

Disability Services Commissioner

# A review of disability service provision to people who have died 2017-18



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## About the case studies

This report includes case studies that illustrate our work undertaking investigations into the adequacy of disability service provision to people who have died. We use pseudonyms, and change identifying details of the cases to protect the identity of the people to whom they refer.

## Abbreviations, acronyms and definitions

<b>CCIM</b>	Critical Client Incident Management	<b>shared supported accommodation</b>	A type of accommodation that provides housing and support services for people with a disability. This is typically in the community in a group home where rostered staff are available to provide care and support to people with disability who reside there. DHHS and non-government organisations manage shared supported accommodation
<b>CIMS</b>	Client Incident Management System	<b>Standards</b>	Human Services Standards
<b>Coroners Act</b>	<i>Coroners Act 2008</i>	<b>the Act</b>	<i>Disability Act 2006</i>
<b>DHHS</b>	Department of Health and Human Services	<b>the Charter</b>	<i>Charter of Human Rights and Responsibilities Act 2006</i>
<b>disability services</b>	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	<b>the Inquiry</b>	Means the Inquiry into Abuse in Disability Services conducted by the Family and Community Development Committee in accordance with the terms of reference received from the Legislative Assembly of the Parliament of Victoria on 5 May 2015
<b>disability service providers</b>	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: <ul style="list-style-type: none"> <li>• 'disability service provider' means the Secretary of DHHS, or a person or body registered on the register of disability service providers</li> <li>• 'regulated service provider' means a contracted service provider, funded service provider or a prescribed service provider</li> <li>• 'contracted service provider' means a person who has entered into a contract with the Secretary of DHHS under s. 10 of the Act to provide services to a person with a disability</li> <li>• '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</li> <li>• '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</li> </ul>	<b>the Minister</b>	Minister for Housing, Disability and Ageing
<b>DSC</b>	Disability Services Commissioner	<b>the Secretary</b>	The Secretary of DHHS
<b>ICD</b>	International Statistical Classification of Diseases and Related Health Problems		
<b>NDIS</b>	National Disability Insurance Scheme		

# Message from the Disability Services Commissioner

I am pleased to present this inaugural annual review of disability service provision to people who have died while in receipt of disability services.

On 12 September 2017, the Minister for Housing, Disability and Ageing requested that my office inquire into and, at my discretion, investigate the provision of disability services for Victorians in receipt of disability services at the time of their death. The impetus for the Minister's referral to us was the result of some of the findings and recommendations made by the Family and Community Development Committee Inquiry into Abuse in Disability Services (the Inquiry), of which the final report was tabled in the Victorian Parliament on 26 May 2016. This work has not previously been performed in Victoria.

During 2017–18, my office received 103 notifications from the Department of Health and Human Services (DHHS) and the State Coroner of deaths of people with disability. We commenced our first investigations on 13 November 2017, and since that time we have finalised 20 investigations, issued eight Notices to Take Action to service providers, and provided advice on areas for systemic improvement for the sector to the Secretary of DHHS on two occasions.

This report considers what we have learned from our work to date in this important area. It sets out our approach and preparation in establishing these investigations, and provides analysis of the themes and issues arising from completed investigations. We have identified practice issues in cases where the death of the person was expected and in cases where the death of the person was unexpected. Of particular concern is the number of cases in which expert advice provided by a dietitian or speech pathologist about implementing modified diets has not been followed, placing people with a disability at significant risk of health complications or death.

The outcomes of this work are relevant for all disability service providers, not just those subject to our investigations and Notices to Take Action. They will inform the refinement of practice approaches and safeguarding arrangements as the disability sector transitions to the full roll out of the NDIS.

Over the coming 12 months, DSC will continue to progress and complete individual investigations into disability service provision to people who have died, as well as identifying and reporting on broader systemic issues. DSC will continue to gather and analyse data and information obtained through completed questionnaires, together with information provided by the State Coroner, to enable the office to provide advice to the sector on areas that require service improvement, particularly to prevent avoidable deaths.

The next and final annual report on our work in this area will report on a greater number of completed investigations, and provide a more detailed analysis of data derived from deaths of people receiving disability services.

We are privileged to undertake this critical work, and I thank all the staff involved in this work for the diligence and respect they demonstrate in relation to the cases and families we work with.

In closing, I extend my condolences to the families, friends and carers of the people who have died. We are grateful for their valuable input, at a difficult time in their lives, to assist in informing areas for service improvement for others.



**Laurie Harkin AM**  
Disability Services Commissioner  
30 June 2018

# Chapter 1: Background

## 1.1 Parliamentary Inquiry and the Victorian Government's response

On 5 May 2015, the Legislative Assembly of the Parliament of Victoria requested that the Family and Community Development Committee conduct the Inquiry into Abuse in Disability Services. The terms of reference included considering why abuse in disability services was not reported or acted upon, and how abuse could be prevented. Drawing on information from a variety of sources, including other inquiries and investigations, the Inquiry considered the strengths and weaknesses of Victoria's regulation of the disability service system, systemic issues that impacted on abuse occurring, research to consider best practice approaches and an evaluation of the powers and processes of Victorian oversight bodies.<sup>1</sup>

The Inquiry heard compelling evidence about widespread abuse and neglect of people with disability in Victoria. Abuse was found to take many forms, including physical and sexual assault, verbal and emotional abuse, financial abuse and neglect endangering life.<sup>2</sup>

Abuse was found to occur in a variety of settings, from day services to residential accommodation operated by both DHHS and non-government service providers. The Inquiry also highlighted the shortcomings of essential safeguarding and oversight systems in Victoria. The final report of the Inquiry presented confronting evidence of sexual and physical assault of people with disability, and of a sector that had normalised the experience of abuse and neglect.<sup>3</sup>

In collaboration with the State Coroner, the Inquiry also examined deaths of people with disability in supported accommodation. The State Coroner identified that 570 deaths occurred in residential care facilities from 2007 until the time of the Inquiry which contained mention in its database of the *Disability Act 2006* (the Act). Two hundred of these deaths were reviewed by the Inquiry. The Inquiry reported there were data limitations in the National Coronial Information Service database that made it difficult to isolate deaths involving clients of disability services.<sup>4</sup>

Seven deaths of people with disability in receipt of disability services were identified by the Inquiry as potentially relating to cases of abuse or neglect in disability services. These cases included examples of:

- physical restraint
- accidental choking on food and other ingested items
- inadequate supervision
- inappropriate access to medication.<sup>5</sup>

Accidental choking on food occurred in four of the seven deaths. Expert evidence highlighted the link between neglectful practices such as failing to safely support someone with their meals, and subsequent death from choking or aspiration pneumonia.<sup>6</sup>

The Inquiry identified that there were no processes in Victoria to systematically review deaths in disability services, which meant that it was not possible to readily identify leading causes of death, or to meaningfully assess possible links between a death and the adequacy of care.<sup>7</sup>

The Inquiry report was tabled in the Victorian Parliament in May 2016. To address the deficiencies identified in the Inquiry, 49 recommendations were made for legislative, practice and safeguarding reform. The recommendations were directed towards the Victorian Government, DHHS, disability services and the Disability Services Commissioner.

A key recommendation was for legislative amendments to the Act to empower the Disability Services Commissioner to become the key oversight body in Victoria for people with disability.<sup>8</sup>

Other recommendations of relevance to deaths in disability services included:

- improvements to the information and communications technology of the State Coroner to facilitate accurate reporting and analysis of deaths of people with disability<sup>9</sup>
- legislative change to provide for the State Coroner to report all deaths in disability services to the Disability Services Commissioner<sup>10</sup>
- funding the Disability Services Commissioner to undertake a comprehensive, annual review of all deaths that occur in disability services, with the results being publicly available.<sup>11</sup>

1 Parliament of Victoria, Family and Community Development Committee 2016, *Inquiry into abuse in disability services: final report*, State Government of Victoria, Melbourne, pp. ix–x.

2 *Ibid.*, p. xiii.

3 *Ibid.*, p. xiii.

4 *Ibid.*, p. 17.

5 *Ibid.*, p. 17.

6 *Ibid.*, p. 18.

7 *Ibid.*, p. 18.

8 *Ibid.*, pp. xiv; xxxiv; Recommendation 7.1.

9 *Ibid.*, p. xxvii; Recommendation 1.1.

10 *Ibid.*, p. xxvii; Recommendation 1.2.

11 *Ibid.*, p. xxvii; Recommendation 1.3

# Background

## Legislative reform

In November 2016, the Victorian Government committed to strengthening the oversight powers and functions of the Disability Services Commissioner.<sup>12</sup>

In May 2017, the Victorian Government introduced the Disability Amendment Bill 2017 into the Victorian Parliament, and announced that the Disability Services Commissioner would be funded to initiate investigations into allegations of abuse and neglect of an individual or systemic nature, to appoint authorised officers to visit and inspect relevant premises without notice, and to undertake a comprehensive annual review of all deaths that occur in disability services.<sup>13</sup>

Prior to the legislative amendments commencing in August 2017, the Minister made a referral to the Disability Services Commissioner to commence inquiries into systemic and practice issues arising from reports of unexpected deaths in disability services under existing provisions of the Act.<sup>14</sup> The scope of the referral was extended in September 2017, following amendments to the Act.

## First referral from the Minister – death review

On 24 July 2017, the Minister requested that the Disability Services Commissioner receive reports of unexpected client deaths from DHHS and the State Coroner.

The referral tasked the Disability Services Commissioner to inquire into and provide advice to DHHS on any practice and systemic issues identified in disability services provided to people in receipt of those services at the time of their death.<sup>15</sup>

## Amendments to the *Disability Act 2006*

On 16 August 2017, a range of amendments to the Act commenced, providing increased powers to the Disability Services Commissioner, including the ability to:

- initiate investigations into allegations of abuse or neglect in the provision of disability services<sup>16</sup>
- undertake investigations into matters referred by the Minister or the Secretary of DHHS<sup>17</sup>
- appoint authorised officers and undertake visits and inspections of premises on which a disability service provider is providing a service that is being investigated<sup>18</sup>
- issue a Notice to Take Action to a service provider where it has been identified that there are opportunities to improve the disability services, or to prevent abuse or neglect<sup>19</sup>
- receive reports from a service provider on actions it has taken to comply with a Notice to Take Action<sup>20</sup>
- undertake follow-up investigations.<sup>21</sup>

## Second referral from the Minister – death review

Following amendments to the Act, the Minister replaced the first referral and from 12 September 2017, requested that the Disability Services Commissioner receive reports of expected and unexpected client deaths<sup>22</sup> from DHHS and the State Coroner.

The referral requested that the Disability Services Commissioner inquire into and, at the discretion of the Commissioner, investigate any matter relating to the provision of disability services (including abuse or neglect in the provision of services) by disability service providers identified in the following:

- incident reports that the Commissioner receives from DHHS of all deaths where the deceased was a person with a disability receiving these services at the time of their death
- deaths referred to the Commissioner by the State Coroner where the deceased was a person with a disability receiving these services at the time of their death.

Further, the Minister's referral requested that the Disability Services Commissioner provide a comprehensive annual review of deaths that occur in disability services, including the number, type and outcomes of investigations conducted under this referral, any related follow-up investigations, as well as an overview of any practice or systemic issues identified.<sup>23</sup>

At the time of writing, our power to inquire into and investigate the provision of disability services to people in receipt of those services at the time of their death will not apply to any deaths that occur after 30 June 2019, which is when the referral from the Minister ends and our office closes as part of the transition to the NDIS Quality and Safeguards Commission.

12 State Government of Victoria 2016, *Zero tolerance of abuse of people with disability: response to the Inquiry into Abuse in Disability Services*, tabled 23 November 2016, <<https://www.parliament.vic.gov.au/fcdci/inquiries/article/3209>>, accessed 4 July 2018; The Hon. Martin Foley, Minister for Housing, Disability and Ageing 2016, *Protecting the safety of people with a disability*, <<https://www.premier.vic.gov.au/wp-content/uploads/2016/11/161123-Protecting-The-Safety-Of-People-With-A-Disability.pdf>>, accessed 4 July 2018.

13 The Hon. Martin Foley, Minister for Housing, Disability and Ageing 2017, 'More protections for people with a disability', <<https://www.premier.vic.gov.au/more-protections-for-people-with-a-disability/>>, accessed 4 July 2018.

14 *Disability Act 2006*, s.16(c).

15 The Hon. Martin Foley, Minister for Housing, Disability and Ageing 2017, Letter to the Disability Services Commissioner, dated 24 July 2017.

16 *Disability Act 2006*, s. 128B.

17 *Ibid.*, s.128I.

18 *Ibid.*, ss.132B,132E.

19 *Ibid.*, ss.128E, 128G, 128M, s.128N.

20 *Ibid.*, s. 128P.

21 *Ibid.*, s.128R.

22 This included major impact, category 1, non-major impact and category 2 incident reports relating to a death of a person in receipt of disability services.

23 The Hon. Martin Foley, Minister for Housing, Disability and Ageing 2017, Letter to the Disability Services Commissioner, dated 10 September 2017.



# Chapter 2: Preparing for death reviews

Preparing for the commencement of death review investigations was a significant achievement for our office in 2017–18. It involved considerable planning, research and resourcing to ensure our processes are effective in the timely completion of investigations, and to identify opportunities for improvements to disability services being investigated.

## 2.1 Resourcing and systems

In preparation for these inquiries and investigations, we established the Systemic Review team, and recruited staff with a range of backgrounds including disability sector experience, government investigation experience, social work, legal, academic, medical and data analysis. Adequate staff resourcing to meet the volume of deaths being reported to our office remains an ongoing challenge.

We enhanced our case management system to ensure we could gather and record information about our investigations to inform systemic analysis.

We developed procedures and guidelines to ensure our investigations are conducted with rigour and consistency. Our investigations are phase based. All investigations commence as an initial desktop review and document analysis. Where required, a more comprehensive approach is employed including Authorised Officer visits and inspections and interviews.

## 2.2 Research and literature

Our processes and approach to establishing this work were informed by the experience of other jurisdictions, notably staff from the New South Wales Ombudsman, whom we thank for providing valuable insight and guidance as a result of their work in this area over a number of years.

In November 2017, we met with visiting Winston Churchill Memorial Trust scholar, Dr George Julian. Dr Julian had previously worked as a special adviser to the United Kingdom's Care Quality Commission national review into the way National Health Service Trusts investigated and learned from deaths. Dr Julian advised us on the poor experiences in England of families often not being treated with kindness, respect and sensitivity. The importance of meaningfully engaging families in our investigations was evidently clear and a priority for us.

In our preparatory work, we were informed by research that reported alarming statistics about the high rate of potentially avoidable deaths of people with disability. A search for peer-reviewed journal articles was conducted using the EBSCO host database. A combination of the terms 'disability', 'death', 'mortality', 'review', and 'investigation' were applied. Grey literature<sup>24</sup> was also sought to understand the themes emergent from death reviews and investigations in other jurisdictions.

An Australian peer-reviewed paper published in 2017 examined deaths of people with intellectual disability who received disability services in New South Wales. The research reported that people with intellectual disability have a premature mortality rate. Further, 240 out of 637 deaths (38 per cent) were potentially avoidable and caused by conditions that are preventable for people aged less than 75 years with the appropriate individualised care. This could either be through their existing primary or hospital care in the context of what is available in Australia's health system.<sup>25</sup> The potentially avoidable causes of death included diseases of the circulatory system, respiratory system, infections and cancer.<sup>26</sup>

The particular factors that place people with disability at increased risk of early death are similar to those in the general population, including smoking, poor diet, and lack of exercise. The impact is, however, amplified for those people with an intellectual disability who may not be able to communicate their health needs, thereby limiting their access to preventive health measures. Death investigations in other jurisdictions such as New South Wales, the United Kingdom, and the United States have shown that the deaths of people with disability are more likely preventable or avoidable than the general population if appropriate support is provided to access primary health care.<sup>27</sup>

Poor coordination of services, inadequate staffing, and weak staff competencies have been proven to affect the quality and adequacy of services for people with disability.<sup>28</sup> These factors have been shown to play a role in the occurrence of death for people using disability services. These findings must be placed in the context of a global trend in disability services being characterised by staff that are poorly paid and have inadequate training. This therefore makes it particularly difficult for staff to provide the appropriate support to people whose needs are complex, and which require specific skills and expertise.<sup>29</sup>

24 Grey literature includes materials and research produced by organisations outside of the traditional commercial or academic publishing and distribution channels.

25 Trollor J, Srasuebku P, Xu H and Howlett S 2017, 'Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data', *BMJ Open*, vol. 7, no. 2, e013489, doi: 10.1136/bmjopen-2016-013489.

26 Ibid.

27 Ibid.; Heslop P, Blair PS, Fleming PJ, Hoghton MA, Marriott AM and Russ LS 2013, *Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD): final report*, Norah Fry Research Centre, Bristol; New South Wales Ombudsman 2013, *Report of reviewable deaths in 2010 and 2011: volume 2 – deaths of people with disabilities in care*, State Government of New South Wales, Sydney; 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*, State Government of Queensland, Brisbane; Ras M, Woittiez I, van Kempen H and Sadiraj K 2010, 'Steeds meer verstandelijk gehandicapt?', *Zorg en Financiering*, vol. 9, no. 4, pp.118–119, doi: 10.1007/BF03095370; World Health Organization 2018, 'Disability and health', <<http://www.who.int/news-room/fact-sheets/detail/disability-and-health>>, accessed 20 July 2018; Ervin DA, Hennen B, Merrick J and Morad M 2014, 'Healthcare for persons with intellectual and developmental disability in the community', <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4098023/>>, accessed 4 July 2018.

28 World Health Organization 2011, *World report on disability*, <<http://apps.who.int/iris/handle/10665/70670>>, accessed 4 July 2018.

29 Trollor J et al. 2017, op. cit.; Ervin DA et al. 2014, op. cit.

# Preparing for death reviews

In Victoria, the Inquiry into Abuse in Disability Services reported that 'as a workforce, disability support workers are among the lowest paid workers in the care sector, work in challenging environments that are often poorly managed, and are frequently poorly trained, or undertrained, for the complex tasks they are required to undertake'.<sup>30</sup>

The New South Wales Ombudsman reported that support staff often struggled to deal with the increasing support needs of clients, including not knowing when to escalate concerns and raise them with senior management.<sup>31</sup> They found there was rarely proactive re-assessment of the person's changing needs, and thus needs went unmet and were neglected over time. Improving the coordination of care is central to addressing this issue. Without coordinated care, the findings showed that deaths had occurred that otherwise could have been prevented.<sup>32</sup>

The provision of high-quality support to people with a disability is important in the context of their diverse and sometimes complex needs, as well as their increased risk of premature death, particularly for individuals with intellectual disability.

The capacity of the disability workforce to respond to the deteriorating health of people with disability has been a prominent issue identified in the investigations we have completed to date.

Outside of disability services, inequitable access to primary health care is a consistent theme across the national and international literature that has been proven to contribute to the premature deaths of people with a disability.<sup>33</sup>

In the United Kingdom, the Confidential Inquiry into Premature Deaths of People with Disability (CIPOLD) reviewed the deaths of 238 people with learning disability, with 43 per cent of the deaths assessed as premature. Common reasons for premature death were delays in diagnosis and treatment, accompanied by a lack of reasonable adjustments to help people to access healthcare services.<sup>34</sup>

World Health Organization survey data from 51 countries revealed that people with disability were more than twice as likely to report finding healthcare provider skills inadequate to meet their needs, four times more likely to be treated poorly, and nearly three times more likely to be denied health care. The CIPOLD found considerable evidence of 'fragmented' care and a lack of holistic approaches to health and support needs.<sup>35</sup> Similarly, the New South Wales Ombudsman found that many people with disability miss out on crucial health treatment because they are not supported to attend medical appointments, or to follow medical advice or other recommendations.<sup>36</sup>

Access to primary health care must be complemented by staff being more aware and responsive to health changes – with some people with disability becoming critically ill within a short period.<sup>37</sup> In Victoria, the disability service workforce is largely comprised of medically untrained staff and therefore, such an expectation is arguably unrealistic. At an absolute minimum, basic training for support staff is critical to reduce accidents, for example to reduce the risk of choking and respiratory infection through safe approaches to the provision of mealtime assistance methods following swallowing assessments.<sup>38</sup> Furthermore, advanced training on topics of health and wellbeing is required in order for staff to be competent in identifying symptoms early and seeking the relevant course of preventive action.

The ability to identify that certain behaviours or presentations are abnormal for an individual is reliant on the degree to which a staff member knows the typical behaviour of that individual. Therefore, having consistency in staffing is important so that there is ample opportunity to become familiar with an individual's needs. This may prove to be a challenging endeavour in Australia given the increasingly casualised nature of the disability services workforce, for which there is a high turnover rate.<sup>39</sup>

30 Parliament of Victoria, Family and Community Development Committee 2016, op. cit. p. 113–114.

31 New South Wales Ombudsman 2013, op. cit. 32 Ibid.

33 Li JL 2017, 'Cultural barriers lead to inequitable healthcare access for aboriginal Australians and Torres Strait Islanders', *Chinese Nursing Research*, vol. 4, no. 4, pp. 207–210. <<https://www.sciencedirect.com/science/article/pii/S2095771817301044>>, accessed 20 July 2018; World Health Organization 2017, *Health inequities*, World Health Organization, Geneva, <[http://www.who.int/features/factfiles/health\\_inequities/en/](http://www.who.int/features/factfiles/health_inequities/en/)>, accessed 20 July 2018.

34 Heslop P et al. 2013, op. cit.

35 Ibid.

36 New South Wales Ombudsman 2013, op. cit.

37 Heslop P et al. 2013, op. cit.; MENCAP 2007, *Death by indifference: following up the 'Treat me right!' report*, <<https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf>>, accessed 4 July 2018; New South Wales Ombudsman 2013, op. cit.

38 Finalyson J, Morrison J, Jackson A, Mantry D and Cooper SA 2010, 'Injuries, falls and accidents among adults with intellectual disabilities: prospective cohort study', *Journal of Intellectual Disability*, vol. 54, pp. 966–980.

39 National Disability Service Australia 2017, *Workforce report July 2017*, <<https://www.nds.org.au/news/australian-disability-workforce-report-first-edition-released>>, accessed 4 July 2018.

## 2.3 Legislative and practice framework for investigations

We have adopted a person-centred and human rights approach to our investigations.

We utilise and consider principles of the Act, the *Charter of Human Rights and Responsibilities Act 2006* (the Charter) and the United Nations' Convention on the Rights of Persons with Disabilities in assessing the adequacy of disability service provision in our investigations.

Our investigations are conducted pursuant to s. 128I of the Act, and in accordance with the rules of natural justice and procedural fairness.

In addition to the overarching legislative considerations, we also utilise the following DHHS guidelines to assess the adequacy of disability service provision:

- *Residential services practice manual*
- Human Services Standards
- *Critical client management instruction*, technical update 2014
- *Client incident management guide: client incident management system 2017*.

The *Residential services practice manual* defines the roles and responsibilities of staff working in DHHS-managed residential services, and outlines the practical application of some of the legislative obligations in the Act, the Charter and the *Occupational Health and Safety Act 2004*.

While non-government service providers are not required to follow the *Residential services practice manual*, the guidelines are used in our investigations as a benchmark for assessing practice.

The DHHS Human Services Standards provide a set of four main service quality standards ('empowerment', 'access and engagement', 'wellbeing' and 'participation') that apply to DHHS-managed or funded disability service providers delivering services to clients.<sup>40</sup> In evaluating disability service provision to people who have died, we look for evidence that these standards have been demonstrated in practice.

## 2.4 Memorandum of understanding with the State Coroner

We partnered with the State Coroner to develop the operational relationships necessary to enable us to work effectively together in supporting our respective roles in relation to the deaths of people with a disability.

On 16 August 2017, the Disability Services Commissioner signed a memorandum of understanding with the State Coroner to:

- facilitate information exchange and referral of deaths
- to provide for the identification of and accurate data collection relating to deaths of people in receipt of disability services
- to provide a mechanism to identify factors that contribute to the unexpected or early death of people with disability in receipt of disability services
- to facilitate making recommendations and provision of advice to government, service providers and others as relevant, about practice and systems to improve the quality and longevity of life for people with disability who are receiving disability services.

We work closely with staff from the Coroners Court of Victoria to exchange information about deaths of people with disability that are in scope for our investigation. The State Coroner provides us with records and information including medical examiners' reports, police reports, medical records, and coronial findings.

We provide our final investigation reports to the State Coroner for all matters where the person's death was a 'reportable death'<sup>41</sup> under the Coroners Act.

## 2.5 Engagement with family and next of kin

Feedback from family and next of kin is critical to informing our investigations.

Families are often in the best position to speak about the perspective of the person who has died. They provide us with important information about what worked well with their loved one's disability service provider, and the areas that could benefit from improvement.

<sup>40</sup> Department of Health and Human Services 2017, *Human Services Standards policy*, State Government of Victoria, Melbourne.

<sup>41</sup> *Coroners Act 2008*, s. 4.

# Preparing for death reviews

## 2.6 Questionnaire

We devised an extensive 70-question questionnaire to gather data and information about important factors relating to the person who died including:

- general demographic information
- health
- wellbeing
- disability service provision.

The purpose of the questionnaire is twofold.

First, it gathers critical information from the disability service provider to inform our initial risk assessment of the disability service provision and circumstances of the death that may necessitate further immediate follow-up action.

Second, the data obtained through the questionnaire builds a rich base of information to assist us to fulfil the Minister's referral request that we undertake a comprehensive annual review of deaths of people receiving disability services at the time of their death.

## 2.7 Engagement with the sector

Our Capacity Development team developed fact sheets to educate and support the sector about our new role in undertaking this work. Fact sheets have been devised for service providers and for families and next of kin.

These fact sheets are available on our website, and are provided to service providers and families for each investigation we undertake.

Our Systemic Review team met with key sector stakeholders, including DHHS and National Disability Services, to consult about our approach to undertaking these investigations.

Additionally, staff from our Capacity Development team delivered information about our strengthened functions and investigation powers, including the power to conduct these investigations, through a series of information sessions for service providers leading up to and after the amendments to the Act.

# Chapter 3: Investigation process

Not all deaths of Victorians with disability are subject to our review and investigation.

In-scope deaths are those where the person was in receipt of disability services as defined by the Act, and that are subsequently reported to us by DHHS through its client incident reporting system or by notification from the State Coroner.

In 2017–18, we had a total of 88 notifications of deaths that were in scope for our investigation. As a consequence of the scope of DHHS incident reporting guidelines and legislative definitions of a ‘reportable death’ in the Coroners Act, most of the deaths reported to us relate to people residing in shared supported accommodation.

Chapter 4 contains information about deaths reported to us in 2017–18 that were out of scope for our investigation.

## 3.1 Deaths reported by DHHS

In 2017–18, we received 91 incident reports from DHHS relating to reports of the expected and unexpected deaths of people with disability. Of these reports, six were out of scope for our investigation and 85 were in scope.<sup>42</sup>

All funded service providers, including those delivered by DHHS, are required to comply with incident management and reporting processes. Incidents, including the deaths of people with a disability in receipt of a disability service are reported in order to learn from them and, if possible, prevent future occurrence of similar incidents.

DHHS has two incident reporting systems: Critical Client Incident Management (CCIM) and the Client Incident Management System (CIMS).

The CCIM system ceased being used by non-government funded service providers from 15 January 2018, when it was replaced with CIMS.

DHHS-delivered services continue to use the CCIM reporting system.

The following disability services are required to report client incidents:

- individual support services (day services, flexible support packages, individual support packages, outreach support, respite)
- information, planning and capacity building services (case management, access)
- targeted services (behaviour intervention services, independent living training)
- residential services (residential institutions, shared supported accommodation)
- Victorian approved National Disability Insurance Scheme (NDIS) providers of disability and psychosocial supports.<sup>43</sup>

## Unexpected deaths

### CCIM system: category 1 incidents

The CCIM reporting system provides guidance about a range of circumstances where the death should be classified as a category one incident, such as:

- the person’s death was in unusual or unexpected circumstances
- the person’s death had a direct or obvious correlation to the service being received
- the person’s death is reportable, (for example, to the State Coroner or Commission for Children and Young People)
- the death related to a child under the age of 18 years
- the person resided in a residential facility or housing property where the condition of accommodation or standard of care provided may have been a contributing factor to the death.<sup>44</sup>

Category 1 incident reports must be sent to the DHHS divisional office for review as soon as possible and at the latest within one working day of the incident occurring. Following such review, DHHS sends all category 1 incident reports relating to the death of a disability client to our office via email. We typically receive such reports within three days of the person’s death.

### CIMS system: major impact incidents

The CIMS guidelines advise that all deaths of clients in unexpected or unanticipated circumstances must be reported as a major impact incident.<sup>45</sup>

Major impact incident reports must be submitted by service providers to DHHS within 24 hours of the incident occurring.<sup>46</sup> DHHS then reviews the report and following review, in cases relating to the death of a person with a disability, will submit the report to us via an online portal. Our office generally receives major impact client death reports within three days of the death occurring.

## Expected deaths

### CCIM system: category 2 incidents

The CCIM guidelines advises that a category 2 death is assigned to deaths where the person was living in a disability residential service and the death was the progression of a diagnosed condition or illness.<sup>47</sup>

The guidelines further advise that an incident report is not required in situations where a person was in receipt of disability services but was not living in disability residential care, and their death was the result of a diagnosed condition or illness.<sup>48</sup>

42 In addition, we received three additional referrals from the State Coroner to bring the total of in-scope cases in 2017–18 to 88.

43 Department of Health and Human Services 2014, *Critical client management instruction, technical update*, State Government of Victoria, Melbourne; Department of Health and Human Services 2017, *Client incident management guide*, State Government of Victoria, Melbourne.

44 Department of Health and Human Services 2014, op. cit.

45 Department of Health and Human Services 2017, op. cit.

46 Ibid.

47 Department of Health and Human Services 2014, op. cit.

48 Ibid.



# Investigation process

Category 2 incident reports must be submitted to DHHS divisional offices within two working days of the incident for review.<sup>49</sup> Following DHHS review, the reports relating to the death of a person with disability are emailed by DHHS to our office. This means our office typically receives such reports within a week of the death occurring.

## CIMS system: non-major impact incidents

The CIMS guidelines advise that people with a disability who die as the consequence of the progression of a diagnosed condition or illness are not reported as a client incident unless the death occurred in a disability residential service, in which case, the incident is graded as a non-major impact incident.<sup>50</sup>

The CIMS guidelines allow service providers to submit non-major impact reports to DHHS for review at the end of each calendar month.<sup>51</sup> Following receipt of the batch of reports, DHHS then reviews the reports. Following this review DHHS will submit the report to our office via an online portal.

In effect, this means that there may be a delay of up to six weeks between the death occurring and the report being received by us to review and subsequently investigate. We have raised our concerns with DHHS about the impact of the new incident reporting system and continue to closely monitor the impact of these changed arrangements.

## 3.2 Deaths reported by the State Coroner

The amendments to the Act, the Minister's referral, and the subsequent memorandum of understanding between our office and the State Coroner permits us to receive and exchange information with the State Coroner about deaths of people who were receiving disability services at the time of their death.

In 2017–18, we received 68 notifications of deaths from the State Coroner. Of these, 59 were in scope for our investigation.<sup>52</sup>

Not all deaths investigated by our office are reviewed by the State Coroner. This is because the State Coroner may only review deaths that meet the definition of 'reportable death' in the *Coroners Act 2008*. In 2017–18, 66 per cent of our investigations (59 investigations) were also classified as a 'reportable death' and subject to review by the State Coroner.<sup>53</sup> This means that 29 deaths have not been examined by the State Coroner and a cause of death will not be known.

## Reportable deaths

Under the *Coroners Act 2008* (Coroners Act), the death of a person in receipt of disability services is a 'reportable death', and must be reported to the Coroner if the body is in Victoria, or the death occurred in Victoria, or the cause of death occurred in Victoria, or the person ordinarily resided in Victoria at the time of death,<sup>54</sup> and it meets one of the following criteria:

- the death appeared unexpected, unnatural or violent or to have resulted directly or indirectly from an accident or injury<sup>55</sup>
- the death occurred during a medical procedure or following a medical procedure where the death is or may be causally related to the medical procedure and a registered medical practitioner would not, immediately before the procedure was undertaken, have reasonably expected the death<sup>56</sup>
- the deceased person was immediately before their death, placed in custody or care.<sup>57</sup> A person placed in custody or care includes a person who was under the control, care or custody of the Secretary of DHHS<sup>58</sup>. This includes people in receipt of disability accommodation services administered by DHHS under the Act. In these cases, the death must be reported to the Coroner, regardless of the circumstances of the death
- the deceased person who immediately before their death was a patient within the meaning of the *Mental Health Act 2014*<sup>59</sup>
- the deceased person was under the control, care or custody of the Secretary of the Department of Justice or a police officer<sup>60</sup>
- the deceased person was subject to a non-custodial supervision order under ss. 26 or 38ZH of the *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997*<sup>61</sup>
- the identity of the deceased person is unknown<sup>62</sup>
- if the death occurs in Victoria and a death notice under s. 37(1) of the *Births, Deaths and Marriages Registration Act 1996* has not been signed or is not likely to be signed by a doctor who was responsible for the person's medical care immediately before their death, or who examined the body of the person after their death<sup>63</sup>
- the death occurs outside Victoria and the cause of death is not certified by a person who is authorised to certify the death and the cause of death<sup>64</sup>
- the death is of a prescribed class of person<sup>65</sup>
- the death occurs in prescribed circumstances.<sup>66</sup>

49 Ibid.

50 Department of Health and Human Services 2017, op. cit.

51 Ibid.

52 Of these 59 referrals, 56 were also subject to an incident report from DHHS.

53 *Coroners Act 2008*, s. 4.

54 Ibid., s. 4(1).

55 Ibid., s. 4(2)(a).

56 Ibid., s. 4(2)(b).

57 Ibid., s. 4(2)(c).

58 Ibid., s. 3.

59 Ibid., s. 4(2)(d).

60 Ibid., s. 4(2)(e).

61 Ibid., s. 4(2)(f).

62 Ibid., s. 4(2)(g).

63 Ibid., s. 4(2)(h); and *Births, Deaths and Marriages Registration Act 1996*, s. 37(1).

64 Ibid., s. 4(2)(i).

65 Ibid., s. 4(2)(j)(i).

66 Ibid., s. 4(2)(j)(ii).

### 3.3 Investigation establishment

Upon receipt of a notification of a person's death that is in scope for our investigation, we write to the relevant service provider/s to advise of the establishment of the investigation under s. 128I of the Act.<sup>67</sup> An information sheet is provided to explain our process and approach to undertaking the investigation.

In addition, we provide the service provider/s with a questionnaire to complete about the person who has died. We also request a range of documents dating three to 12 months prior to the person's death from the service provider. These documents inform our initial desktop review. Such documentation includes:

- palliative care or treatment plans for expected deaths
- non-critical client event logs
- communication, shift handover, staff meeting and daily case notes
- staff rosters
- plans including behaviour support, health and general person-centred plans
- client file notes
- previous reviews or investigations as relevant
- current health assessments at the time of the person's death
- hospital discharge summaries as relevant
- incident reports.

### 3.4 Desktop review

Following receipt of the completed questionnaire and documentation from the service provider, we undertake a detailed review of the information to assess the adequacy of disability service provision.

If issues are identified that may place other people with disability at risk, such matters are quickly escalated with the service provider to rectify immediately. In cases where we identify that potential criminal conduct may have occurred, we refer these matters to Victoria Police.

Some examples to date have included:

- capacity of a service provider to safely support people at risk of choking following the report of a death of a person who had choked on food at their shared supported accommodation service
- concerns about potential breaches of record-keeping requirements or the destruction of potential evidence with advice that documents had been shredded after a person's death by a staff member of a disability service
- concerns about potential abusive and criminal behaviour by a staff member
- risk of medical neglect of other people in a shared supported accommodation service following concerns that timely medical assistance had not been sought for a person who had died at the service.

### 3.5 Further investigation

Where it is determined the investigation would benefit from additional enquiries, we use other methodologies. These include site visits, either through exercising our Authorised Officer powers or by pre-arrangement with the service provider, and conducting interviews with family members, next of kin and staff from disability service providers.

### 3.6 Investigation report

The Act requires that upon completion of an investigation, we provide a report to the Secretary of DHHS and the Minister.<sup>68</sup> We also provide the investigation report to the service provider to promote continuous improvement. We also provide the completed investigation reports to the State Coroner, where the death was a 'reportable death' and within scope for the State Coroner to review.

Investigation reports are not publicly available.

If the investigation report makes an adverse comment or opinion about an individual person or about a service provider, in accordance with our legal obligations and the rules of natural justice and procedural fairness, we provide the person or service provider with an opportunity to comment on these adverse comments or opinions prior to finalising the report.<sup>69</sup>

In 2017–18, we completed 20 investigation reports and of those, 10 contained adverse comments or opinions about a service provider.

<sup>67</sup> *Disability Act 2006*, s. 128K.

<sup>68</sup> *Ibid.*, s. 132ZE(3).

<sup>69</sup> *Ibid.*, s. 132ZF.

# Investigation process

## 3.7 Notice to Take Action

At the completion of an investigation, the Disability Services Commissioner may determine that action should be taken to improve the services investigated.<sup>70</sup> In such cases, a Notice to Take Action is issued to the service provider outlining the decision, the reasons for the decision and the actions required to improve the services being investigated.<sup>71</sup>

The Act articulates that following receipt of a Notice to Take Action, a service provider has 45 days to report in writing to the Disability Services Commissioner about the action the service provider has taken to comply with the notice (unless an extension of time, a legislated maximum of 15 days, has been granted).<sup>72</sup> A penalty may be imposed on any service providers who fail to report to the Disability Services Commissioner.<sup>73</sup>

In 2017–18, we issued eight Notices to Take Action to service providers (see Chapter 5 for more detail).

## 3.8 Advice to the Minister or to the Secretary of DHHS

In addition to a Notice to Take Action, amendments to the Act also enable the Disability Services Commissioner to provide recommendations or give advice to the Minister or Secretary of DHHS on improvements that can be made to the services that were investigated.<sup>74</sup>

In 2017–18, we provided recommendations and advice of a systemic nature on two occasions to the Secretary of DHHS in her role as funder and regulator of Victorian disability services (see Chapter 5 for further details).

## 3.9 Advice to disability service providers

The Act allows the Disability Services Commissioner to provide advice generally on any matter with respect to accountability investigations and the prevention of abuse and neglect to disability service providers.<sup>75</sup>

As a result of our completed investigations, we provided advice to disability service providers on two occasions in 2017–18 (see Chapter 5 for further details).

70 *Ibid.*, s. 128M(1).

71 *Ibid.*, s. 128N.

72 *Ibid.*, s. 128P.

73 *Ibid.*, s. 128P(1).

74 *Ibid.*, s. 128L.

75 *Ibid.*, s. 17(1)(da)(i).



# Chapter 4: Our early findings

## 4.1 Overview: Deaths of people with disability in 2017–18

In this section, we report on data and information relating to deaths reported to our office in 2017–18 drawn from incident reports, documents from the State Coroner, and completed questionnaire data.

As can be seen in Table 1, we received 103 reports of deaths from DHHS and the State Coroner; 88 were in scope for our investigation and 15 were out of scope.

Out-of-scope reports included the following:

- deaths that occurred prior to the Minister’s first referral of 24 July 2017
- deaths where the person was receiving a service but where the service provider was not a disability or regulated disability service as defined by the Act.<sup>76</sup>

A full dataset is available for 85 of the 88 deaths in scope for our investigation. Three questionnaires were outstanding at the time of completing this report.

In our first seven months of conducting this work, we have finalised 20 investigations and carry over 68 investigations to 2018–19. Of the 20 completed investigations, we have issued eight Notices to Take Action to disability service providers to improve service provision (see Table 2).

**Table 1:** Deaths reported 2017–18

Deaths reported 2017–18	No.
Deaths reported to DSC by DHHS and the State Coroner	103
Out of scope for DSC	15
In-scope deaths for DSC	88

**Table 2:** Investigations overview 2017–18

Overview of investigations	No.
Investigations commenced	88
Investigations completed	20
Investigations carry over to 2018–19	68
Notices to Take Action issued	8
Authorised Officer visits undertaken	1

Most of the deaths (71 per cent) were reported to us as unexpected deaths (see Table 3). In total, we received 85 incident reports from DHHS. Three deaths reported to us by the State Coroner were not subject to an incident report but were in scope for our investigation.

**Table 3:** Incident reports received from DHHS 2017–18

Type of incident report	%	No.
Unexpected deaths (Category 1 / major impact incident report)	71%	60
Expected deaths (Category 2 / non-major impact incident report)	29%	25
<b>Total incident reports in scope</b>	<b>100%</b>	<b>85</b>
<i>Total incident reports received</i>		91
<i>Out of scope for DSC</i>		6

**Table 4:** Notifications of deaths from the State Coroner

Notifications of deaths from the State Coroner	No.
Total notifications	68
In scope for DSC investigation	59
Out of scope for DSC investigation	9
Notifications also subject to an incident report from DHHS	56
Notifications not subject to an incident report from DHHS	3

<sup>76</sup> Ibid., s. 3.

## Our early findings

### Service provider and service type

As can be seen in Table 5, half of the deaths reported to us were in relation to people in receipt of disability services provided by DHHS and the other half by non-government disability service providers.

At the time of finalising this report, the Victorian Government is in the process of tendering out its disability accommodation and respite services to the non-government sector. It is anticipated that DHHS will begin the handover of its disability accommodation and respite services from 1 January 2019.<sup>77</sup> It is not clear whether this may have a negative impact on the reporting of future deaths of people with disability to the State Coroner, given that some of these people may not meet the definition of 'reportable death' because they will no longer be in the care or custody of DHHS.

We have brought our concerns regarding this change to the attention of the Secretary of DHHS and will continue discussions about this issue with both DHHS and the State Coroner during 2018–19.

**Table 5: Investigations by service provider type 2017–18**

Service provider	%	No.
DHHS	50%	44
Non-government service provider	50%	44
<b>Total</b>	<b>100%</b>	<b>88</b>

Most of the investigations (83 per cent) have related to people in receipt of shared supported accommodation at the time of their death. Table 6 indicates that DHHS provided shared supported accommodation to 41 people who died, while 32 people who died were in receipt of shared supported accommodation from a non-government service provider.

**Table 6: Investigations by service provider and primary service type 2017–18**

Service type	DHHS		Non-government service provider		Total	
	%	No.	%	No.	%	No.
Shared supported accommodation	47%	41	36%	32	83%	73
Individual support package	1%	1	7%	5	8%	6
Flexible support package	0%	0	3%	3	3%	3
Outreach support	0%	0	2%	2	2%	2
Case management	1%	1	1%	1	2%	2
Respite	0%	0	1%	1	1%	1
Service type not known	1%	1	0%	0	1%	1
<b>Total</b>	<b>50%</b>	<b>44</b>	<b>50%</b>	<b>44</b>	<b>100%</b>	<b>88</b>

<sup>77</sup> State Government of Victoria 2018, 'Tender to deliver disability accommodation and respite services', <<https://www.vic.gov.au/ndis/tender-to-deliver-disability-accommodation-and-respite-services.html>>, accessed 4 July 2018.

## Age at death

The age at death of people in receipt of disability services ranged from 10 years to 78 years. Table 7 provides a breakdown of categories of age at death.

In 2016, the median age at death for the Victorian population was 80.3 years for males and 85.5 years for females.<sup>78</sup> The median age at death for deaths of people with disability reported to us in 2017–18 was 52 years for males and 54 years for females.

Our data indicates that people receiving disability services in Victoria die younger compared with the general Australian population; based on the median age, about 29 years younger.<sup>79</sup>

Premature death of people with disability is confirmed in Australian and international literature<sup>80</sup> and can to some extent be explained by comorbidities.<sup>81</sup>

However, the proportion of potentially avoidable deaths remains higher for people with an intellectual disability compared with the general population.<sup>82</sup>

Research undertaken in the United Kingdom shows that potentially avoidable deaths of people with an intellectual disability have been found entirely amenable to good quality health care.<sup>83</sup>

Another difference between people who died and were receiving disability services compared with the general population is the absence of a substantial difference in median age at death for males and females.

Although narrowing over time, in the general population there is an apparent gender gap for median age at death; males die over five years earlier than females.<sup>84</sup> This is less so for the death notifications received by our office. In 2017–18, there was only a two-year difference between the median age at death for males and females.

Australian and international literature on deaths of people with a disability finds a similar disparity, however potential explanations by academics and practitioners diverge.<sup>85</sup> Most ascribe the disparity as an interaction between being female and having a disability; females with a disability die younger due to a variety of risk factors associated with their gender.<sup>86</sup> However, Trollor et al. propose a different explanation: young males with an intellectual disability might be relatively under-represented due to the lower proportion of injury and poisoning deaths compared with the general population.<sup>87</sup>

**Table 7: Age at death 2017–18**

Age at death	%	No.
0–18 years	2%	2
19–30 years	4%	4
31–35 years	6%	5
36–40 years	6%	5
41–45 years	11%	10
46–50 years	15%	13
51–60 years	25%	21
61–70 years	22%	19
71–80 years	9%	8
<b>Total</b>	<b>100%</b>	<b>87</b>

Note: one transgender person has been excluded from this table to protect the individual's privacy.

78 Australian Bureau of Statistics 2016, *Deaths, Australia*, 3302.0, <<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3302.02016?OpenDocument>>, accessed 4 July 2018.

79 Ibid.

80 Dieckmann F, Giovis C and Offergeld J 2015, 'The life expectancy of people with intellectual disabilities in Germany', *Journal of Applied Research in Intellectual Disability*, vol. 28, no. 5, p. 380, doi: 10.1111/jar.12193; O'Leary L, Cooper SA, Hughes-McCormack L 2018, 'Early death and causes of death of people with intellectual disabilities: a systematic review', *Journal of Applied Research in Intellectual Disability*, vol. 31, no. 3, p. 340, doi: 10.1111/jar.12417; Trollor J et al. 2017, op. cit., p. 6.

81 Ibid. p. 7; O'Leary et al. 2018, op. cit., p. 339.

82 Trollor J et al. 2017, op. cit., p. 5; Heslop P, Blair PS, Fleming P, Houghton M, Marriott A, Russ L 2014, 'The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study', *The Lancet*, vol. 383, no. 9920, p. 892, doi: 10.1016/S0140-6736(13)62026-7.

83 Heslop et al. 2014, op. cit., p. 892.

84 Australian Bureau of Statistics 2016, op. cit.

85 O'Leary et al. 2018, op. cit.; Tyrer F, Smith LK and McGrother CW 2007, 'Mortality in adults with moderate to profound intellectual disability: a population-based study', *Journal of Intellectual Disability Research*, vol. 51, part 7, pp. 520–527, <<https://doi.org/10.1111/j.1365-2788.2006.00918.x>>, accessed 4 July 2018; Dieckmann F, Giovis C, Offergeld J 2015, op. cit.; Trollor J, et al. 2018, op. cit.

86 O'Leary et al. 2018, op. cit., p. 325; Tyrer F et al. 2007, pp. 520–527; Florio T and Trollor J 2015, 'Mortality among a cohort of persons with an intellectual disability in New South Wales, Australia', *Journal of Applied Research in Intellectual Disabilities*, vol. 28, no. 5, p. 391, <<https://doi.org/10.1111/jar.12190>>, accessed 4 July 2018; O'Leary et al. 2018, op. cit., p. 3; O'Leary et al. 2018, op. cit., p. 340.

87 Trollor J 2017, et al., op. cit.

# Our early findings

## Gender

The majority of the people whose deaths were reported to us were male (59 per cent). Females accounted for 40 per cent and one transgender person's death was reported (see Table 8).

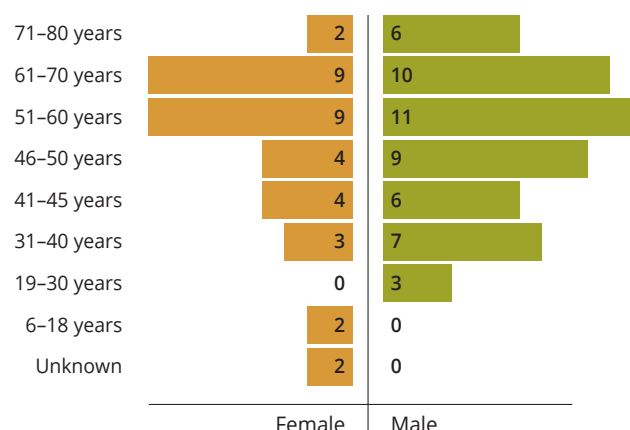
The higher male to female ratio of death in disability services has been evident in other national and international jurisdictions.<sup>88</sup> Even higher ratios of male deaths were reported by the Office of the Public Advocate in Queensland, with 2.3 male deaths to each female death (70 per cent males) reported in 2016.<sup>89</sup>

**Table 8: Gender 2017–18**

Gender	%	No.
Male	59%	52
Female	40%	35
Transgender	1%	1
<b>Total</b>	<b>100%</b>	<b>88</b>

(n = 88 people)

**Figure 1: Gender and age at death distribution 2017–18**



Note: one transgender person has been excluded from this figure to protect the individual's privacy.  
(n = 87 people)

## Cultural status

According to information provided to us by service providers in 85 completed questionnaires, no person who died in 2017–18 identified as Aboriginal and/or Torres Strait Islander. Eight people had a culturally and linguistically diverse background.

## Primary disability type requiring most support

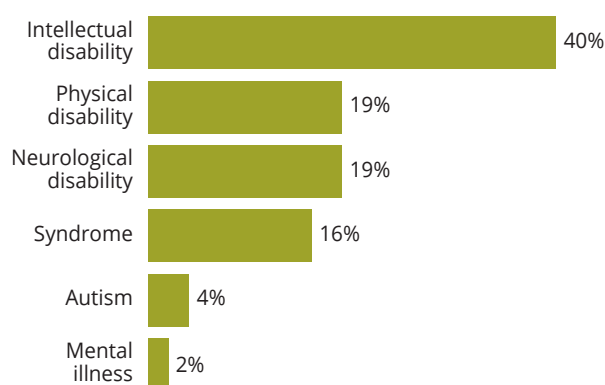
The questionnaire gathers information from the service provider about the primary type of disability that required the most support. For more than a third (40 per cent) of deaths reported to us, the person's primary recorded disability was intellectual disability (34 people). Other common disability types were physical (19 per cent, 16 people), neurological (19 per cent, 16 people), syndrome related (16 per cent, 14 people) (see Figure 2). People with autism and people with disability who also had a mental illness accounted for smaller proportions of primary disability type requiring most support.

Of the people with a physical disability whose death was reported to us, 75 per cent (12 people) had cerebral palsy.

Most of the international literature examining deaths of people with a disability relates to people with an intellectual disability.<sup>90</sup> However, even in research where the cohort is not narrowed to intellectual disability only, it appears to be the most common disability for people who died while receiving disability services.<sup>91</sup>

Completed questionnaire data indicated that most people (70 per cent) required assistance with mobility including wheelchair, walking frame, walking stick or other aide.

**Figure 2: Primary disability type requiring most support 2017–18**



Source: data from completed questionnaires.  
(n = 85 people)

88 Medical Committee on Client Mortality (Intellectual Disability) 2007, *Disability services: a review of client mortality 2002–2005*, Melbourne, Australia; New South Wales Ombudsman 2015, *Report of reviewable deaths in 2012 and 2013, volume 2 – deaths of people with disability in residential care*, State Government of New South Wales, Sydney; Trollor J et al. 2017, op. cit, p. 4; Heslop P et al. 2013, op. cit.

89 Office of the Public Advocate 2016, op. cit.  
90 Tyrer F et al. 2007, op. cit.; Trollor J et al. 2017, op. cit.; O'Leary L et al. 2018, op. cit.; Heslop P et al. 2014, op. cit.; Young C, Shankar R, Palmer J, Craig J, Hargreaves C, McLean B, Hillier R 2015, 'Does intellectual disability increase sudden unexpected death in epilepsy (SUDEP) risk?', *Seizure*, vol. 25, pp. 112–116, <<https://doi.org/10.1016/j.seizure.2014.10.001>>, accessed 4 July 2018.

91 Ombudsman New South Wales 2015, op. cit.; Ombudsman New South Wales 2013, op. cit.

**Table 9:** Detail of primary identified disability type requiring most support 2017–18

Primary identified disability requiring most support	Primary identified disability detail	%	No.
Intellectual disability	Mild	11%	9
	Moderate	14%	12
	Profound	4%	3
	Severe	9%	8
	Unknown	2%	2
	<b>Total</b>	<b>40%</b>	<b>34</b>
Physical disability	Cerebral palsy (including spastic quadriplegia) <sup>92</sup>	14%	12
	Other	5%	4
	<b>Total</b>	<b>19%</b>	<b>16</b>
Neurological disability	Acquired brain injury (ABI)	7%	6
	Huntington's disease	4%	3
	Multiple sclerosis (MS)	4%	3
	Muscular dystrophy	2%	2
	Other	2%	2
	<b>Total</b>	<b>19%</b>	<b>16</b>
Syndrome	Down syndrome	7%	6
	Fragile X	4%	3
	Tourette	1%	1
	Other	5%	4
	<b>Total</b>	<b>17%</b>	<b>14</b>
Autism	Level 2 – requiring substantial support	2%	2
	Level 3 – requiring support	1%	1
	<b>Total</b>	<b>3%</b>	<b>3</b>
Mental illness	Other	2%	2
	<b>Total</b>	<b>2%</b>	<b>2</b>
<b>Total</b>		<b>100%</b>	<b>85</b>

Source: data from completed questionnaires.  
(n = 85 people)

92 In order to be consistent with other Australian jurisdictions, including the NDIS, cerebral palsy is classified in this table as a physical disability. See: <<https://www.nds.org.au/disability-types-and-descriptions>>, accessed 4 July 2018.

93 Source: completed questionnaires by service providers for 85 investigations undertaken in 2017–18.

94 Heslop P et. al. 2013, op. cit.

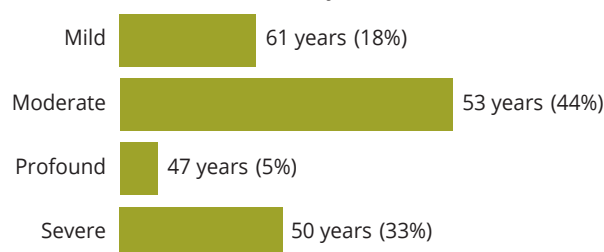
## Intellectual disability

In 2017–18, almost three-quarters of all people with disability whose deaths were subject to our investigation (63 people) had some form of intellectual disability (primary or additional disabilities). It is noted this is similar to the proportion of people with intellectual disability who died while in receipt of services as reported by the New South Wales Ombudsman in 2015 (85 per cent).

Of the 63 people with intellectual disability who died, over one-third (23 people) were recorded as having a severe or profound level of disability, while almost two-thirds (38 people) were recorded as having a mild or moderate level of intellectual disability.<sup>93</sup> The level of intellectual disability was not known for two people.

We have observed that on average, people with a profound or severe intellectual disability died four years younger than those with mild or moderate levels of intellectual disability. This preliminary finding confirms research conducted in the United Kingdom, which found that people with a profound intellectual disability had a median age at death of 46 years, while people with a mild intellectual disability had a median age at death of 67.5 years.<sup>94</sup>

**Figure 3:** Median age at death by level of intellectual disability and proportion of people with intellectual disability 2017–18



Note: data about level of intellectual disability was not available for two people with intellectual disability.  
(n = 61 people)

# Our early findings

## General information

Data from completed questionnaires by service providers indicated that:

- seven people (8 per cent) were parents
- 36 people (42 per cent) had a prior history of institutional care
- eight people (9 per cent) were attending school
- two people (2 per cent) were in paid employment
- 55 people attended a day program (65 per cent).

## Effective communication support

Effective communication support is a strong area of interest in our work and is underpinned by legislation and human rights instruments.

The Act articulates that people with a disability have the same rights and responsibilities as other members of the community, and people with disability should be empowered to exercise those rights and responsibilities.<sup>95</sup> The Act also affirms the rights of people with disability to be respected for their human worth and dignity as individuals.<sup>96</sup>

The Act clearly states that people with disability also have the right to access information and communicate in a manner appropriate to their communication and cultural needs.<sup>97</sup>

The Charter imposes an obligation on all public authorities to act in a way that is compatible with human rights, and to give proper consideration to relevant human rights when making decisions.<sup>98</sup> The Charter articulates that every person has the right to freedom of expression, which includes the freedom to seek, receive and impart information and ideas of all kinds; whether orally, in writing, in print, by way of art or in another medium chosen by the person.<sup>99</sup>

Article 21 of the Convention on the Rights of Persons with Disabilities (the Convention) states that 'States Parties shall take all appropriate measures to ensure that people with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice ...'<sup>100</sup> This includes accepting and facilitating the use of sign languages, braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by person with disabilities in official interactions.<sup>101</sup>

DHHS policy and practice advice recommends that for people in shared supported accommodation with complex communication needs, staff must ensure a speech pathologist completes a communication assessment. The assessment is to provide recommendations to assist staff to support and understand residents when they express their feelings, wishes, likes or dislikes when making choices.<sup>102</sup> Additionally, the instruction requires that recommended communication strategies are implemented and documented in individual support plans.

Research suggests that where a person has difficulties with communication, or cannot communicate verbally, support staff must be alert to the signs of illness.<sup>104</sup> Such indicators may include behavioural changes, such as refusing to eat or displaying behaviours of distress. It has been recommended that such behavioural changes should prompt staff to conduct further investigations including measuring and recording basic observations, including heart rate, temperature, and pulse,<sup>105</sup> which are relatively easy procedures to undertake.

Data from completed questionnaires by service providers for 85 people indicated that:

- 35 people (41 per cent) were described as non-verbal requiring aides or gestures to communicate, and 11 of the 35 people did not have a communication plan (31 per cent)
- five people were described as being unable to communicate at all, and two of the five people did not have a communication plan (40 per cent)
- five people were described as having verbal language but requiring communication support, and four of these five people (80 per cent) did not have a communication plan
- 40 people had verbal language and no communication support was required.

We are deeply concerned by this preliminary data, which appears to indicate there is a lack of priority and focus on ensuring people with communication support needs have the necessary assessments and plans developed to assist staff to provide optimal care. Such information is critical to enable disability support staff to recognise and understand indicators of deteriorating health or illness of people in receipt of disability services.

In the coming 12 months, we will focus further attention on this area and attempt to understand the barriers that exist to ensuring these fundamental human rights.

95 *Disability Act 2006*, s. 5(1).

96 *Ibid.*, s. 5(2)(a).

97 *Ibid.*, s. 5(2)(f).

98 *Charter of Human Rights and Responsibilities Act 2006*, s. 38(1).

99 *Ibid.*, s. 15.

100 UN General Assembly 2007, United Nations Convention on the Rights of Persons with Disabilities.

101 *Ibid.*, Article 21(b).

102 Department of Health and Human Services 2015, *Residential services practice manual*, section 4.10, 'Complex communication needs', State Government of Victoria, Melbourne.

103 *Ibid.*

104 Office of the Public Advocate 2016, *op. cit.*

105 *Ibid.*



## Health issues

The general health of an individual with a disability is intrinsically linked to their mortality. Given that the healthcare needs of people with disabilities are often greater than the general population, the risk of death is amplified, increasingly so when an individual is overweight, consuming high levels of alcohol, and/or smoking.<sup>106</sup>

We note with interest that in June 2018, the New South Wales Government committed \$4.7 million to enhance and expand its specialised intellectual disability health services.<sup>107</sup> Specialist hubs with expertise in intellectual disability will deliver specialised health services for people with intellectual disability who have complex health needs. The initiative aims to act on the findings of recent research about the prevalence of avoidable deaths of people with intellectual disability and the need for specialist services.<sup>108</sup>

In Victoria, the Centre for Developmental Disability and Health supports mainstream health services to build their capacity to address the health needs of adults with intellectual and associated disabilities.<sup>109</sup> Our data and research more broadly suggest that consideration should be given to providing increased access to this type of service.

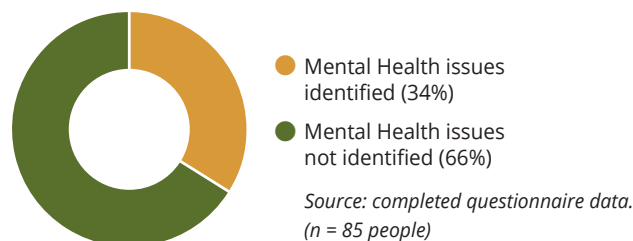
Information gathered from completed questionnaires in 2017–18 indicated that 95 per cent of the people who died had multiple and chronic physical and mental health conditions. A summary of our analysis of the questionnaire data follows.

### Mental health

Completed questionnaire data indicated that in addition to disability, over one-third of people who died (29 people, 34 per cent) were identified as having a mental illness (see Figure 4). Of these people, many had multiple mental health issues identified by the service provider. Analysis of the information indicated that:

- nine people (11 per cent) were reported to have schizophrenia
- 16 people (19 per cent) were reported to have depression
- 12 people (14 per cent) were reported to have anxiety
- six people (7 per cent) were reported to have bipolar disorder
- 13 people (15 per cent) were reported to have a known history of self-harming behaviours.

**Figure 4:** Mental health issues identified by the person's service provider 2017–18



### Physical health

Completed questionnaire data indicated that 96 per cent of people (82 people) had a known health condition (see Figure 5 on p. 22). Of these people, many had multiple and complex health conditions, with an average of four health conditions per person.

Recorded health conditions included:

- 43 people (51 per cent) had some teeth missing, no teeth or required dental aids
- 43 people (51 per cent) had urinary incontinence
- 34 people (40 per cent) were known to experience constipation
- 34 people (40 per cent) were known to have faecal incontinence
- 24 people (28 per cent) had epilepsy
- 23 people (27 per cent) had a history of respiratory infections
- 18 people (21 per cent) were known to have heart problems
- 16 people (19 per cent) were known to have gastro-oesophageal reflux disease
- 16 people (19 per cent) were known to have hypertension
- 12 people (14 per cent) had diabetes
- 12 people (14 per cent) had diseases of the eye.

106 Office of the Public Advocate 2016, op. cit.; Heslop et al. 2013, op. cit.; Decoufle P and Autry A 2002, 'Increased mortality in children and adolescents with developmental disabilities', *Paediatric and Perinatal Epidemiology*, vol. 16, no. 4, pp. 375–382, doi: 10.1046/j.1365-3016.2002.00430.x.

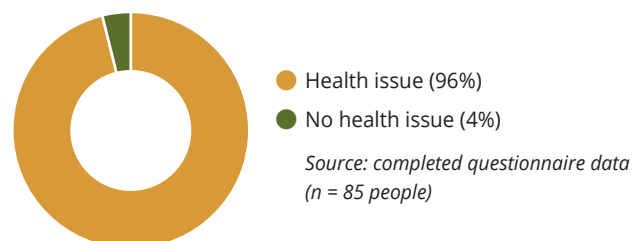
107 New South Wales Ministry of Health 2018, *Improving specialised intellectual disability health services in NSW*, <[http://www.nswcid.org.au/images/Advocacy/Budget\\_announcement\\_0618.pdf](http://www.nswcid.org.au/images/Advocacy/Budget_announcement_0618.pdf)>, accessed 4 July 2018.

108 New South Wales Council for Intellectual Disability 2018, '#DeadlyDisabilityDiscrimination sees Health Minister act on preventable deaths', <<http://www.nswcid.org.au/deadlydiscrimination.html>>, accessed 4 July 2018.

109 See <<http://www.cddh.monashhealth.org/>>.

# Our early findings

Figure 5: Physical health issues 2017–18



A 2016 report by the Office of the Public Advocate in Queensland reported the link between sedentary behaviours, poor diet and constipation, with a number of people subject to their review reporting to have chronic and severe constipation.<sup>110</sup> The use of psychotropic medications, which are commonly prescribed for people with an intellectual disability, contributed further to chronic constipation.<sup>111</sup>

The study highlighted that this is a potentially disabling and painful condition that can cause urinary and faecal incontinence, rectal prolapse, chronic nausea, anal fissures (ulcers) and haemorrhoids, impacting an individual's quality of life. Resulting faecal impaction can lead to hospitalisation where treatment and management is required in order to prevent serious bowel trauma and death. The potentially fatal condition of sigmoid volvulus (blockage at the bowel, where a loop of the bowel twists and creates a blockage) was noted to be a risk in people with chronic constipation.

## Vaccination

### Influenza

According to the *Australian immunisation handbook*, on average each year in Australia, approximately 100 deaths and 5,100 hospitalisations are recorded as being directly attributed to influenza.<sup>112</sup> The number of deaths related to influenza increases in particular at-risk groups. A study using mathematical modelling estimated that for people over the age of 50 years, there are more than 3,000 deaths annually and more than 13,500 hospitalisations annually due to influenza.<sup>113</sup> Another study has estimated mortality rates for those 65 years and over are as high as 25.8 per 100,000 people in Australia.<sup>114</sup> Further, people with chronic diseases experience a greater rise in morbidity during annual influenza epidemics.<sup>115</sup>

Influenza vaccination is described as '... the single most important measure in preventing or attenuating influenza infection and preventing mortality.'<sup>116</sup>

Annual vaccination is recommended for most individuals over the age of six months, and particularly for clinically at-risk groups who have conditions that predispose them to severe influenza, including people with:

- cardiac disease
- Down syndrome
- obesity (body mass index over 40)
- chronic respiratory conditions
- certain immunocompromising conditions
- chronic illnesses requiring regular medical follow up such as diabetes mellitus, chronic renal failure, chronic metabolic diseases.<sup>117</sup>

The Australian Government recommends influenza vaccination for residents and staff of aged care and long-term residential facilities due to high rates of influenza transmission and complications during outbreaks in such facilities.<sup>118</sup>

In Victoria, influenza vaccination is not a mandatory practice for residents and staff in shared supported accommodation. The DHHS *Residential practice manual* provides guidance about how to respond to an infectious disease outbreak, but does not propose proactive measures such as vaccination.<sup>119</sup>

110 Office of the Public Advocate 2016, op. cit.

111 Coleman J and Spurling G 2010, 'Easily missed? Constipation in people with learning disability', *British Medical Journal*, vol. 340, pp. 531–532.

112 Newall AT, Scuffham PA 2008, 'Influenza-related disease: the cost to the Australian healthcare system', *Vaccine*, vol. 26, pp. 6818–23; Li-Kim-Moy J, Yin JK, Patel C, et al. 2016, 'Australian vaccine preventable disease epidemiological review series: Influenza 2006 to 2015', *Communicable Diseases Intelligence*, vol. 40, E482–95, cited in, Australian Technical Advisory Group on Immunisation 2013, *The Australian immunisation handbook*, 10th ed., Australian Government, Canberra, <<http://www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/Handbook10-home-handbook10part4-handbook10-4-7#4-7-3>>, accessed 4 July 2018.

113 Newall AT, Wood JG and MacIntyre CR 2008, 'Influenza-related hospitalisation and death in Australians aged 50 years and older', *Vaccine*, vol. 26, pp. 2135–41, cited in Australian Technical Advisory Group on Immunisation 2013, op. cit.

114 Muscatello DJ, Newall AT, Dwyer DE, MacIntyre CR 2014, 'Mortality attributable to seasonal and pandemic influenza, Australia, 2003 to 2009, using a novel time series smoothing approach', *PLoS ONE*, vol. 8, e6473, cited in Australian Technical Advisory Group on Immunisation 2013, op. cit.

115 Mertz D, Kim TH, Johnstone J et al. 2013, 'Populations at risk for severe or complicated influenza illness: systematic review and meta-analysis', *BMJ*, vol. 347, f506, cited in Australian Technical Advisory Group on Immunisation 2013, op. cit.

116 Australian Technical Advisory Group on Immunisation 2013, op. cit.

117 Ibid.

118 Ibid.

119 Department of Health and Human Services 2015, op. cit.



## 4.2 Categories of deaths

**'When people die from choking or are in hospital with aspiration pneumonia because the person supporting them with eating was doing something else, that is not a deliberate abuse, it is ignorance. If you are compromised in your eating, you should never be left alone to eat ...'**<sup>124</sup>

Evidence of Professor Susan Balandin, Chair in Disability and Inclusion, Faculty of Health, School of Health and Social Development, Deakin University, to the Inquiry into Abuse in Disability Services.

We analysed completed questionnaire data for people who resided in shared supported accommodation, respite or a nursing home at the time of their death. We found that 78 per cent of people (56 out of 72 people) had been immunised for influenza within the past 12 months.<sup>120</sup>

Considering what is known about the increased risk for people residing in this form of accommodation, coupled with the chronic health conditions many people in receipt of disability services experience, we are concerned that there is an absence of consistent preventive effort to mitigate risk of contracting influenza and potential death.

Over the coming 12 months, we will continue to monitor and review this issue and provide advice to the sector.

### Pneumococcal disease

Pneumococcal disease refers to a range of illnesses caused by an infection with the bacterium known as pneumococcus.<sup>121</sup>

Pneumococcal pneumonia is the most common presentation of invasive pneumococcal disease, and there are certain groups known to be at increased risk, including people with the following circumstances:

- immunocompromising conditions
- cochlear implants
- intracranial shunts
- chronic cardiac disease
- chronic lung disease
- diabetes mellitus
- Down syndrome
- alcoholism
- chronic liver disease
- pre-term at birth
- tobacco smoking.<sup>122</sup>

Vaccination is recommended for certain groups in the community who are at increased risk, including the very young and the elderly. The vaccination schedule varies according to the risk profile of the person.<sup>123</sup>

Analysis of completed questionnaire data for people who resided in shared supported accommodation, respite accommodation or a nursing home at the time of their death indicated that only 17 per cent of people (12 out of 72 people) were confirmed to have had a pneumococcal vaccination in the 12 months prior to their death.

In 2017–18, 59 deaths subject to our investigation (67 per cent of total investigations) were within scope for review by the State Coroner. In 17 of the 59 deaths, a coronial finding had been made identifying the cause of death.<sup>125</sup> In 31 cases, advice was provided to the State Coroner by way of an autopsy report, medical examiner's report or inspection report about a preliminary cause of death. Eleven cases did not yet have a preliminary cause of death identified at the time of finalising this report.

We are unable to report on the category of death for 29 deaths that were not reported to the State Coroner; these limitations are described further at Chapter 4.3 of this report.

Where there was a coronial finding about cause of death, or advice about preliminary cause of death had been provided to the State Coroner, we have categorised the deaths according to the International Statistical Classification of Diseases and Related Health Problems (ICD). The ICD is the international standard for health classification published by the World Health Organization for coding diseases for statistical aggregation and reporting purposes.

As indicated in Table 10, the categories of death identified in 48 cases, either through a coronial finding, or information received from the medical inspection or examiner's report, or autopsy report for deaths in scope of review by the State Coroner and subject to our investigation in 2017–18, were:

- respiratory system diseases (16 people, 33 per cent) – mainly aspiration and pneumonia. This was the most common category of death for males and females
- circulatory system diseases (13 people, 27 per cent) – mainly ischaemic heart disease. Males overrepresented females for circulatory system deaths
- neoplasms (four people, 8 per cent) – mainly abdominal and bowel cancers
- external causes (three people, 6 per cent) – all related to choking on food
- nervous system diseases (three people, 6 per cent) – primarily sudden unexplained death in epilepsy
- unascertained (three people, 6 per cent).

120 Note: 73 people resided in shared supported accommodation at the time of their death. Questionnaire data was not available for one person, therefore analysis has been provided for 72 people.

121 Better Health Channel 2015, 'Pneumococcal disease', <<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/pneumococcal-disease>>, accessed 4 July 2018.

122 Australian Technical Advisory Group on Immunisation 2013, op. cit.

123 Ibid.

124 Parliament of Victoria, Family and Community Development Committee 2016, op. cit.

125 Fifteen of these coronial findings were made under s. 17 of the *Coroners Act 2008* where the coroner determined not to continue with an investigation into the reportable death because the death was due to natural causes. Two of these coronial findings were made under s. 67 of the *Coroners Act 2008* where the coroner investigated the death and made findings without holding an inquest.

# Our early findings

**Table 10:** Categories of deaths by gender 2017–18

Category of death	ICD10 chapter	Female		Male		Total	
		%	No.	%	No.	%	No.
Respiratory system diseases	(J00–J99)	26%	5	38%	11	33%	16
Circulatory system diseases	(I00–I99)	16%	3	35%	10	27%	13
Neoplasms	(C00–D48)	16%	3	3%	1	8%	4
Unascertained		16%	3	0%	0	6%	3
External causes of morbidity and mortality	(V00–Y98)	5%	1	7%	2	6%	3
Nervous system diseases	(G00–G99)	11%	2	3%	1	6%	3
Digestive system diseases	(K00–K93)	0%	0	7%	2	5%	2
Congenital malformations, deformations and chromosomal abnormalities	(Q00–Q99)	5%	1	0%	0	2%	1
Genitourinary system diseases	(N00–N99)	5%	1	0%	0	2%	1
Injury, poisoning and certain other consequences of external causes	(S00–T88)	0%	0	7%	2	5%	2
<b>Total</b>		<b>100%</b>	<b>19</b>	<b>100%</b>	<b>29</b>	<b>100%</b>	<b>48</b>

*Note: categories of death identified through information and documentation received from the State Coroner including coronial findings, medical inspection/examiner's reports, and autopsy reports.  
(n = 48 people)*

## Respiratory diseases

Over a third of deaths that were in scope for the State Coroner had respiratory diseases as a preliminary cause of death. Of these deaths, aspiration pneumonia featured for seven people who died.

Aspiration pneumonia is a life-threatening infection caused by inhaling food, fluid, saliva or vomit into the lungs.<sup>126</sup> Aspiration pneumonia is often avoidable if, in the event of aspiration occurring, timely medical treatment is obtained to reduce the risk of the condition progressing to a state of infection.<sup>127</sup> Recent Australian research highlighted data about a large proportion of avoidable deaths due to infections, and noted that people with intellectual disability experience delays, difficulties or differences in accessing specific and effective interventions for infections.<sup>128</sup>

Preventive measures including eating and swallowing assessments, along with awareness of vulnerability to infections and respiratory conditions, has been emphasised in the literature and through reviews of deaths in other jurisdictions.<sup>129</sup>

We have observed that while some service providers we have investigated have excellent policy and procedure manuals to guide staff to provide high standards of care in areas such as safe mealtime assistance, such guidelines and advice are not consistently adhered to and at times, disregarded altogether. The outcomes for people with disability in such cases are bleak.

<sup>126</sup> Department of Health and Human Services 2015, op. cit., '5.14 Managing deteriorating health'.

<sup>127</sup> Güngen AC, Aydemir Y, Güngen BD, Yazar EE, Yağız O, Aras YG, Gümüş H and Erkorkmaz U 2017, 'Effects of aspiration pneumonia on the intensive care requirements and in-hospital mortality of hospitalised patients with acute cerebrovascular disease', *Archives of Medical Science*, vol. 13, no. 5, pp. 1062–1068, doi: 10.5114/aoms.2016.61011; Office of the Public Advocate 2016, op. cit.

<sup>128</sup> Trollor et al. 2017, op. cit. p. 7.

<sup>129</sup> Office of the Public Advocate 2016, op. cit.

## Choking deaths and aspiration risk

It is of significant concern that during the relatively short period we have been undertaking this work, there have been three cases reported to our office where the person's preliminary cause of death was choking on food. This represents 6 per cent of cases where there was a coronial finding about cause of death, or where the State Coroner had received information about the preliminary cause of death. All three people were in receipt of shared supported accommodation at the time of their death. At the time of finalising this report, our investigations into the disability service provision for the three people whose preliminary cause of death was choking, and whose deaths therefore may have been avoidable, are ongoing.

We have undertaken preliminary analysis of questionnaire data completed by service providers for the three people whose preliminary cause of death was choking on food and the seven people whose preliminary cause of death was aspiration pneumonia. Of the 10 people, we have observed that:

- all resided in shared supported accommodation
- three were female, seven were male
- ages at death ranged from 39 years to 77 years, and the average age at death was 54 years
- eight people were described as having an intellectual disability
- six people were known to have dysphagia<sup>130</sup>
- service providers were unsure if swallowing and eating issues were present for three people
- six people were described as either always or sometimes requiring assistance with eating or drinking
- the eating and drinking support needs for one person who was identified as having swallowing issues were not known by the service provider
- three people were described as having no eating or drinking issues
- two people were provided with a normal diet
- five people required modified diets
- the dietary needs for three people were not known by the service provider
- four people had seen a dentist in the previous 12 months
- five people had seen a dietitian in the previous 12 months
- five people had seen a speech pathologist in the previous 12 months
- none of the people had been to a specialist dysphagia clinic in the 12 months prior to their death.

People with intellectual disability are well known to be at higher risk of choking. This is due to physical factors such as difficulties with chewing and swallowing (known as dysphagia), and behavioural factors such as gorging or pica (eating non-food items).<sup>131</sup>

Research has indicated people with cerebral palsy are at a high risk of dysphagia in childhood, and may experience a worsening of symptoms after the age of 30 years.<sup>132</sup>

Other common causes of nutrition and swallowing issues are identified by DHHS in its *Residential services practice manual*:

- poor oral health, broken or rotting teeth, gum inflammation and disease
- mouth, throat or gastrointestinal system damage or impairment
- impaired muscle control or weakness
- medication that may cause nutrition and swallowing issues
- acquired brain injury
- degenerative neurological diseases such as motor neurone disease, Parkinson's disease or multiple sclerosis
- cancers or tumours
- dementia
- normal ageing processes
- stroke.<sup>133</sup>

Poor management of choking and aspiration risk have been identified as common contributors to premature death in people using disability services. The most common factors related to choking deaths identified by the New South Wales Ombudsman in 2010–11 and 2012–13 were inadequate supervision of people with eating-related behaviour problems and a failure by service providers to proactively reduce the risk of choking. In some cases, the individual's risk of choking was known, yet the service provider did not adopt adequate measures to mitigate the risk.

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**In only the first seven months of our work in this area, there have been three cases reported where the person's preliminary cause of death related to choking on food and was potentially avoidable.**

<sup>130</sup> Dysphagia is the medical term used to describe having difficulty swallowing. This includes problems with sucking, chewing, swallowing, drinking, eating, dribbling saliva, closing lips or when food and drink goes down the wrong way. Early signs of dysphagia are coughing, gagging or choking while eating and drinking which may result in food, liquid or saliva entering the lungs which may cause pneumonia. Source: <<https://www.healthdirect.gov.au/dysphagia>>, accessed 4 July 2018.

<sup>131</sup> Samuels R and Chadwick D 2006, 'Predictors of asphyxiation risk in adults with intellectual disabilities and dysphagia', *Journal of Intellectual Disability Research*, vol. 50, no 5, pp 362–370; Thacker A, Abedelnoor A, Anderson C, Whote S and Hollins S 2007, 'Indicators of choking risk in adults with learning disabilities: a questionnaire survey and interview study', *Disability and Rehabilitation*, vol. 30, no. 15, pp. 11312–38; Department of Health and Human Services 2015, op. cit.

<sup>132</sup> Balandin S, Hensley B, Hanley L and Sheppard J 2009, 'Understanding mealtime changes for adults with cerebral palsy and the implication for support services', *Journal of Intellectual and Developmental Disability*, vol. 34, no. 3, pp. 197–206.

<sup>133</sup> Department of Health and Human Services 2015, op. cit., '5.7 Nutrition and swallowing'.

## Our early findings

In Victoria, accidental choking was the most common cause of death noted in four of the seven deaths considered by the Inquiry into Abuse in Disability Services.<sup>134</sup> Additionally, the Inquiry found that recommendations made by health providers that meals should be modified and fluid intake monitored were often not followed in the sample studied. We have found similar practice issues in our completed investigations.

Similarly, the Office of the Public Advocate in Queensland found that compliance with food plans was poor, and of five people in a sample who died due to choking, only three had been provided with swallowing assessments and mealtime management plans.<sup>135</sup> Consistent compliance with those plans was found to be minimal.

Appropriate reduction in the use of antipsychotic medication, anticonvulsant medication, sedatives and muscle relaxants was also linked to reducing the risk of choking and subsequent aspiration for people with a disability.<sup>136</sup> The Office of the Public Advocate in Queensland has suggested that regular medication reviews by a specialist pharmacist and psychiatrist should be adopted as standard practice for all people with disability.<sup>137</sup>

### Circulatory diseases

The number of deaths that had a preliminary cause of death related to circulatory diseases was almost equal to the number of deaths that had a preliminary cause of death related to respiratory illnesses. In 2017–18, there appear to be 13 deaths in scope for the State Coroner where the preliminary cause of death related to heart disease – primarily ischaemic heart disease. Of these people, 10 resided in shared supported accommodation prior to their death.

We analysed completed questionnaire data by disability service providers for 10 people whose preliminary cause of death related to heart disease, and who were residing in shared supported accommodation. It was evident that of the 10 people:

- all were described as having an intellectual disability
- seven were male, three were female
- age at death ranged from 46 years to 72 years, and the average age at death was 62 years
- daily physical activity levels were low or unknown in most cases
- three people were current or former smokers
- three people consumed alcohol occasionally or weekly
- five people had not seen either a cardiologist or dietitian in the previous 12 months.

Our findings are consistent with those reported in other jurisdictions.

The New South Wales Ombudsman found that over half the people with disability who died in 2010 and 2011 were overweight or obese.<sup>138</sup> In this cohort, there was a correlation between obesity or severe obesity and underlying causes of death such as heart disease, heart attack and chronic obstructive pulmonary disease. People with disability who died from ischaemic heart disease had a number of identifiable risk factors, including hypertension, being overweight, a lack of physical activity, and smoking.

The 2016 report by the Office of the Public Advocate in Queensland showed that lifestyle issues such as diet and exercise were evident in the context of vulnerability to certain conditions, including circulatory system diseases and cancers.<sup>139</sup>

We will continue to monitor these issues and gather and analyse information to share with the sector.

### Sudden unexplained death in epilepsy

Two deaths in 2017–18 had a preliminary cause of death of sudden unexplained death in epilepsy (SUDEP).

Our review of the literature pertaining to mortality and disability indicated that sudden unexpected death in epilepsy was noted by researchers as a growing trend in the number of people with an intellectual disability dying as a consequence of epilepsy.<sup>140</sup> In SUDEP cases, the cause of death is generally unknown.

This is a relatively new area of research; however, it is beginning to indicate that specialised methods of care may be required for people with a disability who have epilepsy in order to prevent sudden, unexpected death.

### Neoplasms

Four deaths in 2017–18 had a preliminary cause of death related to neoplasms. The data is therefore small in number and unlikely to be statistically significant. The cancers were abdominal, colorectal and germ cell.

Over the coming 12 months, we will continue to monitor and share information of relevance in this area to the sector.

The New South Wales Ombudsman reported cancer was the second highest underlying cause of death in their review of the deaths of people with disability, and the median age at death from cancer (56.5 years of age) was almost 20 years younger than the median age at death from cancer in the general population.<sup>141</sup>

134 Parliament of Victoria, Family and Community Development Committee 2016, op cit., p.17.

135 Office of the Public Advocate 2016, op. cit.

136 Singh AN, Matson JL, Coopera CL, Dixon D and Sturme P 2005, 'The use of risperidone among individuals with mental retardation: Clinically supported or not?' *Research in Developmental Disabilities*, vol. 26, pp. 203–218; Webber L and Lambrick F 2010, 'Restraint and seclusion of people on compulsory treatment orders in Victoria, Australia in 2008–2009', *Psychiatry, Psychology and the Law*, vol. 17, p. 562; Holden B and Gitlesen J 2004, 'Psychotropic medication in adults with mental retardation: prevalence, and prescription practices'. *Research in Developmental Disabilities*, vol. 25, pp. 509–521.

137 Office of the Public Advocate 2016, op. cit.

138 New South Wales Ombudsman 2013, op. cit.

139 Office of the Public Advocate 2016, op. cit.

140 Kiani R and Tyrer F 2014, 'Mortality from sudden unexpected death in epilepsy (SUDEP) in a cohort of adults with intellectual disability'. *Journal of Intellectual Disability Research*, vol. 58, pp. 508–509.

141 New South Wales Ombudsman 2013, op. cit.

The main form of cancer that caused death was bowel or colon cancer, similar to the general population in Australia,<sup>142</sup> with a very short time between diagnosis and death (ranging from two to nine months).<sup>143</sup> These findings are consistent with international literature, which has found cancer to be a leading underlying cause of death in studies involving both children and adults with intellectual disabilities.<sup>144</sup>

In a meta-analysis of over 20 studies conducted throughout the world, there were four studies that specifically mentioned the type of cancer that caused death for people with disability, revealing that death from cancer of the digestive organs was most prevalent,<sup>145</sup> a finding that differs from cancer deaths in the general population.<sup>146</sup>

### 4.3 Deaths not in scope for review by the State Coroner 2017–18

A significant gap in our information relates to the ability to categorise deaths that were not in scope for review by the State Coroner. In 2017–18, there were 29 deaths reported to us in this cohort.

We have analysed the circumstances of these deaths, and note that the client incident reports provided by DHHS about these deaths indicated that 17 (59 per cent) were classified as ‘unexpected’ deaths (either category 1 or major impact incident reports), and 12 deaths (41 per cent) were considered to be ‘expected’ deaths (either category 2 or non-major impact incident reports).

As can be seen in Table 11, most of these deaths (69 per cent, 20 deaths) occurred in a hospital setting.

Most of the deaths (90 per cent) not reported to the State Coroner were for people receiving disability services from a non-government service provider (see Table 12).

Three deaths related to people in receipt of services from DHHS who had died in a hospital setting. It should be noted that the DHHS *Residential services practice manual*, requires these deaths to be reported to the State Coroner. It is then for the State Coroner to determine whether these deaths are ‘reportable deaths’ that may or must be investigated by the Coroners Court of Victoria.

It is noteworthy that most of the people who died in hospital had immediately prior to their death, resided in shared supported accommodation (17 people).

In 2018–19, we will continue to liaise with DHHS and the State Coroner about the current limitations of matters that are reported to the State Coroner for review. It is evident many people with disability who were in receipt of services are excluded from the potential for referral to the State Coroner, thereby missing the opportunity to gain important insights into the circumstances of their death for the person’s family, disability service provider and disability sector more broadly.

**Table 11:** Deaths not in scope for review by the State Coroner by place of death 2017–18

Location	Expected death	Unexpected death	Total
	No.	No.	No.
Hospital	7	13	20
Family home	3	1	4
Shared supported accommodation	1	2	3
Nursing home	1	0	1
Other	0	1	1
<b>Total</b>	<b>12 (41%)</b>	<b>17 (59%)</b>	<b>29 (100%)</b>

*Note:* deaths not reported to the State Coroner 2017–18 in scope for investigation by DSC.  
(n = 29 people)

**Table 12:** Deaths not in scope for review by the State Coroner by service provider type 2017–18

Service provider type	Expected death	Unexpected death	Total
	No.	No.	No.
DHHS	1	2	3 (10%)
Non-government service provider	11	15	26 (90%)
<b>Total</b>	<b>12 (41%)</b>	<b>17 (59%)</b>	<b>29 (100%)</b>

*Note:* deaths not reported to the State Coroner 2017–18 in scope for investigation by DSC.  
(n = 29 people)

142 Australian Institute of Health and Welfare 2014, *Cancer in Australia: an overview*, <<https://www.aihw.gov.au/reports/cancer/cancer-in-australia-an-overview-2014/contents/table-of-contents>>, accessed 4 July 2018.

143 New South Wales Ombudsman 2013, op. cit.

144 Forsgren L, Edvinsson SO, Nystrom L and Blomquist HK 1996, ‘Influence of epilepsy on mortality in mental retardation: an epidemiologic study’, *Epilepsia*, vol. 37, pp. 956–963; Glover G and Ayub M 2010, *How people with learning disabilities die*, Improving Health and Lives, Learning Disability Observatory, Durham <<http://www.ihal.org.uk/gsf.php5?f=8586>>, accessed 4 July 2018.

145 Tyrer F and McGrother C 2009, ‘Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability’, *Journal of Intellectual Disability Research*, vol. 53, pp. 898–904; Patja K, Mölsä P and Iivanainen M 2001, ‘Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study’, *Journal of Intellectual Disability Research*, vol. 45, pp. 30–40.

146 O’Leary L, Cooper S-A and Hughes-McCormack L 2018, ‘Early death and causes of death of people with intellectual disabilities: a systematic review’, *Journal of Applied Research In Intellectual Disabilities*, vol. 31, no. 3, pp. 325–342, doi: 10.1111/jar.12417.



# Chapter 5: Outcomes of completed investigations

In seven months, we have finalised 20 investigations and issued eight Notices to Take Action to disability service providers. Advice in lieu of a Notice to Take Action has been provided to service providers on two occasions, for deaths reported to us as both expected and unexpected.

We have also provided advice and recommendations to the Secretary of DHHS, in her role as funder and regulator of Victorian disability services, as a consequence of significant practice deficits identified in two completed investigations, both in cases where the deaths were reported as being expected.

Analysis of the practice issues identified in the completed investigations has indicated the following general themes which are consistent with practice issues identified in the literature and in other jurisdictions:

- service providers failing to meet the principles of the Act related to disability services being provided in a manner that promotes the upholding of the rights, dignity, wellbeing and safety of people with a disability<sup>147</sup> (evident in eight investigations)
- service providers failing to meet their legal obligation to provide a support plan<sup>148</sup> (evident in two cases)
- service providers failing to take reasonable steps to discharge their duty of care obligations to the person who had died – this related to taking reasonable steps to respond to identified health needs (evident in seven investigations)
- service providers failing to provide a service that was consistent with the rights of the person with disability as articulated under s. 5 of the Act (evident in three investigations)
- failures by service providers to meet the requirements of the DHHS Human Services Standards – predominantly standards relating to wellbeing (evident in 10 investigations)
- absent and inadequate case recording by service providers (evident in six investigations)
- absence of adequate health support plans (evident in five investigations)
- poor management by service providers of the deteriorating health of people in receipt of services (evident in three cases)
- poor management by service providers of nutrition, swallowing, choking and aspiration risks for people in receipt of services (evident in three investigations).

Ricardo's story (see case study on opposite page) represents many of the issues evident in our completed investigations.

## 5.1 Provision of advice to disability service providers

As a result of the findings of two completed investigations, we have provided advice<sup>149</sup> to the disability service providers subject to the investigations in lieu of a Notice to Take Action.

The advice has related to implementing the following practice improvements:

- developing opportunities and strategies to promote physical activity for residents in a shared supported accommodation facility
- ensuring that support plans include all known health conditions
- reviewing and improving the service provider's policies and procedures about record-keeping requirements
- ensuring where possible that more than one staff member is present when medication is administered in a shared supported accommodation facility
- promote healthy eating by engaging a dietitian or health specialist to educate and support staff and residents at a shared supported accommodation facility.

## 5.2 Notices to Take Action issued

We have issued Notices to Take Action for eight completed investigations. The actions have been targeted to address the practice deficits identified in the particular investigations, and have included the following priority areas in the provision of disability supports:

- addressing swallowing and choking risks
- improving the quality of health plans
- bowel management
- improving record keeping and incident reporting
- duty of care training for staff
- training for staff to support health and wellbeing of people with disability.

147 Disability Act 2006, s. 5(3)(ma).

148 Ibid., s. 54.

149 Ibid., s. 17(1)(da)(i).

## Case study: **Ricardo**

**Ricardo\*** was described as a cheerful person who enjoyed laughing and interacting with others. He was a man of Spanish descent, and his culture was important to him.

He had a supportive family who were involved in his care and visited him regularly. Ricardo died at the age of 65.

Ricardo lived part of his life in institutional residential care. At the age of 38, he moved into the shared supported accommodation home where he lived until he died.

Ricardo had intellectual disability and severe spastic quadriplegia due to cerebral palsy. He communicated via vocalising sounds and using facial expressions. Ricardo had a medical history of epilepsy, swallowing difficulties and constipation, and was prone to aspirate. He was largely reliant on disability support workers to assist him with his daily and nightly routines.

One morning, Ricardo was being supported during his morning routine, when a disability support worker noticed signs of a possible seizure. An ambulance was called, and Ricardo was taken to hospital where he was diagnosed with refractory seizures, electrolyte imbalance, kidney failure, pleural effusion (fluid around the lungs) and aspiration pneumonia. Ricardo died in hospital a month later.

DSC initiated an investigation into disability services provided to Ricardo. As part of

the investigation, DSC received a range of documents from the disability service provider and the Coroners Court of Victoria. Such documents included case notes, support plans and health records.

The investigation found that while Ricardo had a mealtime management plan, records provided indicated that this plan was not followed by the disability support workers. Further, the disability service provider was not proactive in managing Ricardo's risk of dehydration.

A review of the documents further found that records were inconsistent, illegible, incomplete and contradictory, and critical incidents about injuries to Ricardo were not reported in line with the service provider's policies and procedures.

A Notice to Take Action was issued to the service provider. The service provider was required to take action to review the health and support requirements of other residents at the shared supported accommodation facility with the aim of preventing similar issues occurring for them. As a result of the findings of the investigation, the service provider has established a governance group to oversee the implementation of the actions, and to ensure practices at the shared supported accommodation home are in line with best practice models of service delivery.

# Ricardo

*\* Names and details have been changed.*

Case study:

## Maria

**Maria**\* lived in shared supported accommodation with two other residents. Maria had lived in the home for over 20 years. Prior to this, she had resided in institutional care.

Maria enjoyed craft activities, and had a close friendship with a co-resident whom she had known for a long time. Maria was described as a sociable person who attended a day service four days a week.

Maria had cerebral palsy and used a wheelchair for mobility. She required assistance from support workers for all aspects of her daily living. In particular, Maria required her food to be provided in a soft consistency due to her swallowing difficulties, which had been identified by a speech pathologist. Maria's speech was sometimes difficult to understand, though she was able to provide 'yes' or 'no' responses. She would at times use signs or pictorial cues to aid communication.

In July 2017, Maria was noted by disability support workers to be unwell. She had been coughing for several days and was not improving. Maria was taken to see her doctor who subsequently arranged for Maria to be transferred to hospital that day. Maria was diagnosed with aspiration pneumonia and died the following day at the age of 72 years.

Our investigation found that Maria's swallowing difficulties were poorly managed by the disability service provider. Case notes regarding Maria's nutritional intake were found to be minimal and

the records that were kept indicated she was provided with foods inconsistent with the advice of her speech pathologist and dietitian. Maria was provided with foods such as fish and chips, barbecued meat, sandwiches and cake.

Additionally, the investigation found that communication between the shared supported accommodation service and Maria's day service was inadequate. Staff from the shared supported accommodation service had placed responsibility on Maria to communicate her health and support needs with the staff from the day service. This was unreasonable considering Maria's limited communication abilities.

As a result of the investigation, we issued the service provider with a Notice to Take Action. The service provider undertook an audit of the practices at the shared supported accommodation service to ensure swallowing risks were assessed for all other residents, and appropriate mealtime management plans were implemented. Additionally, staff received training to ensure the plans were understood and followed. The service provider also established improved processes to communicate and share information with other disability services providing services to people residing at the shared supported accommodation.

# Maria

\* Names and details have been changed.



## Addressing swallowing and choking risks

Poor management of swallowing and choking risks have been evident in a number of our completed investigations. Even where there has been expert advice provided by a dietitian or speech pathologist about providing modified diets, we have found repeated examples of such advice not being followed, resulting in people with disability being placed at significant risk of health complications or death.

Consequently, for five completed investigations, we have issued the relevant service provider with Notices to Take Action to improve practices in this area. Such actions have included requirements that audits of case records and meal practices for residents in shared supported accommodation facilities occurs, to ensure any resident with nutrition and swallowing issues has the relevant management plans, alerts on client files, annual nutrition and swallowing assessments, and to ensure medical reviews occur as required. Additionally, actions have been targeted at ensuring staff skill and capacity to safely support residents at risk of choking.

Maria's story (see case study on opposite page) describes the outcomes of an investigation where practice issues were identified about safely supporting people at risk of aspiration.

## Improving the quality of health plans

Our investigations have indicated that the quality or even existence of health plans for people in receipt of disability services has been haphazard. In some cases, this has resulted in poor outcomes for people in receipt of disability services.

As a result of this issue being apparent in five investigations, the relevant service providers have been issued with Notices to Take Action. The actions have required the service providers to review the health plans of all residents at their supported accommodation facilities to ensure that every resident's health needs are documented, that an associated health plan has been developed in consultation with the resident's doctor and reviewed regularly.

## Bowel management

For people with an intellectual disability who are prone to constipation, there is the risk that they may experience the associated symptoms, but be unable to effectively communicate their experience to others, including carers or health practitioners. For this reason, proactive prevention of constipation and timely referral for treatment if constipation does occur is important to reduce the risk of hospitalisation and prevent further complications, which can ultimately result in premature death.

One service provider was issued with a Notice to Take Action to ensure that proactive bowel monitoring and management was put in place for residents in a shared supported accommodation service. This action was in response to practice issues identified for a person with intellectual disability who had chronic constipation and whereby the service provider had not tracked or monitored the person's bowel movements as recommended by the person's doctor.

Another Notice to Take Action was issued to a service provider requiring them to take proactive steps to ensure adequate fluid intake and monitoring of fluid intake occurred for residents in a shared supported accommodation service. This action was required in response to a person with intellectual disability who experienced constipation and did not have sufficient monitoring of their fluid intake.

## Improving record keeping and incident reporting

The Act provides a range of principles that apply to service providers. Of relevance to record keeping, s. 5(3)(r) of the Act states that disability services and regulated disability services should:

'be accountable for the quality of those services and for the extent to which the rights of persons with a disability are promoted and protected in the provision of those services.'

Furthermore, health privacy principle 3 of the *Health Records Act 2001* requires:

'an organisation must take steps that are reasonable in the circumstances to make sure that, having regard to the purpose for which the information is to be used, the health information it collects, uses, holds or discloses is accurate, complete, up to date and relevant to its functions or activities.'

Eight completed investigations have resulted in the relevant service provider being issued with Notices to Take Action directed towards improving record keeping.

Many investigations have revealed deficits in record-keeping practices, with missing case notes, illegible case notes, lack of appropriate documentation, inaccurate and outdated information being commonplace. This is a significant area for improvement. Additionally, one investigation revealed inadequacies with incident reporting. A Notice to Take Action was issued to a service provider requiring them to audit records and check the adequacy and compliance with incident reporting processes. This was as a consequence of an investigation that found many instances of unexplained bruising of a person in a shared supported accommodation service were not formally reported as required.

We have noted that many service providers maintain paper-based files that are often inaccurate, poorly organised and poorly maintained. Clear, accurate information in case records is an essential component of a service provider's privacy obligations as well as their duty of care obligations to take reasonable steps to prevent reasonably foreseeable injury. These reasonable steps include ensuring that critical information about a person's support needs can be understood by all staff providing support or care to the person.

# Outcomes of completed investigations

## Duty of care training for staff

A number of completed investigations have found practices where service providers have failed to discharge their duty of care obligations to the person in receipt of the disability service.

In one example, a service provider did not take reasonable steps to respond to the changing health needs of a person who subsequently died. A Notice to Take Action was issued to require the service provider to ensure and demonstrate that all staff are trained in relevant laws, policies and procedures to support them to discharge their duty of care to people receiving their services.

## Training for staff to support health and wellbeing of people with disability

A fundamental requirement of the Act is that disability services must be of a high quality and delivered by appropriately skilled and experienced staff who are provided with opportunities for ongoing learning and development.<sup>150</sup>

Deficits have been identified in a number of completed investigations with reference to the skill and capacity of staff to ensure that instructions about health issues for people in receipt of disability services are followed. Accordingly, on three occasions, Notices to Take Action have been issued to service providers requiring them to educate and support staff to adequately equip them to safely support people with complex medical issues and recognise and respond to deteriorating health.

## 5.3 Advice and recommendations to the Secretary of DHHS

As a result of significant practice deficits identified in two completed investigations in 2017–18, we have provided the following advice and recommendations to the Secretary of DHHS in her role as funder and regulator of Victorian disability services:

- recommending that consideration be given to replacing paper-based client record systems with electronic file records for people in receipt of disability services
- that the *Residential services practice manual* be updated to include guidelines for ensuring and monitoring adequate fluid intake for residents in shared supported accommodation
- that consideration be given to updating the Human Service Standards to require that disability service providers regulated by DHHS must ensure record-keeping practices are contemporaneous to demonstrate accountability in service provision
- that serious practice issues identified in a completed investigation are referred to the DHHS Standards and Regulation unit
- that DHHS processes be amended to require that clinical evidence must inform any decision to grade a disability client incident as a category 2 or non-major impact (expected) death
- that DHHS processes be amended to require that the decision to categorise a disability client death as a category 2 or non-major impact incident must be endorsed by a divisional Deputy Secretary, given that the decision may impact on whether the death is reported to the State Coroner.

In addition to the above, and as previously noted in this report, we have also brought to the attention of the Secretary our concerns about the potential impact that the tendering out of DHHS disability accommodation and respite services may have on the reporting of future deaths of people with a disability to the State Coroner.

<sup>150</sup> Ibid., s. 5(3)(g).

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