

Disability Services Commissioner

# A review of disability service provision to people who have died 2018-19



It's  
**OK**  
to complain

 Disability  
Services  
Commissioner

DSC thanks the people who consented to having their photos shown on the cover of this report. They are not people who have died but are people who have worked with us or been involved with one of our projects.

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# Reading this report

## Glossary of terms

### The Act

*Disability Act 2006 (Vic)*

### Aspiration pneumonia

A condition caused by food, saliva, stomach acid or liquid entering a person's airway

### Authorised Officer

A person appointed as an Authorised Officer under the Act, who has the power to visit and inspect premises where disability services are being provided

### Complex communication needs

A term used to describe the needs of people who require support to communicate effectively

### DHHS

Department of Health and Human Services

### Disability services

As defined in s. 3 of the Act. It means a service specifically for the support of persons with a disability which is provided by a disability service provider

### Disability service providers

In this report, disability service providers refers to 'disability service providers' and 'regulated service providers' as defined in the Act. The Act defines these as follows:

- 'disability service provider' means the Secretary of DHHS, or a person or body registered on the register of disability service providers
- 'regulated service provider' means a contracted service provider, funded service provider or a prescribed service provider
- 'contracted service provider' means a person who has entered into a contract with the Secretary of DHHS under s. 10 the Act to provide services to a person with a disability
- 'funded service provider' means a person who provides services to a person with a disability, and receives funding from the Secretary of DHHS under s. 9 of the Act for the purpose of providing those services
- 'prescribed service provider' means a person who provides services to a person with a disability specifically for the support of that person, and who is specifically declared as a 'prescribed service provider' for the purposes of the Act

### DSC

Disability Services Commissioner

### Dysphagia

Medical term for difficulty swallowing

### Group home

A type of accommodation that provides housing and support services for people with disability. This is typically a community-based house where rostered staff are available to provide care and support to the people who reside there. Group homes are sometimes referred to as Shared Supported Accommodation (SSA) or Supported Disability Accommodation (SDA)

### ICD

International Statistical Classification of Disease and Related Health Problems

### In-scope

In-scope means matters that we have the legislative authority to handle.

### The Minister

Minister for Disability, Ageing and Carers

### NDIA

National Disability Insurance Agency

### NDIS

National Disability Insurance Scheme

### NDIS Commission

National Disability Insurance Scheme Quality and Safeguards Commission

### NDS

National Disability Services

### Neoplasm

An abnormal tissue growth, includes benign tumours and cancers

### Notice of Advice

Formal advice that we provide on any matter regarding complaints, accountability investigations, and the prevention and response to abuse and neglect in disability services. These can be provided to disability service providers, the Minister and the Secretary of DHHS

### Notice to Take Action

A notice that we have issued to a disability service provider after an investigation. This notice specifies actions that the disability service provider is required to undertake to resolve issues identified during the investigation

### Out-of-scope

Out-of-scope means any matter that we do not have legislative authority to handle

### Pro re nata (PRN)

Medication administered 'as needed'

### The Secretary

The Secretary of DHHS

### Service providers

See 'disability service providers'

### The State Coroner

Coroner's Court of Victoria

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## About the case studies

We have used case studies throughout the report to highlight the findings from our investigations into disability service provision to people who have died. We use pseudonyms and have changed identifying details to protect the identity of the people to whom they refer.

# Message from the Commissioner

As we move into the final stages of the transition to the National Disability Insurance Scheme (NDIS) – with all the hope that this new approach brings – my office’s second annual review of disability service provision to people who have died is a timely reminder that more still needs to be done to ensure the safety and wellbeing of people with disability.

In 2017, my office began conducting investigations into disability service provision to Victorians with disability who have died. These investigations provide an opportunity to identify concerns relating to the provision of disability services and develop actions to address risks to other people with a disability. In 2018–19, we received 100 notifications of deaths that were in-scope for investigation. We completed 38 investigations and issued 23 Notices to Take Action to service providers to improve their services. We also issued nine Notices of Advice to the Secretary of the Department of Health and Human Services to address systemic issues identified through our investigations.

Many of the service issues we highlighted in our inaugural report, *A review of disability service provision to people who have died 2017–18*, continue to pose risks for people in receipt of disability services. My office’s investigations found significant practice issues including, inadequate mealtime supports, poor bowel management, the use of unauthorised restrictive practices, and a lack of support for people with complex communication needs. Poor record keeping also remains a key factor in most of our investigations; this is not simply an administrative issue, but in some cases a contributor to poor health outcomes and potentially avoidable deaths.

Over the past two years, respiratory diseases were the most common cause of death (38%) in cases received by my office that were also in-scope for investigation by the Coroners Court of Victoria. Of these cases, aspiration pneumonia was the cause of death in 59% of cases.

I am particularly concerned that deaths by choking and aspiration pneumonia are continuing to occur even in situations where the person with disability had a formal mealtime support plan in place. This is a blight on the sector that requires urgent action. My office is currently working with key stakeholders – including service providers, speech pathologists, the National Disability Insurance Agency and the new National Disability Insurance Scheme Quality and Safeguards Commission – to identify ways to ensure that people with disability receive the mealtime supports they need.

Every death is tragic, expected or unexpected, and is an opportunity for service providers – and the sector as a whole – to learn and to further improve the quality of the disability services to which people have access. If we are to collectively achieve the expected benefits of the NDIS, it is critical that first and foremost we ensure that people are safe. I urge everyone involved in supporting people with disability to maintain this focus.

I thank my staff involved in this work for the professionalism and sensitivity they have brought to their investigations over the last 12 months.

In closing, I extend my condolences to the families, friends and carers of the people who have died. Your willingness to engage with our office, at what must be a difficult time, has made a significant contribution to our ability to safeguard the rights and wellbeing of others in receipt of disability services.



**Arthur Rogers**  
Disability Services Commissioner  
16 August 2019

# Introduction and background

In this report we discuss the findings from the investigations completed in 2018–19 of disability service provision to people who have died.

We provide insight into the practice issues of concern that emerged from our investigations, and compare the data from our first two years' work in this area with Australian and international research on disability and mortality.

We found there is still considerable work to do in the sector to improve health outcomes and to prevent the potentially avoidable or premature deaths of people with disability. Key issues of concern include inadequate mealtime supports, poor bowel management, the use of unauthorised restrictive practices, poor record keeping, and a lack of support for people with complex communication needs. We also found that staff require further support and training, particularly on how to manage deteriorating health and recognise the signs of choking.

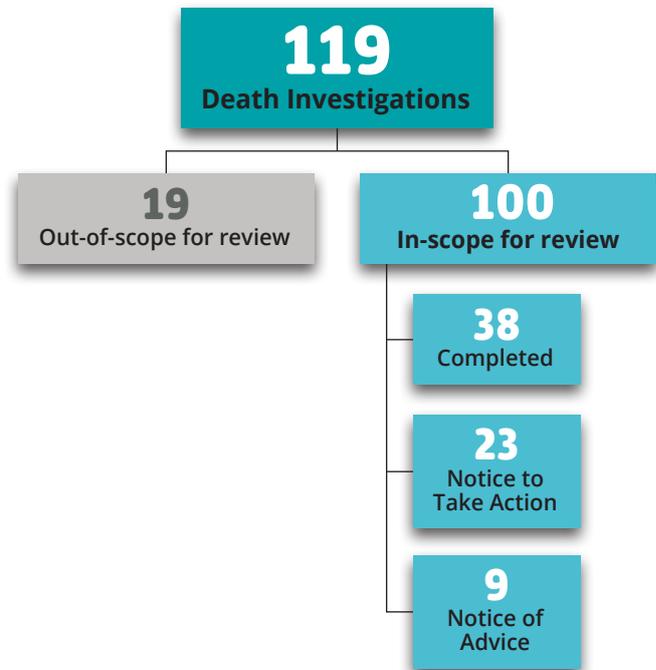
On 10 September 2017, the then Minister for Housing, Disability and Ageing requested that the Disability Services Commissioner enquire into and, at his discretion, investigate any matter relating to the provision of disability services or regulated disability services to a person who was receiving these services at the time of their death. On 28 June 2019, the Minister for Disability, Ageing and Carers (the Minister) extended the referral until 30 June 2020, in recognition that there remain people with disability in Victoria that are yet to transition to the NDIS and still receive disability services funded by the Department of Health and Human Services (DHHS). We conduct our investigations into disability service provision to people who have died under s. 128I of the *Disability Act 2006 (Vic)* (the Act).

We do not investigate the deaths of all Victorians with disability. In-scope deaths are those where the person was in receipt of disability services as defined in the Act and that are reportable to our office under DHHS' incident reporting guidelines. Section 3 of the Act defines disability services as those services provided specifically for a person with disability where the disability service provider is the Secretary of DHHS or is a person or body registered on the register of disability service providers.

We also investigate deaths that are considered 'reportable deaths' and referred to us by the Coroner's Court of Victoria (the State Coroner). Section 3 of the *Coroners Act 2008* defines 'reportable deaths' to include cases where the deceased person was in custody or care immediately before their death. This covers situations where a person was under the control, care or custody of the Secretary of DHHS. The deaths of people living in group homes managed by DHHS are reportable, regardless of the circumstances of the death.

Unlike the State Coroner, our investigations do not determine cause of death – our focus is on the quality and appropriateness of services provided to the person who died. However, we do receive information about the cause of 'reportable deaths' through our Memorandum of Understanding with the State Coroner.

Figure 1: Death investigations: 2018–19



# Investigation process

The aim of a death investigation is to consider the quality and appropriateness of the disability services provided to the person who died.

Once we receive notification of a death, every investigation begins with the service provider/s completing a questionnaire about the person who died to collect demographic and other information about the person's life. We also request and review a range of documentation including, the participant file and communication notes, incident reports, staff rosters, plans (such as behaviour support, health and person-centred plans), hospital discharge summaries and, in the case of expected deaths, palliative care plans. Where possible, we also interview the family of the person who died and relevant disability support staff.

We assess whether the service provider complied with relevant practice guidelines and legislation and consider whether there is evidence of abuse or neglect in the provision of services. Each investigation considers the quality of the supports provided to the person who died, including the adequacy of:

- health and support planning
- management of known health risks
- communication plans
- appropriate implementation of restrictive practices
- record keeping practices
- service provider responsiveness to issues of concern.

After completing the investigation, we prepare a report outlining our findings for the service provider, the Secretary of DHHS, the Minister and, for reportable deaths, the State Coroner. In the future we will also forward our reports, where relevant, to the National Disability Insurance Scheme Quality and Safeguards Commission (NDIS Commission). The Act does not provide for our reports to be made public.

Where we identify matters during an investigation that are best handled by another body (for example, Victoria Police) we refer those matters accordingly. Where we identify deficiencies in service provision or risks to other people with disability, we issue the service provider with a Notice to Take Action (NTTA) requiring them to make service improvements and report back to us.

**Over the last two years, diseases of the respiratory system were the preliminary or confirmed cause of death in 38% of cases that were in-scope for the State Coroner. Of these, aspiration pneumonia was the cause of death in 59% of cases. Other common causes of death were diseases of the circulatory system at 17% and neoplasms at 7%. It is particularly concerning that 6% of deaths were due to external causes – of these 6 were due to choking on food (3 in each reporting period).**

# Overview of deaths of people with disability in Victoria

This section provides an overview of data we have collected on the deaths of people with disability that were reported to our office.

We found that Victorians with disability die at a significantly younger age than the general population and experience a higher rate of death due to respiratory system disease and sudden unexpected death in epilepsy. Crucially, death by choking is rare in the broader community but is a key risk for people with disability who are in receipt of disability services.

## Deaths reported

Our inaugural report *A review of disability service provision to people who have died 2017–18*, reported findings from our first seven months undertaking death investigations.<sup>1</sup> In that time, we received 88 notifications of deaths that were in-scope for investigation, completed 20 investigations, and issued eight NTTAs to service providers.<sup>2</sup> In 2018–19 we received notifications about 100 deaths that were in-scope for investigation, completed 38 investigations, and issued 23 NTTAs.<sup>3</sup>

We carried over 68 investigations from 2017–18 and have 130 investigations that remain open.

**Table 1:** Deaths reported 2017–18 and 2018–19

	2017–18		2018–19	
In-scope for DSC	85%	88	84%	100
Out-of-scope for DSC	15%	15	16%	19
Total	100%	103	100%	119

<sup>1</sup> While deaths were reported to us over an 11-month period in 2017–18, we began conducting investigations in November 2017.

<sup>2</sup> Disability Services Commissioner (2017–18), *A review of disability service provision to people who have died 2017–18*, Melbourne: Disability Services Commissioner, p. 11.

<sup>3</sup> 'Completed' investigations includes those that have been finalised, as well as those where we have issued a NNTA and are waiting on a final response from the service provider/s.

## Service provider and service type

Under DHHS incident reporting guidelines deaths are categorised as either expected, such as where the person receiving disability services died because of a diagnosed condition or illness, or as unexpected. Most deaths reported to DSC continue to be unexpected. In 2018–19, 77% of deaths reported were unexpected, an increase from 68% in 2017–18. In our first year, half of deaths reported to us came from DHHS-managed services and half from non-government community service organisations. This year, we received more reports of deaths from DHHS-managed services (57%) than community service organisations (43%).

**Table 2:** Investigations by service provider type

	2017–18		2018–19		Total	
CSO	50%	44	43%	43	46%	87
DHHS	50%	44	57%	57	54%	101
Total	100%	88	100%	100	100%	188

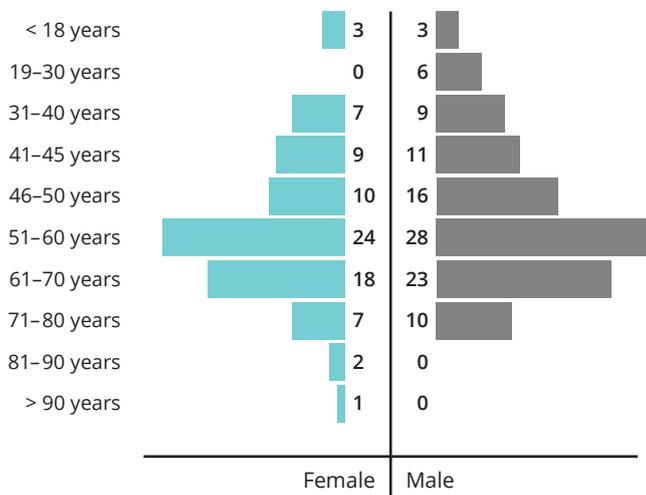
## Age, gender and type of disability

More than half of people (54%) whose death was reported to DSC in 2018–19 had an intellectual disability as their primary disability. Of this group, 65% were described as having low or moderate support needs and 35% as having high to very high support needs. In 2017–18, 40% of deaths reported to DSC were of people with intellectual disability as their primary disability. In 2018–19, 56% of deaths were of people with a prior history of institutional care, compared to 46% in 2017–18. This may at least in part reflect the ageing profile of this group of people.

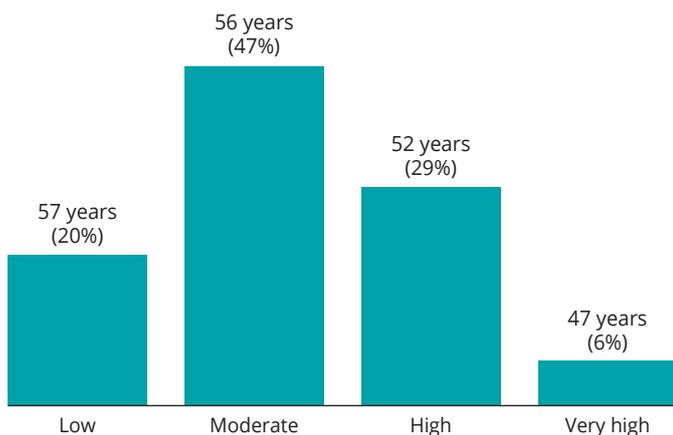
**Table 3:** Age at death

Age	2017–18	2018–19	Total
Under 18 years	2	4	6
19–30 years	3	3	6
31–40 years	11	5	16
41–45 years	10	10	20
46–50 years	13	13	26
51–60 years	22	31	53
61–70 years	19	22	41
71–80 years	8	9	17
81–90 years	–	2	2
Over 90 years	–	1	1

**Figure 2: Gender and age at death distribution**



**Figure 3: Median age at death by support needs**



Our work demonstrates that on average Victorians with disability in receipt of disability services die approximately 25 to 30 years younger than the general population. In 2018–19, the median age at death for people in receipt of disability services was 56 years for females and 54.5 years for males; compared to 54 years for females and 52 years for males in 2017–18. In 2017, the median age for the broader Victorian population was 85.7 years for females and 80.2 years for males.<sup>4</sup>

This data is consistent with Australian and international research and confirms that people with disability in receipt of disability services have a significantly lower life expectancy compared to the general population.<sup>5</sup> In addition, people with an intellectual disability are more likely to die younger and from potentially avoidable causes than people with physical disability.<sup>6</sup> Recent research undertaken in the UK found that life expectancy for people with an intellectual disability was 19.7 years lower than for people without an intellectual disability.<sup>7</sup> A further study analysing data related to the deaths of people with intellectual disabilities in several countries, including Australia, over the period 1975 to 2016 concluded people with intellectual disability were dying 20 years younger than the general population, although this has improved over time.<sup>8</sup>

Research also indicates that people living in group homes have a lower life expectancy. Investigations into the deaths of people with disability undertaken by the New South Wales (NSW) Ombudsman have found that people living in group homes died at least 25 years earlier than the general population.<sup>9</sup> Most deaths reported to us have related to people living in group homes, comprising 88% of deaths reported in 2017–18 and 85% in 2018–19.

### Cultural status

In 2018–19, one person who died identified as being Aboriginal. No deaths reported in 2017–18 were of people who identified as either Aboriginal or Torres Strait Islander. A small number of people who died identified as being from a culturally and linguistically diverse background; eight people in 2017–18 and seven in 2018–19.

4 Australian Bureau of Statistics (2017), *Deaths, Australia*, 3302.0, <<https://www.abs.gov.au/AUSSTATS/abs@nsf/DetailsPage/3302.02017?OpenDocument>>, accessed 24 July 2019.

5 Trollor J, Srasuebku P, Xu H, Howlett S (2017), 'Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data', *British Medical Journal*, 7.

6 Glover G, Williams R, Heslop P, Oyinla J, Grey J (2017), 'Mortality in people with intellectual disabilities in England', *Journal of Intellectual Disability Research*, 61, 1, pp. 62-74.

7 Arvio M, Salokivi T, Bjelogrić-Laakso N (2016), 'Age at Death in Individuals with Intellectual Disabilities', *Journal of Applied Research in Intellectual Disabilities*, 30, 4, pp. 782-785.

8 O'Leary L, Hughes-McCormack L, Dunn K, Cooper S A (2018), 'Early Death and Causes of death of people with Down syndrome: A systematic review', *Journal of Applied Research in Intellectual Disabilities*, 31, 5, pp. 687-708.

9 New South Wales Ombudsman (2018), *Report of Reviewable Deaths in 2014–2017*, Sydney, Australia.

# Cause of death

In 2018–19, 63 deaths reported to us were also in-scope for investigation by the State Coroner. Of these cases, the State Coroner has provided a preliminary or confirmed cause of death for 49 people.

Using information provided by the State Coroner, we have categorised cause of death using the International Statistical Classification of Diseases and Related Health Problems (ICD), the international standard for health classification published by the World Health Organization.<sup>10</sup>

Over the last two years, diseases of the respiratory system were the preliminary or confirmed cause of death in 38% of cases that were in-scope for the State Coroner. Of these, aspiration pneumonia was the cause of death in 59% of cases. Other common causes of death were diseases of the circulatory system at 17% and neoplasms at 7%. It is particularly concerning that 6% of deaths were due to external causes – of these, six were due to choking on food (three in each reporting period).

Our data contrasts significantly with national data on cause of death for the general population. In 2017, the top five causes of death for Australians were coronary heart disease, dementia and Alzheimer's disease, cerebrovascular disease (including stroke), lung cancer and chronic pulmonary disease.<sup>11</sup> In particular, 10% of Australians died due to diseases of the respiratory system, compared to 38% for the

deaths of people with disability investigated by our office that are in-scope for the State Coroner.<sup>12</sup> Crucially, deaths caused by aspiration pneumonia are rare in the general population, accounting for approximately 0.5% of all deaths.<sup>13</sup>

There is a significant gap in our knowledge on the cause of death people with disability in Victoria who are in receipt of disability services from non-government service providers. This is due to the limitations of the definition of a 'reportable death' under the *Coroners Act 2008*, which does not require deaths in group homes managed by non-government service providers to be reported to the State Coroner, unless they are unexpected. In contrast, all deaths in DHHS-funded services must be reported. This means that the sector is missing opportunities to understand, and potentially address, factors that may have contributed to the deaths of people with disability.

We are particularly concerned that as DHHS continues to transition its supported accommodation services to the non-government sector, the number of deaths in-scope for coronial investigation may reduce significantly. As the *Coroners Act 2008* currently stands, once the former DHHS group homes have all fully transferred to both the non-government sector and the NDIS, the definition of a reportable death will no longer apply to those houses, as the residents will no longer be 'in custody or care' of DHHS. DSC is continuing to advocate for this to be addressed.

**Table 4:** Cause of death of in-scope reportable deaths by ICD10 chapter

Cause of death	2017–18		2018–19		Total	
Respiratory system diseases	23	38%	24	38%	47	38%
Circulatory system diseases	14	23%	7	11%	21	17%
Neoplasms	4	6%	5	8%	9	7%
External causes of morbidity	4	6%	4	6%	8	6%
Nervous system diseases	3	5%	5	8%	8	6%
Digestive system diseases	2	3%	2	3%	4	3%
Congenital malformations, deformations and chromosomal abnormalities	1	2%	1	2%	2	2%
Injury, poisoning and certain other consequences of external causes	2	3%	1	2%	3	2%
Genitourinary system diseases	1	2%	–	–	1	1%
Unascertained by the Coroner	4	6%	–	–	4	3%
Unknown or non-reportable	4	6%	14	22%	18	14%
Total	62	100%	63	100%	125	100%

<sup>10</sup> World Health Organization (2016), *International Statistical Classification of Diseases and Related Health Problems (ICD-10)*, <<https://icd.who.int/browse10/2016/en#D05>>, accessed 24 July 2019.

<sup>11</sup> Australian Institute of Health and Welfare (2019), *Deaths in Australia*, <<https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/leading-causes-of-death>>, accessed 24 July 2019.

<sup>12</sup> Australian Bureau of Statistics (2017), *Underlying Causes of Death, Australia, 3303.0*, <<https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3303.02017?OpenDocument>>, accessed 24 July 2019.

<sup>13</sup> *Ibid.* Note: aspiration pneumonia is recorded in ABS data as 'pneumonitis due to solids and liquids'.

## CASE STUDY: **Truc**

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**In early 2019, Truc\* died from choking on food while having lunch at her day program. During lunch, Truc appeared to be trying to vomit and quickly became unresponsive. Staff called an ambulance, but paramedics could not revive her. Truc was 41 years old.**

Truc had lived in her group home for six years, after moving from her family home. Truc was close to her family, particularly her older brother who regularly visited and took her on outings. Truc enjoyed walking to the local shops, doing puzzles, listening to music and spending time in the garden. For over a decade, Truc attended a day program five days a week. Truc communicated using some words, gestures and a photo book. Truc required assistance from support workers for personal care and daily living activities.

Truc had a moderate intellectual disability, epilepsy and gastro-oesophageal reflux disease. She also had a history of choking. Our investigation found that Truc's group home had not communicated important information about her choking risk and mealtime supports to her day program. This meant that the day service provider did not have enough information to provide Truc with appropriate support during mealtimes. As a result, support workers did not always assist her to eat at a safe pace, ensure her mouthfuls were appropriately sized, or ensure that all her food was fully chewed.

We also found that the information that the group home held about Truc's mealtime support needs was contradictory and outdated.

We issued a NTTA to the group home to undertake an audit to ensure that, where required, residents had up-to-date mealtime support plans. We also directed the group home to audit the documents it had provided to residents' day programs, and to ensure that day service providers had the information necessary to provide effective support.

*\*Names and details have been changed*

# Key issues from our investigations

A range of key issues have emerged in our first two years completing death investigations, including concerns relating to service provision as well as systemic factors that contribute to the number of potentially avoidable deaths of people with disability.

These factors include the failure of disability services to manage the risk of choking and aspiration, inadequate bowel management, and poor record keeping practices. We have also found that the risk of premature death increases if a person with complex communication needs is not supported to express their needs effectively. Other common themes in our investigations include the continued use of unauthorised restrictive practices, including both chemical and physical restraint, a failure to recognise and manage deteriorating health, and poor communication within and between service providers.

Key service issues we identified in our investigations include:

- **choking and aspiration risks**
- **bowel management**
- **communication needs**
- **record keeping**
- **unauthorised restrictive practices**
- **managing health needs**
- **staff support and training.**

## Choking and aspiration risks

Choking and aspiration pneumonia – a condition caused by food or liquid entering a person’s airway – continue to be the leading causes of potentially avoidable deaths in cases reported to our office. In each of our first two years conducting investigations into the deaths of people with disability, we received three cases where a person died by choking on food. In all six cases the person had a known swallowing issue, and in five cases the person had either a formal mealtime management plan or had received a swallowing assessment. In two cases, the person’s group home was aware of their mealtime support needs but failed to effectively communicate this to the day service attended by the person. In 2017–18, we received notifications for seven deaths where the preliminary or confirmed cause of death was identified as aspiration pneumonia. In 2018–19, we received a further 18 notifications for deaths where aspiration pneumonia was either the preliminary or confirmed cause of death.

Researchers have identified dysphagia – the medical term for difficulty with swallowing – as a significant factor in the premature deaths of people with disability from respiratory diseases.<sup>14</sup> Dysphagia can have several causes, including mechanical difficulties in dealing with food or drink in the mouth and behaviours around eating, such as pica, a compulsive eating condition where people eat non-food items such as dirt or clay.<sup>15</sup> Beyond its health risks, dysphagia can also have a significant impact on a person’s quality of life, due to the important social function of mealtimes. People with intellectual disability are particularly at risk of developing dysphagia as they are more likely to be prescribed anti-psychotic medication, which can impact a person’s ability to swallow by lowering muscle tone and alertness.<sup>16</sup>

In our investigations, the overwhelming majority of deaths involving choking, aspiration pneumonia or respiratory disease occurred in people with intellectual disability. Despite this, there are some indications that awareness of the risk of dysphagia is increasing, as evidenced by the increase in the number of people who had visited a speech pathologist in the twelve months prior to their death, from 29% in 2017–18 to 86% in 2018–19.

14 Oppewal A, Schoufour J D, van der Maarl H J K, Evenhuis H, Hilgenkamp T I M (2018), 'Causes of Mortality in Older People With Intellectual Disability: Results from the HA-ID study', *American Journal on Intellectual and Developmental Disabilities*, 123, p. 1. Robertson J, Chadwick D, Baines S, Emerson E, Hatton C (2017), 'Prevalence of Dysphagia in People with Intellectual Disability: A Systematic Review', *Intellectual and Developmental Disabilities*, 55, 6, pp. 377-391.

15 Department of Health and Human Services (2019), *Residential Services Practice Manual* <<https://das.dhhs.vic.gov.au/nutrition-and-swallowing>>, accessed 24 July 2019.

16 Robertson J, et al (2017), 'Prevalence of Dysphagia in People with Intellectual Disability'. See also Hampshire County Council Adult Services Department (2012), *Reducing the risk of choking for people with a learning disability, a multi-agency review in Hampshire*, Hampshire, United Kingdom.

Although our data only relates to two years, it is consistent with findings about the causes of death for people with disability from other jurisdictions. The NSW Ombudsman noted that respiratory disease was the leading underlying cause of death in 15.5% of people whose deaths they reviewed from 2014 to 2017.<sup>17</sup> Similarly, a recent review by the Queensland Office of the Public Advocate of deaths in care of people with disability also highlighted the prevalence of deaths resulting from respiratory disease.<sup>18</sup> Studies have also shown that 40% of people with learning disabilities and dysphagia experience recurrent respiratory tract infections, including pneumonia.<sup>19</sup>

Mealtimes speech pathology assessments and support plans are key tools to promote the safety and wellbeing of people with disability who experience dysphagia. However, our investigations have found that deaths by choking are occurring even where appropriate assessments and support plans are in place. Further, in two deaths, disability support staff did not immediately recognise the signs of choking, which delayed appropriate medical intervention. This highlights how vital it is for disability support staff to receive training in how to recognise and respond to the signs of choking.

17 New South Wales Ombudsman (2018), *Report of Reviewable Deaths in 2014 – 2017*, Sydney, Australia.

18 Queensland Office of the Public Advocate (2016), *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland a systemic advocacy report*, Brisbane, Australia.

19 Robertson J. et al (2017), 'Prevalence of Dysphagia in People with Intellectual Disability'.

## CASE STUDY: **Samer**

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**Samer\* was a 44-year-old man, who loved socialising and dancing. Samer had an intellectual disability and lived in a group home with four other residents. He had several health conditions, including chronic constipation, that required management by his group home staff. Samer died as a result of an obstructed bowel, after having experienced constipation for over a week prior to his death.**

In investigating his death, we found that for more than a year prior to Samer's death, the group home staff failed to fill in his daily bowel chart. We also found that although Samer's health plan required staff to give him laxatives when he was constipated for longer than three days, this did not always occur. Our investigation identified that Samer had experienced constipation for longer than three days 18 times over the year prior to his death, and often for longer than a week. However, during this time his group home had not sought a medical review.

The group home also failed to promote preventative measures to reduce the risk of constipation, such as ensuring Samer drank enough fluids and had a nutritious diet.

Our investigation also found the service provider had been aware of staffing issues and practice concerns related to record keeping and medication administration at the group home prior to Samer's death; however, it did not take effective action to address these concerns. As a result, there was a failure to monitor and manage Samer's constipation.

We issued the service provider with a NTTA that required it to engage an independent specialist to review the organisational culture at the group home. We also required the service provider to provide training and supervision to staff about constipation management and to review monitoring and auditing practices.

*\*Names and details have been changed*

## Bowel management

Our investigations demonstrate that there is an urgent need to improve the way service providers manage constipation experienced by people with disability. Constipation is a painful and potentially fatal condition that can lead to urinary and faecal incontinence, rectal prolapse, chronic nausea, haemorrhoids and faecal impaction.<sup>20</sup> People with chronic constipation are also at risk of the fatal condition sigmoid volvulus, where a loop of the bowel twists and creates a blockage.<sup>21</sup>

Since we began conducting our investigations in 2017, bowel obstruction or volvulus was the cause of death in five deaths reported to our office that were also in-scope for review by the State Coroner. In another case, the person's cause of death was aspiration pneumonia, however they had also experienced chronic constipation prior to their death. In two instances, the person who died had a specific health management plan in place to manage their constipation, however staff did not follow its requirements.

People with disability, particularly an intellectual disability, are more likely to experience constipation than the general population. Of all deaths reported to DSC in 2018–19, 53% of people had issues with constipation and 47% had experienced faecal incontinence. Research in NSW identified that, from 2014 to 2017, three quarters of people in group homes who died were known to experience constipation.<sup>22</sup> This could be because people with disability are more likely to lead inactive lifestyles and have a poor diet than other members of the community, both of which are contributing factors to constipation.<sup>23</sup> People with intellectual disability are also more commonly prescribed psychotropic medications, which are known to contribute to the development of chronic constipation.<sup>24</sup>

20 Public Health England (2016), *Making reasonable adjustments for people with learning disabilities in the management of constipation*, <[https://www.ndti.org.uk/uploads/files/Constipation\\_RA\\_report\\_final.pdf](https://www.ndti.org.uk/uploads/files/Constipation_RA_report_final.pdf)>, accessed 24 July 2019.

21 Queensland Office of the Public Advocate (2016), *Upholding the right to life and health*.

22 New South Wales Ombudsman (2018), *Report of Reviewable Deaths in 2014–2017*, Sydney, Australia.

23 Office of the Public Advocate QLD (2016), *Upholding the right to life and health*.

24 *bid.* See also Coleman J, & Spurling G (2010), 'Easily Missed? Constipation in people with learning disability' *British Medical Journal*, 340, pp. 531-532.

# Key issues from our investigations

## Communication needs

Our investigations highlight the importance of effective communication supports for people with disability with complex communication needs. Section 5 of the Act articulates the right of people with disability to access information and communicate in a manner appropriate to their communication and cultural needs. Further, the core principle of the NDIS is that people should have 'choice and control' over their supports, which fundamentally relies on people having the capacity and/or support to communicate their needs and preferences. Supporting the communication needs of people with disability is central to promoting their basic human rights. Importantly, it also plays a role in reducing the risk of premature or avoidable death, by increasing the likelihood that they can effectively communicate their experiences of pain or illness.

In 2018-19 we investigated two instances where a person with no formal communication died who had never had a communication assessment or access to communication aids, despite having lived in group homes for most of their lives. In one case, the individual had lived in the same group home for 28 years, in the other, the person had been in various forms of state care for more than 50 years. It is fundamentally unacceptable that someone could have received disability supports for so long without a formal communication assessment to facilitate their ability to communicate with, and be understood by, their support staff and service provider.

In 2018-19, 57% of people who died required communication support. It is of significant concern that the number of deaths reported to us where the person had no formal means of communication more than doubled – from 6% in 2017-2018 to 16%.

Communication difficulties are one of the most significant barriers to the provision of effective healthcare to people with intellectual disability.<sup>25</sup> Research suggests that where a person has difficulties with communication, or cannot communicate verbally, support staff must be alert to the signs of illness or pain, indicators of which may include behavioural changes, such as refusing to eat or displaying behaviours of distress.<sup>26</sup> This highlights the importance of people having access to support staff who know them well enough to be able to observe such differences, a significant challenge for the disability sector given the difficulties many service providers have recruiting and keeping suitable support staff.

While there are resources available to assist health professionals and disability support staff to identify signs of pain or distress in people with complex communication needs – such as the disability distress assessment tool (DisDAT) – we investigated several cases where communication issues prevented people from receiving appropriate support.<sup>27</sup> In one of our investigations, we found that a communication assessment could have helped reduce the person's behaviours of concern and the use of restrictive practices, by supporting them to communicate their distress to staff. In two investigations, we found that staff had difficulty recognising a person's deteriorating health as the person did not have a communication plan or any strategies to communicate their pain. In one case, a person's support plan noted that they relied on staff to identify if they were in pain or unwell, but the plan did not include information or strategies to assist staff to determine this.

25 Ryan K, Guerin S, Dodd P, Mcevoy J (2011), 'Communication contexts about illness, death and dying for people with intellectual disabilities and life-limiting diseases', *Palliative & Supportive Care*, 9, 2.

26 Office of the Public Advocate QLD (2016), *Upholding the right to life and health*.

27 St Oswald's Hospice, 'What is DisDAT', <<https://www.stoswaldsuk.org/how-we-help/we-educate/education/resources/disability-distress-assessment-tool-disdat/what-is-disdat/>>, accessed 8 August 2019.

## CASE STUDY: **Sandra**

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**Sandra\* was a 45-year-old woman who had lived in the same group home since she was 17 years old. Sandra's family regularly visited her and supported her, including empowering her to make decisions for herself.**

Sandra had high support needs arising from her intellectual disability. She did not have verbal language skills, rather she mainly communicated by making loud vocalisations. Sandra received assistance from group home staff for all aspects of her personal care, including supervision while eating.

Prior to her death, support workers had observed that Sandra had a cold and sought medical attention for her. By the next evening Sandra had a fever, rapid breathing and mucus around her mouth, and a doctor prescribed her an antibiotic. The following morning, staff called an ambulance, which took Sandra to hospital where she later died of pneumonia.

We conducted an in-depth investigation into the support Sandra received from her group home, which included interviews with group home support workers and an Authorised Officer visit.

Our investigation found that during the 28 years she resided in her group home, Sandra had not had a communication assessment, communication plan or any communication aides to support her to participate actively in daily life. The lack of formal communication supports for Sandra made it extremely difficult for her to meaningfully communicate her needs, including about potential health issues.

We also found that staff had been using a range of strategies to seclude and isolate Sandra within her group home, none of which had been authorised and were therefore unlawful.

Our investigation found that the treatment Sandra received from her group home constituted abuse and neglect, including the violation of her human right to communicate. We issued a NTTA to the service provider. The provider acknowledged our findings and implemented a range of measures to improve their services, including speech pathology assessments for any residents at risk of choking or with communication needs, staff training about the use of restrictive practices, and an audit of record keeping practices.

*\*Names and details have been changed*

## CASE STUDY: **Sebastian**

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**Sebastian\* had lived in his group home for over 30 years and was known as an outgoing person who enjoyed walking his dog, socialising with friends and attending church. Sebastian had a number of complex health issues that needed to be managed. He had cerebral palsy, type 2 diabetes, congestive cardiac failure, asthma and gastro-oesophageal reflux disease. He also had a moderate swallowing disorder and was at risk of choking. Sebastian used an electric wheelchair for mobility and required assistance with his personal care needs. Sebastian communicated verbally and could express his needs clearly.**

In his last year, Sebastian experienced deteriorating health, and he was admitted to hospital frequently. Sebastian died at the age of 64. Prior to his death, Sebastian had been unwell for a couple of days. Late one afternoon, disability support workers noted that he had become more unwell, that he was very drowsy, non-responsive and his breathing was rapid and shallow. Staff called an ambulance, which took Sebastian to hospital. Medical staff were of the opinion it was unlikely he would survive hospitalisation. Sebastian was treated with antibiotics and pain medication and died in hospital ten days later.

Our investigation found that the service provider had poor record keeping practices, which impacted the ability of staff to proactively manage Sebastian's health conditions. Sebastian's file records were inconsistent, illegible in places, missing crucial information and in some cases missing altogether.

His health management plans were also incomplete, and key information about his health and dietary requirements did not accompany him to hospital. We also found that the service provider did not act upon concerns it had about the medical care Sebastian was receiving.

We identified that Sebastian's diet was unsuitable for a person with type 2 diabetes and his risk of choking was poorly managed by the service provider. Sebastian's participant notes included contradictory information about whether he should drink thickened fluids, and there was no evidence that the service provider liaised with the hospital about Sebastian's swallowing disorder.

Following our investigation, we issued a NTTA to the service provider. As a result, the service provider conducted a one-day workshop for disability support workers to learn about the importance of record keeping, effective meal time support and managing deteriorating health. It also engaged a dietician to review the diets of residents and audited all participant files to ensure health and support plans were current. The service provider nominated a primary support worker for each resident to ensure that when they are admitted to hospital all their necessary health information accompanies them.

*\*Names and details have been changed*

## Record keeping

Poor record keeping is a recurring issue in our investigations into disability service provision to people who have died. We regularly find missing or illegible case notes and participant files with inaccurate and outdated information. It is also not uncommon to note missing health care plans, screening tools and incident reports, despite legislation and policies mandating their inclusion in participant files.

This is not simply an administrative issue. Participant files need to include clear, accurate information to ensure that disability support staff understand an individual's support needs and ensure that services can communicate effectively with each other.

Recent Australian research found that almost half of deaths of people with disability reviewed in NSW were linked to how documentation was handled. The research found that information that could affect the quality of care for people with disability was being overlooked or ignored, or was not accessible.<sup>28</sup>

We have investigated cases where people who have died had health plans clearly outlining their needs, but these were either inaccessible to staff or not included in participant files. In one investigation where choking was the cause of death, we found that an allied health professional had identified the person's choking risk, but the group home misplaced this information, meaning staff did not know about the person's critical mealtime support needs.

Handovers and participant notes are particularly important given the high volume of casual staff in the sector. Record keeping is also essential for effective communication between services. In the past year, we investigated two deaths where the failure by group homes to provide day services with important information about a participant's mealtime support needs potentially contributed to a person's death. In another case we investigated – where the individual died following a fall – the person's group home had failed to effectively communicate the person's seizure activity and mobility needs to their day service.

## Unauthorised restrictive practices

The use of unauthorised restrictive practices is a concerning theme that has emerged from our death investigations. Section 3 of the Act defines a restrictive intervention as 'any intervention that is used to restrict the right or freedom of movement of a person with a disability', including chemical restraint, mechanical restraint and seclusion.

Since 2017, we have completed five investigations which uncovered the use of unauthorised restraint or a failure to administer restraint in accordance with an approved Behaviour Support Plan. These cases included the unauthorised use of mechanical restraint including restrictive clothing, chemical restraint including the use of psychotropic drugs, and seclusion.

In one particularly concerning case, we found that a woman with disability had her menstruation suppressed for over thirty years to address undefined behaviours of concern. In another case, staff routinely administered pro re nata (PRN, medication administered 'as needed') chemical restraint to manage a person's behaviours of concern, without attempting to use the less restrictive practices noted in their authorised Behaviour Support Plan.

Restrictive practices infringe on a person's rights and can have a serious impact on an individual's health and wellbeing. Australia has made a commitment to reducing and eliminating the use of restrictive practices for people with disability. Our findings clearly highlight there is further work for service providers and staff to do to address people's behaviours by using the least restrictive option possible and to correctly identify and report any use of restrictive practices.

28 Dahm M R, Georgiou A, Hill S, Hemsley B (2018), 'Health information and the quality and safety of care for people with a disability: an analysis of Australian reports of reviewable deaths in residential care'. *Journal of Patient Safety*.

## CASE STUDY: **Matthew**

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**Matthew\* had lived in a group home since the age of 20. He loved watching his favourite movies and playing with his collection of toys. Matthew had an intellectual disability, autism and used non-verbal communication. Matthew had demonstrated some behaviours of concern, including harm to himself and others.**

Matthew was prescribed anti-psychotic medication to manage his behaviours of concern (routine and PRN). If Matthew's behaviours were escalating, the group home staff were supposed to encourage Matthew to go for a walk, a drive or to engage in another favourite activity. They had to exhaust all options before providing chemical restraint to Matthew. However, our investigation found that on several occasions staff administered chemical restraint to Matthew before using any positive behaviour support strategies. This contravened the Act and Matthew's human rights.

A few weeks before he died, Matthew's psychologist had increased the dose of chemical restraint prescribed to him. As a result of the increased dose, Matthew often appeared drowsy. This may have contributed to the service provider not recognising the early symptoms of pneumonia and delaying seeking medical attention. Matthew was in his twenties when he died of pneumonia.

Through our investigation, we found that Matthew did not have access to all of his toys, as group home staff kept half locked up. Staff also restricted Matthew from accessing the fridge and kitchen cupboards. The service provider told us they did this to ensure there were always clean toys available and because Matthew would help himself to food and had difficulty moderating his appetite. The service provider had not tried any less restrictive ways of supporting Matthew to look after his toys and to have safe access to food. The service provider had also not documented these support strategies or sought approval for these restrictive practices, as required by the Act.

We issued a NTTA to the service provider, requiring them to audit the supports provided to other residents to ensure that any restrictive practices were implemented in accordance with the Act. We also required the service provider to ensure all Behaviour Support Plans were current and to undertake training and supervision with staff about restrictive practices and positive behaviour supports.

The audit identified unauthorised restrictive practices were in place for another resident at the group home. The service provider has since addressed this and ensured all restrictive practices are included in a Behaviour Support Plan as per the Act.

*\*Names and details have been changed*

## Managing health needs

Our investigations demonstrate that there is a need to improve how service providers and staff manage the health of people with disability. This includes both the management of known health conditions, often outlined in specific health plans, and recognising the signs of illness or deterioration.

We have investigated several cases where disability support staff failed to recognise that a person's health was deteriorating and failed to seek appropriate medical advice, delaying potentially life-saving treatment. In one case, staff did not recognise the signs of a stroke and in two cases, staff did not immediately recognise the signs of choking. In other cases, we found that staff did not follow the relevant health management plan. It is vital that staff are supported to understand and respond to signs of deteriorating health to ensure people receive timely, and potentially lifesaving, treatment.

Research has indicated the importance of health checks in identifying unrecognised health needs, including life-threatening conditions, for persons with an intellectual disability.<sup>29</sup> Comprehensive annual health reviews provide an opportunity to identify and manage emerging health conditions and associated risks before these health conditions become acute. Health checks have been found to detect less serious conditions as well as those that might be considered serious and life threatening.<sup>30</sup> A trial conducted in Australia in 2002 to 2003 showed that comprehensive health assessments lead to improved health outcomes for people with disability.<sup>31</sup>

Our investigations confirm the need for people with disability to receive regular health checks to identify underlying conditions or manage specific health needs. In the majority of investigations where we issued a NTTA, we directed service providers to audit participant files to ensure that all necessary health checks and assessments are complete and up-to-date, and to confirm that staff are complying with the advice of health professionals. In some cases, these audits have uncovered concerning gaps in healthcare for people with disability.

## Staff support and training

A core theme in all our investigations is the need for service providers to support their staff to provide safe, high-quality disability services. However, this issue is not unique to Victoria. Research has demonstrated that poor service coordination, inadequate staffing, and limited training affects the quality of services provided to people with disability worldwide.<sup>32</sup>

In Australia, the NSW Ombudsman reported that support staff often struggled to deal with the increasing support needs of participants, and were sometimes unsure of when to raise concerns about residents with their manager.<sup>33</sup> Ensuring timely access to primary health care for people with disability who may not be able to access this independently, requires staff to be more aware of and responsive to health changes. At an absolute minimum, all disability support staff should receive consistent or industry standard training in how to identify the signs of choking, how to respond to falls and other accidents, and how to recognise the signs of deteriorating health.

The roll out of the NDIS across Australia is a time of both promise and concern for the competency of Australia's disability workforce. National Disability Services (NDS) is the peak body representing the interests of disability service providers in Australia. Their *State of the Disability Sector* report included the findings from their annual market survey, which received responses from more than 600 service providers.<sup>34</sup> Among the challenges identified by the disability service providers surveyed, were the following:

- recruiting disability support workers is becoming more difficult, with nearly two thirds of service providers who responded to the survey reporting 'extreme or moderate' difficulty in recruiting disability support workers
- specialist allied health workers, including psychologists, physiotherapists, speech therapists and occupational therapists, were the most difficult positions to fill
- respondents highlighted concerns regarding insufficient time to induct, train and facilitate staff development.

While the NDIS is presenting opportunities for the expansion of disability services throughout the sector, that very expansion has placed intense pressure on disability service providers to be able to recruit good quality staff. Not surprisingly, recruitment has been most difficult in rural and regional areas.

29 Robertson J, Roberts H, Emerson E, Turner S, Greig R (2011), *Journal of Intellectual Disability Research*, 55, pp. 1009-1019.

30 Wilson D N, Haire A (1990), 'Health care screening for people with mental handicap living in the community', *British Medical Journal*, 15, pp. 1379-1381; Alborz A I, McNally R, Glendinning C (2005), 'Access to health care for people with learning disabilities in the UK: Mapping the issues and reviewing the evidence', *Journal of Health Services Research and Policy*, 10, pp. 173-182.

31 Gordon L, Holden L, Ware R S, Taylor M T, Lennox N G (2012), 'Comprehensive Health assessments for adults with intellectual disabilities living in the community: weighing up costs and benefits', *Australian Family Physician*, 41, pp. 969-972.

32 World Health Organisation (2011), *World report on disability*, <<http://apps.who.int/iris/handle/10665/70670>>, accessed on 24 July 2019.

33 New South Wales Ombudsman (2018), *Report of Reviewable Deaths in 2014–2017*, Sydney, Australia.

34 National Disability Services (2018), *State of the Disability Sector Report*, <<https://www.nds.org.au/news/state-of-the-disability-sector-report-2018-now-available>>, accessed on 24 July 2019.

## CASE STUDY: **Gemma**

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**Gemma\* had lived in supported accommodation her whole life, and described living in two institutions during her childhood as ‘horrible’. Gemma had lived in her last group home for 11 years. Gemma had an intellectual disability, Tourette’s syndrome and mild vision impairment. She communicated verbally and by using photographs.**

One evening, a support worker observed that Gemma appeared distressed and was vomiting. Staff observed Gemma periodically as she went to sleep; however, they did not seek medical assistance for her during the night. Gemma was taken to hospital the next morning, where it was discovered she had suffered a stroke. She died later that day.

Our investigation found that Gemma had experienced neglect, due to the failure of staff to manage her deteriorating health over several months. While staff did identify that Gemma’s health was deteriorating, they did not proactively consult with NURSE-ON-CALL or seek urgent medical care, in accordance with practice guidelines for the group home. We formed the opinion that it is possible that the delayed medical treatment of Gemma’s stroke may have contributed to her death.

We also identified a range of other issues impacting the quality of care provided to Gemma, including the absence of a communication assessment and plan. Although Gemma had lived in care for most of her life, she had never had her communication assessed by a speech pathologist. This failure violated her human right to communicate, making it difficult for her to express her needs and preferences, particularly when unwell.

We issued a NTTA that required the service provider to ensure that, where necessary, all residents were assessed and provided with communication plans. It also required the provider to ensure that reports by residents’ health professionals were actioned and to audit the completeness of all resident files. In response to our report, the service provider set up a governance group to oversee the way the NTTA was implemented and initiated an internal review and disciplinary action against the support worker who failed to respond to Gemma’s deteriorating health.

*\*Names and details have been changed*

In June 2019, our office released the report *Building Safe and Respectful Cultures*, which outlined the findings of a pilot project that aimed to identify practical approaches to promoting safety and respect in disability services.<sup>35</sup> The impetus for the project was the Victorian Parliamentary *Inquiry into the Abuse of People with Disability*, which highlighted the urgent need for the sector to address the incidence of abuse.<sup>36</sup> Following the Inquiry, our office partnered with researchers at La Trobe University to produce a literature review collating information on best practice supports in disability services for the prevention of abuse of people with disability.<sup>37</sup> The review found that work in this area was limited.

The *Building Safe and Respectful Cultures* project – co-produced by academic researchers, DSC staff and community researchers with lived experience of disability – sought to address the lack of research into abuse that is focused on preventative factors. The project considered practical ways to create safe environments within disability services and identified three strategies that can assist providers to create safe and respectful cultures, including:

- relationship-based practice
- embedding a prevention approach into support
- reflective practice and supervision.<sup>38</sup>

The findings from the Building Safe and Respectful Cultures project align with research on the impact of poor organisational cultures on the safety and wellbeing of people with disability. Research has identified a range of factors as contributing to poor organisational cultures in group homes, including:

- a sense that people with disability are fundamentally different or ‘other’
- an attitude of doing ‘for’ not ‘with’
- staff-centred working practices
- staff resistance to change and new ideas.<sup>39</sup>

We identified issues relating to staff culture in several investigations, including concerns about staff skills, attitudes and work processes. In one investigation, we found that staff had difficulty maintaining professional boundaries with residents and had poor knowledge of the policies and procedures necessary to provide safe, high-quality disability supports.

Research has also identified poor staff culture, including low morale, high levels of staff sickness and staff shortages, as an early indicator associated with abuse in disability services.<sup>40</sup> In disability group homes, night shifts, weekends and evening shifts (times when there is usually less staff and less supervision from management) have been associated with higher instances of abuse of residents.<sup>41</sup> Without appropriate training and supervision, staff may improvise responses to a person’s challenging behaviour under pressure, and these responses may be harmful, or even abusive, to the person.

Supervision and active monitoring of staff practice is essential in producing and maintaining safe, high quality living environments for people with disability living in group homes.

35 Robinson S, Oakes P, Murphy M, Codognotto M, Ferguson P, Lee F, Ward-Boas W, Nicks J and Theodoropoulos D (2019), *Building safe and respectful cultures in disability services for people with disability: report*, Disability Services Commissioner, Melbourne.

36 Family and Community Development Committee (2016), *Inquiry into abuse in disability services: final report*, Parliament of Victoria, Melbourne.

37 Araten-Bergman T, Bigby C, Ritchie G (2017), *Literature review: best practice supports in disability services for the prevention of abuse of people with a disability: Report for the Disability Services Commissioner*, Living with Disability Research Centre, La Trobe University, <<https://www.odsc.vic.gov.au/abuse-prevention/resources-on-preventing-and-responding-to-abuse/>>, accessed 26 July 2019.

38 Robinson S et al (2019), *Building safe and respectful cultures in disability services for people with disability: report*.

39 Bigby C, Knox M, Beadle-Brown J, Clement T, Mansell J (2012), ‘Uncovering Dimensions of Culture in Underperforming Group Homes for Individuals with Severe Intellectual Disability’, *Intellectual and Developmental Disabilities*, 50, 5, pp. 452 – 467.

40 Marsland D, Oakes P, White C (2007), ‘Abuse in care? The identification of early indicators of the abuse of people with learning disabilities in residential settings’, *The Journal of Adult Protection*, 9, 4, pp. 6 – 20.

41 Ibid.

## CASE STUDY: **Rosemary**

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**Rosemary\* lived in residential institutions for most of her life, including as a child, and had lived at her group home for 18 years. Rosemary had a moderate intellectual disability and a diagnosis of bipolar disorder. She communicated verbally and had monthly contact with her family.**

Rosemary required support with all aspects of her personal care, including regular help with her personal hygiene as she experienced incontinence. Rosemary also had difficulty with swallowing, placing her at high risk of choking and pneumonia. In the twelve months prior to her death, Rosemary received an extensive range of allied health support, including dental, dietetic, and speech pathology assessments.

One morning, staff found Rosemary on the floor of her bedroom, shaking, unsteady and pale. Staff called an ambulance, which transported Rosemary to hospital, where she was treated for pneumonia. She died the following day, aged 56 years.

When we investigated the services provided to Rosemary prior to her death, we found that staff did not follow Rosemary's mealtime support plan, as specified by her speech pathologist. Despite the recommendation for soft and moist food types, support workers provided Rosemary with a range of foods that the speech pathologist had identified as 'foods to avoid'. The most recent recommendations by her speech pathologist, which noted that Rosemary required a higher level of mealtime supervision than she had previously received, had not been recorded in her file notes.

DSC issued a NTTA to the service provider, which required an audit of mealtime support plans for all residents and referrals to health experts where necessary. The audit undertaken by the service provider found other residents that either did not have a current swallowing assessment, or had outdated plans, placing them at significant risk of choking and aspiration. The NTTA also required the service provider to provide all staff with training that reinforced their duty of care to implement all recommendations made by medical and allied health professionals and to maintain consistent record keeping practices.

*\*Names and details have been changed*

# Investigation outcomes

If a death investigation identifies issues of concern with the provision of disability services, we may issue a service provider with a NTTA. This details the actions that we require a service provider to take to address the concerns identified in an investigation. Under the Act, we have the power to undertake a follow-up investigation if a service provider does not respond to a NTTA adequately.

NTTAs aim to improve the disability supports provided to other service users and address factors that may contribute to the premature or preventable deaths of people with disability. In 2018–19, we issued NTTAs for 23 completed death investigations. Typically, each NTTA contains a number of separate actions. In every NTTA we include the requirement that providers share the investigation findings with their staff. DSC considers each investigation an opportunity for providers to reflect on their practice and support staff to improve the way they deliver services.

The most frequent actions included in our NTTAs relate to improving the training and supervision provided to disability support staff. Staff skills and knowledge are fundamental to the provision of high-quality disability supports. We issued 21 NTTAs for service providers to improve staff training in a range of areas, including training on:

- duty of care responsibilities, the principles of person-centred active support and the requirements of the Act (six investigations)
- record keeping practices, particularly the need to maintain participant files for medication, specific health plans, bowel and food/fluid charts (five investigations)
- appropriate behaviour support strategies and recognising restrictive practices (four investigations)
- how to provide appropriate mealtime supports (three investigations)
- recognising and responding to the signs of deteriorating health (three investigations).

In five NTTAs we required service providers to improve or develop policies to guide staff practice in areas including manual handling, falls risks, palliative care, mental health and oral health.

In four NTTAs we required service providers to address specific staffing matters, including ensuring that enough staff are rostered on to provide necessary staff-to-client support ratios, and providing enough time during shifts for staff to complete participant notes and conduct handovers.

The other key focus in our NTTAs has been requiring providers to audit participant files to ensure that all case notes, records and plans are complete and legible, and that staff are complying with all support and health plan requirements. File audits are also an opportunity for providers to identify gaps in an individuals' supports and arrange for any missing health assessments. In 18 cases we issued a NTTA that required service providers to audit client files, with the aim of:

- ensuring that staff were following mealtime support plans and, if necessary, arranging swallowing and nutrition assessments for participants without one (nine investigations)
- determining the completeness of Behaviour Support Plans and ensuring that staff are using any approved restrictive practices appropriately (six investigations)
- identifying whether communication plans were complete, whether participants had access to necessary communication aids and, where necessary, arranging for clients to have communication assessments (five investigations)
- arranging medication reviews for participants and reviewing the quality of record keeping for medication administration (five investigations).

In addition to NTTAs, as part of our investigations we issued nine Notices of Advice to the Secretary of DHHS to address systemic issues within service provision. While our investigations typically focus on one site – such as an individual group home or day service location – Notices of Advice to the Secretary of DHHS allow us to highlight issues across the sector. In our Notices of Advice, we have recommended a number of sector-wide practice improvements, including:

- auditing the use of unauthorised chemical restraint in targeted group homes
- updating practice guidelines to include information on managing falls risks
- updating the process of moving residents into new homes, to ensure everyone is assessed for swallowing and choking risks
- issuing advice regarding influenza vaccination and flu prevention strategies in group homes.

In November 2018, we also sent a Notice of Advice to all Victorian disability service providers highlighting a number of systemic issues that required immediate attention, including inadequate mealtime supports, lack of support for people with complex communication needs, poor record keeping practices and the need to ensure that people have appropriate health plans.<sup>42</sup>

<sup>42</sup> Disability Services Commissioner (2018), 'Notice of Advice: Systemic issues arising from the review of disability service provision to people who have died', <<https://www.odsc.vic.gov.au/2018/11/26/notice-of-advice-systemic-issues-arising-from-the-review-of-disability-service-provision-to-people-who-have-died/>>, accessed 8 August 2019.

# Looking ahead

## New process for death investigations

Over the past two years, we have collected valuable data and developed a detailed understanding of the key service issues relating to the deaths of people in receipt of disability services. This knowledge base has allowed us to revise the way we investigate disability service provision to people who have died to enable a more focused approach to the work.

From August 2019, we will be implementing a revised process for these investigations. We will still collect and review a questionnaire and other documents and information from service providers when a death occurs. In addition, we will require service providers to conduct their own review to identify any practice issues with service delivery and develop an action plan to address these – using information provided by our office to guide their work. The key risk areas we will be asking service providers to focus on when conducting their internal reviews will include:

- choking and/or aspiration risks (including the assessment and subsequent development of mealtime support plans and training for staff)
- bowel management
- recognition and management of deteriorating health
- falls or history of falls
- unexplained injury/bruising
- signs of possible abuse or neglect
- poor documentation and communication of people's health-related support needs.

We will assess service providers' reviews and action plans and compare them to our own review of the information available. If we are satisfied that the service provider's review addresses the key risks, will ask providers to report back on the outcomes of their improvement actions and close our investigation. Where we disagree with the outcomes of a provider's review – or in particularly complex cases – we will conduct our own comprehensive investigation.

The revised process aims to further strengthen the capacity of service providers to identify and take early action in response to the death of a participant. It also aims to support providers to transition to their new incident reporting responsibilities under the NDIS Commission.

## Transition to NDIS

On 1 July 2019, the NDIS Commission began providing oversight of NDIS-funded disability services provided to Victorians with disability. However, some people with disability in Victoria are yet to become participants in the NDIS. DSC will continue to provide oversight of – and where necessary, conduct death investigations – into disability services registered with DHHS, which includes:

- services for people with a disability delivered through service systems outside the NDIS
- matters which fall outside the jurisdiction of the NDIS Commission
- all existing people with disability that have not transitioned to the NDIS
- all in-kind supports, which do not fall under the remit of the NDIS Commission because they are not funded under the NDIS Act.

## Influencing future mealtime supports

In June 2019, DSC convened a working group on ensuring people with disability receive appropriate mealtime supports. A range of sector representatives have committed to participating, including representatives from the NDIA, NDIS Commission, DHHS, NDS, Speech Pathology Australia, Deakin University, advocacy groups VALID and STAR Victoria, and the Dietitians Association of Australia. The initial work undertaken identified a number of factors relevant to improving mealtime supports for people with swallowing difficulties, including:

- the role of mealtimes in people's quality of life
- the need to establish a good practice benchmark across the sector for the provision of quality mealtime supports
- the need to ensure that mealtime supports are automatically covered in NDIS plans
- ensuring that, where necessary, NDIS plans fund swallowing and communication assessments and mealtime supports in line with the established benchmark
- addressing the difficulties in accessing speech pathologists that specialise in dysphagia, particularly in rural and remote areas
- the importance of service providers having clear, concise and accessible policies and procedures in relation to the provision of mealtime supports
- the importance of staff training and supervision.

We will continue to work with key sector stakeholders to ensure action is taken to prevent the avoidable deaths of people with disability due to inadequate mealtime supports.

## Challenges for the future

Our work over the past two years clearly demonstrates that more needs to be done to prevent the premature deaths of people with disability. It is unacceptable that people with disability continue to die around 30 years earlier than other Victorians, and that they are more likely to die from factors that are uncommon in the broader community, such as choking and aspiration pneumonia.

We are particularly concerned to have investigated several cases where it was known that a person had difficulty swallowing and eating, but the person died because staff were either unaware of, or did not follow, their mealtime support plan. Mealtimes are a necessary part of life – and a key time for social interaction – and should not be a common factor in the deaths of people with disability.

We understand that disability service providers are experiencing a period of rapid change, including new funding and oversight arrangements. However, it is vital that service providers support their staff to deliver safe services to people with disability, by providing targeted training and supervision. We consider it urgent that the sector improves practices in the following areas:

- mealtime supports
- bowel management
- positive behaviour support
- complex communication needs
- record keeping and inter-service communication
- specific health needs management
- identifying and managing deteriorating health (including the signs of stroke or choking).

As Victorian disability services continue to transition to the NDIS, it is essential that all of us in the sector are alert to practices that infringe on the safety and wellbeing of people with disability, or prevent them from effectively exercising their 'choice and control'.