Ombudsman
New South Wales

Report of Reviewable Deaths in: 2014 and 2015 2016 and 2017

Deaths of people with disability in residential care

31 August 2018

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Ombudsman
New South Wales

31 August 2018

The Hon John Ajaka MLC
President
Legislative Council
Parliament House
SYDNEY NSW 2000

The Hon Shelley E Hancock MP
Speaker
Legislative Assembly
Parliament House
SYDNEY NSW 2000

Dear Mr President and Madam Speaker

Pursuant to section 43 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993*, I am providing you with a report titled *Report of Reviewable Deaths in 2014 and 2015 & 2016 and 2017: Deaths of people with disability in residential care.*

I draw your attention to the provisions of section 31AA of the *Ombudsman Act 1974* in relation to the tabling of this report and request that you make the report public forthwith.

Yours sincerely

Michael Barnes
Ombudsman

Foreword

This is the ninth report on the deaths of people with disability in residential care, and my first as the NSW Ombudsman. It examines the deaths of 494 people with disability that occurred in the four-year period 2014-2017 – and also draws on our work over the past 16 years.

This report is being released at a time of change in the safeguarding arrangements for the NDIS in NSW. With the start of the NDIS Quality and Safeguards Commission on 1 July 2018, some of our functions related to NDIS providers and people with disability have transferred to the NDIS Commission. In relation to the deaths of people with disability in residential care in NSW, we are working with the NDIS Commission on a joint approach that should enhance the work in this critical area. This will include the NDIS Commission examining the involvement of NDIS providers, while my office will maintain our ongoing review of the health and other service systems in NSW. We welcome the opportunity afforded by the joint arrangements to continue this vital work, with a view to potentially informing a national approach to reviewing the deaths of people with disability.

The issues identified in this report underscore the importance of continuing to examine the involvement of both disability supports and health services. Our reviews consistently demonstrate that improving health and other outcomes for many people with disability is heavily reliant on effective and cooperative work between the person with disability, disability providers, and health services. There are multiple, powerful examples of the need for effective interagency work in this report. These include individuals who did not receive the crucial support they needed to minimise their resistance to medical treatment, did not obtain timely and appropriate access to assessments and community-based support to identify and manage swallowing, falls, respiratory and obesity risks, and did not receive the assistance they required in hospital.

There have been notable developments for people with disability since our last report. These include actions by NSW Health to improve data collection, and recent additional recurrent funding to improve access to specialised support through intellectual disability health teams. However, significant change is still required to make a fundamental difference to the health outcomes of not only people with disability in residential care, but to people with disability generally.

Michael Barnes
Ombudsman

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SNAPSHOT

Deaths in 2014-2017 of people with disability in residential care

Major gaps in life expectancy when compared with the general population

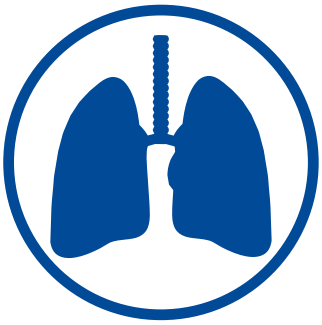
People in disability services
died at least **25 years earlier**

-25 years

People in assisted boarding houses
died around **20 years earlier.**

-20 years

Most of the deaths were **unexpected** and from **natural causes**.



Respiratory diseases
were the leading contributory
cause of death of people
in disability services

Circulatory diseases
were the leading contributory
cause of death of people in
assisted boarding houses.

Our reviews of **preventable deaths** highlight the need for concerted action to:

- **Identify illness or injury and take swift action to obtain urgent medical assistance**
- **Improve access to preventive health services and supports - particularly for smoking, obesity and other lifestyle risks**
- **Identify and effectively manage breathing, swallowing and choking risks**
- **Ensure that treatment limitation decisions are informed and not based on perceived quality of life**
- **Provide an effective first aid response**
- **Improve support and coordination of care in hospital**
- **Report 'near misses' and take action to prevent recurrence and death**
- **Provide behaviour and other support to help to minimise aversion and resistance to health services and treatment**
- **Reduce risks associated with medication - including medication errors and unsafe storage**

Executive summary

We review the deaths of people with disability in residential care in NSW – in accommodation provided by disability services (such as group homes and residential centres), and in assisted boarding houses. We identify issues that may contribute to deaths or that may affect the safety and wellbeing of people with disability in residential care, and make recommendations to reduce preventable deaths.

This is our ninth report to Parliament on the reviewable deaths of people with disability, and focuses on deaths in 2014-2017.

About the people who died (Chapter 1)

Between 2014 and 2017, the deaths of 494 people with disability in residential care were reviewable, including:

- 236 people who died in 2014 and 2015.
- 258 people who died in 2016 and 2017.

Of the 494 people:

Where they lived

234 in FACS accommodation

238 in NGO accommodation

18 in assisted boarding houses

3 in other accommodation

Average age at death

Disability services:
55 years

Assisted boarding houses:
60 years

Gender

Disability services:
Male 59%
Female 41%

Assisted boarding houses:
Male 83%
Female 17%

Main causes of death (Chapter 2)

The vast majority (89%) of the 494 deaths of people with disability in residential care in 2014-2017 were due to natural causes (illnesses and diseases). Twenty-seven people (5%) died from external (unnatural) causes, mainly associated with choking on food.

People in disability services

In 2014-2017, the leading underlying causes of death of people in disability services were:

Nervous system diseases (16.1%)
Mainly epilespy and cerebral palsy

Respiratory diseases (15.5%)
Mainly aspiration pneumonia, pneumonia and chronic obstructive pulmonary disease (COPD)

Neoplasms (13.2%)
Mainly cancer of the lung, breast and colon

Congenital and chromosomal conditions (13.2%)
Mainly Down syndrome

Circulatory system diseases (11.8%)
Mainly chronic ischaemic heart disease

Diseases of the respiratory and nervous systems have consistently been the leading causes of the deaths of people in disability services. 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 help with eating, drinking and nutrition, and mobility problems.

People in assisted boarding houses

In 2014-2017, the leading underlying causes of death of people in assisted boarding houses were:

Circulatory system diseases (27.8%)
Mainly chronic ischaemic heart disease and acute myocardial infarction

Neoplasms (27.8%)
Mainly cancer of the lung, bladder and rectum

Heart disease has consistently been one of the leading causes of death of assisted boarding house residents, as they tend to have many of the relevant risk factors, including smoking, hypertension and obesity.

Key issues identified through our reviews (Chapter 3)

Recognising and responding to critical situations

Every year, there are preventable deaths that occur because the individuals did not get timely help – including at least 42 people who died in 2014-2017.

We found that disability support staff did not consistently call for emergency help as early as possible when they were concerned or had any questions about the seriousness of the person's presenting condition. In some matters, it was clear that the person was significantly unwell – but staff did not seek urgent medical assistance.

We also found significant problems with the first aid and other responses to critical incidents, including staff who waited for a long time for an after-hours doctor to arrive and did not recognise the need to call emergency services.

The stand-out areas for improvement relate to:

Identifying illness and taking timely action

- **Support staff need to be alert to notable changes in the person's health and/or behaviour.**
- **Support staff need to call for emergency help as a matter of priority if they have concerns or any questions about whether the person's presenting condition is serious.**

Providing an effective first aid response

- **Providers need to support staff to contact emergency services first, not management.**
- **Staff need to know how to provide first aid and what to do in an emergency.**
- **Providers need to identify and address any factors that may affect first aid (such as faulty equipment).**

Escalating significant matters

- **Providers need clear guidance for staff on what they need to do if they have concerns about a person's health or behaviour - including how to escalate the matter in the organisation.**
- **Providers need robust systems for receiving and responding to concerns, and to track progress in addressing the issues.**

Managing individual risks

Breathing, swallowing and choking risks

Deaths from choking

Choking was a factor in the deaths of 11 people in 2014-2017. Most of the 11 people had known risk factors for choking, including swallowing difficulties, missing teeth, and eating and drinking behaviours (such as eating too quickly, overfilling their mouth, swallowing without adequately chewing).

Although most of the involved providers had identified the risk management strategies, our reviews have emphasised that:

Staff need to consistently follow the person's eating and drinking requirements

Effective supervision is a significant factor in reducing preventable deaths due to choking

Restrictive practices (eg: locked fridges) are not a failsafe, and do not replace effective supervision

There needs to be good communication between providers about significant risks (eg: choking) and agreed management strategies

'Close calls' (previous non-fatal choking events) must be recorded, and action taken to stop recurrence.

Deaths from respiratory diseases

Respiratory diseases routinely feature as a leading cause of death of people with disability in residential care – mainly pneumonia, aspiration pneumonia, and chronic lower respiratory diseases such as chronic obstructive pulmonary disease (COPD). Our reviews of deaths due to respiratory diseases in 2014-2017 highlighted:

- **The importance of being alert to changes in health and/or behaviour and getting swift medical assistance.** There tended to be very little time between staff identifying symptoms of illness and the person's death from influenza or pneumonia, typically a matter of hours to one week.
- The need to ensure that people with disability in residential care have **timely access to the annual influenza vaccination.**
- The need to improve the access of people with disability in residential care to specialist and preventive health programs. **Few of the people who died from chronic lower respiratory diseases in 2014-2017 had access to respiratory specialists or community-based chronic disease management support.**

We have consistently raised concerns about the very limited access of people with disability in residential care (and people with cognitive impairment more broadly) to chronic disease management and other out-of-hospital programs. Although there have been some developments, we have not identified improved access or inclusion of people with disability to these supports – despite an evident need.

Fracture risks

At least nine people with disability in residential care who died in 2014-2017 experienced fractures ahead of their death, mainly as a result of an unwitnessed fall. In most cases (6), the fracture was a factor in the person's death, including development of respiratory illness and death within a short period.

A key issue we identified in relation to many of the people who experienced fractures ahead of their death was delayed identification of the fracture – either by disability support staff and/or by health services. These matters underscored the importance of:

Disability supports

- **knowing the person and being alert to any changes**
- **getting medical help without delay where there are any concerns or questions about the seriousness of the condition (eg: signs of pain)**
- **making sure health professionals have all relevant information to enable an accurate diagnosis**
- **clearly identifying and managing falls risks, including taking timely action in response to falls to prevent recurrence.**

Health services

- **making sure they understand the person's communication needs, and consult with people who know them well to enable an accurate diagnosis**
- **having mechanisms to coordinate access and care for people with disability - such as a clinical pathway for people with cognitive impairment, or specialised roles to provide advice.**

Bowel management

A high proportion of people in disability services who have died had constipation and other bowel dysfunction, and bowel obstructions and other bowel issues consistently feature as their cause of death.

Our reviews of deaths in 2014-2017 identified a range of matters in which there were deficits in bowel management for the person, such as:

- inadequate guidance for staff on what they needed to do to help the person to manage their bowel health
- lack of investigation into the cause of faecal incontinence
- staff not consistently following bowel management recommendations
- staff not seeking medical help for people who had been constipated for an extended period of time
- staff not recognising and responding in a timely way to signs of bowel obstruction.

Consistent with our advice about identifying and managing other key health risks, our reviews of these matters emphasise the need for disability supports to:

Know the person - the support they need with their bowel health, their usual presentation, and common signs of critical health changes for them (such as signs of bowel obstruction)

Be alert to changes in health or behaviour, including any common indicators of illness for the person

Get medical assistance for the person without delay

Obesity, smoking and other lifestyle risks

Our reviews of deaths in 2014-2017 continued to identify the substantial health risks faced by people with disability in residential care associated with smoking, obesity, poor diet and lack of physical activity.

Smoking

- **The rates of daily smoking in the general population have dropped to around 15%.**
- **The smoking rates of the people in assisted boarding houses who died in 2014-2017 were 61%. In the 15 year period 2003-2017, 78% of the assisted boarding house residents who died had smoked.**
- **The adverse effect on their health outcomes is significant - their leading causes of death over the 15 years to 2017 are all associated with smoking: acute myocardial infarction, chronic ischaemic heart disease, COPD, and lung cancer.**

Obesity, poor diet and lack of physical activity

- **In disability services, 37% of the people who died in 2014-2017 were above the healthy weight range - including 76 people (16%) who were obese or severely obese.**
- **In assisted boarding houses, 44% of the residents who died in 2014-2017 were above the healthy weight range - most of whom (7) were obese or severely obese.**
- **Chronic respiratory disease, diabetes and heart disease featured prominently in the deaths of the people who were above the healthy weight range when they died.**

With support, people with disability can reduce many of these lifestyle risk factors that can lead to death. However, our reviews of deaths in 2014-2017 have shown that significant action is required to ensure that they have access to the necessary support.

Our reviews continue to identify the need for:

People with disability in residential care who smoke, and the people who support them, to have access to information about the help that is available to quit.

Proactive efforts by disability services, health providers, and population health programs to help people with disability in residential care to address their critical weight issues.

Medication risks

People with disability in residential care face substantial risks related to medication, such as medication toxicity and adverse effects from medication interactions. Our reviews of the deaths of people in residential care in 2014-2017 identified significant issues relating to the management of medication risks, including:

- multiple medication errors, and poor reporting of the errors
- staff not administering medication as prescribed
- poor medication administration records
- poor responses to medication refusal by individuals
- failure to safely store medications.

The evident gaps in the systems of providers to readily identify when errors have occurred, review the incidents to identify the cause(s), and take action to prevent recurrence are concerning.

Our reviews have pointed to the need for providers to ensure that staff induction and training is supplemented by:

Robust internal systems for monitoring and improving practice

A strong workplace culture that supports and encourages the reporting of incidents and concerns

Clear mechanisms for ensuring that early and effective action is taken to mitigate risks

Support to access health services and treatment

Support to minimise resistance to health assessments and treatment

Every year, we identify people with disability in residential care whose behaviour or decisions adversely affected their health and medical treatment. Our reviews of deaths in 2014-2017 identified at least 24 people whose access to necessary medical assistance was compromised as a result of their resistance to assessment or treatment.

The resistance of the individuals often had significant and adverse consequences for them – including that it affected the treatment and life-limiting decisions that were made by their health professionals and family members.

It is critical that individuals who are resistant or averse to treatment receive support to address these issues and reduce the adverse impact on their health outcomes. 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.

Our reviews emphasise the vital importance of:

Person-centred and coordinated support to help to minimise the person's aversion and resistance to health examinations and treatment.

Making sure that resistance to health examinations or treatment is identified and specifically targeted for positive behaviour support.

Support in hospital

In many cases, the greatest impact of a person’s resistance or aversion to medical treatment is experienced in the hospital setting. Our reviews of deaths in 2014-2017 identified people with disability whose behaviour or actions affected their health and medical treatment in hospital, with significant consequences, including:

- incomplete examinations and investigations because of physical resistance
- decisions by medical practitioners (and families) to stop or limit treatment because of the person’s distress, behaviour, or other presentation
- the use of mechanical and chemical restraints to prevent individuals from removing or pulling out treatment and/or from getting out of bed.

Our reviews continue to emphasise the importance of:

Ensuring that behaviour support strategies specifically target the person's resistance to medical assessment and treatment - including in the hospital setting.

Health and disability support staff working together, and with the person with disability, to facilitate appropriate and person-centred support in hospital.

Support providers clearly identifying individuals who have this behaviour/aversion, and taking steps to ensure that the need for this support is understood by the NDIA to enable the provision of behaviour assessment and support, and support in hospital.

Transfer of care

Some of our reviews raised concerns about the actions of health services in relation to the transfer of care of individuals from hospital to home (discharge planning). This included where:

- vital information was not provided in the discharge plan – such as a change to the person's meal consistency
- the person was discharged back home without consideration as to whether their health needs could be adequately met with the existing supports – despite multiple admissions and readmissions over a short period of time, a decline in their health, and increasing risks.

Since our last report, NSW Health has reviewed and revised its policy on responding to the needs of people with disability during hospitalisation and this provides useful guidance. However, our work has shown that good policy does not guarantee good practice. Effective monitoring of the implementation of the policy across health services is critical.

End-of-life care and decision-making

Advance Care Directives

Our reviews of the deaths of people with disability in residential care in 2014-2017 identified a number of individuals who had Advance Care Directives, despite not having the evident capacity to make such a directive. We also had concerns that family members and staff members were signing the directives, and in some cases the directives appeared to be developed as standard practice, with multiple residents having the same document.

It is important that:

Advance Care Directives are only developed by people who, at the time that the directive is drafted, have the capacity to make informed decisions about their health care.

The development of an Advance Care Directive is optional, and is not developed as a matter of course.

Decisions based on perceived quality of life

In some of the deaths of people with disability in residential care in 2014-2017, we had concerns about the treatment limitation decisions of family members, including:

- decisions for conservative treatment – despite health practitioners providing options for active treatment of reversible conditions, including surgery
- treatment limitation decisions based on a perceived quality of life of the person, including that active treatment would not be in their 'best interests' or 'appropriate'.

Given the serious and irreversible consequences for the person with disability, it is important that:

Treatment limitation decisions are informed by the people who know the person well, including, where relevant, disability support staff.

Treating practitioners clearly explain to family members the available options, including active treatment.

Maximum efforts are made to address any issues that are influencing the treatment limitation decision, including options for providing support to reduce distress and pain.

Any party with concerns about the treatment limitation decision - including health practitioners and disability support staff - consider whether an application needs to be made to NCAT for the appointment of an alternative substitute decision-maker.

Incident reporting and internal reviews

The disability reportable incidents scheme has facilitated improvements in incident reporting by staff, with an emphasis in the scheme on service providers developing and maintaining a staff culture of reporting. However, our reviews of the deaths of people with disability in residential care in 2014-2017 have identified areas for further improvement. There is particularly the need for an increased focus on reporting:

- significant behaviour or changes in behaviour – including resistance or objection to medical treatment
- medication incidents
- falls – including unwitnessed falls
- significant health events or changes in health
- 'close calls' or 'near misses' – such as near-fatal choking incidents.

It is only through reporting, reviewing and responding to incidents that effective action can be taken to prevent recurrence or worse outcomes for individuals.

Our reviews identified a range of matters where, had incident reports been lodged and critically examined, it would have enabled the providers to:

- identify at an early point where staff needed greater assistance in providing support or managing risks
- recognise where staff needed refresher training
- identify unacceptable staff practices that required early action.

It is critical that providers:

Provide clear guidance to staff about the matters that need to be reported as incidents, rather than just recorded in progress notes or communication books.

Have documented, robust, and well-understood systems in place for reviewing and responding to incident reports.

Recommendations

Managing breathing, swallowing and choking risks

1. NSW Health should consider the information in this report relating to swallowing assessments, mealtime management plans and the NDIS, in particular:

   a) the responsibilities of the health system to diagnose and assess dysphagia and develop the mealtime management plan for people with disability, and

   b) the risks faced by people with disability if the health system is not sufficiently equipped to meet their needs and/or the demand.

   NSW Health should provide this office with details of current or proposed strategies to address these issues and meet demand in relation to people with disability.

2. NSW Health should consider the issues identified in this report relating to the access of people with disability and chronic respiratory diseases to community-based chronic disease management support, and provide this office with details of current or proposed strategies to address these issues.

Managing fracture risks

3. NSW Health should consider the information in this report relating to the diagnosis of fractures in people with cognitive impairment and communication difficulties, and provide this office with details of current or proposed strategies to address these issues.

Support to access health services and treatment

4. NSW Health should consider the information in this report relating to support for people with disability to access health services and treatment, in particular:

   a) patients with disability who are resistant to examination or treatment in hospital, and

   b) mechanisms to coordinate access and care for people with disability.

   NSW Health should provide this office with details of current or proposed strategies to address these issues.

5. NSW Health should provide this office with a copy of the report from its joint research project with FACS on how to achieve the best hospital discharge for clients with disability and complex needs, and provide details of the actions it will take in response.

6. NSW Health should provide this office with a copy of the report from the evaluation of the Joint Guideline, and provide details of the actions it will take in response.

7. NSW Health should provide this office with a detailed progress report on its actions to implement its Disability Inclusion Action Plan in relation to:

   a) Strategy 6: 'Provide support to consistently improve disability inclusion and extend existing good practice in delivering person centred care to people with disability across the system' (actions 6.1 and 6.2)

   b) Strategy 7: 'Service delivery organisations will engage meaningfully with people with disability, their carers and families and relevant key partner agencies' (action 7.1), and

   c) Strategy 8: 'Deliver enhanced services and build greater accountability by improving our data collection and reporting on disability inclusion' (action 8.1).

Introduction

Since December 2002, the Ombudsman's office has had responsibility for reviewing the deaths of people with disability in residential care.

This is the ninth report of reviewable disability deaths, and covers two biennial periods:

- 1 January 2014 to 31 December 2015, involving the deaths of 236 people with disability in residential care
- 1 January 2016 to 31 December 2017, involving the deaths of 258 people with disability in residential care.

Our role in reviewing the deaths of people with disability

Under Part 6 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CS CRAMA), the Ombudsman is required to review the deaths of certain children, and the deaths of any person living in, or temporarily absent from, residential care provided by a service provider[1] or an assisted boarding house. Until 30 June 2018, our reviewable deaths jurisdiction included residential care provided by persons or organisations that are funded under the National Disability Insurance Scheme (NDIS).

Our reviews focus 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 changes or strategies that may help to prevent avoidable deaths. In part, we do this by considering how agencies have acted, and can act, to promote the health, safety and wellbeing of people with disability in residential care.

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

Our work arising from deaths in 2014-2017

In some cases, our reviews highlight issues that warrant further inquiries about the conduct of an agency, or other action. The *Ombudsman Act 1974 and* CS CRAMA enable us to take a range of further actions, including conducting preliminary inquiries, investigating the conduct of agencies, making reports to agencies about issues arising from reviews and seeking information, and referring issues to other agencies, such as the Health Care Complaints Commission (HCCC) and the Coroner.

At time of writing this report, we had raised issues with agencies in relation to our reviews of the deaths of 84 people in 2014-2017.[2] In some cases, the issues related to more than one agency.

We brought issues to the attention of multiple agencies, including the Department of Family and Community Services (FACS) and 20 non-government disability service providers, 10 health services (including nine Local Health Districts), the NSW Ambulance Service, and the Department of Education.

We met with agencies to obtain further information and to discuss our concerns about the deaths of 35 people. Most of these matters also involved reports to agencies or other action.

We obtained advice from members of our reviewable disability deaths expert advisory panel in relation to the deaths of 55 people, and made referrals to the HCCC about the conduct of medical practitioners in relation to the deaths of seven people.

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1. 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; a person or organisation that is covered by an arrangement between a NSW Minister 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.
2. The 84 people include 61 people who died in 2014-2015, and 23 people who died in 2016-2017.

The issues identified through our reviews of deaths in 2014-2017, including those raised in our reports to agencies, are reported in Chapter 3.

Key developments since our last report

We tabled our last biennial report on the deaths of people with disability in residential care in June 2015. Since that time, there have been significant developments in the support, quality and safeguarding arrangements for people with disability. Some of these arrangements directly affect our reviews of the deaths of people in residential care.

Deaths of people with disability and the NDIS Quality and Safeguarding Framework

On 1 July 2018, the NDIS Quality and Safeguards Commission (the NDIS Commission) commenced in NSW and South Australia. Its functions include:

- the registration and regulation of NDIS providers, including practice standards and a code of conduct
- compliance monitoring, investigation and enforcement action
- responding to complaints and reportable incidents, including abuse and neglect of a person with disability
- national policy setting for the screening of workers
- national oversight and policy in relation to behaviour support and monitoring restrictive practices within the NDIS
- information sharing arrangements.

Under section 73Z of the *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Act 2017,* the reportable incidents scheme includes incidents that 'occur, or are alleged to have occurred, in connection with the provision of supports or services by registered NDIS providers', and include the death of a person with disability.

At the same time, the NSW Minister for Disability Services and the Commonwealth Minister for Social Services entered into an arrangement to enable our office to continue to have jurisdiction in relation to the deaths of people with disability in residential care for the period 1 July 2018 to 1 July 2019.[3] The Ministers agreed that the NDIS Commission and the NSW Ombudsman should work together to establish operational arrangements to ensure that there is no duplication of effort in relation to any individual matter, including the current functions of our office and the NSW Coroner in relation to reviewable deaths.

In effect, this arrangement will ensure that the deaths of people with disability in residential care continue to be examined, with an ongoing focus on preventing or reducing avoidable deaths. The arrangements and joint approach between our office and the NDIS Commission for the deaths of people with disability in residential care will enable:

- the NDIS Commission to examine the actions of registered NDIS providers
- the NSW Ombudsman to examine the intersection with, and actions of, NSW service systems – such as health, justice and other services.[4]

It is also important to note that the deaths of people with disability that registered NDIS providers are required to notify to the NDIS Commission are not limited to people living in residential care. This wider scope, and national reach,[5] provides a valuable opportunity to examine contributory factors to the preventable deaths of people with disability on a broader scale.

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3. The arrangement extends the definition of a 'service provider' within the meaning of s4(1) of the CS CRAMA to include 'a person or organisation who provides supports to a NSW NDIS participant where that person or organisation is authorised or funded as part of a participant's plan' for the period 1 July 2018 to 1 July 2019.
4. CS CRAMA provides the Ombudsman with continued jurisdiction over the deaths of people with disability in assisted boarding houses and residential care provided by services funded, authorised or licensed by relevant NSW Ministers (such as the remaining residential centres operated by FACS). In relation to the deaths of people with disability in these residential care settings, the review of the person's death by our office will continue to encompass both the actions and involvement of the disability provider(s) and the broader NSW service systems.
5. The NDIS Commission started in NSW and SA on 1 July 2018, and will progressively commence in the other states and territories over the next two years, including Victoria, ACT, NT, Queensland and Tasmania on 1 July 2019, and WA on 1 July 2020.

The arrangements in NSW during 2018/19 may also provide a template for other jurisdictions to consider, and potentially lead to a national approach to reviewing the deaths of people with disability and to identifying strategies for reducing deaths.

Research on potentially avoidable deaths of adults with intellectual disability

We are a partner in a National Health and Medical Research Council Partnerships for Better Health Project on *Improving the Mental Health Outcomes of People with Intellectual Disability*. In 2017, supported by the project, the Chair of Intellectual Disability Mental Health, Professor Julian Trollor, and other researchers at the UNSW Department of Developmental Disability Neuropsychiatry, published research on *Cause of death and potentially avoidable deaths of Australian adults with intellectual disability using retrospective linked data*.[6] The research examined retrospective population-based standardised mortality of a cohort of adults with intellectual disability and a comparison NSW general population cohort. The research identified that:

- Adults with intellectual disability experience premature mortality and over-representation of potentially avoidable deaths.
- The median age at death of the cohort with intellectual disability was 54 years.
- People with intellectual disability had much higher proportions of potentially avoidable deaths (38%) than people without intellectual disability (17%). Potentially avoidable deaths were dominated by deaths due to infections, diseases of the circulatory system, cancer and other external causes.
- Overall, people with intellectual disability had 1.3 times the death rate of the comparison group. The difference was substantially higher for 20-44 (4.0) and 45-64 (2.3) year age groups.

The research reinforces the findings from our reviews of the deaths of people with disability over the past 15 years relating to premature mortality and causes of death. However, as our reviews are limited to a subset of the population of people with disability (those in residential care), it is difficult to make comparisons with the general population. The research by Trollor et al is an important comparative study that highlights the disparity in health outcomes for people with intellectual disability. It adds weight to the evidence we have reported over an extended period of time, including in this report.

This report

This ninth report on the reviewable deaths of people with disability in residential care covers two periods – deaths in 2014 and 2015, and deaths in 2016 and 2017. We have covered both periods in this report because:

- The issues identified in our reviews of deaths in both periods are largely consistent, and an examination of the four-year period supports enhanced analysis while reducing duplication in reporting.
- The recommendations in our June 2015 report are far-reaching and have required a longer time frame for agencies to progress.
- On 1 July 2018, our reviewable deaths jurisdiction for people with disability in residential care changed.

In line with our reporting requirements in CS CRAMA, we have reported the key data and information for each two-year period. Where relevant, we have also reported trends and patterns over the 15-year period, 2003-2017, for comparative analysis.

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[6] Trollor J, Sraseubkul P, Xu H, et al Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. BMJ Open 2017:7:e013489. Doi: 10.1136/bmjopen-2016-013489. http://bmjopen.bmj.com/content/7/2/e013489.

Part One provides key data for each period, including:

- demographic and other information about the people who died (Chapter 1)
- causes of death (Chapter 2).

Part Two outlines the issues arising from the reviews of deaths in both biennial periods – and – where relevant – over a longer period (Chapter 3).

Part Three details the recommendations we made in our last report and the progress made by agencies in implementing them (Chapter 4).

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

Part One:

Key data

Chapter 1. About the people who died

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

In this chapter, we report demographic and other information about the people who died in the two biennial periods spanning 1 January 2014 to 31 December 2017. Where relevant, we have compared deaths in these periods to those that occurred across the 15 years between 2003 and 2017 and noted differences, where they exist.

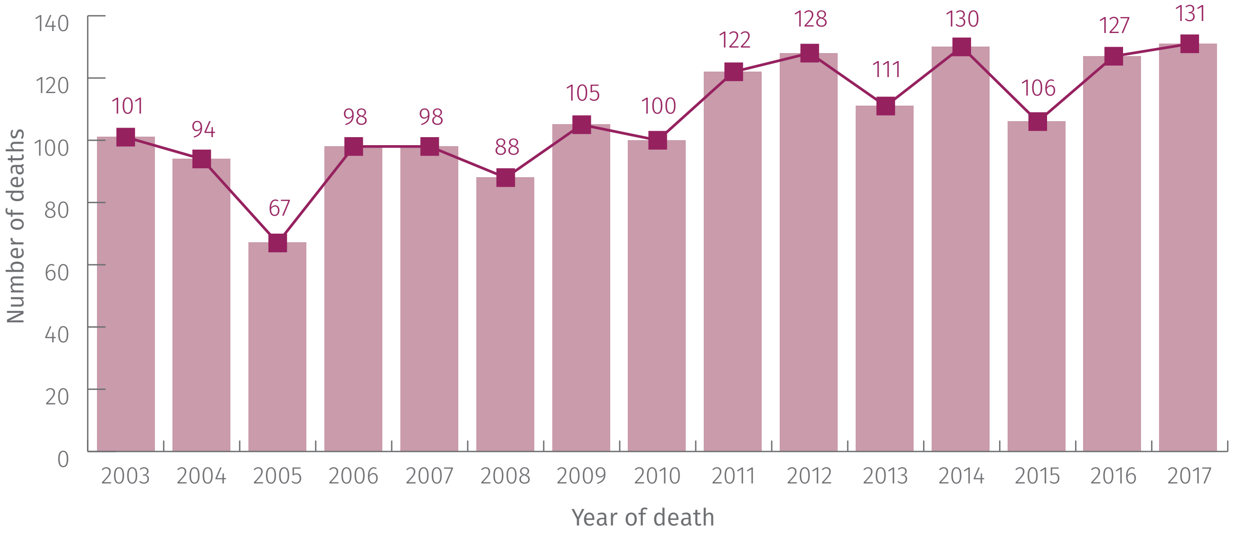
1.1. Reviewable disability deaths in 2014-2017

Residential care includes group homes, residential centres (institutions), assisted boarding houses, and other accommodation for people with disability, such as centre-based respite.[7]

Between 2014 and 2017, the deaths of 494 people with disability in residential care were reviewable. This included:

- 236 people who died in 2014 and 2015.
- 258 people who died in 2016 and 2017.

Figure 1: Number of deaths of people with disability in residential care, 2003-2017



As shown in Table 1, of the 494 reviewable deaths of people with disability in residential care in 2014-2017:

- 234 people (47%) lived in FACS accommodation
- 238 people (48%) lived in non-government organisation (NGO) accommodation – FACS or NDIS funded
- 18 people (4%) lived in assisted boarding houses
- three people (0.6%) were living in private or community housing with FACS or NGO support.

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[7] We also include the deaths of some people with disability who received drop-in support from a disability service provider. In the main, we include the deaths of people receiving drop-in support where: a) the person was receiving support to the extent that they would not have been able to continue to live independently in the community without that assistance; b) the person was living in accommodation that was owned or managed by a disability service provider; and/or c) the person was living in accommodation that had overnight staffing support on-site.

Where relevant, we have separated the data on the deaths of people in FACS 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.

Table 1: Deaths of people with disability in residential care, by provider, 2014-2017

Provider	2014-2015	2016-2017	Total
FACS operated accommodation	110	124	**234**
NGO operated accommodation	117	121	**238**
Assisted boarding houses	8	10	**18**
Other	1	2	**3**
Total	**236**	**258**	**494**

As shown in Table 2 and Table 3, NGO group homes make up the largest proportion (52%) of people with disability in residential care, and accounted for the largest proportion (39%) of reviewable deaths in 2014-2017.

Table 2: Deaths of people with disability in residential care in 2014-2015

Accommodation	Estimated total no. of residents 2014-2015	No. of deaths 2014-2015 (N=236)	% of population who died in 2014-2015	% of reviewable disability deaths
Group home (funded)	3667	96	2.6	40.7
Group home (FACS)	1613	30	1.9	12.7
Residential centre (funded)	307	21	6.9	8.9
Residential centre (FACS)	740	80	10.8	33.9
Assisted boarding houses	463	8	1.7	3.4
Other	-	1	-	0.4
Total	**6788**	**236**	**3**	**100**

Table 3: Deaths of people with disability in residential care in 2016-2017

Accommodation	Estimated total no. of residents 2016-2017	No. of deaths 2016-2017 (N=258)	% of population who died in 2016-2017	% of reviewable disability deaths
Group home (funded)	3597	99	2.8	38.4
Group home (FACS)	1768	47	2.7	18.2
Residential centre (funded)	257	22	8.6	8.5
Residential centre (FACS)	591	77	13.0	29.8
Assisted boarding houses	1051	10	1.0	3.9
Other	-	3	-	1.2
Total	**7262**	**258**	**4**	**100**

1.1.1. Length of time in accommodation

On average, the people in disability services who died had lived in residential care for over 30 years,[8] and had lived at their current residence for 12 years.[9]

On average, the people in assisted boarding houses who died had lived in residential care for over 10 years,[10] and had lived at their current residence for eight years.[11]

1.2. Age, gender and cultural status

1.2.1. Age

For people in disability services, the mean age at death was 55 years for both biennial periods,[12] slightly higher than the 15-year average of 53.7 years.

For people in assisted boarding houses, the mean age at death was 58.3 years in 2014 and 2015, and 62.5 years in 2016-2017. The 15-year average age at death for assisted boarding house residents was 63 years.

1.2.2. Gender

Consistent with previous years, most of the people in residential care who died in 2014-2017 in both disability services and assisted boarding houses were male.

- Over half of the people who died in disability services in 2014-2015 (137; 60%) and in 2016-2017 (145; 58%) were male.
- The majority of the people who died in assisted boarding houses in 2014-2015 (6; 75%) and in 2016-2017 (9; 90%) were male.

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.

1.2.3. Cultural status

Aboriginal and/or Torres Strait Islander status

In disability services, two people (1%) who died in 2014-2015 were identified as Aboriginal and/or Torres Strait Islander, as were six people (2%) who died in 2016-2017.

In assisted boarding houses, one person who died in 2014-2015 was identified as Aboriginal and/or Torres Strait Islander, as was one person who died in 2016-2017.

Culturally and linguistically diverse background

In disability services, 17 people (7%) who died in 2014-2015 were identified as having a culturally and linguistically diverse background, and 12 people (5%) who died in 2016-2017.

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[8] For people in disability services, the average length of time in residential care was 31 years for people who died in 2014-2015; and 32 years for people who died in 2016-2017.

[9] For people in disability services, the average length of time at their current residence was 13 years for people who died in 2014-2015; and 10 years for people who died in 2016-2017.

[10] For people in assisted boarding houses, the average length of time in residential care was 12 years for people who died in 2014-2015; and 13 years for people who died in 2016-2017.

[11] For people in assisted boarding houses, the average length of time at their current residence was nine years for people who died in 2014-2015, and six years for people who died in 2016-2017.

[12] The mean age at death was 54.8 in 2014-2015, and 55.3 in 2016-2017.

In assisted boarding houses, one person who died in 2014-2015 was identified as having a culturally and linguistically diverse background, and two people (20%) who died in 2016-2017.

1.3. Disability and support needs

Information about the disability and support needs of people who died in 2014-2017 is largely consistent with previous years.

1.3.1. Disability

As shown in Table 4 and Table 5, the vast majority of the people in disability services who died in 2014-2017 had a cognitive impairment (including intellectual disability, dementia, and acquired brain injury). Most also had other impairments, including sensory, physical and psychosocial disability.

Most of the people in assisted boarding houses who died in 2014-2017 had a psychosocial disability. Some also had a cognitive impairment, including intellectual disability and alcohol-related brain damage, and a sensory impairment.

Table 4: Number and percentage of people with disability in residential care who died in 2014-2015, by impairment and service type

	Disability services (N = 228)		Assisted boarding houses (N = 8)		Total (N = 236)	
	N	%	N	%	N	%
Intellectual	208	91.2	3	37.5	211	89.4
Sensory	169	74.1	4	50.0	173	73.3
Physical	127	55.7	0	0.0	127	53.8
Psychosocial	100	43.9	6	75.0	106	44.9
Neurological	57	25.0	2	25.0	59	25.0
Acquired brain injury	25	11.0	1	12.5	26	11.0
Autism	19	8.3	0	0.0	19	8.1

Table 5: Number and percentage of people with disability in residential care who died in 2016-2017, by impairment and service type

	Disability services (N = 248)		Assisted boarding houses (N = 10)		Total (N = 258)	
	N	%	N	%	N	%
Intellectual	225	90.7	3	30.0	228	88.4
Sensory	186	75.0	2	20.0	188	72.9
Physical	137	55.2	0	0.0	137	53.1
Psychosocial	129	52.0	8	80.0	137	53.1
Neurological	61	24.6	0	0.0	61	23.6
Acquired brain injury	26	10.5	3	30.0	29	11.2
Autism	17	6.9	0	0.0	17	6.6

1.3.2. Consent to treatment

For the majority of the people in disability services who died in 2014-2017, other people – mainly family members – provided consent to medical and dental treatment on their behalf. Family provided consent to treatment for 155 people (68%) who died in 2014-2015, and 166 people (67%) who died in 2016-2017. The proportion of disability services residents who died who had provided their own consent to treatment was 11% in 2014-2015, and 13% in 2016-2017.

The vast majority of assisted boarding house residents who died provided their own consent to medical and dental treatment, including all but one person who died in 2014-2015 (88%), and all but one person who died in 2016-2017 (90%).

1.3.3. Mobility and communication support

Most of the people in disability services who died in 2014-2015 (72%) and 2016-2017 (70%) required help with mobility; half of the disability services residents relied on wheelchair support. Most also needed communication support, including 58% in 2014-2015 and 61% in 2016-2017. The proportion of people in disability services who used verbal language was higher than the 15-year average – 39% of people who died in 2014-2015 and 38% in 2016-2017 communicated using verbal language, compared with 13% overall in the 15-year period 2003-2017.

None of the assisted boarding house residents who died in 2014-2015, and one person who died in 2016-2017 required help with mobility. None of the residents required communication support.

1.3.4. Assistance with eating, drinking and swallowing

Consistent with previous years, most of the people in disability services who died in 2014-2017 required assistance with meals, associated with swallowing difficulties, eating problems, or both. None of the assisted boarding house residents who died required this assistance.

Of the people in disability services who died in 2014-2017:

- 54 (11%) relied on enteral nutrition (tube feeding), primarily via a percutaneous endoscopic gastrostomy (PEG) tube, including 24 people in 2014-2015, and 30 people in 2016-2017. The majority (85%) had seen a dietitian in the year before they died, including 88% in 2014-2015, and 83% in 2016-2017.
- Two thirds (310; 65%) had swallowing difficulties, including 151 people (66%) in 2014-15, and 159 people (64%) in 2016-17. The majority (87%) had seen a speech pathologist and/or attended a dysphagia clinic in the year before they died, including 83% in 2014-15 and 90% in 2016-17.
- Just over half (243; 51%) had eating and drinking mealtime behaviours, such as swallowing without chewing, eating too quickly, overfilling their mouth, and compulsive behaviour around food. This included 43% of the disability services residents who died in 2014-2015, and 58% in 2016-2017.

Over the 15 years to 2017, 65% of disability services residents who died had swallowing difficulties, and 64% had eating problems.

1.4. Health needs

1.4.1. Dentition

Table 6 and Table 7 show that most (68%) of the people with disability in residential care who died in 2014-2017 were missing some or all of their teeth, including the vast majority of the assisted boarding house residents who died.

Over the 15 years to 2017, 71% of people with disability in residential care were missing some or all of their teeth, including 70% of the disability services residents and 77% of the boarding house residents who died.

The proportion of people in disability services and assisted boarding houses who had all of their teeth was slightly higher among people who died in 2016-2017 (35%) compared with 2014-2015 (29%).

Table 6: Dentition status of people with disability in residential care who died in 2014-2015

Dentition	Disability services (N = 228)		Assisted boarding houses (N = 8)		Total (N = 236)	
	N	%	N	%	N	%
All teeth	69	30.3	0	0.0	69	29.2
Only some teeth	74	32.5	5	62.5	79	33.5
No teeth	61	26.8	2	25.0	63	26.7
Dental aid	24	10.5	1	12.5	25	10.6
Total	**228**	**100.1**	**8**	**100.0**	**236**	**100.0**

Table 7: Dentition status of people with disability in residential care who died in 2016-2017

Dentition	Disability services (N = 248)		Assisted boarding houses (N = 10)		Total (N = 258)	
	N	%	N	%	N	%
All teeth	89	35.9	2	20.0	91	35.3
Only some teeth	84	33.9	5	50.0	89	34.5
No teeth	68	27.4	0	0.0	68	26.4
Dental aid	7	2.8	3	30.0	10	3.9
Total	**248**	**100.0**	**10**	**100.0**	**258**	**100.1**

Consistent with previous years, two-thirds (329; 69%) of the people in disability services who died in 2014-2017 had seen a dentist in the year before their death. One-third (6; 33%) of the boarding house residents who died in the same period had seen a dentist, which is a slightly lower proportion than previous years.

1.4.2. Weight

Just over one-third (193; 39%) of the people with disability in residential care who died in 2014-2017 were in the healthy weight range (body mass index (BMI) of 18.5-24.9kg/m$^{2)}$, including 39% of the disability services residents and 28% of the assisted boarding house residents who died.

The proportion of people in the healthy weight range has been low over the 15 years to 2017. Only 36% of the people in residential care who died were in the healthy weight range, including 39% of those who lived in disability services, and 19% of those who lived in assisted boarding houses.

As shown in Table 8, for the people in disability services who died in 2014-2017:

- over one-third (177; 37%) were overweight, obese or severely obese
- a smaller proportion (74; 16%) were underweight or very underweight.

Just over half (141; 56%) of those outside of the healthy weight range had seen a dietitian. A higher proportion (85%) of people who were underweight or very underweight had seen a dietitian, compared with those who were overweight, obese or severely obese (54%).

Table 8: Weight status of people in disability services who died in 2014-2017

Weight range	2014-2015 (N=228)		2016-2017 (N=248)		Total (N=476)	
	N	%	N	%	N	%
Severely underweight (≤16.0kg/m²)	22	9.6	24	9.7	46	9.7
Underweight (16-18.4kg/m²)	9	3.9	19	7.7	28	5.9
Healthy weight (18.5-24.9kg/m²)	99	43.4	89	35.9	188	39.5
Overweight (25.0-29.9kg/m²)	47	20.6	54	21.8	101	21.2
Obese (30.0-39.9kg/m²)	18	7.9	15	6.1	33	6.9
Severely obese (≥40.0kg/m²)	19	8.3	24	9.7	43	9.0
Unknown	14	6.1	23	9.3	37	7.8
Total	**228**	**100**	**248**	**109**	**476**	**100**

As shown in Table 9, just under half (8; 44%) of the people in assisted boarding houses who died in 2014-2017 were overweight, obese or severely obese. One resident was very underweight.

Only a few (3; 33%) of the nine boarding house residents who were outside of the healthy weight range had seen a dietitian. The one boarding house resident who was very underweight when they died in 2016-2017 had not seen a dietitian. Only two of the eight boarding house residents who were above the healthy weight range had seen a dietitian.

Table 9: Weight status of people in assisted boarding houses who died in 2014-2017

Weight range	2014-2015 (N=8)		2016-2017 (N=10)		Total (N=18)	
	N	%	N	%	N	%
Severely underweight (≤16.0kg/m²)	0	0.0	1	10.0	1	5.6
Underweight (16-18.4kg/m²)	0	0.0	0	0.0	0	0.0
Healthy weight (18.5-24.9kg/m²)	2	25.0	3	30.0	5	27.8
Overweight (25.0-29.9kg/m²)	1	12.5	0	0.0	1	5.6
Obese (30.0-39.9kg/m²)	1	12.5	3	30.0	4	22.2
Severely obese (≥40.0kg/m²)	2	25.0	1	10.0	3	16.7
Unknown	2	25.0	2	20.0	4	22.2
Total	**8**	**100**	**10**	**100**	**18**	**100**

1.4.3. Other key health issues

As has consistently been the case, most of the people in disability services who died in 2014-2017 had health conditions that required treatment and/or support. Constipation and incontinence were common, and many of the health issues presented breathing, choking and swallowing risks – including mobility problems, dental problems, swallowing difficulties, gastro-oesophageal reflux disease (GORD), eating problems, epilepsy and aspiration.

Table 10: Main health issues of people in disability services who died in 2014-2017

Health issue	2014-2015 (N=228)		2016-2017 (N=248)		Total (N=476)	
	N	%	N	%	N	%
Constipation	172	75	186	75	358	75
Mobility problems	163	71	172	69	335	70
Incontinence	165	72	165	67	330	69
Dental problems	159	70	160	65	319	67
Swallowing difficulties	151	66	159	64	310	65
Gastro-oesophageal reflux disease (GORD)	145	64	150	60	295	62
Eating problems	99	43	144	58	243	51
Epilepsy	115	50	115	46	230	48
Osteoporosis	84	37	95	38	179	37
Overweight	84	37	93	38	177	37
Vitamin deficiency	67	29	103	42	170	36
Hypertension	71	31	74	30	145	30
Aspiration pneumonia	45	20	63	25	108	23
Arthritis/osteoarthritis	61	27	39	16	100	21
Heart problems[13]	49	21	44	18	93	20
Hypothyroidism	37	16	56	23	93	20
High cholesterol	37	16	55	22	92	19
Underweight	37	16	45	18	82	17
Urinary tract infection	34	15	48	19	82	17
Asthma	33	14	38	15	71	15

The most common health issues for the people in assisted boarding houses who died in 2014-2017 were dental problems, chronic lower respiratory diseases such as COPD, and obesity. Many of the common health issues presented respiratory and/or circulatory risks.

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[13] Including congestive cardiac failure, atrial fibrillation, heart disease, heart failure, cardiomyopathy, angina.

Table 11: Main health issues of people in assisted boarding houses who died in 2014-2017

Health issue	2014-2015 (N=8)		2016-2017 (N=10)		Total (N=18)	
	N	%	N	%	N	%
Dental problems	7	88	8	80	15	83
COPD/CAL/COAD	3	38	6	60	9	50
Overweight	5	63	4	40	9	50
High cholesterol	5	63	1	10	6	33
Gastro-oesophageal reflux disease (GORD)	1	13	5	50	6	33
Hypertension	3	38	2	20	5	28
Incontinence	3	38	1	10	4	22
Arthritis	3	38	0	0	3	17
Osteoporosis	0	0	3	30	3	17
Constipation	1	13	2	20	3	17
Ischaemic heart disease	2	25	0	0	2	11
Diabetes	2	25	0	0	2	11
Cellulitis	2	25	0	0	2	11
Hepatitis C	0	0	2	20	2	11
Kidney disease	1	13	1	10	2	11
Hypothyroidism	1	13	1	10	2	11
Vitamin deficiency	1	13	1	10	2	11

1.4.4. Cigarette smoking

Most (86%) of the people in disability services who died in 2014-2017 did not smoke. This was a higher proportion of non-smokers than the 15-year average (77%).

Table 12: Smoking status of people in disability services who died in 2014-2017

Smoking status	2014-2015 (N=228)		2016-2017 (N=248)		Total (N=476)	
	N	%	N	%	N	%
No	194	85.1	216	87.1	410	86.1
Ex-smoker	13	5.7	9	3.6	22	4.6
Current > 20/day	5	2.2	14	5.7	19	4.0
Current 11-20/day	10	4.4	4	1.6	14	2.9
Current ≤ 10/day	5	2.2	5	2.0	10	2.1
Occasional	1	0.4	0	0.0	1	0.0
Total	**228**	**100.0**	**248**	**100.0**	**476**	**100.0**

High rates of smoking have featured consistently among assisted boarding house residents who have died. In 2014-2017, 61% of the assisted boarding house residents who died had smoked, including nine people (50%) who were continuing to smoke at the time of their death.

Although still high, the proportion of boarding house residents who died in 2014-2017 and who smoked was substantially lower than the 15-year average (78%).

Table 13: Smoking status of people in assisted boarding houses who died in 2014-2017

Smoking status	2014-2015 (N=8)		2016-2017 (N=10)		Total (N=18)	
	N	%	N	%	N	%
No	3	37.5	3	30.0	6	33.3
Current > 20/day	1	12.5	2	20.0	3	16.7
Current ≤ 10/day	1	12.5	2	20.0	3	16.7
Current 11-20/day	2	25.0	1	10.0	3	16.7
Ex-smoker	1	12.5	1	10.0	2	11.1
Unknown	0	0.0	1	20.0	1	5.6
Occasional	0	0.0	0	0.0	0	0.0
Total	**8**	**100.0**	**10**	**100.0**	**18**	**100.0**

1.4.5. Vaccination

Many of the people with disability in residential care who have died were immunocompromised due to congenital or acquired conditions, and/or chronic diseases. There is an increased risk of morbidity and mortality in immunocompromised people associated with many vaccine-preventable diseases. Influenza and pneumococcal vaccines are routinely recommended for immunocompromised people.[14]

Influenza vaccination

'The administration of influenza vaccine is the single most important measure in preventing or attenuating influenza infection and preventing mortality.'[15]

Annual influenza vaccination is recommended for all people aged six months or older. It is particularly strongly recommended for people with conditions predisposing them to severe influenza, such as cardiac disease, Down syndrome, obesity, chronic respiratory conditions, chronic neurological conditions, immunocompromising conditions; and for residents of long-term residential facilities.[16]

In 2014-2017, three-quarters (76%) of the people in disability services had received the influenza vaccination the year before they died. The influenza vaccination rates for both periods – 78% in 2014-2015, and 73% in 2016-2017 – were higher than the 15-year average (70%).[17]

Overall, in 2014-2017, just over half (52%) of the assisted boarding house residents had received the influenza vaccination in the year before they died, including 63% (5) who died in 2014-2015, and 40% (4) who died in 2016-2017. On average, over the 15 years to 2017, 61% of assisted boarding house residents had a current influenza vaccination at the time of their death.

Our reviews of deaths in 2014-2017 raised concerns about some individuals who had significant risks associated with their chronic health conditions, and who had not received the influenza vaccination. For one person whose death was due to pneumonia and influenza, our review raised concerns about the conduct of their treating medical practitioner in failing to administer the vaccination. We referred the matter to the HCCC. This is discussed further in Chapter 3, in relation to breathing, choking and swallowing risks.

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14. Australian Technical Advisory Group on Immunisation. *The Australian Immunisation Handbook*. 10th ed. Canberra: Australian Government Department of Health. 3.3: Groups with special vaccination requirements. www.immunise.health.gov.au.
15. Ibid, 4.7.4.
16. Ibid.
17. In 2014-2015, 177 people in disability services had current influenza vaccination at the time of their death; in 2016-2017, 180 people had current influenza vaccination.

Pneumococcal vaccination

In adults, pneumonia with bacteraemia is the most common manifestation of invasive pneumococcal disease (IPD). It is estimated that pneumococci account for over one-third of all community-acquired pneumonia and up to half of hospitalised pneumonia in adults. Immunocompromised people have the highest risk of IPD.

Conditions associated with an increased risk and/or severity of IPD include:

- chronic cardiac disease
- chronic lung disease
- diabetes mellitus
- Down syndrome
- tobacco smoking.[18]

In 2014-2017, less than one-third (28%) of the people in disability services who died had received the pneumococcal vaccination, including 33% who died in 2014-2015, and 22% who died in 2016-2017. On average over the 15 years to 2017, one-third (34%) of the people in disability services who died had received the pneumococcal vaccination.

For people in assisted boarding houses, 75% (6) of those who died in 2014-2015 had received the pneumococcal vaccination, and 40% (4) of those who died in 2016-2017 had received the vaccination. On average, over the 15 years to 2017, one-quarter (24%) of the assisted boarding house residents who died had received the pneumococcal vaccination.

1.4.6. Comprehensive health assessment

Disability accommodation services are required to support clients to have an annual GP health assessment. The Medicare Benefits Schedule (MBS) provides for extended consultations for 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.

In the year before their death, over three-quarters (81%) of the people in disability services who died in 2014-2017 had a comprehensive health assessment. This included 201 people (88%) who died in 2014-2015, and 186 people (75%) who died in 2016-2017. Over the 15 years to 2017, 79% of people in disability services had a comprehensive health assessment in the year before they died.

One third (33%) of assisted boarding house residents had a comprehensive health assessment in the year before they died in 2014-2017, including four people (50%) who died in 2014-2015, and two people (20%) who died in 2016-2017. Overall, in the 15 years to 2017, 35% of assisted boarding house residents had a comprehensive health assessment before they died.

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[18] Australian Technical Advisory Group on Immunisation, op cit, 4.13.

Chapter 2. Causes of death

Most (64%) of the 494 deaths of people with disability in residential care in 2014-2017 were sudden unexpected deaths, including the deaths of 307 people (64%) in disability services, and the deaths of 11 people (61%) in assisted boarding houses.[19] The 176 people (36%) whose deaths were expected were typically in the final stages of a terminal condition or degenerative disease, and were receiving palliative care.

The information in this chapter is primarily focused on the 'underlying cause of death'. This is the disease or injury that started the chain of events that led directly to the person's death.[20]

2.1. Broad underlying causes of death

The vast majority (442; 89%) of the 494 deaths of people with disability in residential care in 2014-2017 were due to natural causes (illnesses and diseases).[21]

Twenty-seven people (5%) died from external (unnatural) causes, including 11 deaths in 2014-2015, and 16 deaths in 2016-2017. The majority of these deaths (25) were due to unintentional or accidental causes, mainly associated with choking on food or other substances. Two deaths were due to intentional causes, both suicide. Only one of the external cause deaths involved a person in an assisted boarding house – their death was due to a transport-related accident.

For 11 people, the cause of death was unable to be determined.

At the time of writing this report, the underlying cause of death of 14 people had not yet been ascertained.

2.2. Leading underlying causes of death

2.2.1. Leading underlying causes of death of all people with disability in residential care in 2014-2017

Table 14 and Table 15 outline the underlying causes of death of people with disability in residential care in each two-year period. Diseases of the nervous system were the leading cause of death of all people in residential care in 2014 and 2015. Diseases of the respiratory system were the leading cause of death in 2016 and 2017.

Overall in 2014-2017, the main underlying causes of death were:

- nervous system diseases (77 people; 16%) – mainly epilepsy and cerebral palsy
- respiratory diseases (76 people; 15%) – mainly aspiration pneumonia
- neoplasms (68 people; 14%) – mainly lung and breast cancer
- congenital and chromosomal conditions (63 people; 13%) – mainly Down syndrome
- circulatory diseases (61 people; 12%) – mainly ischaemic heart diseases.

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[19] In 2014-2015, the deaths of 147 people (62%) were unexpected, including 141 people (62%) in disability services, and six people (75%) in assisted boarding houses. In 2016-2017, the deaths of 171 people (66%) were unexpected, including 166 people (67%) in disability services, and five people (50%) in assisted boarding houses.

[20] 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 standardisation of coded data and facilitates comparability with other collections of mortality data.

[21] The 442 natural cause deaths included 216 people who died in 2014-2015, and 226 people who died in 2016-2017.

Table 14: Underlying causes of death in 2014-2015 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	%
Certain infectious and parasitic diseases (A00-B99)	1	0.7	4	4.4	5	2.2	0	0.0	1	50.0	1	12.5
Neoplasms (C00-D48)	16	11.7	16	17.6	32	14.0	2	33.3	0	0.0	2	25.0
Endocrine, nutritional and metabolic diseases (E00-E90)	2	1.5	3	3.3	5	2.2	0	0.0	0	0.0	0	0.0
Mental and behavioural disorders (F00-F99)	8	5.8	7	7.7	15	6.6	0	0.0	0	0.0	0	0.0
Diseases of the nervous system (G00-G99)	24	17.5	23	25.3	47	20.6	0	0.0	0	0.0	0	0.0
Diseases of the circulatory system (I00-I99)	21	15.3	6	6.6	27	11.8	3	50.0	0	0.0	3	37.5
Diseases of the respiratory system (J00-J99)	22	16.1	9	9.9	31	13.6	0	0.0	1	50.0	1	12.5
Diseases of the digestive system (K00-K93)	8	5.8	6	6.6	14	6.1	0	0.0	0	0.0	0	0.0
Diseases of the genitourinary system (N00-N99)	3	2.2	1	1.1	4	1.8	0	0.0	0	0.0	0	0.0
Congenital and chromosomal conditions (Q00-Q99)	18	13.1	11	12.1	29	12.7	0	0.0	0	0.0	0	0.0
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	4	2.9	2	2.2	6	2.6	0	0.0	0	0.0	0	0.0
External causes of morbidity and mortality (V00-Y98)	10	7.3	1	1.1	11	4.8	0	0.0	0	0.0	0	0.0
Unclassified	0	0.0	2	2.2	2	0.9	1	16.7	0	0.0	1	12.5
Total	**137**	**100**	**91**	**100**	**228**	**100**	**6**	**100**	**2**	**100**	**8**	**100**

Table 15: Underlying causes of death in 2016-2017 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	%
Certain infectious and parasitic diseases (A00-B99)	3	2.07	2	1.94	5	2.02	0	0	0	0	0	0
Neoplasms (C00-D48)	12	8.28	19	18.45	31	12.5	3	33.33	0	0	3	30
Endocrine, nutritional and metabolic diseases (E00-E90)	6	4.14	2	1.94	8	3.23	0	0	0	0	0	0
Mental and behavioural disorders (F00-F99)	9	6.21	7	6.8	16	6.45	0	0	0	0	0	0
Diseases of the nervous system (G00-G99)	17	11.72	13	12.62	30	12.1	0	0	0	0	0	0
Diseases of the circulatory system (I00-I99)	18	12.41	11	10.68	29	11.69	2	22.22	0	0	2	20
Diseases of the respiratory system (J00-J99)	23	15.86	20	19.42	43	17.34	1	11.11	0	0	1	10
Diseases of the digestive system (K00-K93)	14	9.66	4	3.88	18	7.26	0	0	0	0	0	0
Diseases of the genitourinary system (N00-N99)	4	2.76	2	1.94	6	2.42	0	0	0	0	0	0
Congenital and chromosomal conditions (Q00-Q99)	19	13.1	15	14.56	34	13.71	0	0	0	0	0	0
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	4	2.76	0	0	4	1.61	0	0	1	100	1	10
External causes of morbidity and mortality (V00-Y98)	10	6.9	5	4.85	15	6.05	1	11.11	0	0	1	10
Unclassified	6	4.14	3	2.91	9	3.63	2	22.22	0	0.0	2	20.0
Total	**145**	**100**	**103**	**100**	**248**	**100**	**9**	**100**	**1**	**100**	**10**	**100**

Table 16 and Table 17 show the leading causes of death of people with disability in residential care in each of the biennial periods. These causes accounted for almost half of all deaths.

Table 16: Top 11 leading causes of death of people with disability in residential care, 2014-2015

Underlying cause of death	N	%
Cerebral palsy (G80)	17	7.2
Down syndrome (Q90)	16	6.78
Epilepsy (G40)	14	5.93
Chronic ischaemic heart disease (I25)	13	5.51
Pneumonitis due to solids and liquids (J69)	12	5.08
Pneumonia, organism unspecified (J18)	10	4.24
Severe mental retardation (F72)	6	2.54
Other ill-defined and unspecified causes of mortality (R99)	6	2.54
Paralytic ileus and intestinal obstruction without hernia (K56)	6	2.54
Other chronic obstructive pulmonary disease (J44)	6	2.54
Malignant neoplasm of bronchus and lung (C34)	6	2.54
Total top 11 underlying causes overall	**112**	**47.5**

Table 17: Top 12 leading causes of death of people with disability in residential care, 2016-2017

Underlying cause of death	N	%
Pneumonitis due to solids and liquids (J69)	23	8.9
Down syndrome (Q90)	20	7.8
Paralytic ileus and intestinal obstruction without hernia (K56)	11	4.3
Pneumonia, organism unspecified (J18)	10	3.9
Epilepsy (G40)	10	3.9
Cerebral palsy (G80)	8	3.1
Severe mental retardation (F72)	8	3.1
Chronic ischaemic heart disease (I25)	6	2.3
Other chronic obstructive pulmonary disease (J44)	6	2.3
Other ill-defined and unspecified causes of mortality (R99)	5	1.9
Other specified congenital malformation syndromes affecting multiple systems (Q87)	5	1.9
Heart failure (I50)	5	1.9
Total top 12 underlying causes overall	**117**	**45.3**

Table 18: Top 10 leading causes of death of people with disability in residential care 2003-2017

Underlying cause of death	N	%	Crude mortality rate per 1000	95% Confidence Interval
Pneumonitis due to solids and liquids (J69)	101	6.29	1.08	0.87 - 1.30
Cerebral palsy (G80)	87	5.42	0.93	0.75 - 1.15
Epilepsy (G40)	86	5.35	0.92	0.74 - 1.14
Down syndrome (Q90)	80	4.98	0.86	0.68 - 1.07
Pneumonia, organism unspecified (J18)	75	4.67	0.80	0.63 - 1.01
Chronic ischaemic heart disease (I25)	61	3.80	0.65	0.50 - 0.84
Acute myocardial infarction (I21)	51	3.18	0.55	0.41 - 0.72
Other chronic obstructive pulmonary disease (J44)	40	2.49	0.43	0.31 - 0.58
Malignant neoplasm of bronchus and lung (C34)	39	2.43	0.42	0.30 - 0.57
Inhalation and ingestion of food causing obstruction of respiratory tract (W79)	38	2.37	0.41	0.29 - 0.56
Total top 10 underlying causes overall	**658**	**40.97**		

2.2.2. Leading causes of death of people in disability services

Overall in 2014-2017, nervous system diseases – primarily epilepsy and cerebral palsy – were the leading cause of death of people in disability services, accounting for the deaths of 77 people (16%). The next leading causes of death were respiratory diseases, mainly aspiration pneumonia and pneumonia. Respiratory diseases accounted for the deaths of 74 people (16%), and were the leading cause in 2016-17.

Diseases of the respiratory and nervous systems have consistently been the leading causes of death for people in disability services.

Figure 2: Leading underlying causes of death of people in disability services in 2014-2017, by ICD chapter

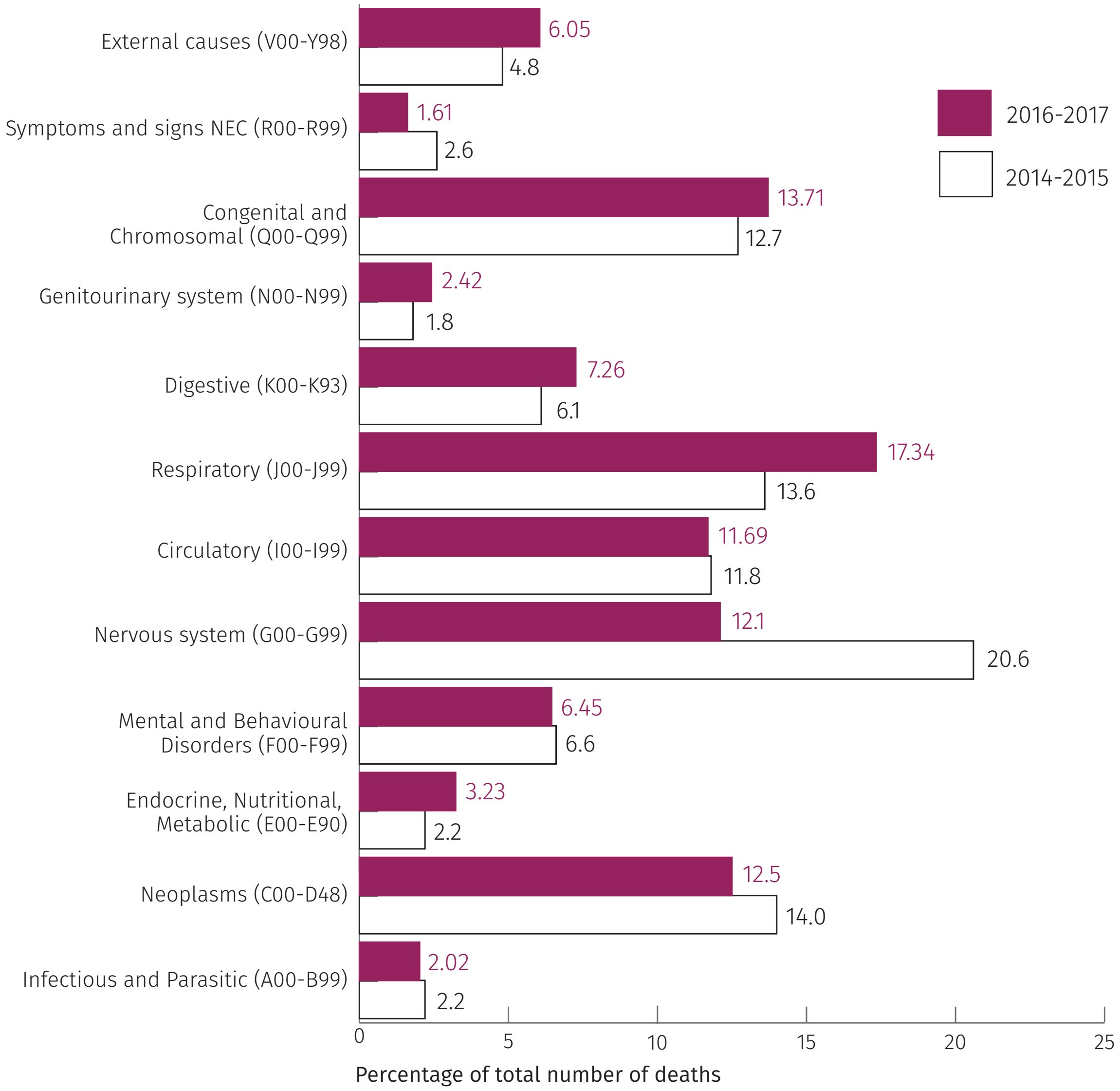

Table 19 and Table 20 show the leading causes of death of people in disability services in 2014-2015 and 2016-2017. Table 21 shows the 15-year trend for 2003-2017.

- In 2014-2015, a lower proportion of people in disability services died from pneumonitis due to solids and liquids (aspiration), and a higher proportion died from chronic ischaemic heart disease.
- In 2016-2017, a lower proportion of people in disability services died from epilepsy, and a higher proportion died from pneumonitis and intestinal obstruction.

Table 19: Top 10 leading causes of death of people with disability in disability services, 2014-2015

Underlying cause of death	N	%
Cerebral palsy (G80)	17	7.46
Down syndrome (Q90)	16	7.02
Epilepsy (G40)	14	6.14
Pneumonitis due to solids and liquids (J69)	12	5.26
Chronic ischaemic heart disease (I25)	10	4.39
Pneumonia, organism unspecified (J18)	10	4.39
Severe mental retardation (F72)	6	2.63
Other ill-defined and unspecified causes of mortality (R99)	6	2.63
Paralytic ileus and intestinal obstruction without hernia (K56)	6	2.63
Other chronic obstructive pulmonary disease (J44)	6	2.63
Total top 10 underlying causes overall	**103**	**45.2**

Table 20: Top 11 leading causes of death of people with disability in disability services, 2016-2017

Underlying cause of death	N	%
Pneumonitis due to solids and liquids (J69)	23	9.3
Down syndrome (Q90)	20	8.1
Paralytic ileus and intestinal obstruction without hernia (K56)	11	4.4
Epilepsy (G40)	10	4.0
Pneumonia, organism unspecified (J18)	10	4.0
Severe mental retardation (F72)	8	3.2
Cerebral palsy (G80)	8	3.2
Chronic ischaemic heart disease (I25)	6	2.4
Heart failure (I50)	5	2.0
Other specified congenital malformation syndromes affecting multiple systems (Q87)	5	2.0
Other chronic obstructive pulmonary disease (J44)	5	2.0
Total top 11 underlying causes in disability services	**111**	**44.8**

Table 21: Top 10 leading causes of death of people with disability in disability services, 2003-2017

Underlying cause of death	N	%	Crude mortality rate per 1000	95% Confidence Interval
Pneumonitis due to solids and liquids (J69)	100	7.01	1.22	0.98 - 1.46
Cerebral palsy (G80)	87	6.10	1.06	0.85 - 1.31
Epilepsy (G40)	85	5.96	1.04	0.83 - 1.29
Down syndrome (Q90)	80	5.61	0.98	0.78 - 1.22
Pneumonia, organism unspecified (J18)	67	4.70	0.82	0.64 - 1.04
Chronic ischaemic heart disease (I25)	42	2.94	0.51	0.37 - 0.69
Inhalation and ingestion of food causing obstruction of respiratory tract (W79)	34	2.38	0.42	0.29 - 0.58
Paralytic ileus and intestinal obstruction without hernia (K56)	34	2.38	0.42	0.29 - 0.58
Malignant neoplasm of bronchus and lung (C34)	30	2.10	0.37	0.25 - 0.52
Other chronic obstructive pulmonary disease (J44)	29	2.03	0.35	0.24 - 0.51
Total top 10 underlying causes in disability services	**588**	**41.2**		

2.2.3. Leading causes of death of people in assisted boarding houses

Overall in 2014-2017, the leading causes of death of assisted boarding house residents were circulatory diseases (mainly chronic ischaemic heart disease and acute myocardial infarction) and neoplasms (including lung, bladder, rectum and skin cancer).

Circulatory diseases and neoplasms each accounted for the deaths of five people (28%), and have consistently been the leading causes of death of boarding house residents.

Figure 3: Leading underlying causes of death of people in assisted boarding houses in 2014-2017, by ICD chapter

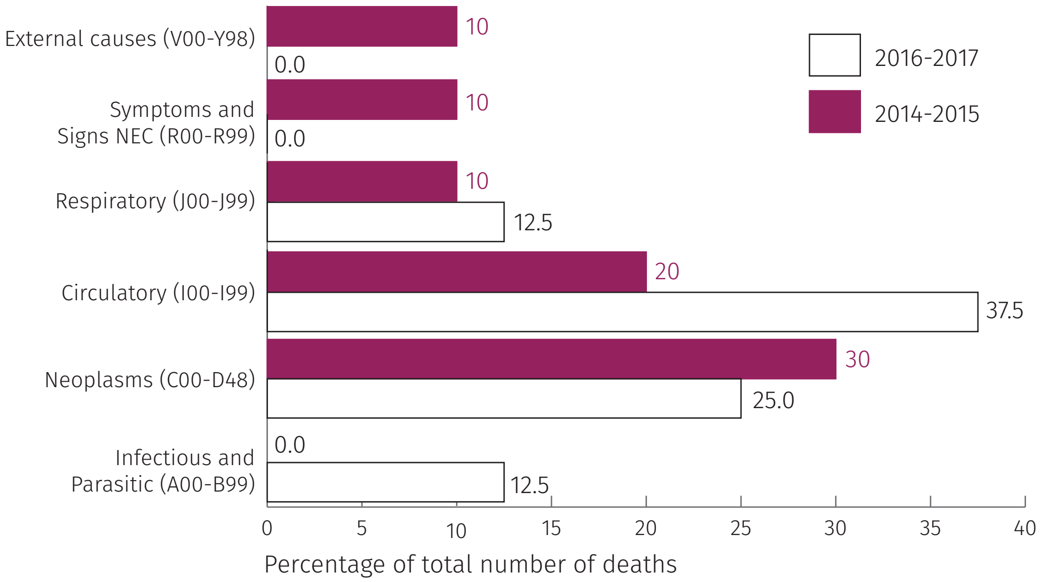

Table 22 and Table 23 show the leading causes of death of people in assisted boarding houses in 2014-2015 and 2016-2017. Table 24 shows the 15-year trend for 2003-2017. The small number of deaths in assisted boarding houses in 2014-2017 limits useful comparison.

Table 22: Top 5 leading causes of death of people with disability in assisted boarding houses, 2014-2015

Underlying cause of death	N	%
Chronic ischaemic heart disease (I25)	3	37.5
Emphysema (J43)	1	12.5
Malignant neoplasm of bronchus and lung (C34)	1	12.5
Other malignant neoplasms of skin (C44)	1	12.5
Other sepsis (A41)	1	12.5
Total top 5 underlying causes in assisted boarding houses	**7**	**87.5**

Table 23: Top 7 leading causes of death of people with disability in assisted boarding houses, 2016-2017

Underlying cause of death	N	%
Acute myocardial infarction (I21)	2	20.0
Malignant neoplasm of bladder (C67)	1	10.0
Malignant neoplasm of rectum (C20)	1	10.0
Malignant neoplasm without specification of site (C80)	1	10.0
Other chronic obstructive pulmonary disease (J44)	1	10.0
Other ill-defined and unspecified causes of mortality (R99)	1	10.0
Pedestrian injured in collision with heavy transport vehicle or bus (V04)	1	10.0
Total top 7 underlying causes in assisted boarding houses	**8**	**80.0**

Table 24: Top 14 leading causes of death of people with disability in assisted boarding houses, 2003-2017

Underlying cause of death	N	%	Crude mortality rate per 1000	95% Confidence Interval
Acute myocardial infarction (I21)	25	13.97	2.18	1.41 - 3.22
Chronic ischaemic heart disease (I25)	19	10.61	1.66	1.00 - 2.59
Other chronic obstructive pulmonary disease (J44)	11	6.15	0.96	0.48 - 1.72
Malignant neoplasm of bronchus and lung (C34)	9	5.03	0.79	0.36 - 1.49
Pneumonia, organism unspecified (J18)	8	4.47	0.70	0.30 - 1.38
Malignant neoplasm without specification of site (C80)	5	2.79	0.44	0.14 - 1.02
Other ill-defined and unspecified causes of mortality (R99)	5	2.79	0.44	0.14 - 1.02
Inhalation and ingestion of food causing obstruction of respiratory tract (W79)	4	2.23	0.35	0.10 - 0.89
Cardiomyopathy (I42)	4	2.23	0.35	0.10 - 0.89
Complications and ill-defined descriptions of heart disease (I51)	3	1.68	0.26	0.05 - 0.77
Malignant neoplasm of breast (C50)	3	1.68	0.26	0.05 - 0.77
Heart failure (I50)	3	1.68	0.26	0.05 - 0.77
Mental and behavioural disorders due to use of alcohol (F10)	3	1.68	0.26	0.05 - 0.77
Stroke, not specified as haemorrhage or infarction (I64)	3	1.68	0.26	0.05 - 0.77
Total top 14 underlying causes in assisted boarding houses	**105**	**58.7**		

2.3. Age and cause of death

2.3.1. People in disability services

Table 25 shows the leading cause of death of people in disability services in the two biennial periods, by age group.

In the younger age groups, nervous system diseases featured as a leading cause of death of people in disability services in both periods. In 2016-2017, people aged up to 35 years also had additional leading causes of death, including respiratory diseases.

While the leading cause of death of people aged 35-54 years in 2014-2015 was nervous system diseases, in 2016-2017 it was external causes and congenital and chromosomal conditions.

For people aged 55-64 years, respiratory diseases were the leading cause of death. The leading causes of death for people aged 65 years and older were similar to the general population, including circulatory diseases and neoplasms.

Table 25: Leading underlying causes of death of people in disability services, by age group, in 2014-2015 and 2016-2017

Age group	2014-2015			2016-2017		
	Leading underlying cause of death	**N**	**%**	**Leading underlying cause of death**	**N**	**%**
Under 15	Diseases of the nervous system	1	100.0	Diseases of the nervous system External causes of morbidity and mortality	1	50.0
15-24	Diseases of the nervous system	2	66.7	Congenital and chromosomal conditions Diseases of the nervous system	2	28.6
25-34	Diseases of the nervous system	7	50.0	Diseases of the nervous system Diseases of the respiratory system	6	35.3
35-44	Diseases of the nervous system	9	34.6	External causes of morbidity and mortality	6	20.0
45-54	Diseases of the nervous system	16	26.2	Congenital and chromosomal conditions	9	17.7
55-64	Diseases of the respiratory system	15	22.1	Diseases of the respiratory system	14	22.2
65-74	Diseases of the circulatory system	9	22.5	Neoplasms	9	20.5
75-84	Neoplasms	4	30.8	Diseases of the circulatory system	7	33.3
85+	Diseases of the genitourinary system Diseases of the respiratory system	1	50.0	Neoplasms	2	50.0

2.3.2. People in assisted boarding houses

Table 26 shows the leading cause of death of people in assisted boarding houses in 2014-2017, by age group. For both two-year periods, similar leading causes of death featured in age groups 55-64 years and 65-74 years, including neoplasms and circulatory diseases.

Table 26: Leading underlying causes of death of people in assisted boarding houses, by age group, in 2014-2015 and 2016-2017

Age group	2014-2015			2016-2017		
	Leading underlying cause of death	N	%	Leading underlying cause of death	N	%
35-44	Neoplasms	1	100.0	-	-	-
45-54	Diseases of the circulatory system	1	100.0	External causes of morbidity and mortality	1	100.0
55-64	Diseases of the respiratory system Neoplasms	1	50.0	Neoplasms	2	40.0
65-74	Diseases of the circulatory system	2	66.7	Diseases of the circulatory system Neoplasms	1	50.0

2.4. 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 chapter level for associated causes and for other contributory causes of death (multiple causes of death) for deaths in 2014-2015 and 2016-2017 of people in disability services (Table 27 and Table 28) and assisted boarding houses (Table 29 and Table 30).

2.4.1. Multiple causes of death of people in disability services in 2014-2017

Consistent with previous years, respiratory diseases were the largest contributory cause of death for people in disability services in both biennial periods. Respiratory diseases contributed to almost half of all deaths of people in disability services in 2014-2015 (106; 46%) and 2016-2017 (114; 46%).

Respiratory diseases commonly feature in the deaths of people whose underlying cause of death is nervous system diseases (such as cerebral palsy and epilepsy), and congenital and chromosomal conditions (such as Down syndrome).

Table 27: 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, 2014-2015

ICD Chapter	Underlying cause		Associated cause		Multiple cause		UCOD %	Rate ratio
	No. of deaths	Deaths per 1000	No. of deaths	Deaths per 1000	No. of deaths	Deaths per 1000		
Certain infectious and parasitic diseases (A00-B99)	5	0.79	24	3.79	29	4.58	17.24	5.80
Neoplasms (C00-D48)	32	5.06	7	1.11	39	6.17	82.05	1.22
Diseases of the blood, blood forming organs, and certain disorders involving the immune system (D50-D89)	0	0.00	1	0.16	1	0.16	0.00	-
Endocrine, nutritional and metabolic diseases (E00-E90)	5	0.79	14	2.21	19	3	26.32	3.80
Mental and behavioural disorders (F00-F99)	15	2.37	65	10.28	80	12.65	18.75	5.34
Diseases of the nervous system (G00-G99)	47	7.43	47	7.43	94	14.86	50.00	2.00
Diseases of the ear and mastoid process (H60-H95)	0	0.00	1	0.16	1	0.16	0.00	-
Diseases of the circulatory system (I00-I99)	27	4.27	35	5.53	62	9.8	43.55	2.30
Diseases of the respiratory system (J00-J99)	31	4.90	75	11.86	106	16.76	29.25	3.42
Diseases of the digestive system (K00-K93)	14	2.21	12	1.90	26	4.11	53.85	1.86
Diseases of the skin and subcutaneous tissue (L00-L99)	0	0.00	2	0.32	2	0.32	0.00	-
Diseases of the musculoskeletal and connective tissue (M00-M99)	0	0.00	2	0.32	2	0.32	0.00	-
Diseases of the genitourinary system (N00-N99)	4	0.63	11	1.74	15	2.37	26.67	3.76
Congenital and chromosomal conditions (Q00-Q99)	29	4.58	14	2.21	43	6.8	67.44	1.48
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	6	0.95	26	4.11	32	5.06	18.75	5.33
Injury, poisoning and certain other consequences of external causes (S00-T98)	0	0.00	20	3.16	20	3.16	0.00	-
External causes of morbidity and mortality (V00-Y98)	11	1.74	5	0.79	16	2.53	68.75	1.45
Unclassified	2	-	-	-	-	-	-	-
Total	**228**							

Table 28: 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, 2016-2017

	Underlying cause		Associated cause		Multiple cause			
ICD Chapter	**No. of deaths**	**Deaths per 1000**	**No. of deaths**	**Deaths per 1000**	**No. of deaths**	**Deaths per 1000**	**UCOD %**	**Rate ratio**
Certain infectious and parasitic diseases (A00-B99)	5	0.79	18	2.85	23	3.64	21.74	4.61
Neoplasms (C00-D48)	31	4.90	6	0.95	37	5.85	83.78	1.19
Diseases of the blood, blood forming organs, and certain disorders involving the immune system (D50-D89)	0	0.00	1	0.16	1	0.16	0.00	0.00
Endocrine, nutritional and metabolic diseases (E00-E90)	8	1.26	24	3.79	32	5.06	25.00	4.02
Mental and behavioural disorders (F00-F99)	16	2.53	63	9.96	79	12.49	20.25	4.94
Diseases of the nervous system (G00-G99)	30	4.74	59	9.33	89	14.07	33.71	2.97
Diseases of the eye and adnexa (H00-H59)	0	0.00	1	0.16	1	0.16	0.00	0.00
Diseases of the ear and mastoid process (H60-H95)	0	0.00	1	0.16	1	0.16	0.00	0.00
Diseases of the circulatory system (I00-I99)	29	4.58	38	6.01	67	10.59	43.28	2.31
Diseases of the respiratory system (J00-J99)	43	6.80	71	11.22	114	18.02	37.72	2.65
Diseases of the digestive system (K00-K93)	18	2.85	16	2.53	34	5.37	52.94	1.88
Diseases of the skin and subcutaneous tissue (L00-L99)	0	0.00	4	0.63	4	0.63	0.00	0.00
Diseases of the musculoskeletal and connective tissue (M00-M99)	0	0.00	3	0.47	3	0.47	0.00	0.00
Diseases of the genitourinary system (N00-N99)	6	0.95	12	1.90	18	2.85	33.33	3.00
Congenital and chromosomal conditions (Q00-Q99)	34	5.37	18	2.85	52	8.22	65.38	1.53
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	4	0.63	24	3.79	28	4.43	14.29	7.03
Injury, poisoning and certain other consequences of external causes (S00-T98)	0	0.00	20	3.16	20	3.16	0.00	0.00
External causes of morbidity and mortality (V00-Y98)	15	2.37	5	0.79	20	3.16	75.00	1.33
Unclassified	9	1.42	4	0.63	13	2.06	69.23	1.45
Total	**248**							

2.4.2. Multiple causes of death of people in assisted boarding houses in 2014-2017

Consistent with previous years, circulatory diseases were the largest contributory cause of death of people in assisted boarding houses in 2014-2015. Circulatory diseases contributed to three-quarters of all deaths of assisted boarding house residents in that period (6 people).

However, in 2016-2017, the largest contributory cause of death of assisted boarding house residents was neoplasms, accounting for half of the deaths in that period. Respiratory diseases contributed to the deaths of four boarding house residents in 2016-2017, mainly as an associated cause.

Table 29: 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, 2014-2015

ICD Chapter	Underlying cause		Associated cause		Multiple cause		UCOD %	Rate ratio
	No. of deaths	Deaths per 1000	No. of deaths	Deaths per 1000	No. of deaths	Deaths per 1000		
Certain infectious and parasitic diseases (A00-B99)	1	2.16	0	0.00	1	2.16	100.00	1.00
Neoplasms (C00-D48)	2	4.32	1	2.16	3	6.48	66.67	1.50
Endocrine, nutritional and metabolic diseases (E00-E90)	0	0.00	1	2.16	1	2.16	0.00	-
Mental and behavioural disorders (F00-F99)	0	0.00	1	2.16	1	2.16	0.00	-
Diseases of the nervous system (G00-G99)	0	0.00	1	2.16	1	2.16	0.00	-
Diseases of the circulatory system (I00-I99)	3	6.48	3	6.48	6	12.96	50.00	2.00
Diseases of the respiratory system (J00-J99)	1	2.16	1	2.16	2	4.32	50.00	2.00
Unclassified	1	2.16	-	-	-	-	-	-
Total	**8**							

Table 30: 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, 2016-2017

ICD Chapter	Underlying cause		Associated cause		Multiple cause		UCOD %	Rate ratio
	No. of deaths	Deaths per 1000	No. of deaths	Deaths per 1000	No. of deaths	Deaths per 1000		
Certain infectious and parasitic diseases (A00-B99)	0	0.00	2	4.32	2	4.32	0.00	0.00
Neoplasms (C00-D48)	3	6.48	2	4.32	5	10.80	60.00	1.67
Mental and behavioural disorders (F00-F99)	0	0.00	2	4.32	2	4.32	0.00	0.00
Diseases of the circulatory system (I00-I99)	2	4.32	0	0.00	2	4.32	100.00	1.00
Diseases of the respiratory system (J00-J99)	1	2.16	3	6.48	4	8.64	25.00	4.00
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	1	2.16	1	2.16	2	4.32	50.00	2.00
Injury, poisoning and certain other consequences of external causes (S00-T98)	0	0.00	1	2.16	1	2.16	0.00	0.00
External causes of morbidity and mortality (V00-Y98)	1	2.16	0	0.00	1	2.16	100.00	1.00
Unclassified	2	4.32	0	0.00	2	4.32	100.00	1.00
Total	**10**							

Part Two:

Issues arising from reviews of deaths

Chapter 3. Issues arising from reviews of deaths in 2014-2017

In this chapter, we report our observations from our reviews of the deaths of the 236 people who died in 2014 and 2015, and the 258 people who died in 2016 and 2017, including those raised in our reports to agencies. We have reported the issues together in one chapter as they have been largely consistent across the four year period (and longer).

3.1. Recognising and responding to critical situations

To reduce avoidable deaths of people with disability in residential care, it is vital that support staff are able to recognise when a resident needs urgent assistance, and to act without delay. It is a simple message, and one that we have consistently emphasised over an extended period of time, including through our factsheets and recommendations in our reports.

However, every year there are preventable deaths that occur because the individuals did not get timely help – including at least 28 people who died in 2014 and 2015, and 14 people who died in 2016 and 2017. The stand-out areas for improvement relate to disability support staff:

- identifying illness and taking timely action
- providing an effective first aid response
- escalating significant matters with internal and external parties.

3.1.1. Identifying illness and taking timely action

Many people with disability in residential care have chronic health concerns, and they may also have non-verbal communication. At times, these factors can make it difficult for staff to recognise when the person they are supporting is unwell. It is important that support staff know the person well enough to be able to identify when there are notable changes in their health and/or behaviour that may indicate potential illness and the need for medical assistance.

However, it is not enough to identify illness – staff must also take action in response, and without delay. Our reviews have consistently shown that there is often a very short period of time between residents showing signs of illness or critical health changes and their death. For example, for the people who died from influenza or pneumonia in 2014-2017, the period of time between staff identifying symptoms of illness and the person's subsequent death tended to range from a matter of hours, through to one week. Time is of the essence.

We recognise that it is not always possible for support staff to identify the point at which a decline in the person's health has become critical. However, it is reasonable to expect that staff will call for emergency help as early as possible when they are concerned or have any question about the seriousness of the person's presenting condition. This is not consistently happening. In addition, in some of the matters that we reviewed, we found that the changes in the person's health were not subtle – it was clear that they were significantly unwell, but staff did not seek urgent medical assistance.

A man showed signs of illness from around 11pm, including groaning with pain, occasionally heaving, and refusing food and drink. Staff's concern was evident – they checked on him every 30 minutes, and recorded what was happening. However, they did not seek any medical help until after he vomited black fluid at 3am the next morning. Our review identified that staff also provided personal care and continued taking observations for another 15 minutes before they called emergency services. In hospital, the man was diagnosed with a small bowel obstruction and sepsis, and died four days later. The service told us that staff had not realised the seriousness of the man's condition, and it recognises that staff should have called 000 immediately.

A staff member arriving for the morning shift identified that a woman was ill, including that she was grey in colour, not responding well to communication, unable to move her right arm, and breathing shallowly. However, staff contacted a senior support worker in the first instance rather than emergency services. The senior worker instructed staff to call for an ambulance. In hospital, the woman was diagnosed with urosepsis, and died two days later.

Residents alerted a staff member to the fact that a man had vomited copious amounts of coffee ground coloured fluid. The staff member did not contact anyone to discuss the matter or seek assistance for another three hours. At that time, the staff member called their supervisor before and after contacting Health Direct. On the second call, the supervisor instructed the staff member to call for an ambulance. The man died from a heart attack the following morning. The provider's internal investigation identified the need for clear procedures to guide staff in the event of an emergency.

A woman indicated that she was in pain during a hoist transfer. Staff noted her continued indication of pain and provided pain relief. The situation was not escalated until two days later (after the weekend) when a manager identified the need for medical assistance, and the woman was transferred to hospital. She was diagnosed with a fractured hip, and died in hospital from aspiration pneumonia and a hip fracture, five days after surgery.

In a number of matters, we found that there had been previous instances of delays in staff seeking medical assistance for the person, or other problems with the response to critical illness – such as contacting on-call staff rather than emergency services. These matters highlight the importance of incident reporting, and service providers reviewing the reports, to enable issues to be identified at an early point and action to be taken to prevent recurrence.

For some deaths in 2014-2017, appropriate internal reporting and analysis of these previous incidents would have enabled the providers to:

- Reinforce with staff the need to call emergency services when they have any concerns or question about the seriousness of the person's condition, and ahead of contacting management.
- Identify the need to strengthen the guidance for staff on identifying signs of critical illness in particular residents (such as signs of a bowel obstruction).

Issues relating to incident reporting are discussed further in section 3.6.

Keep it simple

Over the past few years, we have seen the introduction of tools in some disability services relating to identifying and responding to critical illness, including 'Between the Flags' and 'ISBAR' (Introduction, Situation, Background, Assessment and Recommendation). We support actions to improve staff's understanding of when they need to get urgent medical assistance, and how best to communicate the situation. However, our reviews of a range of deaths in 2014-2017 have raised concerns about staff's understanding and application of these tools, and the extent to which they are useful in a disability support environment.

For example, we have seen staff faithfully recording observations of individuals, but not understanding what the observation results mean. We have also noted staff focused on gathering information to communicate and provide to health services, rather than making urgent contact. Case study 1 illustrates this point.

Case study 1: The need for action to address health risks and to get help

Two people with intellectual disability and significant health concerns died within two months of moving from a large residential centre into community-based accommodation. We reviewed the deaths of the two people, and also conducted our own motion inquiries into the circumstances of a third resident of the group home who had been admitted to hospital at around the same time.

Each of the residents had substantial health risks, including in relation to nutrition, hydration and swallowing, bowel management and pressure areas; and required full assistance with all of their care and support needs.

In addition to reviewing a wide range of records from the disability service, NDIS allied health providers, the GP, Health, and Ambulance Service, our review was informed by fact finding investigations and clinical governance reviews that were conducted by the accommodation provider shortly after the deaths of the two residents.

Consistent with the findings of the provider's investigations and reviews, our analysis identified a range of significant problems relating to:

- The adequacy of the actions by staff at the large residential centre to address substantial health risks for the residents over an extended period of time, and ahead of their transition to the group home. Among other things, the information identified significant and adverse consequences for residents associated with a failure to appropriately act in response to recommendations to address swallowing and nutrition problems; and a lack of action in response to longstanding recommendations relating to the need for more appropriate aids and equipment.
- The adequacy of the actions of the provider to ensure an informed and safe transition of residents with known complex health needs from the large residential centre to the group home. The information indicated that group home staff did not receive adequate practical training and induction before supporting the residents, despite known risks associated with the residents' complex health needs. The information also identified that inadequate arrangements were in place to support a successful and safe transition. This included a lack of evident mechanisms to ensure that:
  - staff understood and could effectively respond to residents' needs
  - there was close and active oversight of the transition process and follow-up post-transition to identify and address critical issues – including access to community-based health supports
  - there was active involvement of service management post-transition, with tracking of progress in addressing pre-existing and new health (and other) issues.
- The adequacy of the actions by staff to provide appropriate and timely support to the residents, including actions to identify and effectively respond to critical health changes.

We found that there were delays in the actions of staff to get medical assistance in response to indicators of critical illness for the three residents. For each of the residents, it was evident that, although staff recorded observations that were outside the normal range for the individual, this did not prompt them to obtain urgent medical assistance. Interviews with staff as part of the investigations identify that this was, at least in part, because most of the staff did not understand what the observation results meant. For some of the residents, there were also broader problems with staff's response, including contacting on-call staff before emergency services; and getting paperwork together over an extended period of time in preparation for transfer to hospital before calling for an ambulance.

Since the deaths of the two residents, the service has developed and is implementing a comprehensive service improvement plan for the large residential centres, including work to improve the quality of current support, clinical and operational governance and accountability, and transition planning and delivery. We are continuing to monitor this work, and to oversight actions in response to disability reportable incidents relating to the conduct of staff. Ahead of the transfer of the group home to a different provider, we conducted a site visit to follow up on the current circumstances of the resident who was admitted to hospital but subsequently discharged home, and the other residents. We identified notable improvements, and have subsequently followed up with the new provider.

In our experience, it is better if staff do not try to exercise clinical judgement to assess the seriousness of the person's condition, or track observations over an extended period of time to know whether medical assistance should be sought.

Consistent with our previous reports, the message is simple – all support staff need to:

- **be alert to notable changes in the person's health and/or behaviour**
- **call for emergency help as a matter of priority if they have concerns or any question about whether the person's presenting condition is serious.**

This also applies to nursing staff employed in disability services. Many of the matters we reviewed in 2014-2017 that involved delays in obtaining critical medical assistance for the person, involved nursing staff.

3.1.2. First aid and other responses to critical incidents

It is evident from some of the case examples provided in section 3.1.1 that, even in urgent situations, staff often contact management or other staff before calling emergency services. Consistent with previous years, our reviews of deaths in 2014-2017 identified numerous occasions in which staff contacted management or on-call staff in the first instance.

However, our reviews also identified other problems with the response of staff to critical health incidents. These included instances in which:

- staff did not perform cardiopulmonary resuscitation (CPR), or only started CPR on the instructions of 000 operators
- first aid equipment was faulty, compromising the ability of staff to provide an effective response
- staff waited for long periods of time for the arrival of an after-hours doctor and did not recognise the need to escalate the matter to emergency services.

Over the 15 years we have reviewed the deaths of people with disability in residential care, there have been considerable advances in relation to the provision of effective first aid for residents, including the introduction of requirements across all residential care settings that at least one staff member on each shift must have current first aid qualifications, and requirements in assisted boarding houses that they must have functioning call bells (or other communication systems) on premises to enable residents to obtain emergency assistance.

However, our reviews of deaths in 2014-2017 reinforce our messages that **disability providers need to:**

- **ensure that they comply with the first aid requirements**
- **ensure that support staff (including casual and agency staff) receive regular refresher information on responding to critical health incidents**
- **take steps to identify and address any factors that may impede an effective response (such as faulty first aid equipment, and non-mobile telephones).**

3.1.3. Escalating significant matters

For some of the people who died in 2014-2017, staff identified and documented concerns about the presenting health or behaviour of the individuals, but did not escalate the matters with internal or external parties to get assistance. In some cases, it was evident that staff were aware that more needed to be done, but their concern did not result in action. In others, the issues were raised with management, but there was no evident action taken in response.

It is vital that disability services have clear processes in place to guide staff in what they need to do if they have concerns about a resident's health or behaviour, including **the steps to take to escalate the matter within the organisation.** Providers also need **robust systems to enable them to receive and respond to concerns** (including those of staff, residents, families, Official Community Visitors (OCVs) and other external parties); **and to track progress** in addressing the issues.

Case study 2 illustrates the point.

Case study 2: The need to escalate and act on significant health concerns

We reviewed the death of a woman with a mild intellectual disability who had significant and chronic health concerns, including type 1 diabetes (with a number of complications, including glaucoma and double below-knee amputations), obesity, hypertension, high cholesterol and incontinence. She also required assistance with personal care and transfers. The Coroner determined that the woman died as a result of acute myocardial infarction caused by hypertension, with insulin dependent diabetes mellitus and morbid obesity identified as significant factors in her death.

The woman clearly indicated to staff a wish to live independently, and her NDIS plan included the goal to be more independent at home. Approximately three months before her death, the woman changed accommodation within the service, moving from a group home with 24/7 and sleepover staff support to a unit with twice daily drop-in visits.

Staff documented concerns about the woman's health and her ability to self-manage her health and support after her move to the unit. A service report two weeks before her death identified that:

- she was unable to complete most household tasks
- her choices in relation to her medical diagnoses were a continued source of concern
- her diabetes was uncontrolled due to her choice of poor diet and excessive consumption of food, her refusal to allow staff to monitor her blood sugar levels, and her misuse of insulin
- continued education of the woman to make better choices had proven to be ineffective, and she continued to place herself at significant risk of harm
- guardianship needed to be in place to prevent her poor judgement and choices resulting in her death.

However, the woman's resistance to support, impaired ability to self-manage her diabetes, and poor decision-making in relation to her health and welfare, were longstanding issues, and pre-dated her move to the unit. Among other things, records indicated that the service had twice indicated to the OCV in the year before the woman's death that staff would lodge a guardianship application due to major concerns for her health and wellbeing related to her unhealthy dietary choices; the woman had disclosed to paramedics attending the house that she was double-dosing her insulin before going to functions; and staff had contacted the woman's GP six months before she died, raising concerns about her health.

It was clear in our review that the woman was highly resistant to support, valued her independence, and self-managed her medication and health care. We noted that staff were supportive of her wish to regain independence in her accommodation support, and worked cooperatively with the woman and her advocate to resolve issues. However, it was evident that she had serious health risks that she was not adequately managing, and she moved to an environment that afforded reduced hours of support and oversight of her health and wellbeing.

We raised concerns with the service that it was not evident what action it had taken to mitigate the serious and increasing health risks that the woman faced. In this regard, we noted that the records did not indicate consideration of a case conference with the woman, her advocate, her GP, and other support providers to discuss the significant risks and agree on a coordinated approach to seeking to reduce those risks; or an application for guardianship to enable independent oversight of her health care management.

We monitored the actions of the service in response to this matter and broader issues we have raised about its governance and practice. These include the adequacy of its systems to identify and effectively manage significant client risks, to meet complex health and other support needs, and to provide clear escalation processes for raising and resolving concerns.

3.2. Managing individual risks

One of the consistent areas of focus in our reviews and reports has been the actions of support providers to comprehensively identify the significant health and other risks for individuals with disability in residential care, and to work together with the person (and other relevant parties) to reduce and effectively manage those risks.

Our reviews of deaths in 2014-2017 have emphasised the need for concerted attention on particular key risks for individuals, including risks associated with respiratory issues, fractures, bowel dysfunction, obesity, smoking and medication. We have highlighted many of these issues in previous reports, including through factsheets for providers on breathing, swallowing and choking risks; and risks associated with smoking, obesity and other lifestyle factors.

3.2.1. Breathing, swallowing and choking risks

Deaths from choking

Choking was a factor in the deaths of seven people in 2014-2015, and the deaths of four people in 2016-2017. This is a reduction on deaths from choking in the previous periods (10 deaths in 2012-2013, and nine deaths in 2010-2011).

All of the 11 people who died from choking in 2014-2017 lived in disability services, mainly group home accommodation (7). Most (7) were at home at the time of the critical event; three people choked while attending a day program; and one person choked while on an outing.

Most (7) of the people choked on food – either during a meal (5), or while accessing food that they were not intended to have (2). Three people choked on vomitus, and one person choked on a latex glove.

The majority (8) of the people who choked on food had identified eating and drinking behaviours and/or nutrition support needs (such as overfilling their mouth, swallowing without adequately chewing, eating too quickly, and missing teeth. In the main, the risks and management strategies had been identified and documented.

However, stand-out issues from our reviews of these deaths included:

- **There needs to be effective communication between providers about significant risks and agreed management strategies for individuals** – including ensuring that support staff in different settings have a consistent approach to managing the risks (such as using a consistent mealtime management plan). **It is important that NDIS support coordination takes into account the need for effective relationships and communication pathways between providers – with the person at the centre – to enable a coordinated approach to the management of critical risks,** such as choking risks.
- **Staff need to consistently apply eating and drinking mealtime management plans.** For some people, there had been multiple instances of them receiving food that did not meet their mealtime requirements.
- **Effective supervision is a significant factor in reducing preventable deaths due to choking. For four of the people who choked, the supervision provided at the time of the critical event was not adequate and/or was not in line with their requirements.** This included two people who were at home with 1:1 staff support at the time of the event. It only takes momentary lapses in supervision to result in fatal choking events.

- **Restrictive practices – such as locked cupboards, fridges and freezers – are not a failsafe, and do not replace effective supervision.** Case study 3 illustrates this point.
- **Providers must reinforce with staff the need to document 'close calls' (previous non-fatal choking events) in incident reports** to enable action to be taken to prevent recurrence and death.

Case study 3: Recognising and effectively responding to choking risks

A woman with an intellectual disability and mental health concerns received 1:1 accommodation support. Support plans identified that she had behaviours of concern related to eating other people's food, and eating raw or frozen food. The management of these risks was focused on redirection and not leaving her unsupervised in the kitchen.

On the morning of her death, the woman was unsettled and anxious. She took some food from the freezer, and was reported to have eaten part of a frozen pastry. In response to the woman's escalating behaviour and anxiety, staff administered PRN medication in accordance with her medication protocol. The staff member also locked the fridge and a freezer to prevent the woman from consuming any more frozen food. After a change of shift, staff observed the woman to be relaxing in the lounge room.

Later in the morning, the staff member was in the bathroom when the woman began banging on the door. The staff member found that the woman was choking on a frozen pastry, and was trying to remove food from her mouth. Staff called for an ambulance and then attempted to assist the woman to remove food from her mouth. Despite intensive intervention, the woman was unable to be revived.

The service conducted an internal review after the woman's death and also obtained independent advice on practice issues relating to her care. Our review found that there were critical aspects of the incident that had not been addressed in the incident reports of the event, in the service's review, or in the independent review. For example, it was not clear how the woman accessed the food, what guidance was provided to staff about reducing her access to food and using restrictive practices, or how staff were to provide full supervision at all times when they were providing 1:1 support. We raised these issues with the service, which subsequently commissioned an independent investigation to further review risk management strategies used by the service before the woman's death.

The investigation showed that, although the woman did not have dysphagia, staff were aware that she had behaviours around food that could increase her risk of choking. Among other things, disability support staff were aware that the woman would overfill her mouth, had difficulty regulating her food intake and safety, would eat inappropriate foods (frozen) when she was upset, and could be impulsive. The investigation found that, at times, staff locked a fridge and freezer to restrict the woman's access to food. However, there was no authorisation for this, and one of the freezers remained unlocked. Information provided by staff during the investigation identified a lack of clarity relating to how the locks came to be used, and the reason for their use. The information raised questions about the adequacy of the mechanisms in the service for monitoring practice and ensuring compliance with requirements.

We wrote to the service requesting detailed advice about its actions to address the issues identified in this matter, including to identify any other unauthorised use of restrictive practices in its accommodation services. The service advised that it would:

- identify and review all use of restrictive practices, incorporating onsite visits
- conduct a survey to assess staff awareness of restrictive practices and risk management
- deliver targeted training after the survey.

The service also updated its policies and issued clearer guidelines to improve staff practice.

Deaths from respiratory diseases

Respiratory diseases routinely feature as a leading cause of death of people with disability in residential care. Consistent with previous years, the main causes of deaths from respiratory disease in 2014-2017 were pneumonia, aspiration pneumonia, and chronic lower respiratory diseases, such as COPD.

Deaths from pneumonia

Our reviews of deaths from pneumonia in 2014-2017 continued to **underscore the importance of staff being alert to changes in health and/or behaviour and getting medical assistance without delay.** There was often a very short period of time between staff identifying symptoms of illness and the person's subsequent death from influenza or pneumonia – typically a matter of hours through to one week. We reported the same issue, and we saw the same short timeframe between symptoms and death, for deaths in 2012-2013.

A number of our reviews of deaths from influenza and pneumonia in 2014-2017 raised concerns that, although the individuals were at risk of pneumonia and respiratory illness, they had not received the **influenza vaccination** for at least a year before they died. In relation to one man whose death was caused by pneumonia and influenza, and after consultation with a medical practitioner member of our expert advisory panel, we referred the conduct of the GP to the HCCC. In our referral, we noted that the GP had not administered the influenza vaccination for the two years before the man's death, despite noting the man's respiratory risks and identifying that the main goal of his chronic disease management plan was to prevent pneumonia. We were advised that, in response to the man's death, the GP had instigated a vaccination recall system for all at-risk patients, to prevent any further vaccination oversight.

Deaths from aspiration pneumonia

The majority of the people who died as a result of aspiration pneumonia in 2014-2017 had multiple risk factors for respiratory disease, such as aspiration. This included:

- swallowing problems
- frequent chest infections
- mobility problems
- gastrointestinal problems, such as GORD
- dental problems, including missing some teeth
- conditions such as cerebral palsy, epilepsy and Down syndrome
- multiple medications, including psychotropic medication.

In the main, we saw active management and responsive approaches to identifying and addressing many of the risks, including the involvement of speech pathologists. There was a small number of people who continued to aspirate despite receiving all nutrition and medication via PEG. The issues we raised about the deaths of people from aspiration in 2014-2017 primarily related to **delays in obtaining medical assistance in response to signs of critical illness, and delays in progressing and resolving discussions about potential PEG insertion.**

Swallowing assessments, mealtime management plans and the NDIS

Towards the end of 2017, concerns were raised with us that the National Disability Insurance Agency (NDIA) had determined that mealtime and dysphagia supports would not be funded under an NDIS participant's plan. We raised the issue with the NDIA, and sought clarification on its position. The Agency advised that the policy under the NDIS in supporting dysphagia and mealtime supports had not changed: '*The Health system remains responsible for the diagnosis and assessment of dysphagia and the NDIS remains responsible for the day to day provisions of functional supports for mealtimes.*'[22]

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[22] Advice from the NDIA to the NSW Ombudsman, 12 December 2017.

The NDIA advised that the NDIS (Supports for Participants) Rules 2013 state that the health systems are responsible for the diagnosis, early intervention and treatment of health conditions, including ongoing or chronic health conditions. *'As the mealtime management plan is prepared by an allied health professional…to prevent a health condition such as aspiration pneumonia, the development of the plan is most appropriately supported by the Health system.'*[23]

The NDIA advised that supports generally funded by the NDIS to manage dysphagia and mealtime support involve:

- A speech pathologist to educate and train informal supports (carers, family members) and other support staff on how to implement the mealtime plan recommendations.
- Assistance such as a support worker to assist with implementing the mealtime plan, including managing behaviours or providing physical assistance to eat.
- A review of assistive technology needs.

Our reviews over the past 15 years have shown that dysphagia has significant and, often, fatal implications for the health of people with disability. It is critical that people with disability in residential care (and elsewhere) have timely access to skilled speech pathologists to obtain an accurate assessment of their swallowing function, and clear recommendations as to the actions that need to be taken to minimise the risks of choking and/or aspiration. We appreciate the reasons why swallowing assessments and the development of guidance about the necessary actions to support safe swallowing are considered to be the remit of the health system. We also welcome the Agency's recognition of the need for NDIS funding to ensure carers and staff are appropriately trained to implement the guidance and to mitigate risks.

However, it is evident from our reviews of the deaths of people in disability services that:

- NDIS funding *has* been used by speech pathologists (and other allied health professionals) to undertake swallowing assessments and develop mealtime management plans for individuals.
- Most of the individuals with dysphagia who have died accessed speech pathology services from within the disability sector, not the health system.
- Although some people have received swallowing assessments in hospital, this has typically been in response to crisis situations after an episode of choking and/or aspirating. A small proportion of people have accessed dysphagia clinics, but these have also been part-funded by FACS.

Against this background, we have significant concerns that people with disability face increased risks during the period in which they are only able to access funded speech pathology services (for swallowing assessment and written guidance) through the health system, but the health system is not yet sufficiently equipped to meet their needs and/or the demand. For people with disability with dysphagia, the consequences of not being able to access timely swallowing assessments can be catastrophic. It is not evident what work has occurred in NSW Health to assess its current capacity to fill the gap left by the disability sector in relation to speech pathology services, and to identify interim and longer-term strategies for addressing needs.

In response to our draft report, the Ministry of Health advised that it has been working on a nutrition support services and products discussion paper for the Disability Senior Officials Working Group's health sub-group – supported by the Speech Pathology Advisory Network and Nutrition and Dietetics, the Agency for Clinical Innovation (ACI), Dietitians Association of Australia (DAA), Speech Pathology Australia (SPA), and the national Disability Nutrition Support Network.

Deaths from chronic lower respiratory diseases

Common issues identified in our reviews of the deaths of people in 2014-2017 from chronic lower respiratory diseases – mainly COPD – related to their access to specialist and preventive health programs and supports, and the adverse impact of their actions and decisions on their respiratory health.

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[23] Ibid.

The majority of the people who died from chronic lower respiratory diseases smoked tobacco, and had typically been long-term heavy smokers. Despite approaches by GPs and/or support staff, many of them refused to quit smoking. They also had other lifestyle-related risks, including obesity and a lack of physical activity. Many of the individuals were regularly non-compliant with aspects of their treatment, such as refusing medication, non-invasive ventilation, medical reviews, and/or specialist appointments. Our reviews identified that the impact of their actions was significant, including that it resulted in medical practitioners making decisions to limit treatment, and to stop providing their services.

Despite substantial respiratory problems, we found that **few of the people who died from chronic lower respiratory diseases had seen a respiratory specialist.** Of the 16 people for whom it was their underlying cause of death, there was evidence that six (38%) had seen a respiratory specialist. Consistent with previous years, **very few people were involved in, or referred to, community-based chronic disease management support, such as the NSW Chronic Disease Management Program** (CDMP).

Case study 4 highlights a range of the significant issues we identified in relation to the support of people with chronic lower respiratory diseases in 2014-2017, including access to community-based chronic disease management support.

Case study 4: Missed opportunities to manage substantial respiratory risks

A 49-year-old man died from COPD caused by smoking. He had a moderate intellectual disability, mental health concerns, and significant and chronic health conditions, including asthma, COPD, respiratory failure, hypertension, atrial fibrillation and obesity.

Our review of the man's death identified problems with the disability and health related supports. We raised issues with both the disability service and the Local Health District (LHD).

Disability service

We found that disability support staff consistently encouraged the man to quit smoking after his diagnosis of COPD. However, we identified problems with the provider's management of his respiratory conditions, including the adequacy of guidance and training for staff, and issues related to medication administration.

Among other things, we found that:

- The man's health care plan contained limited guidance for staff about what they needed to do to help him manage his serious respiratory conditions.
- There were instances in which the man's access to necessary medication was compromised, including a non-functioning nebuliser and the incorrect storage of his inhaler.
- Staff had not received adequate training in the use of his non-invasive ventilation (BiPAP).
- The provider had opportunities to improve guidance for staff and management of the man's respiratory conditions, through access to a FACS clinical nurse consultant and a Health chronic care nurse, but did not progress them.
- On two occasions, staff noted that the man was critically ill (including, on one occasion, collapsed on the bathroom floor), but called the on-call manager before contacting emergency services.

We raised the issues with the provider. In response, the service developed an action plan for how it would improve health outcomes for its clients. This included restructuring its accommodation services to provide enhanced management and supervision, amending its procedures and providing training to staff on responding to critical events, implementing an electronic incident management system, and re-establishing a relationship with the LHD. We monitored the provider's progress in implementing the action plan.

Local Health District

We raised concerns with the LHD about the support provided to the man during hospitalisation, and as an outpatient.

We found that the man had 11 admissions and three presentations to his local hospital in the year before his death. In hospital, he demonstrated behaviour that adversely affected his medical treatment, including pulling out his cannula, removing his oxygen mask, and absconding. During all but one admission, the man made attempts to leave the hospital, and had to be redirected or retrieved from outside the ward. On two occasions, he was discharged from hospital early, before being reviewed by a respiratory specialist, due to his absconding behaviours and insistence on leaving hospital.

We raised concerns with the LHD that there did not appear to be a coordinated approach between the disability service and hospital staff during the man's hospitalisations. Although disability support staff were present at different times while he was in hospital, there was no indication that discussions occurred between hospital and disability support staff about the man's support needs and risks. It did not appear that the LHD applied the NSW Health and Ageing, Disability and Home Care (ADHC) Joint Guideline on supporting people with disability in residential care in hospital.

Our review also identified issues about the adequacy of the support provided by the LHD's Chronic Care Program, after the hospital referred the man to the program's chronic care nurse. We found that the nurse advised disability support staff that her role would be limited due to the man's behaviour, and documented that there was little benefit in supporting or monitoring the man on an ongoing basis. The nurse met with representatives of the disability service (not direct care staff), and took no further action. There was no indication that the nurse met with the man or liaised with his GP. We raised concerns with the LHD that it did not appear that the man received support from the Chronic Care Program, or that strategies were considered by the nurse to help him to access community-based support for his chronic respiratory conditions and reduce the frequency of his hospitalisations.

In response, the LHD advised that the man was an early entrant to the Very Intensive Patient (VIP) program, and was also enrolled in the program for frequent callers to the NSW Ambulance Service to mitigate his need for transport to hospital. The LHD advised us of actions it was taking to improve the awareness of staff of the Joint Guideline.

In relation to the chronic care program, the LHD advised that the exclusion criteria include 'impaired cognitive ability without a carer' and 'unwilling to receive support'. We raised concerns with the LHD that in this case the man did have carers. It also did not appear that the nurse had direct contact with the man to inform her assessment that he was 'unwilling to receive support', and disability service and health records did not identify any discussion with the man about his willingness or otherwise to participate. Although the LHD developed a COPD action plan for the man and made contact with the disability service to follow-up, overall the combined information identified a missed opportunity for:

- the man to obtain support to enable him to gain insight into, and better management of, his significant respiratory condition in the community
- the direct support staff to understand the actions they needed to take to help him.

We monitored the actions of the LHD to address the issues identified in this matter. These included establishing a Disability Inclusion Project Committee to support the implementation of Health's policy on responding to the needs of people with disability during hospitalisation, and educating all chronic care nurses to ensure that assessment of the person with disability forms part of the Chronic Care Program.

We have consistently raised concerns about the very limited access of people with disability in residential care (and people with cognitive impairment more broadly) to chronic disease management and other out-of-hospital programs. Although there have been some developments, including the production of an Easy Read version of the CDMP brochure, our reviews have not identified improved access or inclusion of people with disability to these supports. Case study 4 also highlights some of the broader challenges that exist, including criteria that specifically exclude people with cognitive impairment, and emphasises the importance of ensuring that a person-centred approach is employed, with active consideration of reasonable adjustments.

3.2.2. Fracture risks

At least nine people with disability in residential care who died in 2014-2017 experienced fractures in the period ahead of their death. In the vast majority of cases (8), the fractures were believed to have occurred as a result of a fall, including two people who fell out of bed. Most (6) of the falls were unwitnessed. One person was believed to have sustained the fracture during a hoist transfer.

In most cases (6), the fracture was a factor in the person's death. Most developed respiratory illness and died within a short period (between three days and three weeks of fracture), either with or without surgery.

The majority (8) had osteoporosis or osteopaenia. All had factors that affected their mobility, such as foot problems, an unsteady gait, and/or ageing. Falls risks and strategies to mitigate the risks had been documented for four of the eight individuals (57%) whose fracture resulted from a fall.

A key issue identified in relation to many of the people who experienced fractures ahead of their death was **delayed identification of the fracture:** either delayed identification by disability support staff and/or delayed diagnosis by health services.

Identification by disability services

For most (6) of the nine individuals, we identified delays in disability support staff recognising that the person needed medical attention. For example:

A man was found by disability support staff on the lounge room floor after an unwitnessed fall. He complained of chest pain and was unable to weight bear. An hour later, disability support staff conducted observations and called for an ambulance. The ambulance took two hours to arrive. At hospital, he was diagnosed with a fractured neck of femur. He was assessed as a high risk for surgery and was treated with antibiotics for a respiratory infection. His condition declined and he died three days later.

A woman was found by disability support staff on the ground after an unwitnessed fall, with grazes to her back, elbow and foot, and it was noted that she was unable to weight bear. Staff recorded that her inability to bear weight continued through the day and gradually got worse. They called for an ambulance five hours after finding the woman post-fall. She was diagnosed with a fractured neck of femur.

A woman indicated pain during a hoist transfer. Over the weekend, staff noted her continued indication of pain and provided pain relief. On the Monday, a manager recognised that the woman appeared to be experiencing increased levels of pain and called an ambulance. In hospital, the woman was diagnosed with a fractured hip. She died five days after surgery.

In our last report, we noted that research into patients with disability had identified that fracture detection is often delayed because of disability factors that prevent the individual from reporting the fracture event or associated pain, particularly in relation to unwitnessed events. A lack of evident indication of pain appeared to be a relevant factor for one of the eight individuals whose fracture was believed to have occurred as a result of a fall. However, for the seven others, there *were* indicators of pain, or signs that the person had been affected by the fall, but medical assistance was not immediately sought. In one case, staff's ability to recognise that the person required medical assistance was adversely affected by the person's experience of chronic pain from other conditions.

These matters underscore the importance of disability supports:

- **knowing the person and their usual manner and level of functioning, and being alert to any changes** to their health and/or behaviour
- **getting medical assistance without delay** where there are concerns or any question about the seriousness of the person's presenting condition (including signs of pain)
- **ensuring that health practitioners have all relevant information about the person** to enable an accurate diagnosis of the presenting concern
- **clearly identifying and mitigating falls risks**
- together with practitioners, **taking timely action in response to falls to prevent recurrence** (through a risk management rather than risk elimination approach).

Identification by health services

For three of the nine people, we found that there were delays in hospital staff diagnosing their fracture. For example:

- A man was taken to hospital when he was unable to bear weight after a fall out of bed two days earlier. Hospital staff conducted hip and pelvic x-rays that showed no obvious fracture, and he was discharged with analgesia. A few days later, the man's GP requested a hip and pelvic CT scan, which identified a hip fracture of the greater trochanter (hip).
- A man fell out of bed and was taken to hospital. The hospital diagnosed a fractured scapula, but did not identify that he had also fractured his hip and rib. Back at home, and over the next four weeks, the man showed changes in his behaviour and mobility, including relying on a wheelchair rather than a walking frame; increased agitation and resistance to movement; increased distress, crying, yelling, and groaning. Disability support staff did not seek a medical review. The man's other fractures were only discovered when he went to hospital for treatment of abdominal pain.

Communication difficulties tended to affect the diagnosis of the fractures in hospital, including in case study 5.

Case study 5: The impact of communication difficulties on diagnosing fractures

A woman with a severe intellectual disability and non-verbal communication had an unwitnessed fall at home and was unable to weight bear. Staff called for an ambulance and she was taken to hospital where x-rays were taken of her foot, leg and ankle. No fracture was identified, and the woman was discharged home that day after having her ankle strapped, with recommendations to take analgesics, apply ice, elevate, and follow up with her GP.

The woman vomited during the night and appeared to be in pain during the next day, so staff sent her back to hospital. Hospital staff noted that the woman would screech when touched. She was discharged home after a further physical examination that found no injury.

She vomited brown fluid the following night, and in the morning was yelling and crying, refusing to weight bear, and screaming in pain intermittently. Staff called for an ambulance and she returned to hospital. The woman was transferred to a second hospital, where a CT abdominal scan showed a hip fracture and constipation. The next day, she was transferred to a larger hospital for hip surgery. During preparation for surgery, she regurgitated and aspirated gastric contents into her lungs. After surgery, the woman's prognosis was poor and she received palliative care after consultation with her family.

As part of our review, we consulted with a medical member of our reviewable disability deaths expert advisory panel. The expert advised that, in light of the delay in diagnosing the woman's hip fracture, there may be a need to consider the introduction of routine hip x-rays for older patients who are unable to weight bear without pain and unable to communicate verbally, in order to exclude a hip fracture.

We raised this issue with the LHD, which conducted a multidisciplinary clinical case review. The LHD found that there had not been a comprehensive medical assessment and examination of the cause of the woman's severe pain and inability to mobilise; there had not been a full physical examination of her joints, taking into account that this was a fall in a patient with intellectual disability over 50 years of age; and there had been inadequate consideration by the assessing doctor of the possibility of a hip fracture.

The LHD subsequently developed a Local Operating Protocol on *Assessment of the Injured Patient with Communication Difficulties*, to provide guidance to staff involved in assessing and managing a patient who presents with difficulty weight bearing, but cannot communicate effectively about their symptoms. Among other things, the protocol seeks to ensure that proper consideration is given to the possibility that the patient has a hip fracture, and stipulates the need for a full investigation of the patient's pain and inability to mobilise, including by physical examination and routine hip x-ray.

Our reviews highlighted the importance of health services:

- **Ensuring that they understand the person's communication needs, and consult with people who know them well,** including the person's disability support staff, to enable an accurate diagnosis of their presenting concerns.
- **Having mechanisms to coordinate access and care for people with disability –** such as a clinical pathway for people with cognitive impairment when they present, or are admitted, to hospital; or identified roles to provide leadership and advice.

3.2.3. Bowel management

A high proportion of people in disability services who have died had constipation and other bowel dysfunction. In 2014-2017, three-quarters of the people in disability services who died experienced constipation. Over half of the disability services residents who died experienced both faecal and urinary incontinence (250; 53%). Another nine people (2%) solely had faecal incontinence.

Bowel obstructions and other bowel issues also consistently feature as causes of death of people in disability services. 'Other diseases of the intestines', including bowel obstruction, was a contributing factor in the deaths of 26 people in 2014-2017. Over the 15 years to 2017, paralytic ileus and intestinal obstruction has been the eighth leading underlying cause of death of people in disability services.

Our reviews of deaths in 2014-2017 identified a range of matters in which there were deficits in bowel management for the person. These included where:

- There was inadequate guidance for staff on the actions they needed to take to help the person to manage their bowel health, such as signs of bowel obstruction.
- No evident action had been taken to investigate the cause of faecal incontinence.
- Staff did not consistently follow bowel management recommendations, such as the administration of PRN laxatives or enemas.
- Staff did not seek medical assistance for individuals whose bowels had not opened for an extended period of time.
- Staff did not recognise and respond in a timely way to signs of bowel obstruction, including a number of matters where guidance had been provided – see case study 6.

Case study 6: The importance of knowing the person, recognising critical illness, and taking swift action

A woman with a severe intellectual disability who lived in a residential centre died as a result of a bowel obstruction.

During one afternoon, staff noted that the woman's abdomen was distended and hard to touch. Staff recorded that the woman was constipated, administered a laxative, increased fluids and gave her fibre rich food, which resulted in bowel movements. Staff recorded that her observations were within normal ranges, and she was assisted to bed later that evening. In the early hours of the morning, staff found the woman slumped over her bed with black vomit on her face, and again noted that her abdomen was distended and hard to touch. Staff started CPR and called for an ambulance, but the woman was unable to be resuscitated.

The service's internal review after the woman's death found that all staff of the residential unit had been provided with a factsheet about bowel obstruction earlier that year, including information that '*immediate medical attention should be sought if a person presents with a distended abdomen, with or without a bowel motion.*' The internal review recommendations included that all nursing staff should attend training on bowel management.

We raised concerns with the service that we had previously brought to its attention similar issues in our review of another person who lived at the same residential centre. In response to that matter, the service had circulated the bowel obstruction factsheet, and issued a memorandum to staff reinforcing the need for timely intervention by medical services. Against this background, it was not evident why – after observing the woman's distended abdomen – staff did not seek urgent medical assistance. We also raised concerns that there appeared to be a period of 30 minutes between staff finding the woman in a critical condition in the early hours of the morning, and calling for an ambulance.

We monitored the actions of the service in response to these issues, including training staff in relation to bowel management and obtaining urgent medical assistance.

It is important to recognise that disability support staff are not expected to be health professionals or to otherwise apply clinical judgement. Consistent with our advice about identifying and managing other key health risks, our reviews in relation to the deaths of people from bowel-related concerns emphasise the need for disability supports to:

- **know the person,** including the support they need for their bowel health, their usual presentation and functioning in order to identify changes, and common signs of critical health changes for them (such as indicators of a bowel obstruction)
- **be alert to changes in health or behaviour,** including any of the common indicators of illness for the person
- **get assistance for the person without delay.**

Our reviews of these matters also underscore the **importance of health professionals providing clear written guidance to the person with disability and their disability supports –** through a bowel management plan or similar – about the actions that need to be taken to help the person to manage their bowel health.

We note that the NDIS Practice Standards cover the responsibilities of registered NDIS providers when providing supports and services to participants who need complex bowel care. These are relevant to many of the issues identified in our reviews and include:

- assessing and developing a plan for the person's complex bowel management, which identifies how risks, incidents and emergencies will be managed
- training for staff working with a participant requiring complex bowel care by an appropriately qualified person, relating specifically to the participant's needs.

3.2.4. Obesity, smoking and other lifestyle risks

We have previously highlighted the deaths of people with disability in residential care that are due to health risks associated with smoking, poor diet and lack of physical activity – including heart disease, lung cancer, bowel cancer and respiratory disease. Our factsheet on *Smoking, obesity and other lifestyle risks*[24] emphasises that, with support, people with disability can reduce many of these lifestyle risk factors that can lead to death.

Support to quit smoking

Our previous reports have consistently highlighted the high rates of smoking among people in assisted boarding houses, and the significant health risks they face as a result.

The Australian Institute of Health and Welfare (AIHW) has reported that tobacco smoking is 'the single most important preventable cause of ill health and death in Australia', and in 2011-12, 'people with severe or profound disability were 2 times as likely as those without disability to smoke daily (31% versus 15%).'[25]

The prevalence of smoking among the assisted boarding house residents who have died is much higher. In 2014-2017, 61% of the assisted boarding house residents who died had smoked, including one-third who were smoking more than 10 cigarettes a day at the time of their death. In the 15-year period 2003-2017, 78% of the boarding house residents who died had smoked; half of the residents who died were smoking more than 10 cigarettes a day at the time of their death.

The adverse effect on the health outcomes of this population is significant. The leading causes of death of people in assisted boarding houses over the 15 years to 2017 are all associated with smoking: acute myocardial infarction, chronic ischaemic heart disease, COPD, and lung cancer.

There has been a reduction in the number of assisted boarding house residents who died who had smoked. For example, in 2010 and 2011, 88% of the residents who died had smoked. However, there continues to be a need for concerted attention on this issue. Consistent with our previous messages, including our factsheet on *Smoking, obesity and other lifestyle risks*, it is important that people with disability in residential care who smoke, and the people who support them, have access to information about the assistance that is available to quit.

To reduce preventable deaths, it is critical that people with disability who smoke have every opportunity to quit, with proactive and ongoing support to do so.

Support to address obesity and improve nutrition and physical activity

Obesity continued to feature highly among the people with disability in residential care who died in 2014-2017. Consistent with previous years:

- In disability services, over one-third of the people who died (177; 37%) were above the healthy weight range. Of these, 76 people (16%) were obese or severely obese.
- In assisted boarding houses, almost half of the residents who died (8; 44%) were above the healthy weight range. Most (7) of these individuals were obese or severely obese.

Obesity was identified as a significant condition or contributory factor in the deaths of seven people, including three people in 2014-2015, and four people in 2016-2017. All of the individuals lived in disability services, or were on respite with a disability service at the time of their death. Chronic respiratory disease, diabetes, and heart disease

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[24] https://www.ombo.nsw.gov.au/news-and-publications/publications/fact-sheets/community-and-disability-services/preventing-deaths-of-people-with-disabilities-in-care-smoking,-obesity-and-other-lifestyle-risks.

[25] Australian Institute of Health and Welfare 2016. Health status and risk factors of Australians with disability 2007-08 and 2011-12. Cat. No. DIS 65. Canberra: AIHW.

featured prominently in the deaths of these individuals, as well as the other people who were above the healthy weight range when they died. Overweight and obesity is a significant risk factor for the development of many chronic conditions, and of death (from any cause).[26]

We appreciate that obesity is not only an issue for people with disability in residential care; it is a broader population health issue. In 2014-15, almost two-thirds (63%) of Australians aged 18 and over were overweight or obese, and the prevalence of overweight and obesity has steadily increased.[27] **However, our reviews continue to identify the need for proactive efforts by disability services, health providers, and population health programs to help people with disability in residential care to address their critical weight issues.** In this regard, we note that:

- In the main, people with disability in residential care need assistance to be able to reduce their weight and lead a more active lifestyle. Among other things, most of the elements that affect their weight – including the food they eat, and the physical activity they can be involved in – are typically heavily in the control of disability support staff. However, our reviews of the deaths of people who were obese have rarely identified a proactive approach to helping the person to reach a healthy weight. Some practices by disability services – such as community access outings that comprise a meal at a fast food outlet – promote the opposite.
- There is insufficient evidence of health practitioners and disability services working together, and with the person, to help them to address their obesity. A range of reviews identified individuals whose weight was adversely affecting their health, such as their respiratory function. However, other than recording the significant risks for the person and telling them they needed to lose weight, no support was provided. In some cases, we did not see an attempt to adopt a coordinated and person-centred approach to helping the person to address their weight risks, even when their obesity was noted to be limiting the treatment options for their chronic conditions. As noted in Chapter 1, our reviews of deaths in 2014-2017 identified low rates of access to dietitians for people who were overweight, obese or severely obese.
- Population health programs and strategies aimed at reducing obesity need to actively include people with disability.

The NDIS, including the Information, Linkages and Capacity Building stream, potentially provides additional opportunities for people with disability to obtain supports to make lifestyle changes that will improve their health outcomes – such as links to community activities. However, there is a risk that no provider or individual will take the lead. Making and sustaining change to address the lifestyle factors that adversely affect health outcomes is heavily reliant on a coordinated and cooperative approach, with the person at the centre. It is important that NDIS local area coordinators and support coordinators understand the substantial health risks for people with disability in residential care associated with key lifestyle factors, including insufficient physical activity, and actively consider opportunities to make linkages, enable individual capacity building, and coordinate appropriate supports to reduce these risks.

Inclusion of people with disability in the Healthy Eating and Active Living population health strategy

In previous reports, we have referred to the NSW Healthy Eating and Active Living (HEAL) strategy. This is a population health program aimed at encouraging and supporting the community to make healthy lifestyle changes and to create an environment that supports healthier living. In June 2015, we reported on our discussions with the Centre for Population Health on options for ensuring that the strategy is inclusive of people with disability. At that time, the Ministry of Health indicated that it would progress opportunities to target the Get Healthy at Work program to non-government disability accommodation services, would trial a buddy system for residents and carers as part of the Get Healthy Information and Coaching Services, and would ensure that social marketing resources and assets are inclusive of people with disability.

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26. AIHW 2017 A picture of overweight and obesity in Australia, https://www.aihw.gov.au/reports/overweight-obesity/a-picture-of-overweight-and-obesity-in-australia/contents/summary; and https://www.aihw.gov.au/getmedia/172fba28-785e-4a08-ab37-2da3bbae40b8/aihw-phe-216.pdf.aspx?inline=true.
27. AIHW 2017 An interactive insight into overweight and obesity in Australia, https://www.aihw.gov.au/reports/overweight-obesity/interactive-insight-into-overweight-and-obesity/contents/how-many-people-are-overweight-or-obese.

In November 2015, we held a forum to bring together the Office of Preventive Health and key stakeholders in the disability and mental health sectors to discuss ways in which to improve the inclusion of people with disability in preventive health programs, with a specific focus on the HEAL strategy. At this meeting, it was agreed that the Office of Preventive Health would organise a working group to progress work to improve inclusion, including consultation with consumers. After the forum:

- The Office of Preventive Health convened a working group and developed an action plan.
- The Centre for Population Health contracted the Council for Intellectual Disability to consult with people with intellectual disability on HEAL, and obtained feedback on the changes that were needed to the messages and resources to make them more appropriate to people with disability – including Easy Read formats.
- The Centre for Population Health approached some non-government disability providers about being involved in the Get Healthy at Work initiative, which provides free health checks for staff and supports a comprehensive workplace program. Consultations by the Centre for Population Health confirmed that staff need support and training about healthy eating and active living in order to better support clients to make healthier choices.

Although there has been some action towards improving the access of people with disability to the HEAL strategy, there is further work required. More broadly, the inclusion – and specific targeting – of people with disability in population health programs is relevant to key intended outcomes of NSW Health's Disability Inclusion Action Plan (DIAP), including that 'people with disability are able to access NSW Health services, according to their needs'.[28]

3.2.5. Medication risks

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

The majority of the people with disability in residential care who have died received multiple medications. In 2014-2017, the majority of people (84%) were taking three or more medications at the time of their death. This included 180 people (37%) who received 10 or more medications, nine of whom were receiving 20 or more medications when they died.[29]

For many of the individuals, these medications include major medications – such as psychotropic medications and/or medications that they relied on to prevent them from becoming critically ill.

Our reviews of the deaths of people in residential care in 2014-2017 identified significant issues relating to the management of medication risks. Areas of concern in our reviews of deaths over this period included:

- **Evidence of multiple medication errors in relation to individuals** – including administration of double medication; medication found beside beds, chairs, or on the floor; and missed medication.
- **Staff not administering medication as prescribed** – including instances of staff not filling prescriptions for medications from GPs or hospitals; and people who did not receive their respiratory medications because they were packaged in a separate container, or were out-of-date when they needed to take them.
- **Poor medication administration records** – including staff not consistently signing the medication chart; signing separate charts; and signing for medications on the wrong day.
- **Poor incident reporting of medication errors** – in one case, we identified 23 medication incidents in the three months before the person's death, but staff had completed only three incident reports.

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[28] NSW Health (January 2016) *Disability Inclusion Action Plan 2016-2019*, p 33.

[29] In 2014 and 2015, 194 people were taking three or more medications at the time of their death, including 77 people who received 10-19 medications, and 1 person who received 20+ medications. In 2016 and 2017, 222 people were taking three or more medications at the time of their death, including 94 people who received 10-19 medications, and eight people who received 20+ medications.

- **Poor management of, and response to, medication refusal by individuals** – in one case, staff documented 35 incidents of the person refusing to take their prescribed medications, but there was no behaviour support or other identified strategies for addressing the issue.
- **A failure to safely store medications.**

We recognise that, at times, there will be medication errors and other incidents. However, the evident gaps in the systems of providers to readily identify when errors have occurred, review the incidents to identify the cause(s), and take action to prevent recurrence, are concerning.

In this regard, we note that we identified individuals for whom there had been an unacceptably high number of medication errors, but there was no evident action by the providers to examine the situation and ensure that it did not continue. For example:

- A man with epilepsy whose records identified 87 incidents in 12 months of medications not being signed as administered (including his five anticonvulsant medications).
- A woman whose records identified 51 incidents of staff not signing the medication chart, and included a notation by the GP that medications were not being given as required.
- A man with COPD whose records identified 16 medication incidents in 12 months – including repeated instances of missed medication, and an incident in which staff were unable to locate his PRN medication for over a week.

Arising from our reviews of deaths in 2014-2017, we have raised issues about medication management with many providers. In most cases, the providers identified problems with staff implementation of relevant policies and procedures, and focused on improving staff induction and training. We agree that these are vital elements, and we support the actions of providers to ensure that staff have a sound understanding of practice requirements.

However, it is important that this initial grounding is supplemented by **robust internal systems for monitoring and improving practice; a strong workplace culture that supports and encourages the reporting of incidents and concerns; and clear mechanisms for ensuring that early and effective action is taken to mitigate risks.** This is not consistently the case.

In 2014-2017, the deaths of at least three people were associated with prescribed medications. For example:

- A man in an assisted boarding house was found to have a supra-therapeutic level of one of his two antipsychotic medications at the time of his death. Although unable to ascertain the cause of the man's death, the Coroner noted the potential effect of the high level of the psychotropic medication on his respiratory and cardiac functioning, and the potential combined effects of his other medications (which included three psychotropic medications).
- A man in a disability service was found to have a high blood concentration of an antipsychotic medication at the time of his death from bronchopneumonia. Central nervous system depression is a known side-effect of the antipsychotic medication, and the Coroner noted that the blood concentration of the medication was high enough to cause significant sedation – which may have reduced the man's respiratory function.
- A man in a disability service died from an overdose of an opioid medication (see case study 7).

Case study 7: The importance of managing significant medication and other risks to prevent avoidable deaths

We reviewed the death of a man with an intellectual disability, mental health concerns, and a substance abuse disorder, who lived in a group home. Staff found the man deceased on the floor of his bedroom mid-morning, with a syringe next to him. After an inquest, the Deputy Coroner determined that the man died from an accidental overdose after injecting liquid extracted from a Fentanyl patch; and that his death occurred while he was inadequately supervised by the disability service.

Our review identified a range of concerns about the actions of the disability service and the conduct of staff. These included:

- Inadequate actions by the service to manage the substantial risks associated with the man's history of misuse of prescribed substances and known drug-seeking behaviour.
- A lack of action by staff in response to signs that the man was intoxicated the evening before his death, including no overnight checks.
- The inadequate supervision of the residents.
- Inadequate management and storage of medications – including inadequate actions to ensure that the residents took the medication they were administered, to dispose of unused medication and syringes, to check the medication supply and contents of the medication cupboard to identify any missing drugs, and to ensure that the medications were stored in a secure location that was inaccessible to the residents.
- A lack of evident action in response to incident reports to address the identified issues – including resident access to medications – and prevent recurrence.
- Inadequate staff training – including on the man's support needs, risks, and supervisory requirements.

We raised these issues with the service, and provided relevant information to the Deputy Coroner to inform the inquest. We also sought disability reportable incident notifications from the service relating to the conduct of staff in this matter. After an investigation, the service sustained findings of neglect against four staff members, and found that a fifth staff member had breached the code of conduct.

The service provided information to us about the actions it had taken since the man's death to address the issues and prevent recurrence. Among other things, the actions included greater environmental controls (such as securing all entry and exit points to the staff office; and installing a secure medication cabinet, with keys to the cabinet kept on the support worker); enhanced monitoring systems, including medication audits and client check procedures; and training for staff.

We are continuing to monitor the actions of the service in relation to this matter. With FACS and the Office of the Children's Guardian, we have also monitored the broader reform work that the service has undertaken in response to issues we identified across a range of our functions – including concerns about managing risks, medication administration and security, and identifying and addressing concerns raised by staff.

Case study 8: The need to improve training and oversight of staff in medication administration and incident reporting

We reviewed the death of a woman with a moderate intellectual disability, mental health concerns and chronic health issues who lived in a group home. Staff found the woman not breathing in her bedroom, approximately 40 minutes after she had her evening meal and medications.

Toxicology tests after the woman's death identified the presence of medications that she had not been prescribed, including two anticonvulsant medications and a medication used to treat Type 2 diabetes. The provider engaged an external investigator to look at the circumstances surrounding the woman's death, which found that:

- staff had administered medication in a haphazard manner on both the morning and dinnertime shifts
- staff did not sign the woman's dinner medication records
- the woman appeared to have been given another resident's medication, and it was possible that the other resident was given hers

- it was alarming that the medication error was not picked up or disclosed
- it was not known in which shift the medication error occurred.

The provider's employee conduct unit obtained the opinion of toxicologists to seek to narrow down the likely timeframe in which the medication error occurred, and provided relevant information to the Coroner's office. The Deputy Coroner advised that the woman's death was multifactorial and the administration of the incorrect medications was not causative.

We noted that the provider had sufficient information to progress its investigation into the allegations of neglect against the staff members, irrespective of whether or not the error directly caused the woman's death. The provider re-engaged the external investigator, and found that staff had not followed correct procedures in relation to medication administration. The provider required the staff members to have further medication training, and conducted verbal reliability tests of their understanding; and increased its casual and temporary staff's access to guidance and support.

Use of psychotropic medication for behaviour management purposes

In 2014-2017, 206 people (87%) in residential care were taking psychotropic medication at the time of their death. This included almost one-third of people (146) who were taking antipsychotic medication, one-quarter (111) who were taking antidepressant medication, 68 people (14%) who received anti-anxiety medication, and almost 10 percent (40) who were taking sedatives.

Psychotropic medication has associated risks of adverse events – such as side-effects, toxicity, falls, and swallowing problems. For people in disability services, FACS policies in place during the review period stated that psychotropic medication must not be the primary behaviour support strategy used for a person with intellectual disability, and consent to the use of medication prescribed to manage behaviours of concern 'must be conditional on its use in the context of a Behaviour Support Plan'.[30] [31]

Our reviews identified that, of the 206 people who were taking psychotropic medication at the time of their death, 86 people (42%) had behaviours of concern but did not have a behaviour support plan, including 32 of these people who did not have an identified mental health condition.

We have previously raised concerns about the frequency of the use of psychotropic medication, particularly antipsychotic medication, as a primary behaviour management strategy. In response, FACS surveyed disability supported accommodation providers in 2014 to identify the prevalence of the use of psychotropic medications, and to confirm adherence to policy requirements for using these medications. FACS' analysis of the survey data identified 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. FACS undertook a range of practice improvement strategies with providers, including requiring reporting on all cases where routine psychotropic medication was prescribed for behavioural issues. While we recognise the actions that FACS has taken to improve practice in this area, our reviews of deaths in 2014-2017 suggest that further work is required.

Against this background, we welcome the new requirements for behaviour support and the use of restrictive practices that were introduced on 1 July 2018, on the commencement of the NDIS Quality and Safeguards Commission. Among other things, the use of medication prescribed for behaviour management purposes is considered to be a restrictive practice, and subject to greater regulation and oversight, including enhanced reporting requirements.

Some of our reviews also identified concerns about the actions of treating medical practitioners in prescribing and reviewing psychotropic medications, and resulted in referrals to the HCCC. Case study 9 provides an example.

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[30] ADHC (January 2009) *Behaviour Support Policy*, p 15.

[31] ADHC (January 2009) *Behaviour Support Policy*, p 20.

Case study 9:

A man who lived in an assisted boarding house had a diagnosis of schizophrenia, and significant health risks associated with smoking and obesity. He was prescribed two antipsychotic medications, an anticonvulsant medication, and an anti-anxiety medication. He died as a result of ischaemic heart disease.

As part of our review, we examined records from the assisted boarding house, the man's GP and psychiatrist, and the Boarding House Reform Team, and consulted with a medical member of our reviewable disability deaths expert advisory panel. Our review, and the expert advisor, identified concerns about the treatment provided by the psychiatrist and the management of the man's schizophrenia.

The expert advisor identified that the psychiatrist did not provide clear, written advice to staff of the boarding house or the GP about the man's diagnosis or medication plan. The psychiatrist's records were mostly illegible and did not contain any correspondence to the GP apart from the prescription for antipsychotic medications. There was no evident consideration of the man's physical issues, or of the need to review his antipsychotic medication over time. The expert advisor commented that the brevity of the man's mental state examination by the psychiatrist was thoroughly unacceptable as a standard of record keeping.

On the basis of the expert's advice, we referred the matter to the HCCC. We have been advised that the matter is with the Medical Council of NSW.

3.3. Support to access health services and treatment

3.3.1. Support to minimise resistance to health assessments and treatment

Every year, we identify people with disability in residential care whose behaviour or decisions adversely affected their health and medical treatment. Our reviews of deaths in 2014-2017 identified at least 24 people[32] whose access to necessary medical assistance was compromised as a result of their own behaviour or decisions, including the following individuals.

A man with substantial health needs refused showers despite episodes of incontinence, which compromised his wound care. He refused to attend some GP appointments and refused to allow staff to assist with his diabetes care. His decisions presented significant risks to his health, but his behaviour support plan did not include these issues. The accommodation service worked cooperatively with the man to encourage him to accept medical interventions, but there was a lack of clear guidance for staff – including what action they needed to take to obtain medical assistance despite his objections.

A woman had significant respiratory risks, but was not compliant with most medical intervention. She refused non-invasive ventilation (CPAP), refused to quit smoking, refused health screening, refused to have a sleep study, and refused for an ambulance to be called. She did not have a behaviour support plan. When she became critically unwell, she refused the offer of staff in the early hours to call an ambulance, but called one herself an hour later. She died from COPD later that day.

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[32] The 24 people included 10 people who died in 2014-2015, and 14 people who died in 2016-2017.

A man was unwell for four days before going to hospital, but had refused to see a GP. Staff called for an ambulance when the man became critically ill, and he was admitted to the Intensive Care Unit in hospital. He died four days later from pneumonia. His history showed that the man would see the GP, but would not comply with the recommendations of health professionals, including the GP and dietitian, unless he wanted to. Staff accepted the man's decisions not to see a GP, despite concerns for his health, and the fact that he had a private guardian.

A woman regularly refused medications, non-invasive ventilation (BiPAP), dietary and quit smoking recommendations, and medical and dental appointments. She was resistive to monitoring her weight, blood glucose and oxygen levels and refused to follow necessary fluid restrictions. She had been scheduled to have a CT colonography to exclude a tumour, but she refused to have the necessary clear fluids, demanded food, and refused to have the procedure. The woman's behaviour support plan did not address these issues. She died from chronic respiratory failure due to COPD.

Consistent with previous years, the resistance of individuals to treatment or investigative procedures often had significant and adverse consequences for them. Importantly, aside from the limitations imposed by the person's own actions, their resistance or non-compliance also affected the treatment decisions of health professionals and family members. For the people who died in 2014-2017, this included instances where:

- A decision was made that a man's mental state, and poor likelihood of tolerating or complying with the treatment, meant that he was not suitable for chemotherapy.
- A family made the decision that a woman should not have surgery or other active treatment for a bowel obstruction on the basis that she would be likely to refuse post-operative treatment, intravenous fluids and a nasogastric tube, and would become distressed.
- For two individuals, decisions were made that they would not have surgery to insert a PEG, on the basis that they would be unlikely to tolerate it, and would pull it out.

There are clear elements of preventability in the deaths of many of the people whose decisions or actions adversely affected their access to necessary medical assistance. It is critical that individuals who are resistant or averse to treatment receive support to address these issues and reduce the adverse impact on their health outcomes. It is evident from our reviews over an extended period of time, that resistance to medical examination or treatment are not adequately identified by accommodation staff or behaviour clinicians as matters that need to be included in behaviour support plans. Given the life-threatening nature of the issues, **this must change**.

We appreciate the challenges involved in supporting people 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.**

Our reviews emphasise the vital importance of:

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

Providers supporting the person also need to ensure that **the decisions of the NDIA regarding the scope and funding of the person's NDIS plan is informed by** relevant information about their **need for behaviour support** to address these issues.

We have seen some examples of positive practice on the part of disability and health staff, working cooperatively with the person, with gentle but persistent approaches. We have also seen positive examples of disability and/or health staff working around the problem – for example, looking at other ways for a man to receive his IMI antipsychotic medication when he repeatedly refused to attend the clinic. However, these actions did not prompt or trigger broader action in relation to the person's objections or refusals, such as behaviour management support (or case coordination discussions).

3.3.2. Support in hospital

Our reviews show that, in many cases, the greatest impact of a person's resistance or aversion to medical treatment is experienced in the hospital setting. In addition to the person's pre-existing aversion, they are also typically dealing with an unfamiliar, crowded and busy environment, people they don't know, physical illness, pain and discomfort, and a lack of control over their environment and what is happening to them.

Consistent with previous years, our reviews of deaths in 2014-2017 identified people with disability whose behaviour and actions affected their health and medical treatment in hospital. The impact on the individuals was significant, including:

- incomplete examinations and investigations due to physical resistance
- decisions by medical practitioners (and families) to stop or limit treatment because of the person's distress, behaviour, or other presentation
- use of mechanical and chemical restraints to prevent individuals from removing or pulling out treatment (such as oxygen masks, nasogastric tubes, intravenous medication) and/or from getting out of bed.

In a range of reviews, we saw a substantial difference in the person's experience and outcomes when they had support from disability services staff. The following matters are illustrative:

Shortly after admission to hospital, a man was reported to be highly agitated and resistant to care, screaming, and pulling out tubes. He was given a sedative, and was noted to settle with a disability support worker present. However, the support worker left an hour earlier than the scheduled time, and the man continued to be agitated, aggressive and restless, and attempted to climb out of bed and pull out his tubes. He was given several doses of a sedative and an antipsychotic medication, despite the attendance of a 'nurse special'. On a later admission to hospital, the man had two unwitnessed falls, with the latter occurring shortly after the disability support worker had left for the evening – three hours earlier than had been scheduled. The man was noted to be highly distressed, yelling and screaming out. Management of the man's behaviour at that time involved physical restraint in a chair, and the provision of a 'nurse special'.

The disability service identified in a man's hospital support plan that he was resistant to many types of physical contact and may try to resist having medical interventions, but did not provide any guidance on potential strategies. The man had two admissions to hospital that involved very different experiences. During one extended admission for aspiration pneumonia, hospital staff used chemical and mechanical restraints. Disability support staff were not in attendance for most of the admission, but family visited. The man experienced recurrent agitation, tried to climb out of bed, and tried to pull tubes out while he was in the ICU. He was given a high dose of sedation (four types), and soft restraints were used (four limbs and chest), as well as mittens to protect the tubes from being pulled out. The man still managed to bite a ward person and remove his nasogastric tube, even while restrained. A subsequent admission was very different – group home staff were present, and assisted with his hygiene and meals. The man was cooperative, and no restraint was used.

A woman went to hospital due to exacerbation of asthma, and her treatment included oxygen and IV antibiotics. When disability support staff left, the woman was not compliant with oxygen therapy or the cardiac leads, and she removed her drip. The next day, she was non-compliant with the nebuliser and IV antibiotics, and hospital staff called the disability service for assistance. She had a heart attack that day, and died five days later. We found that her care in hospital was adversely affected by her anxiety and repeated non-compliance with treatment. Although hospital staff sought the assistance of the disability service to reduce these issues on the third day of her admission, there was no indication that action was taken at the time of her admission to hospital to identify her support needs and risks, and to discuss with the disability service the support that would be needed (and who would provide it).

However, the presence of disability support staff is not always effective, or an end in itself. Our reviews continue to emphasise the importance of:

- Ensuring that **behaviour support strategies specifically target the person's resistance or aversion to medical assessment and treatment.**
- **Health and disability support staff working together,** and with the person with disability (and their supporters, where appropriate), **to facilitate appropriate and person-centred support in hospital – including implementing the Joint Guideline** (or equivalent local arrangements).

The NSW Health and ADHC Joint Guideline: *Supporting residents of ADHC operated and funded accommodation support services who present to a NSW Public Hospital* was issued in 2013. It provides a framework for best practice for health and disability staff so they can:

- identify risks that could affect the person and their health outcomes while in hospital
- agree on what additional supports are required to reduce identified risks
- negotiate responsibility and resources for providing the agreed additional support.

Support in hospital for people from disability services has been a source of contention for many years, and is one of the reasons why the Joint Guideline was developed. In our experience, there are individuals with disability who require support in hospital from people who are familiar to them, and who understand their needs. In the main, these are individuals who require the support because of their behaviour support and/or communication needs.

We note that the principles agreed by the Council of Australian Governments (COAG) to determine the responsibilities of the NDIS and other service systems identify that any funding in a person's NDIS package 'would continue for supports for people with complex communication needs or challenging behaviours while accessing health services, including hospitals and in-patient facilities'.[33] It is critical that the need for this support is identified and incorporated into individuals' NDIS plans. It is also important to recognise that not all of the people with disability who demonstrated resistance to treatment and other behaviours that adversely affected their treatment in hospital had behaviours of concern at home.

It is therefore vital that support providers clearly identify individuals who have this behaviour/aversion, and take steps to ensure that the need for this support is understood by the NDIA to enable:

- **the provision of behaviour assessment and support to help to minimise the person's resistance to necessary treatment**
- **the provision of support in hospital.**

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33. COAG Principles to Determine the Responsibilities of the NDIS and Other Service Systems, https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf.

Actions on individual matters relating to support in hospital

In response to the significant issues relating to support for people with disability in hospital that were identified in our reviews of deaths in 2014-2017, we raised concerns with five LHDs and met with four LHDs. The issues we discussed centred on the following common problems:

- **A lack of evident awareness and application of the Joint Guideline.**
- **Inadequate actions to identify and understand the person's support needs and risks on admission to hospital,** and to discuss with relevant parties (the person, disability support staff, family) the best way to address them.
- **Inadequate communication and discussions with relevant parties during hospitalisation,** including strategies to prevent or minimise the use of restraints.
- **A lack of a defined pathway on hospital admission for people with cognitive impairment,** to enable appropriate consideration of key factors and risks.

In response, LHDs took a range of actions to improve their practice, such as:

- Developing an implementation plan for the Joint Guideline.
- Identifying and allocating specific positions and/or committees to oversight implementation of, and compliance with, the National Disability Strategy, the NSW Health DIAP, and Health's policy on responding to the needs of people with disability during hospitalisation.
- Following provision of contact details by our office, holding an afternoon tea with local disability services to facilitate better communication and understanding of the needs of the client group and respective roles and responsibilities.
- Arranging regular, ongoing meetings with local disability services.
- Participating in key projects to improve care to patients with disability, including the Admission2Discharge Together Project, and the 'Say Less – Show More' project, which seeks to improve communication through pictorial aids.
- Introducing a pre-admission program for people who may need extra support when going to hospital.
- Identifying ways to use key hospital-based positions to lead the coordination of care of people with cognitive impairment during admission.

Broader work relating to support in hospital for people with disability

Actions on the part of specific hospitals and LHDs in response to individual matters are important, but our reviews continue to underscore the need for broader and more concerted action to address fundamental issues.

In a range of matters, our reviews found that hospital staff did not take action to identify and have discussions about the person's support needs and risks. This was despite the Joint Guideline, despite prompts in hospital risk assessments about whether the person had any cognitive and/or communication deficits or disability, and despite the existence of the 'Top 5' tool in health services.

In relation to the Joint Guideline, we rarely identified hospital support plans (or similar guidance) in disability or health records. Although we noted the existence of various support plans from disability services in health records, such as mealtime management plans and client profiles, it was not always evident whether, and to what extent, hospital staff considered this information. In some cases, information that had been provided by the disability service, such as the person's enteral nutrition plan, did not appear to travel with them when they moved to a different area of the hospital, resulting in hospital staff having to make calls to the disability service for guidance that had already been provided.

In June 2015 we recommended that NSW Health and FACS should review the implementation and effectiveness of the Joint Guideline, and provide advice to us about the arrangements they intended to put in place with NGO disability providers by the time of the full NDIS transition (that is, 1 July 2018). In response, FACS conducted a survey and identified that consideration should be given to augmenting the 'Top 5' tool into the Joint Guideline. Health contracted an external evaluation of the Joint Guideline, which found relatively low awareness of the guidance, but strong support for its principles and tools. Health indicated that it is considering the evaluation report's recommendations in the context of the changing landscape under the NDIS.

In the period since our last report, we have noted the introduction of the Admission2Discharge (A2D) Together Project. This is an initiative of FACS and the Metro-Regional Intellectual Disability Network in South Eastern Sydney LHD, which was expanded to include South Western Sydney LHD, and has now transferred from FACS to Northcott. The project has included developing an A2D Together folder to facilitate timely transfer of relevant and current information to enable hospital staff to meet the needs of people with intellectual disability. Among other things, the folder includes a document to record the 'Top 5' support strategies and tips, and the hospital support plan (from the Joint Guideline). In 2015-2017, the project trained over 1500 health staff in the two LHDs, as well as over 600 disability support staff and managers. Northcott has advised that it is continuing to work in partnership with NSW Ambulance and NSW Health's ACI and South Western Sydney LHD in relation to the project. Given the progress and outcomes of the interagency project to date, there are valuable opportunities to build on, and upscale, this work to support a consistent approach across health and disability services.

We note that Health's DIAP includes commitments to promote a patient based care model, supported by a range of programs that support coordinated care, including the 'Top 5' program.

Our reviews of deaths in 2014-2017 highlight the need for further work to address the core issues.

3.4. Transfer of care

A number of our reviews of the deaths of people with disability in residential care in 2014-2017 raised concerns about the actions of health services in transferring the care of individuals from hospital to home (discharge planning). This included where:

- Vital information was not provided in the discharge plan – such as information about substantial respiratory problems that had been identified via x-ray, abnormal pathology results, and a change to the person's meal consistency that had been recommended in a speech pathology review (see case study 10).
- The person was discharged back home without considering whether their health needs could be adequately met with the existing supports, despite multiple admissions and readmissions over a short period of time, a decline in their health, and increasing risks.

Case study 10: The importance of coordinated transfer of care to manage key risks

A man with an intellectual disability and chronic health concerns had three hospital admissions in the month before his death. During his first admission, he had a speech pathology assessment that recommended a change to his mealtime requirements, including a puree diet and full supervision when eating. After this assessment, the disability accommodation provider and the hospital reached an agreement that disability support staff would provide support to the man during mealtimes in the hospital. On the day he was being discharged from hospital, and while waiting for staff to collect him, the man was unsupervised at lunchtime, and accessed food that was not meant for him. The man was found choking in the hallway, and collapsed. He was revived, and discharged home after being observed for four hours. The discharge report noted that the man had been reviewed by a speech pathologist, but did not detail any recommendations.

The next day, the man was taken back to hospital as disability staff were concerned that he was continually coughing, had an unsteady gait, and had worsened dysphagia after his hospital discharge. During this admission, he was reviewed by a geriatrician, and discharged two days later with guidance to follow-up with aged care assessors. Three days later, the man had another choking incident at home, and was taken to hospital. His condition deteriorated and he died three days later.

As part of our review, we discussed the matter with the disability accommodation provider. They advised that, although disability support staff were aware from the discharge report that the speech pathologist had reviewed the man in hospital, they were unaware that there had been any recommended changes to his mealtime requirements to reduce his choking risks. We wrote to, and met with, the LHD, who conducted an internal review. The LHD acknowledged that critical information about the man's changed mealtime requirements had not been adequately conveyed to the disability service. The LHD advised us of actions it had taken to ensure that plans are updated and included with documentation for transfer of care; and developed a case study on the choking incident for training purposes in the hospital.

In many of our reports, we have emphasised that, 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. Although NSW Health has issued policy directives[34] to guide staff practice in the transfer of care – including for people with disability in residential care – we continue to identify problems in this area.

Since our last report, NSW Health has reviewed and revised its policy directive on responding to the needs of people with disability during hospitalisation. This policy, like the previous version, provides useful guidance on providing support to, and coordinating the transfer of care of, people with disability in hospital. However, our work has shown that good policy does not guarantee good practice. Monitoring the implementation of the policy across LHDs and Specialty Health Networks (SHNs) is critical. We note that the policy indicates that:

- LHDs and SHNs should develop mechanisms to determine if there is a difference in outcomes for people with disability when compared to the general population, disaggregated by age, gender, type of disability, place of residence, and cultural background (and provides examples of performance indicators and outcome measures.
- Systematic monitoring of the access of people with disability to health services, and comparing their outcomes against those of the general population, 'requires data items to identify people with disability in data collection systems'. The policy refers to relevant commitments in its DIAP.

In our June 2015 report, we noted that there was no consistent mechanism across NSW health services to identify people with disability in health data. We indicated that 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
- facilitate data analysis to inform broader service planning.

In response to our recommendations, NSW Health has provided details of a range of actions that it has taken to progress the development of data identifiers and a minimum dataset for people with disability. Given the importance of this work to improve and measure outcomes for people with disability in contact with health services, we will continue to monitor progress.

3.5. End-of-life care and decision-making

3.5.1. Advance Care Directives

Advance care planning – where people prepare for likely scenarios near the end of life – enables the person and key people in their life to discuss options for future care and treatment. However, there are critical differences between undertaking advance care planning and developing an Advance Care Directive.

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[34] NSW Health (2011) *Care Coordination: Planning from Admission to Transfer of Care in NSW Public Hospitals* policy directive; and NSW Health (2017) *Responding to Needs of People with Disability during Hospitalisation* policy directive.

An Advance Care Directive is a document that describes a person's future preferences and wishes for medical treatment in anticipation of a time when the person is unable to express those preferences because of illness or injury.

There are important points to note in relation to Advance Care Directives:

- An Advance Care Directive that complies with NSW Health policy requirements is legally binding in NSW.
- A person must be 'competent' to make their own health care decisions when the Advance Care Directive is drafted. That is, they must be able to understand, retain, and weigh up the relevant information and then make a choice.

People who lack the capacity to make informed decisions are not able to make Advance Care Directives, and nor can it be done on their behalf.

Our reviews of the deaths of people with disability in residential care in 2014-2017 identified a number of individuals who had Advance Care Directives. Our concerns in relation to these matters is that the Advance Care Directives were developed:

- in relation to individuals who did not have evident capacity to develop an Advance Care Directive
- in some cases, with family members signing agreement to the directive on behalf of the person with disability
- in some cases, with staff members acting as witnesses
- in some cases, as standard practice, with a number of residents at the same accommodation having a directive in place, signed by family members on their behalf.

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

NSW Health guidelines, *Making an Advance Care Directive,* provide clear guidance about both advance care planning and the use of Advance Care Directives.[35]

For one person, a discharge letter from a hospital admission noted decisions that had been made about treatment limitations, and stated 'Advance Care Directive in place'. This document was used seven months later as the basis for disability support staff to not perform CPR, and they advised the arriving paramedics of the same. However, an Advance Care Directive was not in place, and the Public Guardian had been appointed and had not been involved in any discussions regarding treatment limitation.

3.5.2. Decisions based on perceived quality of life

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 concerns have primarily related to treatment limitation decisions being based on the practitioner's view of the individual's quality of life and dependence on others for care, rather than the person's presenting medical condition and treatment options.

However, in some of the deaths of people with disability in residential care in 2014-2017, we had concerns about the treatment limitation decisions of family members. These included:

- Decisions for conservative treatment despite practitioners providing options for active treatment of reversible conditions, including surgery.
- Treatment limitation decisions based on a perceived quality of life of the person, including that active treatment would not be in their 'best interests' or 'appropriate'.

In some cases, the treatment limitation decisions of family members were influenced by the person's behaviour in relation to medical treatment – including their distress, resistance to tests, and attempts to remove tubes and oxygen masks, and so on. However, this was not always the case.

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[35] http://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf.

In a small number of cases, the disability service raised concerns about the treatment limitation decisions of the family. In those matters, the disability provider had not been involved in the discussions, despite providing support to the individuals on a daily basis and potentially being a source of valuable information about them and their preferences.

Given the serious and irreversible consequences for the person with disability, it is important that:

- **Treatment limitation decisions are informed by the people who know the person well,** including, where relevant, disability support staff.
- **Treating practitioners clearly explain to family members the available options,** including active treatment.
- **Maximum efforts are made to address any issues that are influencing the treatment limitation decision,** including options for providing support to reduce distress and pain.
- **Any party with concerns about the treatment limitation decision –** including health practitioners and disability services staff **– considers whether an application needs to be made to the NSW Civil and Administrative Tribunal (NCAT)** for the appointment of an alternative substitute decision-maker.

3.6. Incident reporting and internal reviews

In our last report, we emphasised the need for services to conduct an internal review after the death of a person in their care. We also highlighted the importance of ensuring that any staff on shift at the time of the person's death (or the critical incident that later resulted in their death) complete an incident report detailing what occurred.

Overall, we have seen some improvements in the actions of services after the deaths of people with disability in residential care, including incident reports by staff and an increase in the proportion of services undertaking internal reviews.

It is likely that these improvements have resulted, at least in part, from the introduction of the disability reportable incidents scheme. At the time that we released our previous report in June 2015, the scheme had only been in place for six months. The focus of the scheme on preventing, reporting and effectively responding to incidents, and associated training across the sector, has helped to drive service improvements in a range of key areas – including investigative practice, reporting relevant matters to police, and providing appropriate support to the involved people with disability.

Importantly, the disability reportable incidents scheme has also facilitated improvements in incident reporting by staff, with an emphasis in the scheme on service providers developing and maintaining a staff culture of reporting.

However, our reviews of the deaths of people with disability in residential care in 2014-2017 have identified areas for further improvement in relation to incident reporting. In particular, there is a **need for an increased focus on reporting:**

- **Significant behaviour or changes in behaviour**, including:
  a) resistance or objection to medical treatment
  b) medication refusal
  c) behaviour that presents risks to the person or others – such as a person with swallowing risks taking and consuming food or drink that was not meant for them.
- **Medication incidents** – including administration errors, missing medication, or not signing the administration records.
- **Falls –** including unwitnessed falls.
- **Significant health events or changes in health** – such as matters requiring contact with management, a medical officer, and/or emergency services; and identifying bruising or pressure wounds.
- **'Close calls' or 'near misses'** – such as non-fatal choking incidents, manual handling incidents. Case study 11 illustrates this point.

Case study 11: The need to report 'near misses' to prevent recurrence and death

We reviewed the death of a man with a moderate intellectual disability and autism who lived in a group home. He had ongoing behaviours of concern, including serious behaviours around food that placed him at risk of choking or injury. Due to the behaviours, staff implemented restrictive practices, including locked kitchen cupboards, fridge and freezer.

On the day of the man's death, he returned with a disability support worker from an outing and had lunch. Afterwards, he went to watch television, and the support worker went to the group home's office to do some paperwork. Another staff member was also in the office completing administrative tasks. While the staff were in the office, the man gained access to an unlocked kitchen cupboard and consumed an unknown amount of a sandwich spread, causing him to choke. The support worker found the man outside the house a short time later, unconscious and not breathing. Staff took swift action to call emergency services and conduct CPR, but the man was unable to be revived.

The provider's review after the man's death identified that improvements needed to be made in relation to line of sight from the office to the kitchen, and the kitchen locking mechanisms.

Our review found that there had been four instances of the man inappropriately accessing food in the eight months before his death, such as accessing margarine while the staff member was busy with another resident. However, staff had documented the events in progress notes rather than incident reports, and there was no indication that any action was taken in response to the incidents to prevent recurrence.

The importance of a number of these issues has been highlighted in earlier sections of this chapter. Overall, there are two critical aspects:

1. **Providing clear guidance to staff about the matters that need to be reported as incidents rather than just recorded in progress notes or communication books.**

   Our work has shown that reducing the avoidable deaths of people with disability in residential care relies on staff recognising key events for individuals, and reporting them to enable action to be taken. In some cases, one instance should prompt action in response (for example, a near-fatal choking event). In other cases, it is the existence of multiple reports about the issue(s) that will indicate the need for action (such as medication refusal, or significant decline in the person's health or functioning).

   However, the reports have to be submitted to enable a service to respond. Our reviews have consistently shown that recording events in progress notes or communication books does not enable effective recognition of the issue, or action to be taken in response.

2. **Having documented, robust, and well-understood systems in place for reviewing and responding to incident reports.** To enable improved outcomes for individuals, and to sustain an appropriate reporting culture in the organisation, it is important that management both *takes action* in response to incident reports, and *is seen* to take action.

It is only through reporting, reviewing and responding to incidents, that effective action can be taken to prevent recurrence or worse outcomes for individuals. Our reviews of deaths in 2014-2017 identified a range of matters where, had incident reports been lodged and critically examined, it would have enabled the providers to:

- Identify at an early point where staff required greater assistance in supporting the person and/or mitigating risks – including behaviour support, or assistance from health providers.
- Recognise where staff needed reinforcement of critical messages or refresher training – such as calling for emergency assistance, providing first aid, understanding signs of critical illness, and implementing medication administration requirements.
- Identify unacceptable staff practices that required early action to prevent reportable incidents or other misconduct.

Part Three:

Monitoring our recommendations

Chapter 4. Agency progress against recommendations in our last report

Recognising and responding to critical situations

We directed Recommendations 1-3 to both FACS and National Disability Services (NDS). We included NDS as the peak body for non-government disability services, noting that FACS' role in relation to NGOs was steadily diminishing. However, NDS has emphasised that it does not have a funding or policing role through which it could compel organisations to implement policy and practice changes, and not every organisation providing residential care services in NSW is a member of NDS. We appreciate that NDS is not in a position to 'ensure' that non-government providers take action in relation to our recommendations. It is for this reason that the progress report on the three recommendations focuses on FACS' actions.

More broadly, the number of NGO providers, particularly since the introduction of the NDIS, presents challenges in directing recommendations and monitoring the actions of those providers in response. We will liaise with the NDIS Quality and Safeguards Commission about issues in this report that relate to, or have direct implications for, NDIS registered providers.

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).

Progress

FACS advised that it issued a statewide memorandum to all disability residential care staff and management on 31 December 2015 with clear instructions on how to seek timely medical assistance. The memorandum reinforced that a standard agenda item at monthly team meetings would be to discuss any current health concerns for clients and the proposed course of action.

FACS issued an additional memorandum to districts in February 2016 on indicators of illness that should prompt staff to obtain emergency medical help. FACS also advised that it:

- Updated the ADHC intranet with information about disability residential care staff requirements to seek timely medical assistance as early as possible.
- Released the Health and Wellbeing Policy to Districts in March 2016, which recognises the importance of identifying symptoms of illness and changes in a person's health status before the situation becomes an emergency.
- Has issued a range of health and wellbeing resources and guidelines that include instructions for staff to seek emergency medical assessment or treatment, such as Bowel Care Guidelines and Chronic Disease Guidelines.

Our comments

We note the actions taken by FACS to implement the recommendation, including issuing instructions through different mechanisms.

Our reviews have continued to identify problems in the actions of disability support staff to identify critical illness and take timely action in response – in both FACS and NGO accommodation.

To reduce avoidable deaths of people with disability, and reportable incidents associated with staff failing to obtain timely medical assistance for NDIS participants, it will be important to ensure that the key messages in this report are reinforced with registered providers.

We will discuss with the NDIS Quality and Safeguards Commission potential strategies for pursuing and monitoring improvements on this issue.

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).

Progress

FACS advised that it issued a statewide memorandum to all disability residential care staff and management in the districts with clear instructions that quarterly refreshers are required at team meetings.

The memorandum included the need for frontline staff to have access to a cordless phone or a working mobile phone. FACS advised that it incorporated evidence of access to a cordless phone or working mobile phone into its Continuous Improvement Review Tool (CIRT) to enable regular audits to be done of compliance.

Our comments

We recognise the actions taken by FACS in response to the recommendation, including incorporating key information into the CIRT to check compliance with one aspect.

However, as identified in this report, we have continued to identify problems with the response of staff to critical incidents in both FACS and NGO accommodation.

To reduce avoidable deaths of people with disability, and reportable incidents associated with staff failing to provide an appropriate and timely response to critical incidents involving NDIS participants, it will be important to ensure that the key messages in this report are reinforced with registered providers.

We will discuss with the NDIS Quality and Safeguards Commission potential strategies for pursuing and monitoring improvements on this issue.

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 preventive 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[36] (fact sheet 4), and

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[36] https://www.ombo.nsw.gov.au/__data/assets/pdf_file/0007/9475/Breathing,-swallowing-and-choking-risks-factsheets-4.pdf.

   - ii) **Preventing deaths of people with disabilities in care: Smoking, obesity and other lifestyle risks[37] (fact sheet 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.**

Progress

FACS advised that it updated the Staff Induction Checklist to require new staff to read and certify that they have understood the information in the fact sheets. The fact sheet information has also been included in the Employee Development Program since early 2016.

FACS issued a statewide memorandum requiring disability residential care staff and management in FACS Districts to have quarterly refreshers at team meetings and in individual supervision about the content of the fact sheets. FACS has also referenced the fact sheets in the ADHC Health and Wellbeing resources and the Good to Great e-learning modules, which include a focus on chronic disease, health promotion, and nutrition and swallowing procedures.

Our comments

We note the actions FACS has taken to implement the recommendations.

There remains a need to improve and maintain the awareness and actions of disability support staff in FACS and NGO accommodation about breathing, swallowing and choking risks, and risks associated with smoking, obesity and other lifestyle factors.

We will discuss with the NDIS Quality and Safeguards Commission potential strategies for pursuing and monitoring improvements in these key areas of risk.

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.**

Progress

In relation to incident reporting, FACS advised that it issued a statewide memorandum in 2015 to remind disability residential care staff and management of the need to provide comprehensive incident reports after the death of a client. FACS included a further reminder to staff on this issue when it released its revised *Incident Reporting Guidelines and Policy, on 1 April 2016.*

In relation to internal reviews, FACS advised that it established a Clinical Governance Review Panel in August 2015, which met on a bi-monthly basis to, among other things, identify and report trends and critical issues associated with the deaths of people with disability. In June 2016, the panel reviewed the Operation Guidelines for the Review of the Death of People with Disability and Fact Finding template. The (then) Clinical Innovation and Governance unit also conducted Clinical Governance Reviews to analyse the clinical supports and governance provided to individuals before their death, against FACS policy and standards.

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[37] https://www.ombo.nsw.gov.au/__data/assets/pdf_file/0004/9481/Smoking,-obesity-and-other-lifestyle-risks-factsheets-5.pdf.

Our comments

We have seen some gains in practice in incident reporting after the deaths of people with disability in residential care, as a result of a range of actions by FACS to improve guidance and train staff, and the concurrent roll out of the Disability Reportable Incidents scheme. However, our reviews of deaths in 2014-2017 have identified areas for further improvement in incident reporting by staff, and the systems of providers to ensure that reports are analysed and action is taken in response.

In relation to internal reviews, we have identified an increase in the number of reviews conducted by providers after the deaths of people with disability in residential care. A number of non-government services have also told us about actions they have taken to establish internal mechanisms to review practice after a death and to implement identified improvements. However, internal reviews are still not standard practice after the deaths of clients.

The inclusion of the deaths of people with disability in the NDIS reportable incidents scheme may help to improve practice in internal reviews by registered providers. It will also be important for the NDIS Quality and Safeguards Commission to work with registered providers on ensuring that messages about the need to conduct internal reviews after deaths (and other serious incidents) are reinforced with all providers, to enable timely examination of the key circumstances, and action to address evident risks to others.

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.

Progress

In January 2016, DPC provided us with a copy of the NSW Government's NDIS Transition Plan, and advised that it identifies system improvements that will be required to support transition and/or embed practice change that is responsive to the needs of people with disability. DPC told us that NDIS transition plans have been developed for each cluster in the NSW Government, and NSW has prepared detailed Mainstream Interface Working Arrangements and Operational Guidelines for use by state agencies.

DPC also advised that officials from NSW, the Commonwealth and the NDIA are identifying, escalating and resolving issues through key governance structures, including the NSW NDIS Implementation Steering Committee, Regional Operational Working Groups (ROWGs) and a Bilateral Steering Committee.

Our comments

DPC gave us a copy of the NSW NDIS Transition Plan, the NSW Operational Plan, and the Operational Guidance for NSW Mainstream Services on the Interface with the NDIS. The Transition Plan included performance measures for, among other things, the implementation of the cluster transition plans, and the re-engineering of business and systems for clusters to interface with the NDIS.

We note that implementation of the plans has been completed, with full transition to the NDIS on 30 June 2018.

Recommendation 6

Recommendation 6 focused on the Hunter region. In our June 2015 report, we indicated our view that the disability and health reforms (including Health's integrated care initiatives) and the Hunter NDIS launch site, provided a valuable opportunity to address cross-sector communication and cooperation, as well as longstanding problems and deficits in mainstream health services that have adversely and inequitably affected people with disability.

The Hunter area – given that it was the site of the start of the NDIS, the location of devolving FACS large residential centres accommodating people with complex health needs, and the location of key Health initiatives aimed at improving integration and coordination of care – appeared to us to present a golden opportunity for NSW Health and its partner agencies to look at the inclusion of people with disability, and to trial and evaluate ways of addressing the longstanding problems.

However, in the main, the information identifies that this has not occurred.

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.

Progress

NSW Health advised that HNELHD contributes to the commissioning process of primary health care in the region led by the Hunter New England Central Coast Primary Health Network (HNECC PHN). HNECC PHN has worked closely with HNELHD on mental health and drug and alcohol services, to ensure that primary health services are able to meet the needs of the broader community and the specific needs of an individual with disability.

HNELHD and HNECC PHN have also been partnering in the delivery of integrated care enablers, including HNE HealthPathways[38] and Smart eReferrals.[39] In this regard, HNELHD has been involved in a number of integrated care initiatives across the region, including the Hunter Alliance, which allowed the sharing of information and skills of the four major health care providers in the region – Hunter Primary Care, HNE Health, HNECC PHN, and Calvary. In October 2017, Health advised that the Hunter Alliance was working on four key priority areas, including Care in the Last Year of Life, which had delivered a shared care clinical handover tool, MyNetCare.[40] Health told us that local consideration was being given to how MyNetCare could specifically benefit people in the community who have a disability. In July 2018, Health advised that the Hunter Alliance has since been dissolved, and HNELHD has formed a new HNE Integrated Care Alliance with the HNECC PHN, and has endorsed a shared Integrated Care Plan for 2018/19. The plan sets out an agreement to cooperate to achieve objectives in 11 areas, including integration of mental health services, after hours urgent medical care services, palliative and end of life care services, and chronic disease services.

Health advised that, in addition to the three Integrated Care Demonstrator sites (Western Sydney, Central Coast and Western NSW LHDs), there are 17 integrated care projects underway. HNELHD is funded as an innovator focusing on services around Care in the Last Year of Life. In October 2017, Health advised that a formative evaluation of the Integrated Care sites would be completed and reported at the end of 2017, and that Health proposed to use the outcomes of the evaluation as the mechanism for reporting progress against our recommendation. Furthermore, Health advised that the

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[38] HealthPathways is a web-based information portal providing GPs with advice and guidance on assessment, management and referrals.

[39] Smart eReferrals are supporting GPs to make appropriate and timely referrals to public and private health services in the Hunter region.

[40] MyNetCare is a web-based clinical handover tool that is designed to improve the experience of patients living with advanced illness in the Hunter region.

NSW Government has committed $180 million over six years for the Integrated Care Strategy, and that additional resource allocation, including the need for funding with a disability specific focus, will be determined from the findings of the strategy evaluation.

In relation to the HealthOne NSW service, in October 2017 Health told us that the lessons from its rapid review of the service would contribute to the development of 20 HealthOne NSW services across NSW, with $100 million committed in capital funds. Health advised that care coordination was found to be a central component of the model, and the findings from the review would be circulated to LHDs in early 2018.

Our comments

Our recommendation specifically referred to the integrated care and HealthOne NSW initiatives. This was because the focus of these initiatives on coordinated and integrated care appeared to be directly relevant to addressing a range of the well-documented and consistently reported problems and barriers for people with disability in accessing (and receiving appropriate support from) mainstream health services. There is no indication in the information provided by Health that the needs of people with disability have been considered in relation to either initiative. There may be benefits for people with disability in residential care associated with MyNetCare and the 11 objectives in the Integrated Care Plan, but limited details have been provided to enable our office to assess their likely impact on this group.

It is not clear how the need for funding of integrated care with a disability specific focus will be determined from the findings of the evaluation of the strategy. It is also not evident the extent to which consideration of people with disability has informed the review and operation of HealthOne NSW. At a minimum, the information raises questions as to how Health is measuring progress towards meeting a key objective of HealthOne NSW services to improve service access and health outcomes for disadvantaged and vulnerable groups.

Health's actions in relation to the inclusion of people with disability in integrated and coordinated care initiatives will need to be the subject of ongoing independent monitoring.

b) Implementing mechanisms in HNELHD to coordinate access and care for people with disability.

Progress

Health advised in July 2018 that HNELHD has implemented a number of strategies and systems, aligned with actions in its DIAP, to improve staff awareness, knowledge and skills, to improve access and care for people with disability. These included:

- Establishing a HNE NDIS Project Team, with identified leads in the areas of children and young people, mental health, adult community and inpatients, and rural and regional. The team has produced a suite of resources and guidelines on the HNELHD intranet to support staff in their care of people with disability, and has established an online feedback portal for staff to obtain advice or feedback from the team, or assistance with client issues.
- Partnering with the NDIA to deliver a joint roadshow to health staff and information sessions focused on the interface between health services and the NDIS for people with disability who are in hospital.
- Establishing a permanent Mental Health/Intellectual Disability CNC role, which has a significant focus on creating and maintaining relationships between community-managed organisations and mental health in delivering coordinated care for people with intellectual disability.
- Initiating a project to develop, trial and evaluate an A2D/Hospital Passport type resource to improve the transfer of care between group homes and hospitals.
- Establishing telehealth models of care to improve access to care for people with disability – such as the HNE rural spinal cord injury service, HNE Brain Injury Rehabilitation Service, and local community rehabilitation services.

Our comments

Our recommendation originated from the consistent evidence in our reports of the ongoing problems experienced by people with disability in contact with health services, including hospitals. In our June 2015 report, we noted that our work for over a decade had underscored the need for a mandatory identified role(s) in LHDs to provide both leadership and advice about disability health and inclusion – especially for people with intellectual disability – as well as assistance with the coordination of support.

In our 2015 report, we noted productive work that could inform the way forward in this area. This included the existing 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), and innovative practices identified in the (then) current disability action plans of some LHDs.[41]

We welcome the actions that HNELHD has taken since our previous report to improve the coordination of access and care for people with disability.

However, we note that our reviews of deaths in 2014-2017 have continued to identify issues relating to support for people with disability in hospital, including in the Hunter and Central Coast areas. Given these continuing issues about support for people with disability in hospital, and coordination and transfer of care, there is a need for the work by HNELHD and other districts on this issue to be the subject of ongoing independent monitoring.

c) Developing mechanisms to facilitate the provision of timely, coordinated and multidisciplinary health support to people with disability transitioning from Hunter institutions to community-based accommodation.

Progress

FACS advised that this process is captured in its *LRCSSL-SS Guidelines on the management of risks to safety, health and wellbeing in the transition of residents and staff from ADHC LRCs*. As part of this process, FACS told us that it is working together with residents, families and providers to access allied health professionals needed to support the person in the community-based accommodation, and to organise funding hours in the review of the NDIS plan before transition.

FACS also advised that, through its Mainstream Health Services Capacity Project, it tests the capacity of the local mainstream health sector to meet the service support needs of Hunter Residences. Health told us that this working group had been established to trial the discharge of the first 50 residents of the Stockton Centre into community accommodation under a care coordination model. Health advised that clients transitioning under this model received supports that included engaging with a GP before transition, documenting a care plan, conducting a home medicines review, and developing a disability emergency escalation plan.

In July 2018, Health advised that the mainstream health capacity project was not evaluated or continued due to the 'earlier than expected cessation of the project by FACS', and HNELHD is waiting for further information from FACS about the next transition timeframe. In the interim, HNELHD has coordinated an interagency advisory group to identify efficient mechanisms that will help transitioned clients to access appropriate community-based health services, and to discuss an integrated health service for clients who will be transitioning from LRC environments. Health has advised that HNE Health has been actively involved in the Stockton transition, and continues to review the services it currently provides at Stockton LRC, and to develop strategies on how to deliver these services in the community/hospital environment after transition.

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[41] NSW Ombudsman June 2015 *Report of Reviewable Deaths in 2012 and 2013, Volume 2: Deaths of people with disability in residential care*, p 66.

For patients transitioning out of Morisset Hospital, Health told us that Morisset Psychiatric Rehabilitation Services has a transitional planning process in place. This includes developing and implementing individual plans incorporating (among other things) early engagement of community care providers – such as community mental health teams and community managed organisations.

Health advised that a specialist mental health and intellectual disability project position has been created to provide guidance to mental health service staff, other government agencies, and community managed organisations on the delivery of care and the development of pathways for those individuals with intellectual disability and mental illness. In July 2018, Health advised that it has appointed two new clinicians (an occupational therapist and a CNC) to enhance the transition process into the community for people who are leaving a mental health inpatient unit after an admission of greater than 365 days – including identifying and supporting people with a mental illness and intellectual disability, and ensuring linkages with required community-based services are in place.

Health advised that HNELHD has a project lead exploring potential strategies to streamline access to health services for people with disability, including oral health services and community health services.

Our comments

The advice from FACS and Health indicates that there are a number of areas of work they are undertaking separately and together, to facilitate the provision of coordinated and multidisciplinary health support to people transitioning out of Hunter institutions to community-based accommodation.

Our reviews of the deaths in 2016-2017 of two individuals who moved out of Hunter Residences to community accommodation have raised questions about the extent to which the actions in relation to the residents of those large residential centres have informed transition activities to date.

There is a need for the progress of this work to be the subject of ongoing independent monitoring.

d) Creating a minimum dataset for people with disability.

Progress

Health told us that:

- HNELHD has developed an NDIS Alert process in its patient management system, comprising four alerts to classify a patient's NDIS status along with a comments section to record any useful information.
- As information about the patient's NDIS status needs to be voluntarily given, it is expected to be incomplete.
- HNELHD is working with Hunter Primary Care and FACS to discuss ways to best use the alerts and comments sections specifically for people in large residential centres.

More broadly, Health advised that it has implemented a range of new data fields designed to:

- capture the interaction with Health of people who are existing NDIS participants or eligible for the NDIS
- measure the effectiveness of the NDIS related supports that Health provides
- provide an evidence base for service redesign activities
- provide NSW Health with the ability to ensure that NDIS participants are directed to the most appropriate supports
- help NSW Health in its client based interactions with the primary health sector
- broaden the base of understanding about disability to flag interactions with people with disability who are ineligible for the NDIS.

Health told us that it is continuing discussions within the NSW Government, with interstate health agencies, the NDIA and the Commonwealth on the broader linkage of NDIA participant data with the national MyHealth Record. Health expects that this will create a truly integrated care approach for people with disability accessing different Commonwealth and State delivered services.

Health advised that its DIAP commits the agency to improving the collection and reporting of data on NSW Health service users with disability. The Ministry of Health is discussing, with the DIAP Steering Committee, LHDs and other NSW Health organisations, the collection of data that identifies people with disability. Health advised that it will provide regular updates to our office on this work.

Consistent with the DIAP commitment to report on disability inclusion in NSW Health, the Bureau of Health Information (BHI) published a report on the experiences of hospital care among people with disability in October 2017.

Health advised that the NDIA has not agreed to provide client identifiers to NSW Health to assist with the transition of Health clients to the NDIS. An interim solution to help assess the impact of NSW health service use, is linkage of the NDIA data and NSW Health data collections, looking at: 1) hospital, 2) outpatient clinics, 3) ambulance service usage, 4) costs and impact on EnableNSW, and 5) children with rare, chronic and complex disabling conditions.

The April 2017 data linkage report identified that:

- 69% of the NDIA individuals had either an emergency department (ED) visit or an admission or both.
- *Emergency department use* – preliminary results demonstrate that, among the HNELHD participants with an NDIS plan approval date, there is no evidence of a change in the use of ED. There are relatively low numbers of ED visits (per patient) pre and post NDIS implementation. There is no significant variation in the ED presentations four years before NDIS approval and two years after NDIS approval.
- *Hospital admissions* – preliminary results demonstrate that, among the HNE participants with an NDIS plan approval date, there is a significant reduction in total length of hospital stay, and mean episode length of stay and acute-overnight unplanned admissions. In the first year after the NDIS plan approval date, there is an average reduction of 1.5 days per episode. The analysis of the subset of participants who have been in the program for two years or more indicates that the reduced levels are sustained in the second year of the NDIS.

Our comments

Health's advice identifies that there has been considerable progress in relation to health data identifiers for people with disability. However, it is early days in this work, and there are significant actions remaining.

There is a need for the progress of this work to be the subject of ongoing independent monitoring.

e) Developing and trialling a 'reasonable adjustments toolkit' for Hunter health services.

Progress

Health's response focused on the work it is undertaking across its LHDs to improve disability inclusion, including the use of reasonable adjustments. As it replicates the information provided in relation to recommendation 8e (which is aimed at actions across Health services), we have detailed the progress report and our response in that section.

Our comments

Our recommendation was targeted at HNELHD for the reasons mentioned earlier. There is a need for ongoing independent monitoring of the progress of Health's actions to improve the inclusion of people with disability, including the use of reasonable adjustments, across its health services (see recommendation 8e).

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.

Progress

Health advised that HNELHD established a District Disability Inclusion Working Group in July 2017 to oversee development of its DIAP, which aligns with the NSW Health DIAP. The working group includes staff who have a lived experience of disability. Each action item in the HNELHD DIAP has an allocated Executive Leader(s) who is responsible for its implementation and monitoring against performance indicators, and the DIAP will be included as an Operational Initiative in the District Operational Plans. Disability inclusion progress is included as an item on the agenda every six months at the HNELHD Executive Leadership Team meetings.

Our comments

We appreciate that Health's DIAP incorporates actions to drive system-wide improvements in relation to inclusion, and the HNELHD DIAP is aligned to this plan. The progress of this work will need to be independently monitored (see recommendation 8f).

g) Working with Hunter General Practitioners to improve written health guidance for people with disability and their carers/support staff.

Progress

Health advised that the Primary Health Network (PHN) has principal responsibility for educating and engaging GPs. In July 2018, Health advised that the HNELHD HealthPathways include information for GPs about the NDIS and how clients can be referred for these supports, and information on accessing non-clinical community mental health support.

Our comments

We note Health's advice about the responsibility of PHNs for educating and engaging GPs. Our further comments are incorporated in our discussion of recommendation 8h.

h) Working with Hunter Primary Health Network to establish clinical pathways with local providers and nurses.

Progress

FACS advised that it had established the Clinical Care Coordination model, which supports the identification of mainstream health needs for a defined cohort of people moving out of the Stockton Centre. FACS also advised that HNE and Central Coast PHNs are investigating funding options to review existing health pathways for people with intellectual disability and complex support needs.

In October 2017, Health told us that discussion was occurring between HNELHD and FACS in relation to Health Pathways for disability related health conditions, and the HNELHD NDIS Project Team was developing a plan/proposal based on these discussions. Health also advised that the HNELHD NDIS Project Team had met with the HNE Health Pathways Program Manager to discuss the potential to incorporate NDIS/disability into Health Pathways, including developing NDIS specific pathways, adding links into referral pathways relating to existing packages, and/or the opportunity to create resource pages.

In July 2018, Health told us that there has always been and remains potential for health pathways to include useful information for GPs about pathways to care for people with disability. Health advised that HNELHD previously made this offer to FACS during the NDIS pilot, 'with the proviso that it would require some investment on the side of FACS and some investment from HNELHD'. Health advised that it has 'a very functional platform and way of working that GPs are proven to use. This could be easily adapted to disability services.'

Our comments

We appreciate the advice of FACS and Health on their actions on clinical pathways for people with disability. However, the information is light on detail and progress. This work will need to be the subject of ongoing independent monitoring.

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.

Progress

Health advised that at the end of the Hunter NDIS trial phase, it conducted a formative evaluation of HNELHD to help guide and inform the Ministry and year one sites as the transition continued. The evaluation has informed the NSW Health NDIS Operational Monitoring and Evaluation Framework. This framework includes a transition dashboard that measures performance against the NSW Health Transition Plan, measurements to assess NDIS outcomes, and key performance indicators (KPIs) and performance measures for reporting under the bilateral agreement.

In October 2017, Health also told us that it would commission three evaluations:

- A year one evaluation of the NDIS transition – to better understand the impacts, benefits and opportunities for Health.
- An NDIS Clinical and Services Redesign Evaluation – to understand the changes made by year one LHDs and SHNs to meet the needs of people with disability under the NDIS.
- An NDIS stakeholder survey – designed to assess and understand the experience of transition for a range of service providers across Health.

In July 2018, Health advised that, as part of the Mainstream Health Capacity Project, HNELHD worked with Hunter Primary Care and FACS to implement LRC transition alerts specifically for Stockton residents and people in LRCs, with consent. This information is now being used by clinicians to assist with planning during hospital stays, and by the HNE NDIS Project Team to monitor health service utilisation patterns of this cohort pre and post transition date. Health advised that this information will be used to inform the broader health system and to identify existing gaps.

Health also advised that, as part of the HNELHD DIAP, the District has implemented an alert to identify people with an intellectual disability in its data systems. Health told us that this information is collected to monitor health service utilisation patterns and outcomes of people with an ID, and to help the District to target specific teams and services that see significant numbers of people with an ID to provide relevant support and training.

Our comments

Health's response is heavily weighted towards outcome and performance measures in relation to the NDIS. Although this is important work, we also note the importance of the work that is being undertaken by HNELHD on data identifiers for people with intellectual disability (ID) and people from LRCs.

In our June 2015 report, we indicated that, 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 on agreed key performance indicators and outcomes measures. This would include, for example, adherence to adjustments to meet the needs of people with disability; use of restraints; rates of unnecessary hospitalisations; inclusion in chronic disease management and other out-of-hospital programs; and inclusion in preventive health programs.

The creation of a data identifier for people with an intellectual disability in HNELHD should provide significant scope to analyse health service use by, and outcomes for, this cohort. It will be important to ensure that there is regular public reporting on the performance of HNELHD for this population. The progress of this work will need to be the subject of ongoing independent monitoring (see also recommendation 8i).

Recommendation 7

In addition to HNELHD, NSW Health should use the HealtheNet 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.

Progress

Health has advised that, while HealtheNet is connected to all LHDs in NSW, and continues to be enhanced and act as an effective means of sharing clinical information across different care settings, on its own it is not a sufficient means to identify patients.

Health told us that it is continuing discussions between the NSW Government, interstate health agencies, the NDIA and the Commonwealth on the broader linkage of NDIA participant data with the national MyHealth Record. Health expects that this will create a truly integrated care approach for people with disability accessing different Commonwealth and State delivered services.

Health advised that its DIAP commits the agency to improving the collection and reporting of data on NSW Health service users with disability. The Ministry of Health is discussing the collection of data that identifies people with disability with the DIAP Steering Committee, LHDs and other NSW Health organisations. Health advised that it has engaged the University of Wollongong to do a review of national and international literature on how and for what purposes health services collect data to identify people with disability. Health advised that it received the findings from this work in April 2018, and is currently considering them in the context of disability inclusion and its policy directive on responding to the needs of people with disability during hospitalisation.

Consistent with information it provided about recommendation 6d, Health advised that it does not have access to NDIS identified client data. Although it receives some NDIS client de-identified data mainly via FACS, further work is required to improve data quality. Health told us that it was seeking further detail on NDIS data business rules and the NDIS data dictionary to support improved analysis and interpretation. The linkage of the de-identified NDIA data and NSW Health data collections provide an interim solution.

In July 2018, Health advised that under the NSW Health NDIS Monitoring and Evaluation Operational Framework, it has developed and recommended the implementation by LHDs/SHNs of a series of changes to local information management systems to support the implementation of the NDIS. These changes include:

- NDIS alerts to clarify a patient's NDIS status.
- The introduction of five new NDIS 'Waiting for What' categories in the Patient Flow Portal, used to identify patients experiencing a wait for an NDIS-related reason during their admitted patient stay.

As noted for recommendation 6i, Health has advised that HNELHD has implemented alerts in its data systems for Stockton residents/ people in LRCs, and to identify people with intellectual disability.

Our comments

We note the actions that Health has taken to date to develop health data identifiers for people with disability and a minimum dataset. Given the importance of this work for improving supports and outcomes for people with disability in contact with the health system, it will need to be the subject of ongoing independent monitoring.

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.

Progress

In July 2018, Health told us that integrating care is a priority for NSW Health, and the soon to be released Strategic Framework for Integrating Care will set statewide direction for integrating care. Health advised that the framework applies to all health care services in NSW, and also relates to the intersection of health with social care.

Health told us that the $180 million investment over six years in the Integrated Care Strategy is designed to trigger system change at a local level, and to achieve the delivery of more connected and coordinated care across primary, acute and community settings, as well as focusing on individual patient needs. In July 2018, Health advised that a report on the progress of the strategy was completed in December 2017, and is being used to inform future directions for facilitating coordinated care.

Health also advised that the results from a statewide survey of stakeholders working with integrated care models, have been shared with the LHDs to support strategic planning and operations in relation to integrated working. Other reports on integrated care performance data are released quarterly.

In relation to HealthPathways, the ACI held a workshop in 2015 at the completion of all localised evaluations of the trial sites. The first four sites of the evaluation attended and shared lessons learnt. Further workshops are planned to be held locally at the Pathways sites.

Our comments

We recognise the importance of the Integrated Care Strategy, including its potential significance in leading to improvements in health-related support for people with disability. In Health's response, there is no indication that active consideration has been given to the needs of people with disability in the work to date. At the time of writing, it does not appear that the evaluation report has been publicly released. It is also not evident whether people with disability featured in the evaluations of the HealthPathways trial sites.

Given the focus of Health's DIAP on improving the inclusion of people with disability in its programs, there is a need for greater consideration of the needs of people with disability in relevant initiatives. The progress of this work will need to be the subject of ongoing independent monitoring.

b) Developing mechanisms in LHDs to coordinate access and care for people with disability.

Progress

Health advised that LHDs and SHNs are responsible and accountable for governing hospital and health service delivery for their LHD or SHN. The Ministry of Health's role in setting policy on coordinated access and care for people with disability is implemented through:

Health's policy directive on responding to the needs of people with disability during hospitalisation

Health advised that this policy requires staff to provide inclusive, person-centred and accessible care, and provides enhanced guidance on care coordination for people with disability. The hospitalisation policy includes an implementation checklist, which supports LHDs and SHNs to monitor local care coordination arrangements.

Complex needs

Health advised that it partnered with FACS to conduct a research project aimed at increasing understanding between agencies, districts, the NDIA and the disability sector on how to achieve the best hospital discharge for complex needs clients with disability. In July 2018, Health told us that the report was finalised, and it was reviewing the recommendations.

As part of the *NSW Service Framework to Improve the Health Care of People with Intellectual Disability,* three pilot specialised ID Health Teams, auspiced by South Eastern Sydney LHD, Northern Sydney LHD, and the Sydney's Children Hospital Network, were funded from 2011 to test a coordinated, multidisciplinary approach to meeting the health needs of people with intellectual disability. Funding was also provided to establish the ID Network, auspiced by the ACI, to provide clinical leadership and oversight of the development of both mainstream and specialised health services for people with intellectual disability.

After the three-year evaluation of these initiatives, Health provided a two-year extension of funding for the ID Health Teams and Network up to June 2018. This was to provide time for a considered, systematic approach to identifying and transitioning future models of operation for the Health Teams. The Ministry of Health and an advisory committee worked with key stakeholders to develop a proposal to build on the achievements of the health teams.

In July 2018, Health advised that the 2018-19 NSW Government Budget committed additional recurrent funding of $4.7million per annum to enhance and extend the ID health services in line with the proposed approach. Three new specialised ID health teams will be established to complement the three existing teams. In LHDs without a team, nine new specialised ID nurse or allied health positions will be funded. The six health teams will work with the new specialised positions to deliver outreach services across NSW.

Health advised that the changes extend the implementation of the Service Framework and will deliver new performance indicators, a more consistent service, new consultancy activity to build the skills, confidence and experience of health staff and new services to rural and regional NSW. Health told us that the enhanced and expanded specialised ID health services will be evaluated to inform continuing refinement of the model of care. Health advised that the Ministry is consulting key stakeholders to determine the locations of the new health teams.

NSW Health Disability Inclusion Action Plan

Health advised that its DIAP commits the agency to providing person centred care to people with disability, and notes a number of programs that Health services are using, such as Top 5 and In Safe Hands, to promote communication with carers and the use of multidisciplinary teams to coordinate care.

The Ministry of Health is monitoring progress on the implementation of NSW Health's activities that align with the DIAP, including programs that support the coordination of care for people with disability. This process is helping to identify and promote approaches such as the *Admission 2 Discharge – Together* project developed in South Eastern Sydney LHD.

In July 2018, Health advised that it has circulated two new NSW Health DIAP Progress Reports to its Chief Executives on the activities of NSW Health that are supporting disability inclusion. Health told us that its April 2018 report, which reported on activities from the previous year, identified five key areas for action in 2018, two of which focus on providing accessible and coordinated care for people with disability:

- Building a culture of disability inclusion through targeted communication across the system for service users and employees.
- Partnership and collaboration to meaningfully engage people with disability, their carers, family and key stakeholders for accessible and appropriate service delivery.

Health advised that these key areas of focus will form a central part of the DIAP performance monitoring across all NSW Health organisations, which will be collated as part of the next DIAP progress report.

Hospitalisation projects

Health advised that the ID health network is working with LHDs on hospitalisation projects For example:

- Ryde Hospital has developed pathways for people with ID coming for surgery, which includes staff awareness training and use of visual aids.
- In South West Sydney, a project initiated by the local disability support provider and involving NSW Ambulance, SWSLHD and the ACI is working on the patient journey and hospital pathway.

Our comments

We welcome the announcement of the additional recurrent funding to enhance and extend the intellectual disability health services, with access to expertise across NSW, and look forward to advice about the locations of the new health teams and specialised positions.

We note Health's advice about relevant actions as part of its DIAP, and current hospitalisation projects.

Given the significant issues in this report relating to support for people with disability in hospital, and coordination and transfer of care, the progress of Health's work in this area will need to be the subject of ongoing independent monitoring.

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.

Progress

Health's response to this issue replicated its advice on recommendation 6c.

Our comments

In the period since the release of our previous report in June 2015, FACS has devolved Metro Residences. Hunter Residences comprise the main remaining large residential centres. As noted in relation to recommendation 6c, the progress of this work will need to be the subject of ongoing independent monitoring.

d) Creating a minimum dataset for people with disability.

Progress

Health advised that work continues on the implementation of a minimum dataset for people under the NDIS in NSW Health. In addition to advice provided about recommendation 6d, Health told us that:

- The KPMG evaluation of the three pilot specialised ID Health Teams highlighted areas in which data collection could be improved, including developing a more consistent and broader approach to data collection. A key part of future Ministry work is to work with the three health teams and their LHDs to develop and trial rigorous new quality and performance indicators that will measure value as well as the volume of activity. Where possible, the teams will also record their activity in Health source data systems.
- It is investigating the feasibility of implementing the Standard Disability Flag developed by the AIHW. This is aimed at improving information requirements/ standards for identifying disability clients and collecting services provided and outcomes relating to these clients.

In July 2018, Health advised that the NSW Disability Delivery Plan will be supported by a benefits realisation strategy and risk management approach. NSW Health will contribute data and evaluation expertise, including advice on potential health-related outcomes measures for people with disability, starting with NDIS participants.

As noted for recommendation 7, NSW Health engaged the University of Wollongong to undertake a literature review on how and for what purposes health services collect data to identify people with disability. Health received the findings from this work in April 2018, and is considering them in the context of disability inclusion and the policy directive on responding to the needs of people with disability during hospitalisation.

Our comments

Health's advice identifies a range of actions it has taken since our last report to develop data identifiers and a minimum data set for people with disability. Given the importance of this work for improving and measuring outcomes for people with disability who come in contact with health services, it will need to be the subject of ongoing independent monitoring.

e) Developing and implementing 'reasonable adjustments' guidance for health services.

Progress

Health told us that LHDs have a range of existing fact sheets to guide managers in determining reasonable adjustments for supporting people with disability in the workplace, including links to a range of tools and guides, but these are generally employment specific.

Health also advised that its DIAP aims to support LHDs to embed disability inclusion at the local level. One action in the DIAP is to develop a suite of resources to support disability inclusion across policy and service delivery settings that will establish clear expectations for implementation.

Health's policy directive on responding to the needs of people with disability during hospitalisation, released in January 2017, includes direction and guidance to LHDs and SHNs on reasonable adjustments. The policy includes an implementation checklist which prompts LHDs and SHNs to review local systems and policies to ensure frontline staff are supported and able to implement reasonable adjustments, when required, according to the specific needs of individual patients.

The Ministry of Health is also working with the DIAP Steering Committee, LHDs, SHNs and other NSW Health organisations to identify priority statewide projects and activities that can support disability inclusion. This work will continue to examine whether more support, and if so what type of support, is needed to promote reasonable adjustments.

In July 2018, Health advised that the ACI has developed an interactive self-assessment tool to help health services to identify areas for action and to provide resources to support changes to meet the health needs of people with intellectual disability and their carers. Health told us that the ID health network is working with LHDs to support initiatives identified in their self-assessments.

Our comments

We note the actions that have been taken by Health, consistent with the DIAP, to seek to improve guidance across its health services about reasonable adjustments. The progress of this work through the DIAP will need to be independently monitored.

f) Through the Health Education and Training Institute (HETI), developing and implementing training materials to up-skill health services staff.

Progress

Health advised that 10 educational resources related to disability are available via the State Learning Management System, My Health Learning, which includes (but is not limited to):

- Let's Talk Disability
- Intellectual Disability and Mental Health – Intellectual Disability – Changing Perspectives

- Community and Inclusion
- The Interviewer
- Partnering with Carers.

A further eight learning resources are being developed, such as 'HEEADSSS (Home, Education/Employment, Eating, Activities, Drugs and Alcohol, Sexuality, Suicide and Depression, Safety Assessment) – Get the conversation started'.

Health advised that, in 2016, a needs analysis identified general education and training requirements to upskill health services staff. This has resulted in a move to incorporate scenarios related to disability into non-specific disability resources, as a strategy to promote the recognition of disability needs in a variety of health circumstances.

Our comments

We appreciate Health's advice about the 18 learning resources that relate to people with disability, and its actions to upskill health services staff via non-specific disability resources. We note that in the period since our last report, there have also been other substantial resources developed and released to up-skill health services staff, including the ACI Intellectual Disability Health Network's resource, *Building capability in NSW health services for people with intellectual disability: the Essentials*.

g) In line with the *Disability Inclusion Act 2014*, developing and implementing strategies to develop a culture of inclusion for people with disability.

Progress

Health advised that its DIAP was developed in consultation with key stakeholders, including LHDs. The DIAP outlines actions that build on, enhance, and improve inclusion and accessibility by people with disability to supports and services provided by Health. One of the strategies in the DIAP is to 'Communicate and reflect on the importance of a culture of disability inclusion across the NSW Health System'. A communication strategy for disability inclusion across NSW Health has been finalised.

Health told us that LHD staff have access to the HETI training modules *Partnering with Carers* (February 2015) and *Let's Talk Disability* (March 2015), to help health care workers to meet the diverse needs of people with disability who use Health services.

Our comments

We note the actions taken by Health to develop its DIAP, which is its key mechanism for driving improvements in the inclusion of people with disability in health services. The progress of Health's actions to implement its DIAP will need to be independently monitored.

h) Working with General Practitioners to improve written health guidance for people with disability and their carers/support staff.

Progress

Health advised that the PHN has principal responsibility for educating and engaging GPs. However, the ACI ID Health Network has worked with GPs to develop videos to give advice on communication with people with intellectual disability and their carers. It includes input from people with intellectual disability, their families and carers on what they find most helpful. In July 2018, Health advised that the ACI is currently working with the Centre for Disability Studies to update the resource 'Guidelines for GPs – healthcare for people with intellectual disability'.

Health advised that the ACI has also worked with GPs on the production of translations to the CDMP brochure, including a version for people with intellectual disability. The resource is available on the ACI website and is readily available for GPs to use for people with disability and their carers.

Our comments

We note Health's advice about PHNs being responsible for educating and engaging GPs, and the work being done by the ACI ID Health Network. We also welcome the production of the Easy Read information for people with disability about the CDMP. Health's actions constitute adequate implementation of the recommendation, so we do not believe this issue requires ongoing independent monitoring.

i) Developing key performance indicators and outcomes measures for health services in relation to people with disability, starting with NDIS participants.

Progress

As noted for recommendation 6i, Health advised that the NSW NDIS Operational Monitoring and Evaluation Framework includes a transition dashboard that measures performance against the NSW Health Transition Plan, measurements to assess NDIS Outcomes, and KPIs and Performance Measures for reporting under the bilateral agreement.

Health also told us that it would commission three evaluations:

- A year one evaluation of the NDIS transition – to better understand the impacts, benefits and opportunities for Health.
- An NDIS Clinical and Services Redesign Evaluation – to understand the changes made by year one LHDs and SHNs to meet the needs of people with disability under the NDIS.
- An NDIS stakeholder survey – designed to assess and understand the experience of transition for a range of service providers across Health.

Health told us that KPIs relating to NDIS participants will be captured under the Performance Reporting Framework developed jointly across agencies.

Our comments

As noted in our comments on recommendation 6i, in our June 2015 report we indicated that it will be important to require regular and public reporting on the performance of health services in relation to agreed performance indicators and outcomes measures – facilitated by improved data collection and a minimum dataset for people with disability. We noted that this would include, among other things, adherence to adjustments to meet the needs of people with disability, use of restraints, rates of unnecessary hospitalisations, inclusion in chronic disease management and other out-of-hospital programs, and inclusion in preventive health programs.

As indicated in our previous report, and 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. Performance indicators and measures are necessary to drive and monitor actions across health services.

We recognise that work is still underway to develop the data collection and dataset that will be needed to support the development and use of meaningful performance indicators and outcomes measures for people with disability. This issue will need to be the subject of ongoing independent monitoring.

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.

Progress

DPC told us that arrangements for the provision of FACS funded health-related supports has been a priority area of work for the NDIS Reform Group in DPC, FACS and NSW Health.

In September 2017, DPC advised that:

- FACS would manage arrangements including step-down in most health-related areas of service delivery, including the Community Care and Support Program (CCSP). FACS, Health and DPC formed a working group 'to conduct and consider further analysis focused on supports funded by the CCSP and to monitor impacts of CCSP step-down.'
- Responsibility for three services would be assumed by NSW Health:
  - Comprehensive Health Assessment Program – GP health assessment tool.
  - School Aged Therapy Services – Northern NSW Local Health District.
  - School Physical Disability Therapy Team – St George Hospital, Kogarah.
- Further evidence to support service continuation (with or without change to the service model) was being gathered on the dysphagia clinic at Westmead Hospital and an autism assessment service for families in rural areas.
- NSW Health would advise the NDIS Steering Committee before the end of 2017 on service model options that could improve the integration of support for people with Intellectual Disability Mental Health in the mental health system. This would include continuity of care options for clients of the outreach psychiatry clinics FACS funded. This would also include consideration of whether the Advanced Fellowships in Intellectual Disability Psychiatry should continue.

In July 2018, Health advised that the NSW Government announced $87 million in its 2018/19 Budget ($150 million over three years) for residual disability functions to support people with disability to live independently. These include supports for children with disability residing outside the family home, Ability Links NSW, restrictive practices and transitional advocacy grants to support the successful ongoing delivery of the NDIS. In addition, the Budget provided two years of funding for the following initiatives to be led by NSW Health to address identified service gaps arising from the immaturity in the NDIS, as well as unresolved boundary and interface issues between the NDIS and mainstream services:

- the Safe and Supported At Home (SASH) Program – for clients whose needs will not be met by the NDIS and who would have been serviced by the Community Care Support Program (CCSP), which has now been decommissioned
- support for people with co-morbid intellectual and psychosocial disability and mental health
- the dysphagia service
- the regional assessment service (autism).

Our comments

We welcome advice about the decisions that have been reached about the range of health-related services that were funded by FACS, including additional funding to cover residual disability functions. We will follow up with Health the issues in this report relating to the access of people with disability to swallowing assessments and written guidance from health services.

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.

Progress

FACS advised that governance mechanisms, such as the NDIS NSW Implementation Steering Committee had been established in accordance with the NDIS NSW Operational Plan, and will provide cross cluster representation. FACS told us that:

- Local interagency working groups operate with the NDIA, meeting with Health on a regular basis and addressing local issues as they arise.
- An issues escalation framework is in place and issues are escalated to the ROWGs and then to the NDIS NSW Implementation Steering Committee.
- It has established NDIS Coordination teams to coordinate the FACS Districts and NDIA relationships. Health is also working on a governance structure for issues from LHDs to the ROWG.
- It supports the mapping of district based interfaces with Health to assist with NDIS readiness activities and consistency of messages.

Health advised that the NSW Health transition plan, supported by the Health implementation checklist, provides advice and guidance for LHDs and SHNs to manage their progress into the NDIS.

Established under the governance arrangements in 2016, ROWGs provide an effective platform to resolve local issues locally. All districts and networks have local NDIS governance arrangements in place and these interface with the ROWGs.

In July 2018, Health advised that it is leading five NDIS funded Information, Linkages and Capacity Building (ILC) projects in an effort to support capacity building through mainstream services. These include:

- NDIS skill building for consumers, carers and family
- Yarn ups for people with psychosocial disability and their families and carers
- NDIS and mental health capacity building for mainstream services
- NDIS and mental health communities of practice
- NDIS skill-building for consumers with newly acquired disability, their families and carers.

Our comments

The advice provided by FACS and Health addresses the recommendation.

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 Hospitals 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.

Progress

FACS advised that, consistent with the commitment it made to our office to review the implementation of the Joint Guideline after it had been in place for 12 months, it designed a survey in October 2014 to assess some of the key outcomes of the implementation of the guideline, including the Hospital Support Plan. FACS approached the Ministry of Health to participate in the survey, but was advised that the Ministry would conduct its own evaluation.

In relation to the surveys, FACS told us that it developed one for group home staff, and one for residents and their families. The report from the survey outlined two recommendations:

- that consideration be given to augment the 'Top 5' into the Joint Guideline
- the implementation of regular local meetings within Districts between hospital staff and FACS staff to: further develop tools to share information at hospital admission and discharge home, and exchange additional information about people who have frequent admissions, to identify their particular support needs and strategies to prevent admissions where possible.

FACS advised that the above was being trialled in three FACS Districts in collaboration with LHDs, with extension to other districts over time.

Health advised that the Ministry engaged a research organisation to undertake an evaluation of the Joint Guideline. The Joint Guideline is not mandatory. Health told us that:

- The evaluation explored the implementation of the Joint Guideline within NSW Health and its effectiveness in improving the support provided to residents of accommodation support services. Five LHDs and accommodation support services within those LHDs participated in the evaluation. Despite extensive recruitment by the Council for Intellectual Disability, the evaluation did not include feedback from people with disability.
- The evaluation has been completed, and the final draft report has been submitted to the Ministry. Taking into account the small sample size, the evaluation found relatively low awareness of the Joint Guideline and strong support for its principles and tools.
- The Ministry is reviewing the report recommendations with key stakeholders. Health advised that it would provide the report and NSW Health's response to our office when approved by the NSW Health Executive.

In July 2018, Health advised that the Ministry is currently consulting with DPC to identify potential options for future application of the Joint Guideline principles and tools by NSW Health and multiple NGO disability providers.

Our comments

We appreciate the work undertaken by Health and FACS in response to our recommendation, and note that the findings of the evaluation by Health about a low level of awareness of the Joint Guideline are consistent with what we continue to see in our reviews.

Our reviews also continue to identify significant issues relating to support for people with disability in hospital, and their coordination and transfer of care. We look forward to updated advice from Health about the arrangements that it intends to put in place to address the issues that prompted the development of the Joint Guideline. This issue will need to be the subject of ongoing independent monitoring.

Appendix 1

Expert advisors

We obtained expert advice from the following people on the deaths of people with disability in residential care in 2014-2017:

Dr Cheryl McIntyre
General Practitioner, Obstetrician

Dr Ted O'Loughlin
Senior Staff Specialist, Gastroenterology, The Children's Hospital at Westmead

Dr Rosemary Sheehy
Geriatrician/Endocrinologist, Sydney Local Health District

Dr Aline Smith
General Practitioner

Associate Professor Ernest Somerville
Director, Comprehensive Epilepsy Service, Prince of Wales Hospital

Dr Elizabeth Thompson
Rehabilitation Medicine Specialist, HammondCare

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