012 and 2013 were aged 46 years and older. For residents below 65 years, the leading causes of death were neoplasms and respiratory diseases. For people over 65 years of age, the leading cause of death was circulatory diseases.

3.4. Multiple causes of death

In addition to underlying causes of death, information about contributing and direct causes of death are important for a more complete understanding of what led to a death, and the co-contribution of diseases to mortality.

The following tables show the number and crude mortality rates for the underlying causes at the ICD-10 chapter level, for associated causes, and for other contributory causes of death ('multiple causes of death') for the deaths in 2012 and 2013 of people in disability services and assisted boarding houses.

Multiple causes of death of people in disability services in 2012 and 2013

Table 13: Number and rates of deaths of people in disability services by underlying, associated and multiple causes of death; and rate ratios for multiple to underlying causes of death by ICD chapter, 2012-2013

ICD chapter	Underlying cause		Associated cause		Multiple cause		UCOD (%)	Rate ratio
	No. of deaths	Deaths per 1,000	No. of deaths	Deaths per 1,000	No. of deaths	Deaths per 1,000		
Infectious and parasitic diseases	3	0.47	12	1.88	15	2.35	20.00	5.00
Neoplasms	36	5.65	2	0.31	38	5.96	94.74	1.06
Diseases of the blood, blood-forming organs, immune system	0	0.00	0	0.00	0	0.00	-	-
Endocrine, nutritional and metabolic	3	0.47	17	2.67	20	3.14	15.00	6.67
Mental and behavioural disorders	0	0.00	54	8.47	54	8.47	0.00	-
Diseases of the nervous system	38	5.96	38	5.96	76	11.92	50.00	2.00
Diseases of the circulatory system	25	3.92	25	3.92	50	7.84	50.00	2.00
Diseases of the respiratory system	54	8.47	58	9.10	112	17.56	48.21	2.07
Diseases of the digestive system	8	1.25	8	1.25	16	2.51	50.00	2.00
Skin and subcutaneous tissue	0	0.00	1	0.16	1	0.16	0.00	-
Musculoskeletal and connective tissue	1	0.16	1	0.16	2	0.31	50.00	2.00
Genitourinary system	6	0.94	11	1.73	17	2.67	35.29	2.83
Certain conditions originating in the perinatal period	0	0.00	3	0.47	3	0.47	0.00	-
Congenital and chromosomal	25	3.92	26	4.08	51	8.00	49.02	2.04
Symptoms and signs NEC	10	1.57	32	5.02	42	6.59	23.81	4.20
Injuries	0	0.00	24	3.76	24	3.76	0.00	-
External causes	16	2.51	7	1.10	23	3.61	69.57	1.44
Total	225							

As indicated in table 13, and consistent with previous years, respiratory diseases were the largest contributory cause of death for people in disability services. Respiratory diseases contributed to half of all deaths in disability services in 2012 and 2013 (112 people), either as an underlying or associated cause of death. Respiratory diseases commonly feature as the direct cause of death of people whose underlying cause of death is neoplasms (such as lung cancer), nervous system diseases (such as cerebral palsy), or congenital and chromosomal conditions (such as Down syndrome).

Nervous system diseases were the second leading contributory cause of death of people in disability services, contributing to over one-third of deaths (76 people). Mental and behavioural disorders (including dementia; mental illnesses such as schizophrenia; and intellectual disability) contributed to one-quarter of the deaths of people in disability services (54 people) as an associated cause.

Multiple causes of death of people in assisted boarding houses in 2012 and 2013

Table 14: Number and rates of deaths of people in assisted boarding houses by underlying, associated and multiple causes of death; and rate ratios for multiple to underlying causes of death, by ICD chapter, 2012-2013

ICD chapter	Underlying cause		Associated cause		Multiple cause		UCOD (%)	Rate ratio
	No. of deaths	Deaths per 1,000	No. of deaths	Deaths per 1,000	No. of deaths	Deaths per 1,000		
Infectious and parasitic diseases	0	0.00	0	0.00	0	0.00	-	-
Neoplasms	3	4.42	1	1.47	4	5.89	75.00	1.33
Blood, blood-forming organs, immune system	0	0.00	0	0.00	0	0.00	-	-
Endocrine, nutritional and metabolic	0	0.00	1	1.47	1	1.47	0.00	-
Mental and behavioural disorders	1	1.47	2	2.95	3	4.42	33.33	3.00
Diseases of the nervous system	0	0.00	0	0.00	0	0.00	-	-
Diseases of the circulatory system	6	8.84	1	1.47	7	10.31	85.71	1.17
Diseases of the respiratory system	2	2.95	0	0.00	2	2.95	100.00	1.00
Diseases of the digestive system	1	1.47	0	0.00	1	1.47	100.00	1.00
Skin and subcutaneous tissue	0	0.00	0	0.00	0	0.00	-	-
Musculoskeletal and connective tissue	0	0.00	0	0.00	0	0.00	-	-
Genitourinary system	0	0.00	0	0.00	0	0.00	-	-
Perinatal	0	0.00	0	0.00	0	0.00	-	-
Congenital and chromosomal	0	0.00	0	0.00	0	0.00	-	-
Symptoms and signs NEC	0	0.00	0	0.00	0	0.00	-	-
Injuries	0	0.00	1	1.47	1	1.47	-	-
External causes	1	1.47	0	0.00	1	1.47	100.00	1.00
Total	14							

Consistent with previous years, and as illustrated in table 14, circulatory diseases were the largest contributory cause of death for people in assisted boarding houses. Circulatory diseases contributed to half of all deaths in assisted boarding houses in 2012 and 2013 (7 people), primarily as an underlying cause of death.

The other main contributory causes of death for people in assisted boarding houses were neoplasms (4 people), mental and behavioural disorders (3), and respiratory diseases (2).

Chapter 4. Issues arising from reviews of deaths in 2012 and 2013

In this chapter, we report our observations from our reviews of the deaths of the 239 people with disability who died in 2012 and 2013.

4.1. Recognising and responding to critical situations

Identifying illness and taking action

Our reviews of deaths in 2012 and 2013 have pointed to the vital need for all disability support staff to be alert to notable changes in the person's health and/or behaviour, and to get urgent help.

There is often a very short period of time for some people with disability in care between symptoms of illness or critical health changes and their death.

To reduce preventable deaths, the message is simple: staff need to call for emergency help as early as possible where in any doubt as to the seriousness of the person's presenting condition.

In some cases, there were obvious, negative changes in the person's health before their death, and staff noted that this was the case. This included where the person had developed a wet cough; was vomiting over an extended period of time; or (as in the case study below) had started vomiting dark brown fluid.

CASE STUDY 1: changes in health require urgent action

A man with a moderate intellectual disability and dementia died from the combined effects of acute bronchopneumonia and small bowel obstruction. He had a chronic bowel condition that involved recurrent bowel obstruction, chronic constipation and multiple bowel surgeries.

Our review found that nursing staff monitored the man's bowel activity on a daily basis and maintained a bowel chart. He was supported to exercise and had regular involvement with a medical officer and a dietician.

The morning before his death, the medical officer examined the man's abdomen and found that it was hard with a possible bowel impaction. The medical officer ordered pathology and urinary analysis tests, recommended treatment that included a laxative and routine observations, and instructed staff to recontact the medical officer if they had any concerns. At 10pm that evening, the man vomited blood and faecal-stained fluid. Records indicate that nursing staff provided information to the Registered Nurse on shift about the man's condition and it was agreed that he would be reviewed by a medical officer in the morning.

In the early hours of the next morning, nursing staff recorded that the man had been awake all night, vomiting small amounts, and that his heart rate was 115 beats per minute. The staff member recorded that the man would need to go to hospital that morning. Just before 7am, the Registered Nurse on duty found the man lying on the floor of his bedroom with faecal matter and fluid on his face and body, and called a Nurse Manager. Despite resuscitation efforts, the man was unable to be revived.

As part of our review, we sought advice from a medical member of our disability deaths expert advisory panel. We were advised that:

- the man should have been taken to hospital immediately after he vomited blood and faecal fluid at 10pm, as vomiting faecal fluid is never normal – it means there is a bowel obstruction

-
- when someone vomits faecal matter, they either need to be seen by a doctor or sent to hospital via ambulance within the hour
 - a heart rate over 100 beats per minute in an adult is considered fast (tachycardia) and can be a sign of dehydration or other conditions such as pain or anxiety, and
 - an untreated bowel condition can lead to dehydration and/or rupture of the bowel.

Critically, the expert advisor told us that bowel obstruction is usually a treatable condition, and noted that the man died nine hours after significant deterioration, without having received any treatment. While the nursing staff supporting the man recorded his high heart rate and noted that he was vomiting all night, they did not take any action in response.

The above matter was one of several deaths of people at the same facility that raised concerns about the adequacy of the actions of staff to identify and effectively respond to the critical health needs of residents. Our reviews found that, while nursing staff made clinical observations indicating illness (including ongoing weight loss, vomiting, decreasing oxygen saturations and severe hypotension), these observations did not prompt them to seek immediate medical attention, as was indicated.

In response to these matters, the service has taken concerted and comprehensive action, including referral of four nursing staff involved in the matter in the above case study to the Health Care Complaints Commission; development and provision of guidance and training for staff on appropriate bowel management; and engagement of an external professional to develop and deliver a training program for staff based on the Clinical Excellence Commission's *Between the Flags* program. The program is aimed at ensuring that clinical staff identify and take appropriate action in response to deterioration in a person's health.

In some cases, staff recognised that the person's behaviour had changed and that something was not right, but were not sure whether it warranted immediate action. This included two people who died less than 24 hours after staff identified changes in their behaviour, including screaming and shaking; and groaning, crying, and hitting their head on the floor. In both cases, staff (including those that knew them well) were concerned about the individuals – to the extent that they stayed with the person during the night; or called to check on the person after finishing their shift. However, staff did not seek medical assistance until the situation was critical; unfortunately, the individuals died shortly afterwards.

At times, staff's hesitation in seeking urgent medical assistance appeared to be affected by the person having recently seen a medical practitioner. While the practitioners indicated that staff should seek medical help if the person's condition did not improve or they became distressed, staff did not readily identify the point at which to take this action.

Our work has shown that staff do not need to make a professional or clinical judgement about a person's health – if they have any concerns or any doubt, they should get urgent medical help.

Critical incident response

Mandatory first aid requirements were introduced in 2009 (disability services) and 2010 (assisted boarding houses) in response to recommendations arising from our reviews of the deaths of people with disability in residential care. All disability accommodation services are required to ensure that at least one staff member on shift has current first aid qualifications.

Our reviews of deaths in 2012 and 2013 have emphasised the importance of staff receiving regular refresher training to support them to take appropriate action at the time of a critical health event.

Even with first aid qualifications, it can be difficult at the time of a crisis to think calmly and to readily recollect information from previous training. We found several instances of staff with current first aid qualifications:

- calling their manager in the first instance rather than emergency services
- not being aware of how to check for signs of life (breathing or pulse), and
- being heavily reliant on the first aid instructions of 000 operators.

The latter point was particularly identified as a problem in a small number of matters where the service did not have a cordless phone (or the phone was not charged), resulting in the staff member alternating between the person and the landline phone in the office.

It is important that accommodation services:

- **ensure that direct care staff (with or without first aid qualifications) receive regular refresher information on responding to critical health incidents, including the need to ring emergency services immediately, and**
- **take steps to identify and address any factors that may impede an effective response (such as a lack of cordless or mobile phones).**

4.2. Effectively managing individual risks

For many years we have stressed the importance of comprehensively identifying health and other risks for individuals with disability in residential care, and working constructively with the person to reduce and effectively manage those risks.

Our reviews in 2012 and 2013 have continued to demonstrate the need for solid risk identification and management by disability and health services, with clear guidance for direct care staff.

We found recurring evidence of the need for comprehensive planning based on expert advice from appropriate allied health and other health practitioners; and for support staff to follow the documented risk management strategies.

In the two-year period, this issue was particularly highlighted in relation to risks associated with choking on food, developing respiratory disease, and sustaining fractures.

Managing choking risks

Choking was a factor in the deaths of 10 people in 2012 and 2013.²⁶

Deaths associated with choking have increased in recent years – of the 25 people whose underlying cause of death was choking in the decade to 2013, almost three-quarters (18) died in the last four years.

Unlike previous years, all of the people who died as a result of choking resided in disability services; most (8) resided in group home accommodation. Most (6) of the 10 people were at home at the time of the incident. Four people choked at other locations, including day programs (2), a car, or their family home.

Three people died during celebratory meals – two people choked on their birthday at their day program, and one person choked during a meal at home to celebrate another resident's birthday.

²⁶ Choking was identified as the underlying cause of the deaths of nine people. For one person, choking was the direct cause of their death, with Cri du Chat syndrome identified as the underlying cause.

The deaths from choking in 2012 and 2013 were associated with a range of foods, including sandwiches (2), crepes, carrot, steak, cheese, and dim sims. Two people choked on vomitus.

Risk factors

Most of the 10 people had known risk factors for choking, including:

- eating problems (6), including eating quickly, overfilling their mouth, and eating without adequately chewing
- behaviour-related issues associated with food (5) – mainly taking food off others, and taking food that had not been prepared for them
- dental problems (6), including some or no teeth
- mental illness (6), mainly bi-polar disorder
- taking psychotropic medication at the time of their death,²⁷ including three people who were taking two or more psychotropic medications, and
- swallowing difficulties (5).

One person did not have prior risk factors for choking. For most of the other nine people, services had identified their choking risks (7) and documented strategies to address them (6). The gaps in the service response to identified choking risks primarily involved staff not following the requirements/ support plans.

The most common factors in the choking deaths in 2012 and 2013 were a combination of eating and/or food-related behaviour problems and inadequate supervision. This included where support plans clearly indicated that staff were to supervise the person at all times around food, and to take specific steps to minimise the chances of the person having unsupervised access to food that was unsafe for them (such as not leaving food unattended).

We found that it only took momentary lapses in supervision – due to staff being involved in other activities or responding to other residents – to result in fatal choking events. The case study below is illustrative of this point.

CASE STUDY 2: The importance of clear guidance and staff vigilance in preventing deaths from choking on food

A man with a moderate intellectual disability, bipolar disorder, obsessive compulsive disorder and autism died after choking on a large piece of carrot. He had been identified as having multiple risk factors for choking, including chronic swallowing difficulties, few teeth, eating quickly and without chewing, overfilling his mouth, and taking food not prepared for him.

On the day the man died, the disability support worker placed lunch for him and another client in the dining room. The staff member then went to the hallway to support another client who was unsettled due to tradespeople working in the house. One tradesperson reported to the staff member that the man was lying on the floor in the dining room. The staff member advised the tradesperson that this was a common behaviour for the man, and continued to redirect the unsettled client. When the staff member returned to the dining room, he found that the man was choking. The man died despite the administration of CPR and the involvement of emergency services.

Our review identified that the available guidance for staff on the man's mealtime requirements was inconsistent, and the most recent support plan did not reflect the recommendations of his speech pathologist and GP on the need for softer cut-up meals and the use of sauces and gravies to soften his food. We found that the inconsistent information may have led to staff inadvertently giving the man food that was unsafe for his swallowing requirements.

27 As noted in our previous reports, there are links between mental illness, the use of psychotropic medication, and choking risks. Side effects of some psychotropic medications, including many antipsychotic medications, include drowsiness. Some can cause adverse reactions relating to swallowing problems and/or dry mouth. Prolonged use of antipsychotic drugs can also cause side effects such as tardive dyskinesia, which can affect eating.

The service conducted a review following the man's death that outlined the main factors they assessed as contributing to the event. However, we found that there were substantial gaps in the information relating to the circumstances of the man's death that were not addressed in the review, including the specific contents of the meal that was provided to him; whether he had obtained the food from his own meal, or had taken it from the other resident (or elsewhere); and whether the meal provided to him, and the food he was consuming at the time of the incident, complied with his mealtime requirements.

We wrote to the service and met with them to discuss the issues and the actions to be taken in response. Following the man's death, the service conducted a review to ensure that all mealtime management plans were consistent with speech pathology advice. They also developed resources to assist with the orientation of new staff members, and looked at additional staff support to ensure there was adequate staffing to meet individual client needs.

Following the choking deaths of a number of people in residential care, FACS has taken substantial action to:

- raise the awareness of managers and frontline staff of choking risks and mitigation strategies, and review dysphagia training, and
- develop an audit tool to review the quality of plans and related support across ADHC accommodation services in relation to identifying and managing choking and other risks to residents.

Our reviews of choking deaths in 2012 and 2013 (and in 2014) have highlighted the importance of:

- **providing active supervision of people with swallowing and/or choking risks around food**
- **ensuring that clear and consistent guidance is provided to staff about the choking risks of the people they support, and what they need to do to minimise the risks, and**
- **direct care staff being alert to the choking risks for individuals and always following support plans and other guidance to manage the risks.**

Managing respiratory risks

Deaths from respiratory diseases – mainly pneumonia and aspiration pneumonia – increased in 2012 and 2013. In most cases, the individuals had multiple, and known, risk factors for aspiration and/or pneumonia (as outlined below), and died despite active treatment. This included people who continued to aspirate despite insertion of a PEG; and people whose health continued to decline despite intensive antibiotic and oxygen therapy at an early point in their illness.

In the main, we identified positive and proactive work on the part of disability and health services to identify and manage respiratory risks, including the active involvement of GPs; speech pathologists and other allied health practitioners; and some specialists, including gastroenterologists in relation to recurrent vomiting, and neurologists in relation to seizure management.

You are at risk of respiratory disease if you:^{28, 29}

- have feeding and swallowing problems (including difficulty sitting upright; rely on others to feed you; or a history of choking)
- have eating problems (such as swallowing large mouthfuls of food, eating too fast and not chewing very much)
- have frequent chest infections
- have difficulty moving around
- have gastrointestinal problems (such as GORD and repeated vomiting)
- are drowsy, or are not alert when eating or drinking
- have dental problems or gum disease
- have conditions such as cerebral palsy, epilepsy or Down syndrome
- take medications such as antipsychotics, anticonvulsants, sedatives or muscle relaxants
- smoke

Many of the deaths of people from respiratory illness in 2012 and 2013 underscored the importance of staff being alert to any health changes and seeking urgent medical assistance. There was often a very short period of time (1-7 days) between the person showing symptoms of illness and their subsequent death.

As noted earlier, many of the individuals died despite active and early treatment, highlighting the difficulty for some people with disability in residential care of overcoming respiratory illness once it develops.³⁰ In this context, it is easy to see the importance of preventative action by disability support and health providers to manage the person's risk factors for developing respiratory illness. This includes preventative work to identify and – as much as possible – manage risks associated with:

- **Swallowing and eating difficulties** – in this regard, and as noted in Chapter 2, only one-third of the people in non-government disability services who died and who had swallowing difficulties had a comprehensive nutrition and swallowing assessment.
- **Falls and fractures** – in 2012 and 2013, some of the people who died from pneumonia or aspiration pneumonia developed the infection following surgery to repair fractures, most of which were associated with falls (discussed further below). Noting the risks of respiratory illness associated with limited mobility, it is important that management of falls risks still enables individuals to maintain mobility as much as (safely) possible.
- **Seizures** – each year, some people with disability in residential care develop aspiration pneumonia as a result of aspirating during a seizure and subsequently die from the infection. It is important that people are provided with the best chance to attain seizure control, through obtaining and implementing the recommendations of a neurologist (including management of any seizure triggers); ensuring consistent administration of prescribed medications; and facilitating regular health reviews.

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

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

30 Health has advised that the current build of its inpatient electronic medical record includes identification and referral of all patients admitted with aspiration pneumonia, noting that aspiration is a major contributor to respiratory infections in people with disability.

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- **Medications** – people receiving medications such as antipsychotics, anticonvulsants, sedatives and muscle relaxants are at risk of aspiration. We have previously reported on the high number of people with disability in residential care whose deaths we have reviewed who were receiving multiple psychotropic and other medications; and the number of people receiving psychotropic medication as a primary behaviour management strategy. There are benefits for people with disability in residential care in obtaining regular medication reviews and (where relevant) behaviour support reviews.

Consistent with previous years, the access of people with recurrent or chronic respiratory illness to respiratory specialists was low. In 2012 and 2013, only 27 of the 103 people (26%) in disability services and none of the boarding house residents with recurrent respiratory illness had seen a respiratory specialist.

The poor access to respiratory specialists for people with disability in residential care was particularly notable in relation to the five people whose deaths in 2012 and 2013 were due to chronic obstructive pulmonary disease (COPD). We found that only one of the five people had a comprehensive health review in the year before they died, despite significant health risks. None of the five people had seen a respiratory specialist.

In 2013, we issued a factsheet on Preventing deaths of people with disabilities in care: Breathing, swallowing and choking risks to raise awareness of the risks that many people with disability face that make them highly susceptible to death from respiratory diseases and from choking on food. **It is important that all direct care staff are familiar with the information in the factsheet, and that the messages are reinforced by service management.**

Managing fracture risks

At least nine people with disability in residential care who died in 2012 and 2013 experienced fractures ahead of their death. In the majority (6) of cases, the fracture(s) were believed to have happened as a result of a fall, mainly (4) unwitnessed falls. For two people, their femur fracture reportedly occurred during manual staff transfer. For one person, the likely cause was not identified.

In all but one case, the fracture was a factor in their death – eight people developed respiratory illness or sepsis following the fracture (or surgery to repair the fracture); and one person developed deep vein thrombosis as a result of an ankle fracture.

In three cases, the fractures were not identified immediately due to the individuals not displaying obvious signs of pain. Research in relation to patients with intellectual disability has identified that fracture detection is often delayed because profound cognitive, skeletal, and expressive disabilities prevent the individual from reporting the fracture event or associated pain. It is estimated that up to 73% of fractures in these patients are unwitnessed.³¹

All but one of the individuals had been identified as being at risk of falls and/or fractures, including three people who had experienced multiple previous fractures.

Of the nine people we identified who had a fracture prior to their death, five had been diagnosed with osteoporosis or osteopaenia. Research indicates that osteoporosis and fractures are more prevalent among people with intellectual disability.³² A medical member of our expert advisory panel has advised that osteoporosis is under-diagnosed in the general community, and is also likely to be under-diagnosed among people with disability, despite the multiple risk factors faced by some in this population.

31 Leslie, W D., Pahlavan, P S., Roe, E B., and Dittberner, K 'Bone Density and fragility fractures in patients with developmental disabilities' in *Osteoporosis Int* (2009) 20:379-383.

32 Ibid.

Risk factors for the development of osteoporosis include:³³

- Low calcium intake
- Low vitamin D levels
- Thyroid conditions
- Low body weight or excessive weight
- Chronic conditions such as rheumatoid arthritis and chronic liver or kidney disease
- Conditions leading to malabsorption, such as coeliac disease and inflammatory bowel disease
- Some medicines for epilepsy, breast cancer, prostate cancer, and some antidepressants
- Low testosterone for men or lowered oestrogen for women
- Low levels of physical activity
- Smoking

Five of the individuals had epilepsy and had been identified as being at risk of falls and injury as a result of seizures; and seven people had been identified as being at risk of vitamin D deficiency.

Management strategies included physiotherapy (5) and/or occupational therapy (5) involvement; administration of vitamin D (7) and/or calcium supplements (5); and support plans for risk management, epilepsy management and manual handling.

In two cases, there appeared to have been opportunities to prevent the fracture from occurring. In one case, the fracture occurred during manual handling, when a hoist was supposed to be used; and in the other case, the person had been previously assessed as requiring new shoes to reduce the falls risk, and this action remained outstanding at the time of the fall that resulted in the fracture.

Our reviews of the deaths of people with disability in 2012 and 2013 that were associated with fractures have emphasised the importance of:

- **support staff and practitioners identifying, and taking appropriate action to minimise, the risks faced by people with disability in residential care associated with osteoporosis, falls, and fractures**
- **support staff and practitioners taking timely action in response to falls to prevent recurrence (through a risk management rather than risk elimination approach), and**
- **support staff being alert to any bruising or injury on a person with disability in residential care, and taking timely action to:**
 - **report the injury**
 - **identify the likely cause, and**
 - **identify and implement strategies to manage the risk to the person (and any other people with disability in the accommodation).**

In relation to the latter point, on 3 December 2014, the *Disability Inclusion Act 2014* came into effect, and amended the *Ombudsman Act 1974* to include Part 3C 'Protection of people with disability'. Part 3C comprises a scheme for the reporting and oversight of the handling of serious incidents involving people with disability in supported group accommodation. All incidents outlined in Part 3C – including unexplained serious injury – are now required to be notified to our office.

³³ Osteoporosis Australia, *Risk factors for osteoporosis*, <http://www.osteoporosis.org.au/>, accessed 19 April 2015

4.3. Internal reviews by services

Our reviews of deaths in 2012 and 2013 have emphasised the need for service providers to conduct an internal review following the death of a person in their care.

Internal reviews provide a valuable opportunity for services to identify at an early point any critical issues they need to address, as well as areas of good practice, and broader opportunities for service improvement. However, we have found that internal reviews are not common practice, and they have tended to consist mainly of a file audit rather than consideration of the key factors in play at the time of the person's death.

CASE STUDY 3: the importance of internal reviews

A woman with a severe intellectual disability, schizoaffective disorder, anxiety and multiple health issues who resided in a group home died as a result of choking on food. She had ongoing challenging behaviours, including behaviours around food that placed her at risk of choking.

Our review found that there were critical aspects of the incident that were not addressed in the incident reports or other service information. It also did not appear that the service conducted an internal review of the circumstances of the woman's death or otherwise sought to clarify key aspects of the event, including what food she had choked on; and how she was able to access the food in the presence of, but without being witnessed by, two staff members.

Service records indicate that staff had identified and documented the risks the woman faced as a result of her behaviour around food, including clear written guidance on the support and supervision required to manage her choking risks. However, against the background of the documented guidance for staff on the woman's choking risks and management strategies; a previous episode of choking she had experienced four months before her death; and concerns expressed by staff about her choking risks in the month before her death, it was not clear to us how the fatal event occurred. We identified that, without a clear understanding of the key factors that led to the woman's death, the service could not be confident that it had adequately addressed the issues to prevent recurrence.

The Coroner held an inquest into the woman's death, and heard that the woman arrived home on the afternoon of her death with a support worker, and was momentarily unsupervised. At that time, unknown to staff, she entered the kitchen and took food that had been left unattended on the bench and in pots and pans. In a very short period of time, the woman placed large amounts of food in her mouth and walked quickly to the bathroom. A staff member saw that the woman had bulging cheeks, and encouraged her to chew and spit out the food. She started choking as she ran to her bedroom while simultaneously trying to regurgitate the food. Staff were unable to remove the food from the woman's airways, and she was not able to be revived despite CPR.

The inquest found that staff did not follow the plans the service had in place to mitigate her risk of choking. Meals were left unattended and accessible at the time that the woman returned from her outing, and she was not prevented from accessing the available food.

Consistent with our review, the inquest identified that *'there was no evidence of any investigation into the circumstances and systems issues apparent from that death'*. We noted the evidence of one of the staff members at the inquest that they were not asked about the incident and were not interviewed by anyone from the service. Importantly, the inquest found that *'there was no parallel investigation of the incident to determine, for example, if there were related systems issues at the home and how these could be addressed.'*

In relation to the preventable death of the man in case study 1, the service's internal review focused on record keeping and clinical protocols. It did not examine the significant issues relating to staff's response to the man's critical health changes that directly contributed to his death.

We note that, while ADHC's current *Client Death* policy indicates that services operated, funded or licensed by ADHC must review the circumstances of the death of a client and implement and monitor appropriate actions arising from the review,³⁴ it also states that this review (for ADHC-operated services) is to be focused on 'compliance with ADHC policies and procedures'.³⁵ Our reviews have shown that there is little merit in reviewing compliance with policies and procedures without the full context of the circumstances of the person's death.

As a result of a number of deaths in 2012 and 2013, we raised with FACS the need for a process for conducting internal reviews following the deaths of people with disability in care. In response to these matters, FACS has undertaken work to develop a Clinical Governance Review process in response to critical incidents in FACS-operated supported accommodation. The process will review the clinical supports in place for a person prior to an unexpected death or serious incident, with a view to making systemic recommendations to enhance the quality of ongoing services. FACS also convenes a Clinical Governance Review Panel, which comprises experts in the disability and medical field to review trends in recent serious incidents, to guide ongoing policy and practice development. The panel process will also make recommendations in relation to the reports provided from the supported accommodation units, in order to improve this process.

Our work has demonstrated the need for action by disability services (and clear guidance for staff) in relation to two key aspects:

1. Incident reporting by direct care staff

It is important that any staff on shift at the time of the person's death (or the critical incident that later resulted in the person's death) complete an incident report that details what occurred – with separate incident reports for each staff member. In many cases, we have found no incident report completed by any of the staff who were supporting the person at the time of the critical event, and no entry in the progress notes to indicate what happened.

While we appreciate that it can be difficult for direct care staff to complete an incident report in the wake of a death, it is vital that there is a clear record of the chain of events and relevant details. For example, in relation to the choking deaths of individuals, there must be a record of what the person was eating at the time that they experienced breathing problems, and how they obtained the food/ other substance.

2. Internal review

The death of any person with disability in the care of a service provider should prompt an internal review by the service, including consideration of:

- the person's death and their broader care and circumstances – including the service's internal information about what occurred; the person's risks and support needs; and the guidance that was available to staff to provide appropriate support
- any deficits (and/or positives) relating to service practice, procedure or internal controls that may be relevant to the person's death, or their broader care and circumstances
- whether the issues in this case have larger implications for the service (and warrant examination more broadly), and
- what action will be taken in response to the identified issues.

34 Department of Family and Community Services: ADHC, 2012, *Client death* policy and procedures, p. 2.

35 Ibid. p. 5.

On a separate but related note, in the context of the new disability reportable incidents function under Part 3C of the Ombudsman Act, we have commenced work on a project to develop clear guidance for disability support workers on the early action they need to take to prevent, identify and respond to situations where there is neglect or abuse. The tools will comprise:

- best practice guidelines for an initial and early response
- a ready-reckoner document for disability support workers to quickly refer to immediately after a serious incident, and
- additional information for inclusion in the 'Handling serious incidents in disability services' training for disability support workers delivered by Ombudsman staff.

The project is being informed by consultation with a range of key stakeholders, including police, disability service providers and support workers, advocates, and practitioners. We anticipate completing this work in the second half of 2015.

4.4. Care coordination between health and disability services

Support to access medical treatment

Consistent with previous years, our reviews of deaths in 2012 and 2013 identified multiple people whose behaviour or decisions adversely affected their health and medical treatment. These people included those who were unable to remain still during scans, refused to see a GP or go to hospital, absconded from hospital, and refused medical investigations. The following three individuals illustrate the issues:

- The recurrence of breast cancer in a woman with schizophrenia reportedly remained undetected for an extended period of time because she refused to let anyone help her with showering. Following her cancer diagnosis, she continued to refuse most interventions and was resistant to examination – in the community and in hospital. This situation remained largely unchanged despite the involvement of her family.
- The diagnosis of cancer in a woman with cognitive impairment and schizophrenia with a long history of resistance to health interventions and in-home supports, was delayed by four months due to her repeated refusal to have a CT scan. She had multiple presentations and admissions to hospital in the two months before her death, and frequently refused hospital food, fluids, medications, medical tests, pathology and x-rays.
- The breast and abdomen ultrasounds for a woman with an intellectual disability and psychosis were 'sub-optimal' or incomplete due to her restlessness. Health records indicated that physical examinations were limited, and a biopsy was considered not possible, due to the woman's lack of cooperation.

The resistance to treatment or investigative procedures often had significant implications for the person. By way of example, we identified seven people who died from cancer (lung, breast, ovarian, pelvic, or colon cancer) in 2012 and 2013 who were resistant to investigations and/or treatment. We found that their resistance or non-compliance delayed the diagnosis, and/or affected decisions about treatment of the condition. This included when:

- the person did not receive chemotherapy due to their distress and inability (or, in some cases, perceived inability) to tolerate the treatment
- the treating specialist recommended a particular treatment based on it being the least invasive option, and
- disability support staff cancelled a follow-up breast examination (following suspicious mammogram results) due to the person's difficult behaviour on the day, and did not reschedule the appointment.

We appreciate the challenges involved in supporting people with disability to access necessary health and medical care when they do not want to participate or cooperate, or are otherwise indicating that they oppose it. However, unless the person has made an informed decision to forego examination and treatment, every effort should be made to make it easier for them to access the necessary health care.

The substantial and adverse impact of the behaviour of some people with disability on their access to appropriate health and medical care emphasises the importance of:

- **person-centred and coordinated support to help to minimise the individual's aversion and resistance to health services and treatment, and**
- **ensuring that individuals have access to appropriate behaviour support in relation to these issues, including comprehensive assessment and involvement of the person with disability, and positive behaviour support strategies that provide clear guidance for supporting staff.**

Reasonable adjustments

Reasonable adjustments are modifications or accommodations that an individual needs, because of their disability, so that they are able to participate or access something equally to someone without the disability.³⁶

In our reviews of deaths of people with disability in 2012 and 2013, we noted some examples of health practitioners making reasonable adjustments to make it easier for individuals to access necessary health care services. For example, one GP worked with a practice nurse to manage the anxiety of a new patient with intellectual disability in relation to injections. She recognised that establishing rapport with the man would be gradual, and took the time to establish a therapeutic relationship with him and to discover his interest in music. She would then discuss music with the man while the practice nurse administered the necessary injections.

Our reviews have highlighted the tangible benefit of reasonable adjustments in health services for people with disability – particularly in helping to reduce resistance to medical intervention. The following case study provides an example of collaborative work between medical specialists, disability support staff and family members to support a woman with a suspected critical illness to access the examinations and treatment she required.

CASE STUDY 4: resistance to medical treatment

A woman with schizophrenia who provided her own consent had a history of resisting attendance at medical appointments. A chest x-ray revealed a suspicious lump in her lung that was suspected to be cancer. Medical practitioners recommended a PET scan to confirm the cancer, but the woman was distressed and declined this recommendation, despite the encouragement of her family, support staff and medical support team.

A compromise was reached whereby the woman would see a respiratory specialist on a monthly basis to have the lump monitored through chest x-rays. She did this, and three months later agreed to have the recommended PET scan, which confirmed lung cancer. Unfortunately, the position of the cancer meant that the woman was not a suitable candidate for surgery and she made an informed decision not to have radiotherapy. In consultation with her family, she agreed to receive palliative care support in the weeks before her death.

36 Australian Centre for Disability Law, 2011, *Using Disability Discrimination Law in New South Wales*, p. 1-13.

Support in hospital

Our reviews of deaths in 2012 and 2013 continued to identify people with disability whose behaviour and non-compliance affected their medical treatment and health in hospital. This included the following examples:

- A woman with intellectual disability who was admitted to hospital in relation to breast cancer refused oral medications and examinations by medical staff. Hospital staff sought consent to sedate the woman to provide treatment, but also noted that she was settled and cooperative when her family and carers were around.
- A woman with intellectual disability who was admitted to hospital with pneumonia, was distressed and repeatedly pulled off her oxygen mask. The woman's distress in hospital informed her family's decisions to limit the investigations that were undertaken, and to opt out of invasive treatment measures.
- A man with intellectual disability, bipolar disorder and dementia who was distressed by being in hospital, was physically violent towards nursing and medical staff. Soft restraints were used to reduce the man's falls risks and minimise his violent behaviour.

The use of restraints to manage behaviour was also identified in relation to the man in the following case study.

CASE STUDY 5: Behaviour support in hospital

A man who resided in a group home had six admissions to four separate hospitals during the last year of his life, to treat delirium, a queried urinary tract infection, pneumonia, injuries related to falls, and wounds as a result of self-injurious behaviour.

He was highly agitated and exhibited substantial challenging behaviours during his hospital admissions, including physical and verbal aggression and abuse; absconding; recurrent non-compliance with medical assessments, medications, food, and treatment; and recurrent removal of his feeding tubes, intravenous lines, and indwelling catheters.

During the man's admission to a mental health unit, staff appeared to employ strategies such as redirection, a structured environment, and positive behaviour support to manage his presenting behaviours. During admissions at a different hospital, strategies to manage his behaviour included physical restraint of his hands and sometimes feet; use of additional supervision or a 'special'; psychotropic medication; and regular psychiatric reviews.

It was not clear to us what guidance informed staff practice in relation to the use of restraints, including any requirements relating to time limits, consent, recording and monitoring use, and trialling alternative methods of managing challenging behaviour.

In relation to the man's admission to a third hospital, the Local Health District conducted an internal review regarding the management of his agitation during this admission. Among other things, the review identified that:

- a lack of staff knowledge on the correct implementation of patient restraint measures in both nursing and medical teams led to non-compliance with the 'local restraint policy'
- the administration of sedative medication to treat the man's agitation hastened his death, and alternatives to CNS-acting drugs were not considered, and
- nursing staff inappropriately relied on disability service staff to manage the man's agitation, and made no attempt to get to know him as a person to treat his delirium and distress.

We wrote to two Local Health Districts and the Ministry of Health to obtain further information in relation the support provided to the man in hospital, and the guidance available to health services in relation to the use of restraint. Action taken since the man's death has included changes to care plans to better identify patients with complexity or developmental disability on admission; development of a new policy and patient safety restraint observation chart; and recommendations to promote the use of the TOP5 tool (which records carer advice/strategies about how to care for the patient so that care, safety and comfort can be improved).

In January 2015, Health issued a policy directive on *Principles for Safe Management of Disturbed and/or Aggressive Behaviour and the Use of Restraint*. The policy provides guidance to minimise the use of manual/mechanical restraint in public health facilities, including the use of strategies to prevent escalation of disturbed or aggressive behaviour. It emphasises the need for health staff to engage with the patient and their family/carers to identify risks or triggers for behaviour, and the development of a management plan.

As illustrated in the above case, the impact of non-compliance and other challenging behaviour in hospital tended to be significant for the involved people with disability. It directly and adversely affected the health outcomes of some individuals, with compromised examinations; delays in conditions being able to be diagnosed and effectively treated; and increased anxiety and distress.

Our reviews of these matters underscore the importance of the NSW Health and ADHC Joint Guideline: *Supporting residents of ADHC operated and funded accommodation support services who present to a NSW Public Hospital* which was issued in April 2013. The Joint Guideline was developed in response to concerns raised by our office and disability services about support of people with disability in hospital, and is intended to provide a framework for best practice for health and disability staff so they can:

- identify areas of risk that could compromise a person with disability's capacity to achieve the best health outcomes and their safety and/or dignity during a hospital stay
- agree on what additional supports are required to reduce identified risks, and
- negotiate responsibility and resources for the provision of agreed additional support.³⁷

The Joint Guideline includes a Hospital Support Plan, which details the person's support needs and risks (Part 1 – completed by the disability service) and the agreed support that is required and from whom (Part 2 – completed by both disability and health staff). While we noted use of Hospital Support Plans from the latter part of 2013, this was limited to Part 1 of the plan, authored by disability services. We have not identified examples of the full use of the plan, involving clear agreement between health and disability services about the support to be provided. Our reviews of deaths in 2012 and 2013 identified that individuals tended to come to hospital with some supporting documentation from the disability service, such as a mealtime management plan or client profile. However, it was not always evident whether, and to what extent, hospital staff considered this information.

We note that some of the people with disability who were resistant to examinations and treatment continued to be resistant even with the involvement of family or disability support staff. However, in the main, we found improved management and circumstances of individuals in hospital where they had the involvement of people familiar to them, and person-centred support.

In addition to support for people with challenging behaviours, our reviews of deaths in 2012 and 2013 also highlighted the need to implement the Joint Guideline to ensure that support is coordinated, and health and disability services staff are clear about their respective responsibilities. While Health policies make it clear that responsibility for provision of health-related tasks rests with hospital staff, not disability support workers, this was not consistently reflected in practice. Our reviews identified instances where both disability support workers and hospital staff were unclear about their respective roles and responsibilities, including when a young man with intellectual disability and cerebral palsy presented to his local hospital emergency department. He was fed via a PEG, and experienced recurrent respiratory infections and seizures. Disability service records indicate that, while in emergency, a hospital nurse asked a disability support worker to perform deep suctioning several times. When a nurse from the disability service became aware of this, they immediately told the disability support worker to stop suctioning as they were not qualified and could cause serious damage to the man's throat. Disability service records indicate that the service's nurse raised concerns with hospital staff, who apologised and indicated that they assumed that the disability support worker was a nurse.

37 NSW Health, April 2013, *NSW Health and ADHC Joint Guideline: Supporting residents of ADHC operated and funded accommodation support services who present to a NSW Public Hospital*, p. 1.

It is important that health and disability support staff make every effort to work together and with the person with disability (and their supporters, where appropriate) to facilitate appropriate and person-centred support in hospital. This includes implementing the Joint Guideline (or equivalent local arrangements).

Transfer of care from hospital to home

Referral to out of hospital programs

In previous reports, we have raised concerns about the poor access of people with disability in care to chronic disease management or other out-of-hospital programs. These programs are designed to provide health support to people at home to reduce hospital admissions and facilitate their access to appropriate community-based care.

Our reviews in 2012 and 2013 identified three individuals who had been referred to NSW Health's Acute Post Acute Care (APAC) service on their discharge from hospital. The APAC service is a 'Hospital in the Home' service that provides 'intense, short-term, interdisciplinary acute health care and management to patients as a direct substitution for in-patient hospital care'.³⁸ The APAC services included administration of intravenous antibiotics to treat chronic respiratory illness; provision of physiotherapy; and subcutaneous needle insertion and management for delivery of pain relief.

We noted that the three individuals were supported by disability services that had on-staff registered nurses, and had active involvement with their family and GP. In two cases, the referral to APAC services was prompted by the person's family or disability service flagging the preference for support at home rather than in hospital.

4.5. Access to preventative health support

Our reviews have consistently identified the substantial health risks faced by people with disability in residential care associated with smoking, obesity, and other lifestyle factors such as poor diet and lack of physical activity.

These risk factors featured highly among the people with disability in residential care who died in 2012 and 2013. While our reviews have noted a slight improvement in the number of people with whom there had been discussion about the risks associated with their lifestyle choices and advice about the support that could be provided, we also found that there is substantial room for improvement.

In particular, our work highlights the need for:

- **people with disability to be identified as a priority group in population health strategies aimed at helping people to make healthy choices, including reducing smoking rates and addressing obesity, and**
- **disability support staff and health practitioners to work together, and with the person with disability, to make it easier for them to improve their health prospects.**

In 2013, we issued a factsheet on Preventing deaths of people with disabilities in care: Smoking, obesity and other lifestyle risks to raise awareness of the extent of the problem and the need for concerted and collaborative action.³⁹

38 Northern Sydney Local Health District Acute Post Acute Care Service (APAC), <http://www.nslhd.health.nsw.gov.au/Services/Directory/Pages/APAC.aspx>.

39 The factsheet is available on our website: <http://www.ombo.nsw.gov.au/news-and-publications/publications/factsheets/community-and-disability-services/preventing-deaths-of-people-with-disabilities-in-care-smoking,-obesity-and-other-lifestyle-risks>.

Support to quit smoking

As noted in Chapter 2, and consistent with previous years, the smoking rates of the people in assisted boarding houses who died in 2012 and 2013 were very high – the vast majority (86%) had smoked.

Unlike the general population, in which the rates of daily smoking have dropped over time to around 16%,⁴⁰ the smoking rates of the people in assisted boarding houses who have died have remained consistently high, with a 10-year average of 83%.

While the smoking rates of people in disability services are much lower, with a 10-year average of 17%, this percentage may increase in the wake of the closure of a number of assisted boarding houses, and transition of these residents to disability services.

The serious health risks associated with tobacco smoking are well known,⁴¹ and despite declining rates in Australia, smoking remains a significant factor in preventable deaths.⁴² Among the people with disability in residential care who died in 2012 and 2013, smoking was a prevalent factor in deaths from lung cancer (80% had smoked), COPD (80%), ischaemic heart disease (57%), and heart attack (50%).

People with mental illness in Australia have higher smoking rates than the general population, and are more likely to smoke heavily.⁴³ Of the 19 people with disability in residential care who died in 2012 and 2013 who smoked over 20 cigarettes per day, all but one person had a mental illness.

There is evidence that smoking cessation does not exacerbate depression or anxiety, or make mental health functioning worse.⁴⁴ Research has identified that GPs can play a crucial role in assisting this population with smoking cessation through providing education and positive support;^{45 46} and that useful strategies include co-management of cessation by a GP and Quitline,⁴⁷ and the combined use of nicotine replacement therapies such as lozenges and patches. There are also smoking cessation resources that are targeted at staff who support people with mental illness, such as the SANE Smokefree Kit;⁴⁸ and the Cancer Council NSW's *Tackling Tobacco* program.⁴⁹ Similarly, the Centre for Developmental Disability Health in Victoria has a resource package for assisting people with intellectual disability to stop smoking.⁵⁰

40 ABS, 2013, 4364.0.55.003 – *Australian Health Survey: Updated Results, 2011-2012*. 'Rates of daily smoking have continued to drop to 16.1% of people aged 18 years and over (2.8 million people) in 2011-12, from 18.9% in 2007-08 and 22.4% in 2001.' <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4364.0.55.003main+features12011-2012>.

41 Smoking can increase the risks of developing respiratory diseases such as COPD; ischaemic heart and vascular diseases; and cancers. It can also affect oral and eye health, bone density, and increase complications after surgery. Sources: Quit Victoria *Smoking rates, diseases, secondhand smoke and costs*, <http://www.quit.org.au/downloads/Background%20Briefs/01Rates.pdf>; and Hawn, Mary T., et al. 'The attributable risk of smoking on surgical complications' in *Annals of surgery* 254.6 (2011): 914-920.

42 ABS, 2013, 4364.0.55.003 – *Australian Health Survey: Updated Results, 2011-2012*. <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4364.0.55.003main+features12011-2012>.

43 Ellerman A, Ford. C, Stillman S., *Smoking Cessation*, updated (2011) Scollo, MM, Winstanley, MH [editors]. *Tobacco in Australia: Facts and Issues*. Fourth Edition. Melbourne: Cancer Council Victoria; 2012. Available from: www.TobaccoInAustralia.org.au.

44 Cole M, Trigoboff E, Demler T and Opler L. 'Impact of smoking cessation on psychiatric inpatients treated with clozapine or olanzapine' in *Journal of Psychiatric Practice* 2010;16(2):75–81.

45 Segan C, Borland R, Wilhelm K, Bhar S, Hannan A, Dunt D, et al. 'Helping smokers with depression to quit smoking: collaborative care with Quitline' in *Medical Journal of Australia* 2011;195(3):S7–11.

46 Prochaska J. 'Smoking and mental illness--breaking the link' in *The New England Journal of Medicine* 2011;365(3):196–8.

47 Morris C, Waxmonsky J, May M, Tinkelman D, Dickinson M and Giese A. 'Smoking reduction for persons with mental illnesses: 6-month results from community-based interventions' in *Community Mental Health Journal* 2011. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21556784>.

48 SANE has developed a guide to running a quit smoking program for people with a mental illness, which includes a range of simple and interactive activities. See <http://www.sane.org/bookshop/smokefree/product/18-sane-smokefree-kit>.

49 The Tackling Tobacco program encourages social and community service workers to ask clients if they are interested in stopping smoking, and helps organisations to provide the environments and support that will help people to quit. See <http://askthequestion.com.au/>

50 Centre for Developmental Disability Health Victoria, 2007, *I Can Quit! A smoking cessation program for people with an intellectual disability*. <http://www.cddh.monash.org/quit-manual.pdf> accessed 19 April 2015.

Our reviews identified an increased proportion of smokers with disability who had been counselled by their GP and/or disability support staff in relation to smoking cessation options, including offers of nicotine replacement therapy. While it was not always evident what action, if any, had been taken after this discussion, in some cases we noted coordination between the GP and disability service to initiate and support smoking cessation for the individuals.

Support to address obesity and improve nutrition and physical activity

Obesity featured highly among the people with disability in residential care who died in 2012 and 2013. Over one-third (83) of the people in disability services who died, and over half (8) of the people in assisted boarding houses who died, were overweight, obese or severely obese. Of these 91 people, 48 were obese or severely obese.

Excess weight, especially obesity, is a significant risk factor for cardiovascular disease, diabetes, and some cancers. The risk of developing these conditions increases the more overweight a person is, and being overweight can also adversely affect the management of chronic health conditions.⁵¹ The leading causes of death of the 48 people in residential care who were obese or severely obese included heart attack, heart disease, pneumonia, COPD and cancers. For eight people, obesity was specifically identified by the Coroner as a significant condition or contributory factor in their death.

The main keys to long-term weight loss and reducing waist measurements are healthy eating and regular physical activity.⁵² As noted in Chapter 2, the number of people with disability in residential care who were outside of the healthy weight range and had seen a dietician was low. This included just over half of the people in disability services who were overweight/obese or underweight, and only one assisted boarding house resident.

The physical activity of people with disability in residential care also tends to be low. For some people, this can be complicated by mobility difficulties; drowsiness as a side-effect of certain medications; and the limitations of their physical environment.

However, there is a need to ensure that people with disability in residential care are provided with every opportunity to increase their physical activity, such as through:

- **the implementation by disability services of ‘active support’, both within and outside of residential care settings⁵³**
- **Active Linking Initiative (ALI) options for assisted boarding house residents that include physical activity, and**
- **involvement in mainstream supports for lifestyle changes, such as the *Get Healthy Information and Coaching Service*.⁵⁴**

We note that guidance is available for staff in disability services on overweight and obesity, including the need to refer clients who are overweight to their GP or dietician to obtain an individual eating plan and individualised dietary advice for their weight loss. There is also a physical activity checklist and plan that provides guidance on how to promote physical activity in people with intellectual disability.⁵⁵ However, our work raises questions about staff awareness and application of the guidance on obesity and physical activity.

We recognise that overweight and obesity is a broader community health issue, with obesity rates at

51 Australian Institute of Health and Welfare 2015 *Overweight and Obesity* <http://www.aihw.gov.au/overweight-and-obesity/>

52 Diabetes Australia 2012 *Understanding Diabetes: Are You at Risk?* <http://www.diabetesaustralia.com.au/Understanding-Diabetes/Are-You-at-Risk/>

53 Active support is designed to promote the engagement of people with disability, especially those with extensive to pervasive support needs, in meaningful everyday activities that enhance their health, wellbeing and quality of life. McVilly, K., Gelman, S., Leighton, D., O’Neill, S, 2011, *Active Support: Organisational Preparation and Implementation*. Melbourne, Australia: Jewish Care (Victoria).

54 The Get Healthy Service includes a free six-month telephone-based coaching program to provide assist individuals with support, motivation and information to reach their goals relating to lifestyle changes. <http://www.gethealthynsw.com.au>.

55 ADHC (2007, amended 2010 and 2012) *Health care policy and procedures*.

unprecedented levels in Australia. In 2011, 52.6% of NSW adults were identified as overweight or obese.⁵⁶ In 2013, the Ministry of Health issued the *NSW Healthy Eating and Active Living Strategy: Preventing overweight and obesity in New South Wales 2013-2018*. The strategy aims to 'encourage and support the community to make healthy lifestyle changes at a personal level, and create an environment that supports healthier living'.⁵⁷

The strategy identifies priority populations that warrant particular attention in light of their high prevalence of insufficient physical activity and unhealthy eating, and higher than average rates of overweight and obesity, including socioeconomically disadvantaged communities. While most people with disability in residential care would fit the criteria for inclusion in this priority population, our work highlights the need for consideration of specific strategies for people with disability – particularly those with intellectual disability.

As part of our previous recommendations, we sought advice from NSW Health on its progress in implementing actions under the NSW Implementation Plan for the National Disability Strategy to improve access to information and support to help people with disability to make lifestyle changes through the Get Healthy Information and Coaching Service. NSW Health advised that the service can assist callers with sight, speech and/or hearing difficulty; and noted that some of the actions in the NSW Healthy Eating and Active Living (HEAL) Strategy have the capacity to assist people with disability.

Since then, NSW Health (through the Centre for Population Health) has met with our office in relation to the HEAL Strategy, to discuss options for ensuring that the strategy is inclusive of people with disability. The Ministry of Health has indicated that it will progress opportunities to target the Get Healthy at Work program to non-government disability accommodation services; will trial a buddy system for residents and carers as part of the Get Healthy Information and Coaching Service; and ensure social marketing resources and assets are inclusive of people with disability.

Duty of care versus dignity of risk

Our reviews of deaths in 2012 and 2013 identified a range of people with substantial health risks who resisted efforts to make lifestyle changes to reduce these risks, or actively made choices that placed them at continued or greater risk of premature death. This included people who:

- refused to engage with smoking cessation or weight reduction programs
- continued to smoke despite chronic lung disease or other breathing problems (including in hospital)
- chose unhealthy food options despite morbid obesity and associated health problems, such as diabetes
- drank alcohol at levels that presented substantial risks, including passing out in the street, and
- refused to attend appointments with health practitioners, including dietitians.

Overall, our reviews identified an increased awareness on the part of disability support staff of the serious health risks, and attempts by support staff and health practitioners (including GPs and psychiatrists) to help the individuals to make healthier choices and link them to appropriate support. In this regard, we noted repeated discussions about quitting smoking and making healthier food choices; trials with nicotine replacement therapy; and referrals to dietitians and exercise physiologists. The case study below is illustrative of these issues.

CASE STUDY 6 – the challenge of making lifestyle changes to improve health outcomes

A man with schizophrenia and a mild intellectual disability died from ischaemic heart disease. He had chronic obstructive lung disease, and multiple risk factors for heart disease, including hypercholesterolaemia, morbid obesity, hypertension, and heavy smoking (80 cigarettes per day).

⁵⁶ NSW Ministry of Health 2013, *NSW Healthy Eating and Active Living Strategy 2013-2018*, p. 7.

⁵⁷ *Ibid*, p. 7.

The man was highly independent and made his own decisions. Disability support staff and the man's GP consistently encouraged him to make changes to his lifestyle, including healthier food choices and exercise; however, he resisted these changes. Two years before the man's death, he had seen a dietician with the aim of reducing weight, but he continued to make poor food choices.

Disability support staff contracted an exercise physiologist and encouraged the man to stop smoking. He trialled nicotine replacement therapy and Champix,⁵⁸ without success. Support staff worked with the man to undertake the exercises that had been recommended for him, and continued to prompt him daily despite his frequent refusal. Staff also looked for opportunities for the man to get incidental exercise.

Making major lifestyle changes to improve health outcomes – and seeking to change longstanding behaviour – is challenging for anyone. Taking into account relevant factors for people with disability in residential care, such as boredom; use of psychotropic drugs that have side-effects of drowsiness and weight gain; chronic health concerns that involve pain, discomfort or anxiety; and the pleasure that individuals derive from the behaviour, it is not surprising that it can be particularly challenging for this population to make, and sustain, such changes.

However, even when the person refuses to see a dietician or engage in QUIT programs, there would still be substantial benefit in support staff engaging with these services to obtain advice about supporting the person to make the necessary changes, and how to maximise the chances of success. It is also important that support staff and practitioners take advantage of the services and individuals that are in contact with the person to adopt a multifaceted and coordinated approach to helping the person to make healthy choices.⁵⁹

The advantage of the current residential care support arrangements for people with disability is that the population is known, including the health risks faced by individuals. This presents significant opportunities for the development and implementation of targeted strategies that are able to be tracked and evaluated.

Importantly, most of the people discussed in this section had mental illness, typically a mental illness involving psychosis (such as schizophrenia). Consistent with other research, we have found that the people with a mental illness involving psychosis who died tended to have substantial physical health concerns, including the multiple risk factors discussed above – heavy smoking, obesity, poor nutrition and limited physical activity – that placed them at significant risk of premature death.

The need to improve the physical health of people with mental illness has been identified by the NSW Mental Health Commission in *Living Well: A Strategic Plan for Mental Health in NSW 2014-2024*. One of the actions recommended by the Commission is to '[e]nsure that population health activities appropriately target people with a lived experience of mental illness, including interventions to address smoking, physical activity, nutrition and use of alcohol and other drugs.'⁶⁰

4.6. Support for people in assisted boarding houses

The deaths of people with disability in assisted boarding houses in 2012 and 2013 have underscored the importance of the legislative changes that have been introduced to improve the standard of care and safeguards for residents. They have also highlighted the need for continued support for assisted boarding house residents to access appropriate health services.

58 Champix is a medicine to help adults stop smoking, by reducing craving and withdrawal symptoms.

59 In assisted boarding houses, this includes the boarding house manager, the ADHC case worker, the NSW Health case worker, the ALI service, the Primary and Secondary Health Care worker, the GP, the Official Community Visitor and any family or other supporters. In disability services, this includes support staff at the accommodation service and the day program, the GP, any relevant allied health provider, the Official Community Visitor, and any family or other supporters.

60 NSW Mental Health Commission, 2014, *Living Well: A Strategic Plan for Mental Health in NSW 2014-2024*, p. 71.

Among other things, our reviews identified:

- delays in staff identifying the critical health situation of a resident due to being unable to be woken up by the person's roommate
- under one-third of the assisted boarding house residents who died had evidence of a comprehensive health assessment in the year before their death
- less than one-quarter of residents had received the pneumococcal vaccination, despite the vast majority being smokers (one of the groups recommended to receive the vaccination)
- over half of the residents who died were overweight, obese or severely obese; only one person had contact with a dietician, and
- less than half had evidence that they had ever seen a dentist.

For many years, we have drawn attention to the substantial health and other risks faced by assisted boarding house residents, and their poor health outcomes. We consistently emphasised the need for improved standards and requirements for people with disability in these facilities. In late 2012 and mid-2013, the NSW Government introduced the *Boarding Houses Act 2012* and *Boarding Houses Regulation 2013* to address these issues.

In particular, and against the background of the issues we identified in our reviews of deaths in 2012 and 2013, the legislation requires assisted boarding houses to:

- provide staffing levels that are sufficient to cater for the needs of the people with disability in the boarding house, including at least one staff member present on the premises at all times⁶¹
- provide sufficient functioning call bells (or other communication systems) on the premises to allow people with disability to contact staff members in the case of emergency⁶²
- ensure that residents receive appropriate assistance with their health issues, including access to urgent medical and dental treatment,⁶³ and
- ensure that menus are planned with reference to published dietary guidelines or, when necessary, the advice of a qualified dietician or nutritionist.⁶⁴

With the withdrawal of ADHC from the disability landscape from July 2016, it is not currently clear where responsibility for the monitoring, compliance and coordination activities relating to assisted boarding houses (that currently sit with ADHC) will be located. Our work has consistently shown the substantial risks faced by many people with disability in assisted boarding houses, and the importance of maintaining the existing legislative requirements and associated compliance regime.

We are also mindful of the substantial work that ADHC undertakes in response to the intended closure of an assisted boarding house, to coordinate the relocation of residents to appropriate accommodation and support arrangements. **As part of the planning in NSW for transition to the NDIS, it is important that specific consideration is given to the needs of people with disability in assisted boarding houses, and the existing effective safeguarding arrangements.**

In June 2015, DPC advised that the impact of the NDIS on the need for the current legislative safeguards for assisted boarding house residents will be included in the NSW government transition plan, and identification of any changes that are required when the new national system is introduced will be included in the associated workplan for 2016.⁶⁵

61 Boarding Houses Regulation 2013, Schedule 1, Part 1, section 1.

62 Boarding Houses Regulation 2013, Schedule 1, Part 2, Division 3, section 15.

63 Boarding Houses Regulation 2013, Schedule 1, Part 4, Division 2, section 31.

64 Boarding Houses Regulation 2013, Schedule 1, Part 4, Division 3, section 32.

65 DPC also advised that assisted boarding house residents are expected to benefit from the introduction of the NDIS. For example, in 2013/14, 20 out of 22 assisted boarding house residents referred to the NDIS were found eligible. The funded support in the NDIS for these residents ranged from \$9,757 to \$37,552, and eight people had funded supports valued at over \$20,000. As a comparison, they had received \$5,526 in FACS-funded supports prior to transition.

Part Two: The health needs of people with disability and the transition to the NDIS

Chapter 5. Planning for the health needs of people with disability in the transition to the NDIS

The transition to the National Disability Insurance Scheme (NDIS) presents increased opportunity for people with disability to have greater choice and control over their services and supports. It is part of a range of vital initiatives – including the National Disability Strategy and the UN Convention on the Rights of Persons with Disability⁶⁶ – that recognise the right of people with disability to equitable and appropriate access to services, including mainstream services that are available to the broader community, such as health services. The right of access to mainstream services is critical to providing Australians with disability with equality of status and genuine inclusiveness.

Our reviews of the deaths of people with disability in residential care in NSW over the past 12 years have highlighted significant problems in the mainstream health system – and with the interface between disability and health services – that adversely affect the health outcomes of people with disability. For example, there are barriers to access; problems with the amount, quality and coordination of support; and poor communication, both within health services and between these services and people with disability and their carers, that compromise the health care of people with disability.

Against this background, we have serious concerns about the significant and increased risks that will be faced by people with disability in the transition to the NDIS (and the likely impact on their health and welfare) without concerted and early action by State and Commonwealth Governments.

It is crucial that careful planning and capacity building to meet the health needs of people with disability in the transition to the NDIS occurs now as a matter of priority. We note that there is substantial work required, within a very short timeframe.

5.1. People with disability and access to health services – what we have found

Our reviews of deaths over the last 12 years have consistently highlighted the substantial and chronic health challenges faced by many people with disability in residential care. Our work has also shown the additional challenges these individuals experience in their contact with the mainstream health system.

Substantial disability and health-related support needs

In the main, people with disability in residential care are a highly vulnerable population – they are heavily reliant on paid staff to identify and meet their day-to-day needs and to support them to access appropriate mainstream services.

The majority have significant and permanent disability associated with multiple impairments – including combinations of intellectual, cognitive, sensory, physical and neurological impairments and psychiatric conditions. They typically require substantial assistance with activities of daily living, including communication, personal care, meals, and making decisions.

In addition, many people with disability in residential care have chronic health conditions that require ongoing attention and careful management, and that tend to place them at high risk of premature death. Common health concerns include dysphagia, aspiration and recurrent respiratory infections, chronic obstructive pulmonary disease, epilepsy, gastro-oesophageal reflux disease, constipation and bowel obstructions, obesity, hypertension, diabetes, heart problems⁶⁷ and enteral nutrition.

66 Among other things, Article 25 of the UNCRPD requires States Parties to provide people with disability with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including population-based public health programs; provide those health services needed by people with disability specifically because of their disabilities; require health professionals to provide care of the same quality to people with disability as to others, including on the basis of free and informed consent; and prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

67 Including ischaemic heart disease, congestive cardiac failure, congenital heart disease, cardiomyopathy and atrial fibrillation.

Impact of communication difficulties on health outcomes

Our reviews have shown the adverse impact of communication difficulties and the lack of communication supports on the diagnosis and treatment of mental and physical health needs of people with disability, and emphasised the importance of communication and decision-making support.

Most of the people with disability whose deaths we have reviewed required help with communication – to both communicate their views and feelings, and to understand what was happening and the information relayed to them. However, while health records have frequently recorded the difficulties experienced by health staff in communicating with patients with disability, they have rarely identified the communication support the person required or received.

Major gap in life expectancy

We have consistently reported on the poor health outcomes and premature death of people with disability in residential care. Compared with the general population in Australia, people with disability in care die at a much younger age. The gap in life expectancy is substantial; on average over the past 10 years in NSW:

- people in disability services have died at 53 years of age – almost 30 years earlier than the general population,⁶⁸ and
- people in assisted boarding houses have died at 63 years of age – a gap of almost 20 years.

Inadequate support to facilitate access to health services and treatment

For many people with disability, accessing health services for screening, investigation and/or treatment can be a fraught experience, complicated by a range of personal, social and environmental factors. Our reviews consistently identify individuals whose access to necessary health services and treatment was compromised by factors such as their dislike of hospitals; anxiety in unfamiliar situations; not understanding what was happening or why; their mental health; and the length of time involved. We have seen multiple examples of people who needed, but did not receive, support to minimise their opposition to physical examinations, tests or procedures; and to overcome their resistance to attending or staying for medical appointments.

We have emphasised the importance of disability and health services working collaboratively together, and with the person with disability, to make it easier for the person to access health services and treatment (including making reasonable adjustments to meet their needs).

Importantly, we have seen significant adverse outcomes for people with disability where this crucial support and person-centred approach has not been provided – including missing out on critical treatment, and delayed diagnosis of life-threatening conditions. We have also found that sometimes the person's refusal – and their behaviour in response to attempts to examine them or to provide treatment – affected the medical and/or support decisions that were made. This has included appointments not being made to undertake certain health checks or tests – such as dental or eye examinations; and radiology or blood tests – because of a perception that the person wouldn't be able to cope.

Health care planning and coordination

Disability support staff currently play a critical role in assisting people with disability in residential care to have their health needs met. Since at least 2007, disability support staff have been responsible for the coordination of health care planning and the development of a health care plan (using information from the person's health assessments). To maximise health outcomes for people with disability in residential care, there is a weighty responsibility on disability support workers to ensure that:

- the person's health issues and risks are brought to the attention of appropriate health and medical practitioners (including provision of information related to symptoms and the person's medical history)
- clear guidance is provided to the person with disability and support staff about the steps that need to be taken to meet their health needs

68 In 2010-2012, life expectancy at birth in Australia was 82 years for males and females combined – ABS 2014, 3302.0 – *Deaths, Australia, 2013*.

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- referrals and recommendations are implemented (including appointments with specialists and allied health practitioners), and
 - any changes in health, behaviour or cognition are identified, and the person is supported to obtain timely health reviews.

Our reviews of deaths have repeatedly identified many individuals for whom there were substantial gaps in the work undertaken to fulfil these responsibilities. This has included individuals with no health care plan (or similar document) to guide health support; disability support staff not taking adequate (or any) action to implement the recommendations of health professionals; and disability support staff not identifying (or taking action in response to) changes in the person's health.

We have often found that the health care planning and coordination work of disability support staff has been adversely affected by the quality of the information provided by GPs – including insufficient information about the person's health issues and the steps that needed to be taken. In many cases, we have noted that the comprehensive health assessment completed by the person's GP has resulted in cursory information that would not provide adequate guidance for the person or their support staff – despite the individuals having multiple and chronic conditions that required intervention.

We recognise that health care providers may not always know the person's support arrangements at home (including that they are not supported by clinical staff), which may affect the quality of the information provided. It is important that there is sound communication between the person with disability, disability support staff and health providers to ensure that all parties are clear about the health support required and their respective roles and responsibilities.

We have identified improved health care planning and coordination where disability services have:

- ensured that the person is assisted by someone who knows them well
- had the involvement of FACS' clinical nurse specialists
- engaged other individuals to fulfil a disability health liaison role, and
- linked people with disability to specialist disability health clinics.

Similarly, following the introduction of – and critical changes to – Primary and Secondary Health Care Services in assisted boarding houses, we have found substantial improvements in the access of people with disability to health services, and coordination of their health support.

We have seen the benefit to people with disability in their contact with health services (from primary to acute care) where the health-related supports listed above have been involved – including clearer guidance for staff; more timely and coordinated health intervention; and assistance in liaising with health professionals about the necessary actions and any reasonable adjustments that may be required.

Inadequate support in hospital

The adequacy of the support and quality of care provided to people with disability in hospital has been a consistent area of concern identified in our reviews, and has been raised by the disability sector for over a decade. Despite the release of key policy and other guidance aimed at improving the coordination and provision of support to people with disability in hospital,⁶⁹ information from our reviews and consultation with the disability sector indicates ongoing and substantial problems.

Our reviews have repeatedly identified instances in which the health outcomes of people with disability have been adversely affected by hospital staff not adequately understanding the person's support needs; hospital staff not heeding critical information provided by disability staff about the person (such as eating and drinking requirements); and poor communication between hospital and disability services staff. This has included:

⁶⁹ Including release of NSW Health's *People with a Disability: Responding to Needs During Hospitalisation* policy directive in October 2005, and review of the policy directive in 2007; release of the *Service Framework to improve the health care of people with intellectual disability* in July 2012; and release of the *NSW Health & Ageing, Disability and Home Care (ADHC) Joint Guideline* in April 2013.

- people experiencing choking incidents and aspirating after being given, or accessing, food and drink in hospital that did not comply with their mealtime requirements
- individuals pulling out cannulas, and physically resisting examinations and treatment (including oxygen, medications, IV fluids) without familiar people around them
- compromised health assessments in hospital due to nursing and medical staff failing to ascertain the person's communication needs, and
- medical staff not paying adequate attention to the concerns of disability staff about the person's atypical appearance and behaviour, and failing to recognise deterioration in the person's medical condition.

Relevant to these health risks are longstanding issues concerning the use of disability services staff to provide support to the person during their hospitalisation. Disability services have consistently raised concerns about:

1. being asked by health services to provide and pay for staff to support residents during admission, and
2. the high risk faced by the residents if they do not.

Despite release of a joint guideline between Health and FACS on this topic,⁷⁰ our reviews continue to identify problems and a lack of clarity between health and disability services in relation to support in hospital, including disability staff being asked to perform health-related tasks (such as deep suctioning). While the Hospital Support Plan in the guideline is supposed to be completed jointly by hospital staff and disability support staff, our reviews to date have shown use of the plans only by disability staff. We note the views of NDS members that the aims of the guideline are not translating to the reality of hospital experiences.⁷¹

Poor coordination and transfer of care

Given the substantial health and support needs of many people with disability in care, it is important that their discharge from hospital to home is planned and coordinated. However, while Health policy directives⁷² provide guidance on discharge planning (including in relation to people with disability in residential care), we have constantly identified and reported significant problems with practice in this area.

In particular, we have found:

- people with disability being discharged home without guidance for disability staff on the support required, including:
 - the death of a boarding house resident from choking on a sandwich after being discharged from hospital on a 'soft diet', without any guidance for the person or boarding house staff about what that meant
 - no guidance on how to manage asthma and lung disease or prevent exacerbations for a person who presented to hospital with these conditions four times in the six weeks before her death from an acute asthma attack – the person was noted to be 'hysterical' and 'panicked' about her breathing problems, and
 - no guidance on what steps needed to be taken to manage the pressure areas that had developed while a person had been in hospital.
- people whose deaths resulted from misplaced PEG tubes after being discharged from hospital without checks to ensure the tubes had been inserted in the right position
- people with significant aspiration risks for whom hospital staff had noted in health records the need for the individuals to be reviewed by a speech pathologist as outpatients, but who on discharge: had not made a referral, recorded the need for a review on the discharge plan, or otherwise informed the patient or disability service staff, and

70 NSW Health & Ageing, Disability and Home Care (ADHC) *Joint Guideline* (April 2013).

71 National Disability Services (April 2014) *People with disability and hospitalisation: Challenges and opportunities in NSW background paper*.

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

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- people being discharged back home without consideration of whether their health needs could be adequately met with the existing supports, despite presenting and re-presenting to hospital with complex needs, progressive decline in their health, and/or increasing risks.

Response to complex needs

While we have noted the challenges faced by many people with disability in their interaction with the mainstream health system, our reviews have shown the magnified difficulties experienced by people with particularly complex needs. In this regard, our reviews have raised concerns about the adequacy of the health response to people with:

- intellectual disability and mental illness
- challenging behaviour
- changes and decline affecting multiple areas, including health, behaviour and cognition
- complex needs associated with disability and ageing (including dementia), and
- complex health conditions, including enteral nutrition and ongoing aspiration.

Critically, our reviews of the deaths of people with disability – particularly those with complex needs – have underscored the need for better coordination of care within and across health services; and between disability and health services. We have reported on the poor health outcomes and distress experienced by individuals with complex needs – including multiple presentations and admissions to hospital for treatment of presenting symptoms rather than comprehensive and holistic review; barriers to accessing assessment and treatment due to perceptions of ‘behaviour’ rather than mental illness; and reactive management of the person’s health and other needs by disability support staff (including management of disturbed sleep, falls, agitation and injury) in the absence of clear health guidance.

Our work has pointed to the need for comprehensive and multidisciplinary reviews of people with complex needs to facilitate a coordinated approach to identifying and responding to the person’s needs. However, while we have seen this approach demonstrated to some extent with people who accessed specialist disability health clinics, our reviews have rarely identified this approach for people who relied extensively on the mainstream health system.

Poor access to community-based health care and programs

Chronic disease management and other out-of-hospital programs

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.’⁷³ NSW Health operates chronic disease management and other out-of-hospital programs (including Connecting Care and Community Acute/Post Acute Care), aimed at providing support to help people with chronic disease to access appropriate community-based services to improve health outcomes, prevent complications and reduce the need for hospitalisation.

However, very few of the people with disability in residential care whose deaths we have reviewed had access to chronic disease management or other out-of-hospital programs, despite meeting the eligibility criteria, requiring community-based health support, and having multiple presentations and re-admissions to hospital in relation to their chronic illnesses.

While we have started to see people in our reviews who had received Acute Post-Acute Care (APAC) support, their involvement was still reliant on family members or disability staff actively seeking this support.

Preventative health programs

Many people with disability in residential care have multiple health risks related to lifestyle factors, including obesity, poor diet and insufficient physical activity. People in assisted boarding houses also face significant risks due to very high rates of smoking.

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

However, despite their substantial health risks, our reviews have identified few people who had access to preventative health support – such as the use of nicotine replacement therapy, involvement in quit smoking programs, referral to dietitians, and involvement in weight management or exercise programs.

End-of-life care and decision-making

For many of the people with disability whose deaths we review, decisions had been made ahead of their death about end-of-life care, including palliative care. Over the past 12 years, we have reported concerns about end-of-life decision-making for some people with disability in residential care, including when:

- decisions to limit treatment, start palliative care, or not to perform CPR were made by medical staff without the involvement of the person's family
- the reasons for end-of-life decisions were either not documented or were very limited
- the person with disability was not involved in the palliative care planning, and
- there was a lack of coordinated palliative care provided to assisted boarding house residents with advanced terminal conditions.

Importantly, we have previously highlighted the impact of perceptions of 'quality of life' on decisions relating to end-of-life care for people with disability. Our reviews have identified matters that have raised questions about the documented reasons for treatment limitation decisions – including where the rationale for treatment limitation (such as not for transfer to the ICU and not for CPR) referred to the practitioner's view of the individuals' quality of life and dependence on others for care, rather than the person's presenting medical condition and treatment options.

Disability health roundtable meeting

On 29 May 2014, we hosted a roundtable discussion with representatives from the Ministry of Health, the Department of Family and Community Services (FACS), key academics and advocates, to discuss what needs to be put in place in NSW to enable people with disability to access appropriate mainstream health supports ahead of the full NDIS roll out in July 2018.

The meeting included a briefing from Professor Eric Emerson on strategies that have been implemented in the UK in response to reports on the preventable deaths of people with disability, including:

- the establishment of acute liaison nurses in hospitals with learning disability expertise
- provision of financial incentives for GPs to complete annual health checks and develop associated health action plans for people with learning disabilities over the age of 14, and
- reasonable adjustments in primary and acute health care settings, including the development of a database with examples and resources.

The roundtable discussion highlighted that transition planning in relation to the NDIS and the health sector was at a very early point. We were advised that all NSW government agencies were developing draft NDIS transition plans, and reporting up to a State Government governance structure (including Board, Steering Committee and Reform Group). FACS advised that it was engaging with the Hunter Primary Health Network in relation to setting up clinical pathways with local providers and nurses.

During the meeting, roundtable participants raised concerns about potential gaps during and following the transition to the NDIS, in areas such as:

- therapy and other supports for people with disability who do not meet the criteria for an individually funded package
- disability health services and supports that are currently block-funded by FACS, and
- the clinical leadership, specialist tertiary supports and workforce capacity building provided by the Clinical Innovation and Governance directorate in FACS.

We also heard from participants that considerable work was still required to clearly distinguish between the health supports that would be NDIS-funded and those that would be the responsibility of mainstream health services.

Subsequent to the disability health roundtable meeting, in June 2015, we were advised that key planning documents, including the Bilateral Agreement between the Commonwealth and NSW on the transition to the NDIS; the NDIS operational plan between NSW, the Commonwealth and the NDIA; and cluster transition plans are expected to be finalised in August 2015. Following this, the NSW Government NDIS transition plan will be finalised, which integrates this planning into a single plan.

5.2. Relevant current work

There are various initiatives underway in both NSW and nationally that are focused on improving access to mainstream health services, and advancing health outcomes more generally, for people with disability.

Service Framework to Improve the Health Care of People with Intellectual Disability

Released in 2012, and developed in recognition of the poorer health outcomes and access to health services of people with intellectual disability, the Service Framework is Health's response to:

- promote a broad understanding of the health needs of people with intellectual disability and their right to effective services and care, and
- improve the quality, range, consistency, accessibility and integration of services necessary to meet the health needs of people with intellectual disability.⁷⁴

While the Service Framework includes strategies aimed at improving the health response across five tiers of care (including strategic health policy and population health; primary health and community health; and acute health care services), it is in relation to tier 4 (specialised area/local health services) and tier 5 (specialised regional/ statewide support and clinical leadership) that there has been notable progress.

In this regard, Health is currently funding three specialised clinical service pilots (in South East Sydney LHD; Northern Sydney LHD; and South Western Sydney LHD), and has engaged KPMG to undertake an evaluation of each of the models. Health has also established the Agency for Clinical Innovation (ACI) Intellectual Disability Network, which has undertaken key areas of work in relation to access and equity; research and development; models of care; and workforce and capacity.

Important current areas of work by the ACI ID Network include:

- the development by July 2015 of a blueprint and resources to guide and support LHDs, Primary Health Networks and community-based health organisations to deliver improved health services to people with intellectual disability, and to adopt an inclusive model of delivery (including a focus on identified priorities for reasonable adjustments), and
- the development of a hospitalisation co-design toolkit to improve the patient journey from community to hospital care, and transfer of care back to community-based services (including a focus on managing challenging behaviours).

National Health and Medical Research Council (NHMRC) Partnerships for Better Health Project

UNSW is leading an NHMRC project (with multiple partner agencies, including our office) on Improving Mental Health Outcomes for People with an Intellectual Disability. The project includes work that is directly relevant to the access of people with intellectual disability to mental health services and policy, including linkage and interrogation of datasets; analysis of Commonwealth and State mental health policy; and stakeholder engagement to improve accessibility.

NDIS outcomes framework, Information, Linkages and Capacity Building policy framework, and Quality and Safeguarding framework

In relation to the NDIS, and of direct relevance to the interaction of people with disability with mainstream health services, we note that:

- the NDIA is developing an outcomes framework for the NDIS, including specific indicators/ outcomes for the health domain

74 NSW Health (2012) *Service Framework to Improve the Health Care of People with Intellectual Disability*, p. 5.

- the Commonwealth Government has drafted an Information, Linkages and Capacity Building (ILC – formerly Tier 2) policy framework. The policy framework identifies that a key part of ILC is capacity building for mainstream services, and that local area coordination ‘will ensure that people with disability, their families and carers, are able to make full use of the mainstream and other services (including diagnostic-specific information) available to them’,⁷⁵ and
- the Commonwealth Government has released for consultation a proposal for an NDIS Quality and Safeguarding Framework. The framework includes the current requirement on providers to report the death of participants to the NDIS State Manager and relevant statutory authority in the local jurisdiction. However, it is not clear whether, or what, information would be required to ascertain the key factors in the participant’s death, including gaps in necessary supports.

5.3. Where to from here

In our unique role in reviewing the deaths of people with disability in residential care over the past 12 years, we have consistently identified and reported the significant health challenges and risks faced by this population, and the considerable disadvantage and adversity they tend to experience in their contact with mainstream health services. We have found substantial gaps between what is required (by the UN Convention, the National Disability Strategy and policy directives) and what is experienced by people with disability.

As it stands, the rights of people with disability – including the right to be provided with the same range, quality and standard of health care and programs as other people; to be provided with care of the same quality as other people; and to be free of discriminatory health care practice – are not consistently upheld. It is critical that action is taken as a matter of priority to address this situation, and to close the gap and improve health outcomes for people with disability in NSW ahead of the transition to the NDIS.

The current disability and health reforms⁷⁶ – and the Hunter NDIS launch site – provide a valuable opportunity to address cross-sector communication and cooperation, and the longstanding problems and deficits in mainstream health services that have adversely and inequitably affected people with disability. There is also positive work that has been done in recent years that provides a useful platform to build on, including development of tools and agreements between LHDs and disability accommodation services; and comprehensive actions and good practice examples in the Disability Action Plans developed by some LHDs.

However, our work has underscored the considerable risks that exist for people with disability (in residential care and more broadly) if mainstream services are not ready at the point of transition to the NDIS and withdrawal of NSW Government-funded specialist disability supports. The following information details the gaps and key areas that we consider warrant close attention and timely action by key NSW and Commonwealth agencies.

The need for clarity in relation to funding responsibilities between NDIS and mainstream health services

Primary guidance in relation to the responsibilities of the NDIS and mainstream health has been provided through the *Principles to determine the responsibilities of the NDIS and other service systems* released by the COAG Disability Reform Council, and the *NDIS Operational Guidelines* on the mainstream interface with health and mental health services.

However, further clarity is needed in relation to key aspects of the responsibilities between the NDIS and the mainstream health and mental health systems. In particular, it is not currently clear how mainstream health services in NSW and the NDIS will facilitate a joint approach to supporting people with disability to reduce the risks of poorer health outcomes. For example, while responsibility for preventative health measures rests with the health system, our work has shown that people with disability in residential care require substantial additional assistance – associated with their disability – to help them to take up and maintain preventative health activities (such as smoking cessation).

⁷⁵ NDIS *Framework for Information, Linkages and Capacity Building*, p. 8.

⁷⁶ Including Health’s Integrated care initiatives; implementation and evaluation of the clinical health service pilots; the work of the ACI ID Network; and disability inclusion action planning and the NSW Disability Inclusion Plan.

Health-related services currently funded by FACS

As noted by participants in our disability health roundtable meeting, there are a range of health-related services that are currently block-funded by FACS. Our reviews of the deaths of people with disability have shown the critical role these services play in supporting the health needs of this population. With the withdrawal of FACS from the provision and funding of specialist disability services in NSW from 1 July 2016, these services may be funded under the NDIS, funded by NSW Health, or cease. Given the importance of these supports, discussion and agreement between NSW and the Commonwealth on the future arrangements for these services should occur as a matter of priority.

Table 15: Health-related services currently funded by FACS

Leadership, research and practice improvement

Chair in Intellectual Disability Mental Health at UNSW – held by Associate Professor Julian Trollor since 2009. The position is tasked with improving support for people with an intellectual disability and mental health issues in NSW. Has established the Department of Development Disability Neuropsychiatry (3DN).

Chair in Intellectual Disability and Behaviour Support at UNSW – held by Associate Professor Leanne Dowse since May 2014.

The position is tasked with expanding the body of knowledge and increasing workforce capacity in the delivery of appropriate and effective services to people with an ID with complex and challenging behaviour.

FACS Clinical Innovation and Governance – provides practice leadership and coordination of services for people with complex needs and challenging behaviour.

Specialist services

Outreach psychiatry clinics by Dr Peter Wurth in regional areas of NSW for people with disability (52 days a year).

Multidisciplinary teams

Nurse and dietician positions within the dysphagia clinics at Westmead Hospital and the Children's Hospital at Westmead, coordinated by Dr Helen Somerville.

A range of allied health services in ADHC Community Support Teams, ADHC large residential centres, and some NGO disability services.

Practice Leader positions in nursing, speech pathology, occupational therapy, physiotherapy, and psychology.

School Physical Disability Therapy Team at the Kogarah Developmental Assessment Service, led by Dr Robert Leitner – for children with complex developmental disabilities.

The Stockton Clinic – provides centre-based medical, nursing and allied health specialists, and visiting specialists (whose consultations are funded by Medicare).

Health coordination and support

Two specialist nurse positions in each District to assist with the coordination of health care needs of people with disability, particularly those with complex needs.

FACS Clinical Governance and Performance Team – provide health-related support, coordination and advice for ADHC clients in Western Sydney, Nepean Blue Mountains and Northern Sydney Districts.

Primary and Secondary Health Care services for people in assisted boarding houses.

Comprehensive Health Assessment Program (CHAP) licence for use by FACS operated and funded disability services

Health care planning

In the transition to the NDIS, responsibility for health care planning – and the provision of clear, written guidance for people with disability and their support staff – may increasingly shift from disability services to GPs and other health services. Our reviews have clearly shown the significant risks to the health and welfare of people with disability unless effective and substantial work is undertaken to improve the quantity and quality of the information provided by medical practitioners to people with disability and their support staff about the person's health issues and required actions.

Work to address this issue should be informed by consideration of existing opportunities in the HealthOne NSW⁷⁷ services model of care; recent initiatives in the UK to incentivise GPs to complete annual health checks and develop associated health action plans for people with intellectual disability; and examination of the use of the annual comprehensive health assessment items in the Medicare Benefits Schedule.

Compliance with health policy and upholding the rights of people with disability

Over the 12 years that we have been reviewing the deaths of people with disability in residential care, we have seen considerable improvements in the policy guidance provided to public health services on identifying and meeting the needs of people with disability (including in relation to hospitalisation and transfer of care). However, our work has shown that considerable gaps between policy and practice continue to exist.

While key health policies relating to people with disability indicate that their implementation should be included in LHD disability action plans, this has not consistently been the case in practice. As part of the disability and health reforms, it is imperative that concerted action is taken to embed the rights of people with disability (underpinned by the UN Convention, the National Disability Strategy and the *Disability Inclusion Act 2014*) into the core business of mainstream health services. In this regard, it is important that:

- people with disability (particularly people with intellectual disability) are actively considered – and consulted – in the development and review of all health policies, and
- the actions of health services in implementing the policies and meeting the needs of people with disability are publicly reported against clear performance indicators and outcome measures.

The new disability inclusion action planning requirements in the Disability Inclusion Act provide a valuable opportunity to progress these issues. However, there is a need for clear guidance to health services to inform this work and to enable a consistent minimum standard of accessibility. We note that 'The Guide' for mental health services developed by the Chair of Intellectual Disability Mental Health⁷⁸ provides a useful template for this work.

Reasonable adjustments

A key part of embedding a disability rights framework in the core business of health services involves establishing a person-centred approach; including identifying the particular needs of the person with disability and adapting supports where necessary to meet their needs and facilitate equitable access to health care and treatment.

Our reviews have identified some examples of health services adjusting or adapting their services to meet the needs of people with disability, such as facilitating pre-admission visits for a person with intellectual disability to hospital prior to surgery to increase familiarity and reduce anxiety. However, the examples have been limited.

There is a need to provide clear guidance to mainstream health services about reasonable adjustment principles, and practical examples and options for adapting the supports. We note that there are a number of existing initiatives that should be considered to inform and guide the work, including:

- recent work in the UK to develop a database with practical resources and good practice examples across health services for providers to draw on

77 HealthOne NSW services bring Commonwealth-funded general practice and state-funded primary and community health care services together to provide integrated care. One of the key objectives of HealthOne NSW services is to improve service access and health outcomes for disadvantaged and vulnerable groups.

78 Department of Developmental Disability Neuropsychiatry (2014) *Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers*.

- the inclusion in the current disability action plans of some LHDs of actions relating to reasonable adjustments⁷⁹
- the current work by the ACI ID Network to develop a blueprint to deliver improved health services to people with intellectual disability, which includes a focus on priorities for reasonable adjustments, and
- 'The Guide' for developing accessible mental health services, which includes information and advice on adapting their clinical approach, including reasonable adjustments.

Identification of key positions in health services with lead responsibility for disability inclusion

While NSW Health's *People with a Disability: Responding to Needs During Hospitalisation* policy directive suggests that a senior staff member of LHDs 'be allocated responsibility for leadership in coordinating disability issues and facilitating the development of ongoing staff education and training',⁸⁰ this has not consistently been reflected in practice. Our work for over a decade has underscored the need for a mandatory identified role(s) in LHDs to provide leadership and advice in relation to disability health and inclusion (especially people with intellectual disability) and assistance with the coordination of support. We note that the identification of an acute liaison nurse/ disability health coordinator position in LHDs will be particularly important if the ADHC clinical nurse specialist positions in the districts do not continue.

It is also important to acknowledge that there is productive recent work that should be relied on to inform the way forward in this area, including the current specialised clinical service pilots in three LHDs; the establishment in the UK of acute liaison nurse positions with expertise in learning disability; the Commonwealth/NSW model for Aged Care Services in Emergency Teams (ASET);⁸¹ and innovative practice identified in the current disability action plans of some LHDs.⁸²

Data

In NSW and nationally, substantial work is being undertaken to harness eHealth technology to improve and integrate patient care. NSW Health has implemented the Electronic Medical Record (eMR) in 142 public hospitals (80% of its bed base), and has established HealthNet to link the electronic medical records used by public hospital and community services with the national Personally Controlled Electronic Health Record (PCEHR).

To date, HealthNet has been implemented within the Western Sydney and Nepean Blue Mountains Local Health Districts, and The Children's Hospitals Network (Westmead and Randwick).⁸³ Hospitals in the Illawarra Shoalhaven and South Eastern Sydney Local Health Districts are also connected to the PCEHR.⁸⁴

However, there is currently no consistent mechanism across NSW health services to identify people with disability in health data. The creation and roll out of a health data identifier(s) for people with disability is critical to assist health staff to identify and best support their needs; enable mainstream health services to clearly measure and report on the adequacy of support and key performance indicators related to improving health outcomes; and facilitate data analysis to inform broader service planning.⁸⁵

79 For example, the Northern Sydney LHD Disability Action Plan includes actions targeted at providing training for staff on adapting services to meet the needs of people with co-existing disabilities and other health issues.

80 NSW Health (Feb 2008) *Disability – People with a Disability: Responding to Needs During Hospitalisation*, p. 11.

81 We note that the Commonwealth/NSW model for Aged Care Services in Emergency Teams (ASET) is aimed at improving outcomes of older people during and post-hospital admission: http://www0.health.nsw.gov.au/policies/gl/2014/GL2014_011.html. There would be merit in considering the operation and effectiveness of these teams in examining relevant options for achieving similar outcomes for people with disability.

82 For example, the Sydney LHD Disability Action Plan (2014-2019) includes an action to identify a Senior Clinical Manager to coordinate access and care for people with disability.

83 HealthShare NSW (Dec 2013) *A Blueprint for eHealth in NSW*.

84 NEHTA, *Hospitals and health services connected to the PCEHR*, <http://www.nehta.gov.au/for-providers/ehealth-support-tools/public-hospitals-connected-to-the-pcehr>, accessed 4 March 2015.

85 We note that, even with an identifier/ minimum data set for people with disability, this does not guarantee that all people with disability requiring assistance will be picked up at the outset – particularly people with borderline or mild intellectual disability. It will be important for identification to be supported by staff training; consultation with the identified disability health liaison position; and information and advice provided by any informal or formal supports the person may have.

The existing disability action plans of a number of LHDs include actions aimed at enabling their health services and data systems to identify and flag people with disability (or people more broadly requiring additional support and coordinated care).⁸⁶ The intended work of these LHDs, and the creation of HealthNet lead sites, provides a valuable opportunity to undertake key work to develop and introduce an identifier and minimum dataset for people with disability.

We note that there is recent work that can help to inform the development of a health identifier and minimum dataset for people with disability, including projects led by the Chair of Intellectual Disability Mental Health at UNSW (ID mental health data linkage projects, and a NHMRC Partnerships for Better Health Project), and a current project gathering data on in-patients with intellectual disability at the Children's Hospital at Westmead.

Reporting of performance in relation to people with disability

Facilitated by improved data collection and a minimum dataset for people with disability, it will be important to require regular and public reporting on the performance of health services in relation to agreed key performance indicators and outcomes measures, such as:

- access of people with disability to health services – how many seen; in what services; for what reasons
- adherence to adjustments to meet the needs of people with disability – including audits of identified support needs/ adjustments required and the adjustments made (and type of adjustment)
- rates of presentations, admissions and re-admissions; length of stay; delayed transfers; error rates
- use of restraints (with examination of the identified support needs and the support provided)
- outcomes for people with intellectual disability compared to people without intellectual disability, and
- rates of unnecessary hospitalisations; inclusion in chronic disease management and other out-of-hospital programs; and inclusion in preventative health programs.

Noting the significance of these matters to the lives of people with disability, there is merit in exploring options for linking mandatory reporting on performance with funding of health services, accreditation, or both. In the transition to the NDIS, the development of funding contracts that incentivise, or require, best practice in the inclusion of people with disability warrant active consideration.

In relation to the NDIS, it will be critical to have health domain outcomes measures that adequately encapsulate the experience of people with disability to ascertain, among other things:

- any health supports that were required but not obtained (and why)
- the progress and effectiveness of the implementation of the Commonwealth's Information, Linkages and Capacity Building (ILC – formerly Tier 2) in facilitating access to, and inclusion by, mainstream health services
- satisfaction with mainstream health services (including experience/attitude of health practitioners in relation to disability)
- whether funded health-related supports and strategies achieved the desired outcome
- the adequacy of the actions of funded disability supports to assist the person to link in with appropriate health supports, and to work collaboratively with health services, and
- consideration by the NDIA of the person's existing health conditions and needs as part of the assessment/planning/review process

86 For example, Illawarra Shoalhaven LHD, Sydney LHD, Northern Sydney LHD, and South Eastern Sydney LHD.

Part Three: Monitoring our recommendations

Chapter 6. Agency progress against recommendations in our last report

6.1. Guidance for disability services

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

Progress

ADHC has released the first volume of the Health and Wellbeing Framework policy, procedures and guidelines, including the revised *Nutrition and Swallowing* policy and practice guide.

The broader Framework will also contain guidelines and procedures for health planning, medication, epilepsy, death, and aids and equipment in accommodation services program, as well as guidelines for chronic disease management, health promotion, and advanced care (end-of-life care). ADHC has advised that the health planning procedures will set out Medicare entitlements, including how ADHC will support people to access those entitlements.

The Health and Wellbeing policy resources will be accompanied by a suite of e-learning resources that will be available to all ADHC staff, people with disability and their families. ADHC has advised that the e-learning modules for the Health and Wellbeing Framework will also be made available to ADHC-funded services.

ADHC has also told us that, as part of an Accommodation Support Policy Review, Provider Guidelines will be developed to support good health and wellbeing outcomes for people with disability.

Our comments

ADHC has undertaken substantial work to revise and simplify the guidance for direct care staff in relation to supporting the health needs of people with disability in residential care. The Nutrition and Swallowing Guidelines and Procedures are comprehensive, and include changes to the Nutrition and Swallowing Risk Checklist to provide clearer guidance to direct care staff about how to complete it, and what they need to do in response to identified risks.

We will continue to monitor the progress of ADHC's work to release the full Health and Wellbeing Framework, and its activities to support the sector to understand and apply the guidance.

6.2. Monitoring disability services

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

Progress

A copy of the Risk Identification and Monitoring Guidelines was provided to our office in August 2013.

ADHC-funded services

In relation to the development and implementation of the NSW Quality Framework for ADHC-funded services, ADHC told us that funded services are required to have a quality management system in place, and to undertake a third party verification audit to confirm compliance with the NSW Disability Services Standards, by 30 June 2015. Services also need to establish and publicise a documented complaints process.

ADHC has advised that it provided \$6.75 million from the Industry Development Fund to NDS to develop a range of resources and supports to assist funded services to comply with the new Quality Framework, including:

- providing a financial subsidy to assist funded services to comply with the new quality arrangements
- providing an advisory service, and
- facilitating 19 workshops for funded providers across NSW, with an additional 12 workshops intended in 2014.

In addition, ADHC has indicated that it has developed a range of supports, quality tools, and resources, including:

- engaging a consultant to run 20 Disability Services Standards training workshops across NSW, with a focus on services developing action plans to achieve compliance with the requirements
- developing an online Quality Framework Reporting (QFR) tool, requiring service providers to report every six months on their progress in implementing the new quality system and in obtaining third party verification – ADHC will use this reporting process to monitor the progress of the sector in implementing the system
- developing key performance indicators to assist service providers to review their performance against the disability services standards to inform continuous improvement, including an online tool that was launched in January 2014, and
- developing a Systems Recognition Tool to assist providers to understand the extent to which their existing systems meet the disability services standards.

ADHC also advised that an existing online tool, the Feedback and Complaints Management Log (FCML), has been made available to all funded providers at no cost, to enable services to comply with the requirements to have a documented complaints process.

ADHC-operated services

In relation to ADHC-operated services, ADHC advised that it is developing a reform agenda called *The Good to Great* program, which will establish a Quality Management System.

The reform will reconfigure the accommodation support policy framework into four systems, including:

- lifestyle
- health and wellbeing
- finance, and
- staff and household.

ADHC advised that this will enable person-centred approaches; provide resources to guide staff practice; and reposition the Health and Wellbeing policy framework to improve access to mainstream health care.

ADHC has indicated that it will undertake work to improve existing performance indicators to measure outcomes consistent with the disability services standards, and to establish customer feedback mechanisms, including the development of a survey to gather feedback on outcomes and experiences.

Our comments

ADHC has provided comprehensive advice on the actions it has taken to develop and implement the NSW Quality Framework for ADHC-funded services, and its intended work in relation to the Quality Management System for its own services.

We welcome ADHC's work in promoting and making the Feedback and Complaints Management Log available to funded providers. We are keen to see increased adoption of the tool; noting the benefit for the sector of consistent and streamlined reporting on complaints. We also note the potential for application of the tool on a national basis in the transition to the NDIS, with Victoria, WA and NSW all now using the same disability complaints reporting system.

We will continue to monitor the progress of this work through our discussions with ADHC and NDS in NSW.

6.3. Antipsychotic medication and behaviour management

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

Progress

Between March and August 2014, ADHC's Clinical Innovation and Governance (CIG) directorate surveyed ADHC-operated and funded supported accommodation services to identify the prevalence of the use of psychotropic medications, and to confirm adherence to policy requirements in relation to the use of these medications.

In total, 5,791 people in supported accommodation were surveyed (a 90% response rate across disability services). Just over half (3,056) of the residents were identified as receiving prescribed routine psychotropic medication. Of the 3,056 people:

- Over two-thirds (2,112) were prescribed the medication for behavioural purposes. The majority of these individuals (1,929) had a current Behaviour Support Plan in place as required by the ADHC *Behaviour Support* policy.
- Over half (1,718) have their support managed through a complex case review process.

ADHC told us that its analysis of the data indicates good compliance with the requirement for a current behaviour support plan to be in place when psychotropic medication is prescribed on a routine basis for behaviour issues. However, the implementation of a complex case review process in all cases of routine psychotropic medication usage needs further consideration.

In response to the survey results, CIG indicated that it would undertake a range of practice improvement initiatives, including:

- **Training** – providing regular training opportunities and developing communities of practice in each District to continue to raise the profile of the *Behaviour Support* policy and minimum practice standards across the sector
- **Guidelines** – developing a *Complex Case Review Practice Guide* to reinforce policy requirements and guide the sector in establishing an effective mechanism to manage, monitor and report on cases where routine psychotropic medication has been prescribed
- **Quality** – introducing a policy requirement to complete a Quality Feedback Tool in all cases where routine psychotropic medication has been prescribed for behavioural issues and adherence monitored
- **Review** – conducting periodic surveys to review the prevalence of the use of routine psychotropic medication across supported accommodation
- **Monitoring** – reviewing the Quality Framework for funded services and the Quality and Safety Framework for ADHC-operated services to include evidence of adherence to mandatory *Behaviour Support* policy requirements, and
- **Policy implementation** – using the data from the surveys to inform ongoing policy development and implementation relating to the management of psychotropic medication across supported accommodation.

ADHC has also advised that it has engaged the Centre for Disability Studies (CDS) to review the ADHC *Behaviour Support* policy and practice manual, including mapping the guidance against contemporary person-centred approaches; referencing recent improvements in best practice; and updating the evidence base for specialist behaviour support. The final report from the CDS review is expected in November 2014.

CIG is currently undertaking an Intensive Sector Development project to provide for effective oversight and monitoring of the incidence of Restricted Practices and the Restricted Practice Authorisation (RPA) mechanisms, use of routine psychotropic medications, and Complex Case Reviews. The project is also intended to support the establishment and maintenance of sector capacity to safeguard people with disability in relation to these practices. Key elements of the project include:

- building on the Feedback and Complaints Management Log platform to enable service mapping, and six-monthly monitoring and reporting, on the use of restricted practices and other aspects⁸⁷ across ADHC-operated and funded services (including supported accommodation, centre-based respite, drop-in support and block-funded day programs)
- funding NDS to deliver enhanced training for RPA panels across NSW, with the creation of a register of practitioners who have completed the training and are willing to be independents on RPA panels
- mentoring for less skilled organisations, and
- developing sector readiness for transition to the NDIS.

Our comments

ADHC has undertaken considerable work in response to our recommendation. While we note the high rate of compliance in relation to ADHC's *Behaviour Support* policy identified by the survey, we also note ADHC's advice that it was essentially a self-report survey. The practice improvement initiatives identified by ADHC, including the Intensive Sector Development project and enhancements to the Feedback and Complaints Management Log, will be vital in ensuring that people with disability are supported by appropriate and person-centred behaviour management practices that focus on the least restrictive alternative.

Mechanisms for reporting on, and monitoring, the use of restrictive practices in relation to people with disability are currently being examined as part of the national consultations on the NDIS Quality and Safeguarding Framework. The development of this framework will also be informed by the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector*.

We will monitor the progress of ADHC's practice improvement and sector development initiatives in relation to restrictive practices through our regular discussions with the agency, and intelligence from our complaints, reviews and disability reportable incidents functions.

6.4. People with disability who are ageing

6. In relation to the *Ageing in Place: Impact on Accommodation Services* project, ADHC should:

- a) provide us with a copy of the project report and associated action plan, and
- b) provide advice to us on its progress towards implementing the action plan.

Progress

In August 2013, ADHC provided to our office a copy of the *Ageing in Place: Impact on Accommodation Services* project report. The final report and ADHC's response to the report are also available on ADHC's website.⁸⁸

The purpose of the project was to identify ways in which ageing affects the support needs of people with disability in order to develop a service response strategy that meets changing needs and promotes ageing in place. Among other things, the *Ageing in Place* project identified the need for:

- better planning for the future, including better use of person-centred plans and transition planning

⁸⁷ Monitoring and reporting will include the use of restricted practices, RPA mechanisms, the use of psychotropic medication on a routine basis, and the complex case review mechanism.

⁸⁸ http://www.adhc.nsw.gov.au/__data/assets/file/0003/270714/AIP_Research_Report_Dec2011.pdf and http://www.adhc.nsw.gov.au/__data/assets/file/0004/270715/Response_to_AIP_Research_Report.pdf.

- introduction of a standardised support needs assessment tool
- introduction of an individualised support model to provide greater choice and more person-centred solutions
- better access pathways to health and aged care systems for people with disability, and
- improved access to equipment and home modifications to facilitate a person remaining in their home.

A subcommittee of the Accommodation Models Development Reference Group (AMDRG) has been established to agree on an action and implementation plan. The subcommittee includes representatives from ADHC, NDS, and funded providers.

ADHC told us that the recommendations arising from the research project closely align with the national and NSW disability reform agenda, including the implementation of Ready Together, the Living Life My Way Framework, and the transition to the NDIS. ADHC has advised that implementation of the action plan will be progressed within the context of these broader reforms.

Our comments

The issue of support for people with disability who are ageing has been the subject of recommendations in our reviewable disability deaths reports since 2006. At that time, our consultations with disability services across NSW identified concerns about the lack of policy guidance from ADHC on 'ageing in place' for people with disability in residential care, and the resulting inconsistent practice across disability services.

In May 2010 – and against the background of our repeated recommendations regarding the need for ADHC to provide policy guidance to disability services on supporting ageing people with disability – ADHC commissioned the *Ageing in Place* project. We were advised that the resultant recommendations would be developed into an action plan with clear justification and an outline of new policy direction to re-orient services to enable clients to age in place.

We note that there have been substantial changes in the sector since that time which are directly relevant to the issues identified in the project report, including the roll out of individualised funding arrangements; development and implementation of person-centred planning; and commencement of the NDIS. However, while the project identified important issues (including barriers between the disability and aged care sectors) and some necessary actions, it is not clear to us what tangible improvements have resulted for people with disability in residential services who are ageing. Noting that we have been highlighting issues and making related recommendations over the past decade on support for people with disability who are ageing, progress to date appears to be limited.

The transition to the NDIS presents a valuable opportunity to reduce the barriers between the disability and aged care sectors, and improve support to people with disability – including ageing-specific supports.

6.5. Access to health services for people with dual diagnosis

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

Progress

ADHC and NSW Health have provided our office with a copy of the evaluation of the *Memorandum of Understanding between ADHC and NSW Health in the provision of services to people with an intellectual disability and mental illness* ('the MOU'), which was completed by the Joint Committee on Intellectual Disability Mental Health (JCIDMH).

The agencies advised that implementation of the MOU continues to focus on establishing collaborative working relationships, and building the capacity of the disability and health workforce in relation to intellectual disability and mental illness. Work is also being undertaken to improve referral and access pathways for people with intellectual disability to receive mental health services. ADHC also advised that joint work is underway to improve the alignment of FACS and Local Health Districts, and that joint collaboration will extend to funded services that share clients.

In relation to the evaluation of the MOU, ADHC and NSW Health are reviewing the findings and recommendations to inform the development by the JCIDMH of the second phase of the MOU implementation plan. Phase two will focus on:

- referral and treatment pathways for mental health services – including issues relating to the identification of intellectual/cognitive disability and intake for mental health services, and
- the Children and Young Persons' Intellectual Disability Mental Health Advisory Group, which focuses on the mental health needs of children and adolescents with intellectual disability.

ADHC told us that the JCIDMH anticipates that access to mental health treatment for people with intellectual disability should be improved by:

- the expansion of the NSW Mental Health Commission
- a targeted focus for Primary Health Networks regarding intellectual disability and mental health, and
- support of initiatives arising from the National Roundtable on the Mental Health of People with Intellectual Disability.

ADHC advised that project work was undertaken by the JCIDMH and the University Chair, Intellectual Disability Mental Health, in collaboration with NSW Health, to develop e-learning training modules for disability and health staff to improve knowledge, skills, and attitudes towards mental health concerns in people with intellectual/cognitive disability.

ADHC also told us that a *Partnership Project for Improving Mental Health Outcomes for Persons with an Intellectual Disability* has been initiated to improve cross-sector coordination of mental health services to people with intellectual disability and mental illness. This project will build on the Pilot Data Linkage Project which was undertaken by the University Chair, Intellectual Disability Mental Health.

Our comments

We are pleased to be a partner in the current National Health and Medical Research Council Partnerships for Better Health project, led by UNSW, on *Improving Mental Health Outcomes for Persons with Intellectual Disability*. We also note the considerable work that has been undertaken that is relevant to people with dual diagnoses of intellectual disability/cognitive impairment and mental illness, including the National Roundtable, and the NSW Mental Health Commission's *Living Well: A Strategic Plan for Mental Health in NSW 2014-2024*, which includes a chapter on mental health and intellectual disability.

In regard to the latter, the Commission notes that the strategic plan 'offers the opportunity to address long-standing systemic issues relating to access and co-ordination of care and support and ensure that the potential of the National Disability Insurance Scheme is realised.'⁸⁹

In light of the appropriate and ongoing involvement of the Mental Health Commission in this area, we will not continue to monitor the progress of ADHC and Health's work through further recommendations in our reviewable deaths report.

89 NSW Mental Health Commission, 2014, *Living Well: A Strategic Plan for Mental Health in NSW 2014-2014*, p. 90.

6.6. Improving support in the community for people with disability and chronic illness

8. **The Agency for Clinical Innovation (ACI) should provide detailed advice to us on the progress of its actions to improve the access of people with disability in care to the Connecting Care and other out-of-hospital programs. This should include advice as to the progress and outcomes of its consultations and other work with:**
- a) **GP representatives, including GPNSW and other GP clinical leaders on barriers to service provision for this population and possible strategies for increasing the development of shared care plans for people with disability**
 - b) **the disability sector, including ADHC**
 - c) **carer supports, including Carers NSW and LHD Carer Liaison Officers, and**
 - d) **the ACI Intellectual Disability Network.**

Progress

The NSW Chronic Disease Program (CDMP) Service Model was released in October 2013. NSW Health has indicated that it has developed a self-assessment tool to assist Local Health Districts and Specialist Networks to assess program delivery against the model in order to identify strengths and opportunities to improve.

NSW Health advised that the ACI Primary and Chronic Care Team (PCCT) provides support to LHDs for implementation and ongoing development of the CDMP. The PCCT has developed links with relevant staff of ADHC to improve services to people with disability with chronic conditions residing in boarding houses or group homes, and these key contacts have been shared with CDMP Managers across the state.

Health advised that the PCCT has developed a discussion paper exploring issues regarding access to CDMP for people with disability. The discussion paper has been distributed to CDMP Managers, Networking NSW (formerly GPNSW) and Medicare Locals (now Primary Health Networks) to ascertain current practice and gather opinion regarding service improvement options to people with disability presenting with chronic conditions. As a June 2015, responses to the discussion paper are being collated.

GP representatives

In relation to consultation with GPs, NSW Health told us that a GP Advisory Group has been established by the ACI to provide strategic advice and guidance to integrate initiatives, such as the chronic disease management program, into primary care services. As at July 2014, the focus of this group was to develop a framework and resources to support the health system to work with and build the capacity of general practice to manage people with chronic disease and complex needs.

The Chronic Care Project Officer at Networking NSW (funded by ACI) will consult Primary Health Networks on the discussion paper referred to above to explore barriers and strategies that would support improved access to chronic disease management in primary care.

Disability sector

In relation to consultation with the disability sector, NSW Health advised that the Chronic Care Team met with ADHC's Boarding House Team in May 2014 to discuss strategies to improve access to the program for people living in assisted boarding houses. We were advised that a further meeting was being arranged with ADHC case managers who are supporting assisted boarding house residents to increase their awareness of the program and ensure clear local referral pathways.

NSW Health told us that further discussion would be undertaken with ADHC to develop a similar strategy with ADHC staff responsible for group homes.

Carer supports

In relation to carer supports, NSW Health advised that an Easy English version of the program's brochure has been developed for people with intellectual disability, and carer support agencies (such as Carers NSW and LHD Carer Liaison Officers) will be advised of this publication. The brochures have been distributed to the Chronic Care Network, which includes members from Consumers NSW, carer supports and LHD officers.

ACI Intellectual Disability Network

NSW Health reported that the Chronic Care Network has been documenting the Chronic Disease Management Program service model to support state-wide implementation.

The ACI ID Network has also developed four short videos focusing on primary health and Primary Health Networks, to support integrated models of care, referral pathways, continuum of care, and the importance of the primary health relationship.

Our comments

We note that work that has been undertaken to date by NSW Health's Chronic Care Team and the ACI to improve the access of people with disability in residential care to the chronic disease management program. We welcome the development of an Easy English version of the program's brochure for people with intellectual disability, which is now available on Health's website.⁹⁰

We appreciate that some of the concerns we have identified regarding the access of people with disability in residential care to chronic disease management programs also apply to people with chronic disease in the community more broadly. In this regard, we note the findings of the state-wide evaluation of the NSW Health Chronic Disease Management Program in October 2014 that 'most referrals to the program came from LHD hospitals; there were few referrals from other sources including GPs or rehabilitation programs'.⁹¹

However, while our reviews of deaths in 2012 and 2013 (and 2014) have noted the access of a small number of people to Health's Acute Post Acute Care (APAC) service, we have not identified any improvement in the access of people with disability in residential care with chronic diseases to the Chronic Disease Management Program.

We welcome Health's advice on the meetings between its Chronic Care Team and ADHC regarding strategies to improve the access of people in disability services and assisted boarding houses to the program. However, no details have been provided on the agreed strategies or their implementation, and there is no information as to how people with disability in residential care operated by non-government services are being included. We also note that at the time of the last update from Health, the Chronic Care Team was in the early stages of developing the discussion paper on access to CDMP for people with disability.

Given the significance of this issue for many people with disability in residential care with chronic diseases, we will continue to monitor the work of Health/the ACI to improve the access of people with disability in residential care to chronic disease management and other out-of-hospital programs.

90 <http://www.aci.health.nsw.gov.au/resources/chronic-care/cdmp/nsw-cdmp/NSWHealth-CDMP-DL-Brochure-EE-Int-Dis.pdf>.

91 The George Institute for Global Health., the Centre for Primary Health Care and Equity, UNSW., and the Centre for Health Economic Research and Evaluation, UTS, 2014, *State-Wide Evaluation NSW Health Chronic Disease Management Program Final Report*, p. xix.

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- 9. In relation to improving access to community-based and coordinated care for people with disability who have chronic and complex respiratory disease, NSW Health should provide detailed advice on:**
- a) the progress and outcomes of the preliminary collaborative work between the Clinical Excellence Commission and the ACI on addressing the preventable causes of aspiration pneumonia, and**
 - b) the progress of the Trapeze program to improve support for people with disability aged 16-24 years with chronic conditions, and any plans for evaluating the program.**

Progress

Addressing preventable causes of aspiration pneumonia

NSW Health has advised that a previous project on recognising and preventing aspiration pneumonia recommenced in July 2014, and would be jointly led by the Clinical Excellence Commission and the Collaborating Hospitals' Audit of Surgical Mortality. A speech pathologist has been nominated to join this project.

NSW Health told us that the ACI Aged Health Network has finalised an Enhancing Person Centred Care with Volunteers training program for volunteers who support people with cognitive impairment, including providing assistance with feeding. However, Health advised that the use of volunteers for feeding does not include people with dysphagia or those at risk of aspiration.

NSW Health also advised that the ACI Nutrition and Gastroenterology Networks have collaborated with the Gastroenterological Nurses College of Australia to develop *A clinician's guide: caring for people with gastrostomy tubes and devices*.⁹² The Guide was released in late 2014, and includes advice about managing people with dysphagia and reducing risks of aspiration.

In addition, the ACI Respiratory Network and Intensive Care Coordination and Management Unit have jointly developed a *Care of adult patients in Acute Care Facilities with a Tracheostomy Clinical Practice Guideline*, which includes a section on swallowing.⁹³ A similar guide is being developed for community care providers, patients and carers. Disability services have been identified as key stakeholders in the development of this guide.

Trapeze Program

In relation to the Trapeze program, NSW Health advised that it commenced enrolments in January 2013, with young people in out-of-home care considered a priority population for inclusion in the program. Trapeze is providing comprehensive care coordination services to over 234 young people with chronic conditions as they transition to adult services.

Health has advised that Trapeze brochures are being distributed widely in hospitals and primary care settings, and a website and mobile apps are in development.

The Trapeze program is evaluated through a number of mechanisms, including:

- a 'Transition Research Reference Group' which meets bi-monthly to identify and implement evaluation and research projects for the program
- quarterly reports to the Ministry of Health, and
- analysis of statistical data on key performance indicators, referral patterns, medical diagnosis, and demographics.

⁹² <http://www.aci.health.nsw.gov.au/resources/nutrition>.

⁹³ <http://www.aci.health.nsw.gov.au/resources/respiratory>.

NSW Health has also advised that the ACI Transition Network is contributing to an evaluation of transition processes for young people with cystic fibrosis, neurodegenerative conditions, chronic pain and chronic urological conditions. The evaluation of the Spina Bifida Adult Resource Team model has been completed

The Key Principles of Transition document launched at the joint ACI/Trapeze Transition Workshop in December 2014 provides a framework for LHDs to implement evidence-based transition across their organisations.

In addition, the ACI Transition Care Network and Trapeze are both members of the Western Sydney LHD and Sydney Children's Hospitals Network's District Youth Health and Transition Committee, which began in 2014. As at June 2015, the Committee is considering recommendations arising from transition forums in March and December 2014.

Our comments

In relation to addressing preventable causes of aspiration pneumonia, we welcome the guidance that Health and the ACI Networks have developed in relation to caring for people with a tracheostomy or gastrostomy tubes and devices – including the need for coordinated care and regular monitoring by a nutrition support team. We note that, at the time of Health's last update to us, the project on recognising and preventing aspiration pneumonia had only just recommenced. We will seek advice on the progress and outcomes of this work.

In relation to the Trapeze program, we welcome Health's advice on the priorities and scope of the program to date, and note the current multiple mechanisms that are in place to monitor and evaluate the program's progress and effectiveness. We will not continue to monitor the progress of this work.

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

Progress

NSW Health has advised that the ACI Transition Care Network is working closely with the Trapeze program to ensure continuity of care for young people with chronic illnesses transitioning to adult services, including fortnightly team meetings to discuss models of care, new referrals and to develop joint resources.

The ACI Transition Care Network is also funding a four-year evaluation of the Spina Bifida Adult Resource Team model, and is contributing to an evaluation of transition processes for young people with degenerative neuromuscular disorders. Recommendations to improve access to community and hospital care arising from the transition working group hosted in March 2014 by Western Sydney LHD are being considered.

Our comments

We welcome Health's advice regarding current relevant work of the Transition Care Network in relation to developing models of care. Separately, we also note the recent guidance issued by the Network on the key principles of care for young people transitioning to adult health services, including the importance of follow-up and evaluation to ensure that young people have engaged effectively with adult health care services.⁹⁴ We will not continue to monitor the progress of this work.

94 http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0011/251696/Key_Principles_for_Transition.pdf.

6.7. Supporting people with disabilities in their contact with health services

11. Health should report to us on its progress in implementing actions under the NSW Implementation Plan for the National Disability Strategy to:

- a) improve services to people with disability and carers attending, being admitted to, or leaving hospital by:
 - (i) developing consistent processes to ensure the safe and effective transfer of care of patients who are transferred home or to ongoing care from the acute hospital service (Action 6.c.i), and
 - (ii) encouraging more flexible non-emergency transport services that meet the needs of patients who currently have access issues (Action 6.c.iv).
- b) implement strategies in the NSW Oral Health Strategic Directions 2011-2020 to improve oral health care for people with disability (Action 6.d).

Progress

Improving services to people with disability in hospital

In relation to improving services to people attending, being admitted to, or leaving hospital, NSW Health advised that there are a number of relevant policies, including:

- the NSW Health and ADHC Joint Guideline on *Supporting residents of ADHC operated and funded accommodation support services who present to a NSW Public Hospital* (April 2013)
- *People with a Disability: Responding to Needs During Hospitalisation* (January 2008), which is currently under review and will place emphasis on the importance of person-centred care, the role of families/carers, the use of local protocols between health and disability services, patient consent and communication tools⁹⁵
- *Care Coordination: Planning from Admission to Transfer of Care in NSW Public Hospitals* (March 2011), which is a mandatory policy that outlines the five steps in coordinating patient care to improve patient experience and flow within hospitals, and
- *Departure of Emergency Department Patients*, which was updated in July 2014 and is relevant to people with disability.

NSW Health advised that it is implementing reforms that aim to improve use of the non-emergency patient transport (NEPT) fleets and reduce patient delays. In May 2014, separation of the NSW Ambulance NEPT Fleet from emergency services and establishment of a central booking and dispatch service began. All greater Metropolitan LHD fleets also transitioned to coordination by the central hub in 2014. A satellite booking hub has been established for New England, and three further regional satellites will commence transition from mid-2015. Next steps also include expanding the panel of providers to include private or NGO providers, and market testing is underway in South Eastern Sydney LHD.

Oral health

In relation to oral health, NSW Health told us that an updated strategy, *Oral Health 2020*, was published in 2013, and identifies actions to prioritise children and adults with special needs, including:

- ensuring that integrated oral health promotion programs are appropriately tailored to people with special needs
- identifying and addressing inadequacies in existing models of care

⁹⁵ The policy directive release date will be aligned to the NSW Health Disability Inclusion Action Plan, which is due by the end of November 2015.

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- considering opportunities to include oral disease in other chronic care programs, such as the CDMP, and
 - encouraging research and evaluation into the oral health and dental service needs of priority population groups.

NSW Health advised that the Centre for Oral Health Strategy has commenced the review of models of care and has developed a Carers Guide and Supports with an initial focus on older persons, including those with multiple co-morbidities. Health has advised that the principles in these documents could be applied to other persons with special needs. In addition, strategies to increase the oral health workforce available to treat people with special needs will be included in the draft NSW Oral Health Speciality and Tertiary Clinical Services Plan being developed in 2014/15.

NSW Health also advised that the Australian Society of Special Care in Dentistry conference in November 2014 had a major focus on developmental disability and special needs dentistry.

Our comments

We appreciate Health's advice about the policy guidance that has been developed to ensure the safe and effective transfer of care of patients with disability from hospital to home. However, we note that the People with a *Disability: Responding to Needs During Hospitalisation* policy directive has been under review for an extended period of time, and – as noted in Chapter 5 – there is a continuing need for improved practice in relation to discharge planning for people with disability. We will continue to monitor Health's work in relation to this issue.

We note the range of strategies that have been identified to prioritise and improve the oral health of children and adults with special needs, and will be keen to see the oral health guide distributed to disability accommodation services and assisted boarding houses.

12. In relation to the Health/ADHC Joint Guideline to support residents of disability accommodation support services who attend or are admitted to a NSW public hospital:

a) Health and ADHC should:

- (i) provide advice to us as to the intended date of release of the Joint Guideline**
- (ii) provide us with a copy of the Joint Guideline and any supporting documents, and**
- (iii) provide detailed advice to us on joint plans for evaluating the implementation of the Joint Guideline and its effectiveness in improving support for people with disability in hospital.**

b) Health should:

- (i) provide us with a copy of its letter to the LHD Chief Executives regarding the release and implementation of the Joint Guideline, and**
- (ii) provide advice to us on the details and outcomes of its work with the ACI Intellectual Disability Network in relation to the ongoing implementation and monitoring of the Joint Guideline.**

c) ADHC should provide advice to us on:

- (i) how it will support disability services staff to implement the Joint Guideline, and**
- (ii) how it will monitor the implementation of the Joint Guideline.**

Progress

The Joint Guideline was released in April 2013 and is available on the NSW Health and ADHC websites.⁹⁶ NSW Health has indicated that it has commenced officer-level meetings about the Joint Guidelines with ADHC about next steps. Issues are discussed at senior officer meetings if required.

NSW Health advised that the Joint Guideline has been used to inform the work of the ACI ID Network. The Network currently has a multidisciplinary and multiagency team conducting case study analyses of discharge processes from hospital for people with intellectual disability, including a review of the use of the guideline.

In relation to supporting staff to implement the guideline, ADHC told us that FACS Districts were made aware of the release of the guideline and were requested to review their existing arrangements with local hospitals to ensure those arrangements complied with the guideline. Frontline staff are being made aware of the guideline through ADHC's intranet and e-learning portal, with an e-learning module developed specifically for the guideline.

In relation to monitoring the implementation of the guideline, ADHC advised that it will monitor the number of staff who have successfully completed the e-learning module for ADHC-operated services, with feedback to be provided to the Districts on a monthly basis.

In addition, ADHC advised that a survey will be developed to seek feedback from staff, people with disability and their families, on how the guideline contributed to their experience before, during and after hospitalisation, as well as experiences before and after the guideline was in place.

Our comments

We welcome the release of the Joint Guideline, and note the action taken by ADHC to date to raise awareness of the guideline amongst its staff. However, while our reviews of deaths in 2012 and 2013 have underscored its importance, we have also identified low take-up or use of the guideline (and its Hospital Support Plan), including in relation to people with significant support needs that affected their access to medical treatment.

We will continue to monitor the work of health and disability services in relation to implementing the joint guideline.

96 http://www0.health.nsw.gov.au/policies/gl/2013/pdf/GL2013_001.pdf, and http://www.adhc.nsw.gov.au/__data/assets/file/0011/269345/Hospitalisation_Guideline.pdf.

6.8. Health service framework to improve the health care of people with intellectual disability

- 13. Health and FACS should report to us on their progress in implementing actions under the NSW Implementation Plan for the National Disability Strategy (Action 6.b) to:**
- a) develop enhanced models of care for people with intellectual disability**
 - b) improve referral pathways, with particular emphasis on aspects of care related to challenging behaviour**
 - c) investigate the establishment of a state-wide patient/client database to improve client outcomes**
 - d) map health services for people with intellectual disability, and link with services provided by agencies such as ADHC, Community Services and Department of Education and Communities, and**
 - e) work with key education providers to enhance the curriculum and teaching resources related to health care for people with intellectual disability.**

Progress

Developing enhanced models of care for people with ID

NSW Health told us that the ACI Intellectual Disability Network is working with the three Tier 4 ID pilots to develop models of care and pathways to care for people with intellectual disability. Examples include:

- The ACI Patient Experience and Consumer Engagement Team, the ID Health Network, and the Metro Regional Intellectual Disability (MRID) pilot in SESLHD are working together with consumers on a co-design toolkit to improve the patient journey from community to hospital and transfer of care back to community-based services (with a focus on challenging behaviour).
- The MRID in SESLHD, in partnership with Cairnsfoot School and the NSW ACI, has developed the School Kit website, which provides the key tools to help set up and maintain school-based clinics to support children and adolescents with complex needs.
- The Guideline developed by the ID Health Network on Accessing NSW Health Services for People with Intellectual Disability.

The ACI has recently established two new Clinical Networks – Mental Health Network and Drug and Alcohol Network, with potential for future collaborative work around intellectual disability.

Improving referral pathways

NSW Health has advised that the three multidisciplinary pilot projects, with the support of the ACI ID Network, are conducting forums for discussion and planning regarding pathway development. The ACI ID Network partnered with ADHC and SWSLHD to hold the Dual Diagnosis Forum in October 2014, which presented multidisciplinary models of working with people with intellectual disability and mental health and challenging behaviour.

The Network has produced a guideline to assist parents and carers to make sense of the system that exists to support them and their child with intellectual disability and challenging behaviour and/or mental health problems, at different stages and ages.

The pilots continue to focus on improved health outcomes for people with intellectual disability through patient and carer consultation and referral, support and advice for mainstream health services, and building resources and pathways (for example, a school kit for running school clinics; Paediatrics and Adolescent Pathways through local health services; safe procedural sedation for people with intellectual disability; how to run inclusive forums; and social stories and easy English information brochures).

Investigating the establishment of a state-wide patient/client database

In relation to looking into the establishment of a state-wide patient/client database to improve client outcomes, NSW Health told us that the ACI ID Network is partnering with UNSW, using a National Health and Medical Research Council grant, to build a strong body of evidence on the health and mental health needs of people with an intellectual disability. This work builds on and extends current data linkage projects for disability and health datasets, and will link data sources held by other agencies in order to build a picture of the needs of people with intellectual disability and identify their current service pathways.

Mapping health services for people with intellectual disability

NSW Health has advised that the ACI ID Network has mapped mainstream supports and specialist health services for people with intellectual disability within NSW Health. Through the interview process in the mapping exercise, clinicians' comments were gathered about ways to improve access for people with intellectual disability. The ID Network's survey results of LHD specialist services for people with intellectual disability has been provided to LHDs.

Working with key education providers to enhance curriculum and teaching resources

In relation to work with key education providers to enhance the curriculum and teaching resources related to health care for people with intellectual disability, NSW Health told us that the ACI ID Network has worked with the Australian College of Nursing to run an inaugural two-day course in intellectual disability, and will deliver a second two-day course called Nursing Patients with ID in June 2015 in Newcastle. The ID Network is also investigating further online and postgraduate course development.

The ID Health Network has worked with NSW Health Education and Training Institute (HETI) to develop an eLearning module for health employees on disability awareness (Focus on Disability). The ID Network is currently working with HETI on another eLearning module on Justice and Disability.

The ID Health Network has produced seven short videos about health and people with intellectual disability: one is for clinicians and support staff about common respiratory concerns, including aspiration pneumonia; and another deals with mental health issues in people with intellectual disability, including challenging behaviour.

Our comments

Health's advice indicates progress with implementing each of the areas detailed under Action 6(b) in the NSW Implementation Plan for the National Disability Strategy. As identified in Chapter 5 of this report, these areas are increasingly important in the transition to the NDIS – particularly work in relation to data capture and linkages, and improving the education of health professionals on health care for people with intellectual disability. Noting the importance of this work, we will continue to monitor progress.

14. Health should provide advice to us on the department's plans for, and the progress of its work in, implementing the broader service framework, including implementing the strategies identified in relation to Tiers 1-3 to:

- a) promote the involvement of people with intellectual disability in strategic health policy and population health**
- b) improve primary and community health services' identification of, and response to, the health needs of people with intellectual disability, and**
- c) improve the capacity of the secondary health care system to care for and manage the additional health needs of people with intellectual disability.**

Progress

Promoting involvement in strategic health policy and population health

NSW Health told us that including people with disability in public consultations, advisory boards and committees, is part of the Ministry of Health's Disability Action Plan; and consultation with people with disability will be an essential element of Health's Disability Inclusion Action Plan (required under the *Disability Inclusion Act 2014*).

Health also reported that the Ministry has consulted with people with intellectual disability, their carers, and advocates, as part of its review of the *People with disability: responding to needs during hospitalisation* policy directive. Further consultation will be sought prior to finalisation of the revised policy.

The Ministry of Health is engaging with intellectual disability representative bodies on a number of projects including work on mental health and intellectual disability; guidelines for changing rooms in new NSW health facilities; and the implementation of integrated care projects across NSW LHDs. Health has also indicated that there is engagement with people at the local level through partnerships between LHDs and people with disability and/or their representatives to ensure local health services meet the health needs of people with disability. Health has told us that the development of the new Disability Inclusion Action Plan provides significant opportunities for further engagement.

Improving primary, community and secondary health services' response to disability health needs

Health advised that the three ID clinical pilots and the ACI ID Network continue to work with and support primary and community health services to improve how to identify and respond to the health needs of people with intellectual disability. The pilots also work with these services, GPs, specialists, allied health practitioners, ADHC and DEC staff to improve their capacity to care for and manage the additional health needs of people with intellectual disability.

The policy review of *People with disability: responding to needs during hospitalisation* will include strategies to implement and help promote it among health and disability professionals.

Our comments

The information provided by NSW Health in relation to the involvement of people with intellectual disability in strategic health policy and population health initiatives indicates limited progress. The involvement of people with disability in the development of Disability Inclusion Action Plans is mandatory, and consultation with this population in relation to a policy that is specifically about their needs during hospitalisation is fundamental. No information has been provided regarding how people with intellectual (or other) disability have been meaningfully engaged at large in relation to strategic health and population health policy and initiatives. The advice has underscored our view (as outlined in Chapter 5) that actions are necessary to ensure that people with disability (particularly intellectual disability) are actively considered and consulted in the development and review of all health policies.

Separately, we have welcomed the recent approach by the Ministry's Centre for Population Health to seek our advice on how to ensure that the *NSW Healthy Eating and Active Living Strategy* is inclusive of people with disability. We will also meet with Health to discuss the involvement of people with disability in broader population health initiatives, and will continue to monitor Health's work to promote the involvement of people with disability in strategic health policy and population health.

The information provided by Health in relation to actions to improve primary and community health services' identification and response to the health needs of people with intellectual disability, and to improve the capacity of the secondary health care system to meet their additional needs, is focused on the work of the three clinical pilots and the ACI ID Network. While this is reasonable given their intended roles and responsibilities, our work (as outlined in Chapter 5) points to the need for comprehensive, planned and persistent action across mainstream health services to meet the needs of people with disability in the transition to the NDIS. We will continue to monitor the progress of this work.

15. Health should inform us of its progress in appointing an organisation to undertake an independent evaluation to assess the effectiveness of the ACI Intellectual Disability Network and the three clinical service pilots in meeting the aims of the Service Framework.

Progress

NSW Health told us that KPMG is conducting the review. As at July 2014, a report from the first year had been completed, which has identified a number of strengths, challenges, and areas for improvement. The final report is due in 2015, and will inform future decisions in this area.

Our comments

We note Health's advice about the progress of the independent evaluation, and recognise that decisions relating to the Service Framework and further initiatives will be informed by broader work in NSW in the lead-up to the transition to the NDIS. We will monitor the progress of this work.

6.9. Access to preventative health support

16. Health should report to us on its progress in implementing actions under the NSW Implementation Plan for the National Disability Strategy to:

- a) improve access to information and support to help people with disability make lifestyle changes relating to healthy eating, being physically active, and achieving and maintaining a healthy weight, through the Get Healthy Information and Coaching Service (Action 6.g), and**
- b) develop a cross-agency Overweight and Obesity Plan, which encourages and promotes healthy lifestyles through better eating behaviours and physical exercise (Action 6.h).**

Progress

NSW Health told us that the Get Healthy Information and Coaching Service has the capacity to assist callers with sight, speech and/or hearing difficulty.

Health also advised that the Get Healthy at Work initiative aims to improve the health of working adults by focusing on those workers at risk of lifestyle related chronic disease through individual worker health checks and a workplace health program. Health has advised that strategies are being developed to ensure that this program is accessible to people with disability.

In addition, Health has launched the *NSW Healthy Eating and Active Living Strategy 2013-2014* in an effort to prevent overweight, obesity and lifestyle-related chronic disease in NSW. The strategy is a whole-of-government framework of policies and programs to help people adopt a healthier lifestyle through changing food and physical activity environments, as well as delivering programs and information to support healthier lifestyle choices. While the strategy has a whole-of-population focus, some actions have a focus on priority populations and will be implemented with capacity to assist people with disability.

Our comments

NSW Health's information in relation to the Get Healthy Information and Coaching Service and the Get Healthy at Work initiative highlights the importance of identifying people with intellectual disability (and particularly vulnerable people with disability more broadly) as a priority population in preventative health strategies. While people with disability in residential care have multiple lifestyle-related factors that place them at risk of chronic disease and premature death (including obesity), in the main they would require support to access and implement the Get Healthy service – including the provision of easy English information, and a partnership approach between the Get Healthy service/coach, the person with disability, and their disability support service.

As noted in our comments in relation to recommendation 14, we welcome the recent actions of the Ministry's Centre for Population Health to consult with our office and other bodies (including the Disability Council of NSW) on how to ensure that the Healthy Eating and Active Living Strategy is inclusive of people with disability. We will continue to monitor the progress of this work, and broader actions to include people with disability, including intellectual disability, in population health programs and strategies.

17. The Department of Education and Communities should report to us on its progress in implementing actions under the NSW Implementation Plan for the National Disability Strategy to:

- a) enhance information provided on specific sports for people with disability (Action 1.i.i)**
- b) develop local level inclusive sports directories to provide information, support and network opportunities available in the community for people with disability (Action 1.i.ii)**
- c) develop an online calendar of events for sport for people with disability (Action 1.i.iii), and**
- d) develop Phase 2 of the You're in the Game: NSW Disability Sport and Physical Activity Framework (Action 1.j).**

Progress

The NSW Office of Sport and Recreation has advised that it has:

- developed an online directory, *Gateway to Sport*, to provide information for people with disability to get involved in sporting activities, including 20 specific sporting activities for people with disability
- conducted forums and workshops to promote disability inclusion, including:
 - forums for sports representatives, individuals and community groups to share stories and successful programming strategies to promote disability inclusion
 - an education session for local councils and fitness professionals on creating inclusive fitness environments for people with disability, and
 - workshops involving individuals, carers, advocates and representatives from sporting organisations to better understand the sport and recreational needs of people with disability in NSW.
- introduced new partnership agreements under the *Disability Sport Program 2012-2014*, and facilitated the creation of the Disability Sport Network between nine State Sporting Organisations to enhance participation of people with disability, and
- developed a *Disability Sport Inclusion Plan 2014-2015*.

The Office of Sport and Recreation also advised that it has continued the *School Sport Disability Program*, which exposes students with disability in a number of locations to a range of sporting opportunities, and provides professional development to school staff to implement sporting activities in the school environment.

In addition, the agency told us that it worked in collaboration with the Royal Rehabilitation Centre Sydney, Australian Paralympic Committee, and State Sporting Organisations on the *Return2Sport Expo*. More than 50 organisations provided information and advice to over 650 people with disability at the Expo, and 60 corporate volunteers participated in disability awareness sessions. An inaugural regional forum was also conducted with over 300 participants with disability.

Our comments

We note the considerable work undertaken by the Office of Sport and Recreation in relation to the actions identified in the NSW Implementation Plan for the National Disability Strategy. We will not continue to monitor the progress of this work.

6.10. Support for people in assisted boarding houses

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

Progress

NSW Health advised that four non-government organisations are providing outreach support to residents of assisted boarding houses in six areas across NSW, including:

- Hunter New England
- Central Coast
- Nepean Blue Mountains, South West Sydney
- Sydney and South Eastern Sydney.

As at 30 April 2015, 167 of 190 low support packages have been used under the Boarding House (BH-HASI) program – this is 88% of the 2014/15 performance benchmark set under the National Partnership Agreement on Mental Health Reform.

Health told us that service providers maintain active promotion of the BH-HASI program by engaging and sustaining relationships with boarding house operators to enable access and connection with residents. In addition, work is underway to facilitate access to the program for other eligible boarding house residents to ensure all available packages are filled.

Health also advised that an evaluation of the BH-HASI program is currently being planned, which will 'unpack the unique challenges and lessons learned for service delivery to this client group into the future.' BH-HASI is funded under the Agreement only up to 30 June 2016.

Our comments

We welcome Health's advice on its progress in developing and implementing outreach support for people in assisted boarding houses. We will monitor the provision of this support through our reviews.

Appendix

Appendix 1

Expert advisers

We obtained expert advice from the following people in relation to the deaths of people with disability in residential care in 2012 and 2013:

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

Assoc Prof Ernest Somerville

Director, Comprehensive Epilepsy Service, Prince of Wales Hospital





NSW Ombudsman
Level 24, 580 George Street
Sydney NSW 2000

General enquiries: 02 9286 1000

Toll free (outside Sydney Metro Area, NSW only): 1800 451 524

Facsimile: 02 9283 2911

Email: nswombo@ombo.nsw.gov.au

www.ombo.nsw.gov.au