



OCCASIONAL PAPER No. 3

Learning from reviews of Victorian disability service provision to people who have died 2017 to 2021 – A reflection for future safeguarding

Authorised by | **Treasure Jennings** Disability Services Commissioner

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The DSC thanks the model who consented to having his photo shown on the cover of this report. He is not a person who has died and has been involved with previous DSC projects.

Content alert

This report contains references to people with disability who have passed away while in receipt of disability services.

I acknowledge the people who are represented within this report and extend my condolences to their families, friends and carers. I also acknowledge assistance provided to my office by service providers and staff. Your willingness to engage with our office, at what must be a difficult time, has made a significant contribution to our ability to safeguard the rights and wellbeing of others in receipt of disability services.

Treasure Jennings, Disability Services Commissioner

Acknowledgement of Country

We acknowledge the Traditional Owners of country throughout Australia and recognise their continuing connection to land, waters and culture. We pay our respects to their Elders past, present and emerging.

About the Disability Services Commissioner

The Disability Services Commissioner (the DSC) is a Victorian independent oversight body resolving complaints and promoting the right of people with disability to be free from abuse. Our complaints service is free, confidential and accessible. We work under the *Disability Act 2006* (the Act).

Through a Ministerial Referral made under s 128I(2) of the Act, we also investigate matters relating to the provision of disability services identified in incident reports received from the Department of Health and Human Services (DHHS), now known and hereafter referred to as the Department of Families, Fairness and Housing (DFFH). This includes deaths, and major impact incidents of assault, injury and poor quality of care. The State Coroner and the Community Visitors Board also refer matters to us.

The purpose of our inquiries and investigations are to identify issues in disability services and develop service improvements in response to those issues. Following an investigation, we can provide a Notice to Take Action to a service provider, or a Notice of Advice to all service providers and to funding bodies and regulators, to help improve the safety and quality of disability services. We report on the outcomes of our investigations to the Minister for Ageing, Disability and Carers, the Secretary of DFFH, and in some cases the State Coroner and the NDIS Quality and Safety Commission (the NDIS Commission). We also report annually on our review of disability service provision to people who have died.

The DSC's oversight jurisdiction of service providers is predicated on service providers being registered under the Act. The Commissioner does not have jurisdiction over unregistered providers. Many formerly registered providers are becoming unregistered. This is because they have transitioned to funding under the National Disability Insurance Scheme (the NDIS) and are subject to the oversight of the NDIS Commission.

While our oversight role will gradually decrease over 2021/2022, we will continue to ensure quality, safeguarding and oversight mechanisms are in place for people outside the NDIS who are provided residual disability services by the Victorian Government.¹

¹ Disability Services Commissioner, Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, June 2020, p.1.

Contents

Executive Summary	4
Background	5
Victorian Parliamentary Inquiry into Abuse in Disability Services.....	5
Legislative Reforms	6
Changes to the Victorian disability sector	7
Summary	8
Timeline.....	8
Part A: Partnerships, jurisdiction and processes	9
Memorandum of understanding with the Coroners Court of Victoria (State Coroner)	9
Jurisdiction and Reportable deaths	10
Reporting implications of potentially avoidable deaths	11
Processes for inquiring into and investigating deaths	13
Preparing for death investigations	13
Investigations	13
Summary and recommendations	17
Part B: Data, themes and systemic change	20
Data	20
Key themes	22
Identifying systemic issues	26
Summary and recommendations.....	27
Part C: The future of reviewing deaths in Victoria	31
Summary and potential gaps	33
Conclusion.....	35
Appendices	36
Appendix A: Finalised investigation data from completed reviews 2017 to June 2020	36
Appendix B	45

Executive Summary

This paper aims to reflect on the experience of the past three and a half years reviewing service provision to those people who died while in receipt of state funded disability services. Reviewing and investigating these services at the time of a person's death provides a significant insight into their life, and their personal story. People's stories need to be heard² to effect real change.

Our reviews tell us that some people do live good lives, and their disability services enhance and empower them to engage meaningfully in all aspects of their community. However, while some people's deaths may be 'expected', the quality of service provision may not have been good enough. Sadly, the majority of deaths we review are 'unexpected' and raise significant concerns about the quality of service provision, possible preventable early deaths, and teach us that oversight and action must continue to be taken on both an individual and system-wide level.

In reviewing and investigating deaths, the DSC has gained valuable insight into essential elements of disability service provision and identified systemic improvements required to protect people's rights, dignity, wellbeing and safety. However, in delivering this function, we have learned significant lessons regarding what we have done well, what we would do differently, opportunities we have missed, and opportunities and risks for the future. These lessons have informed eight recommendations and four potential gaps:

Recommendations:

1. Key partnerships
2. Timeframes
3. Workforce
4. Data and information
5. Compliance versus Continuous Improvement
6. Quality of life analysis
7. Continuity and co-design in Victoria
8. Primary prevention

Potential gaps:

1. Opportunity gaps
2. Oversight gaps
3. Information gaps
4. Systemic gaps

Under the current format, these reviews offer a true voice for all.³ It is the DSC's view that critical insights, evidence and data regarding the quality of service would not have otherwise surfaced without the opportunity afforded to the DSC to inquire into, and investigate, the deaths of people with disability.

In considering the future for reviewing disability service provision to Victorians who have died, it is hoped that the reflections and recommendations made in this paper can inform ongoing decisions regarding disability safeguarding and quality monitoring considered by both the Victorian and Federal governments.

2 Disability Royal Commission Interim Report, 2019, p.70.

3 Disability Royal Commission Interim Report, p.253.

Background

Victorian Parliamentary Inquiry into Abuse in Disability Services

The Victorian Parliamentary Inquiry into Abuse in Disability Services (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 being provided to the deceased before their death.⁴

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. 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.⁵

In collaboration with the State Coroner, the Inquiry also examined the deaths of 200 people living with disability in supported accommodation/group homes. 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.⁶

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 instances of physical restraint, accidental choking on food and other ingested items, inadequate supervision and inappropriate access to medication.⁷

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.⁸

The Inquiry report was tabled in the Victorian Parliament in May 2016 and 49 recommendations were made for legislative, practice and safeguarding reform.

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 disability⁹
- legislative change to provide for the State Coroner to report all deaths in disability services to the DSC¹⁰
- funding for the DSC to undertake comprehensive, annual reviews of all deaths that occur in disability services, with the outcomes being publicly available.¹¹

4 Parliament of Victoria, Family and Community Development Committee 2016, *Inquiry into abuse in disability services: final report*, State Government of Victoria, Melbourne, p.18.

5 *Ibid.*, p.ix-x.

6 *Ibid.*, p.17.

7 *Ibid.*, p.17.

8 *Ibid.*, p.18.

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

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

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

Legislative Reforms

In November 2016, as a result of the Inquiry, the Victorian Government committed to strengthening the oversight powers and functions of the DSC by amending the *Disability Act 2006* (the Act).¹² On 16 August 2017 a range of amendments to the Act commenced providing increased powers to the DSC, including the ability 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 services¹³ within the Commissioner's jurisdiction.

Referral from the Minister – death review

Initially on 24 July 2017, the Minister requested that the DSC receive reports of unexpected deaths from DFFH and the State Coroner.

Following amendments to the Act, the Minister replaced the first referral and from 12 September 2017, requested that the DSC receive reports of expected and unexpected client deaths¹⁴ from DFFH and the State Coroner. The referral requested that the DSC 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 DFFH 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 DSC 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.¹⁵

The current Ministerial referral is due to cease on 30 June 2021.

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/fcdc/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 Services Commissioner, *A review of disability service provision to people who have died 2017-18*, p.6. 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.

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

Changes to the Victorian disability sector

In August 2011, following the release of the Productivity Commission's report regarding the inquiry into a long-term disability care and support scheme,¹⁶ the then Council of Australian Governments (COAG) agreed to the need for a reform to disability services through a National Disability Insurance Scheme (NDIS).

In 2013, the NDIS commenced in Victoria with a trial site in the Barwon region and later expanded throughout the state from 2016. On 1 July 2019, the NDIS Commission commenced in Victoria, responsible for regulating quality and safeguards for people who are participants in the NDIS.

In 2019, in accordance with the bilateral agreement between the Victorian and Commonwealth Governments on the NDIS, group homes previously operated by DFFH commenced transferring to non-government service providers.¹⁷ Participants residing in these group homes remain in the jurisdiction of the DSC due to the shared commonwealth and state roles in governance and funding¹⁸ and until such time when these in-kind services transfer (cash-out) to the NDIS. It is expected that the cash-out process to the NDIS will be fully completed by 30 June 2021.

Additionally, the commencement of the Victorian Disability Worker Commission (VDWC), and the Disability Worker Registration Board of Victoria (DWRB), from 1 July 2020 offers oversight of both registered and unregistered Disability Support Workers to ensure safer services, quality work performance and better choices for people with disability.¹⁹

16 <https://www.ndis.gov.au/about-us/history-ndis>

17 <https://www.vic.gov.au/transfer-disability-accommodation-and-respite-services>

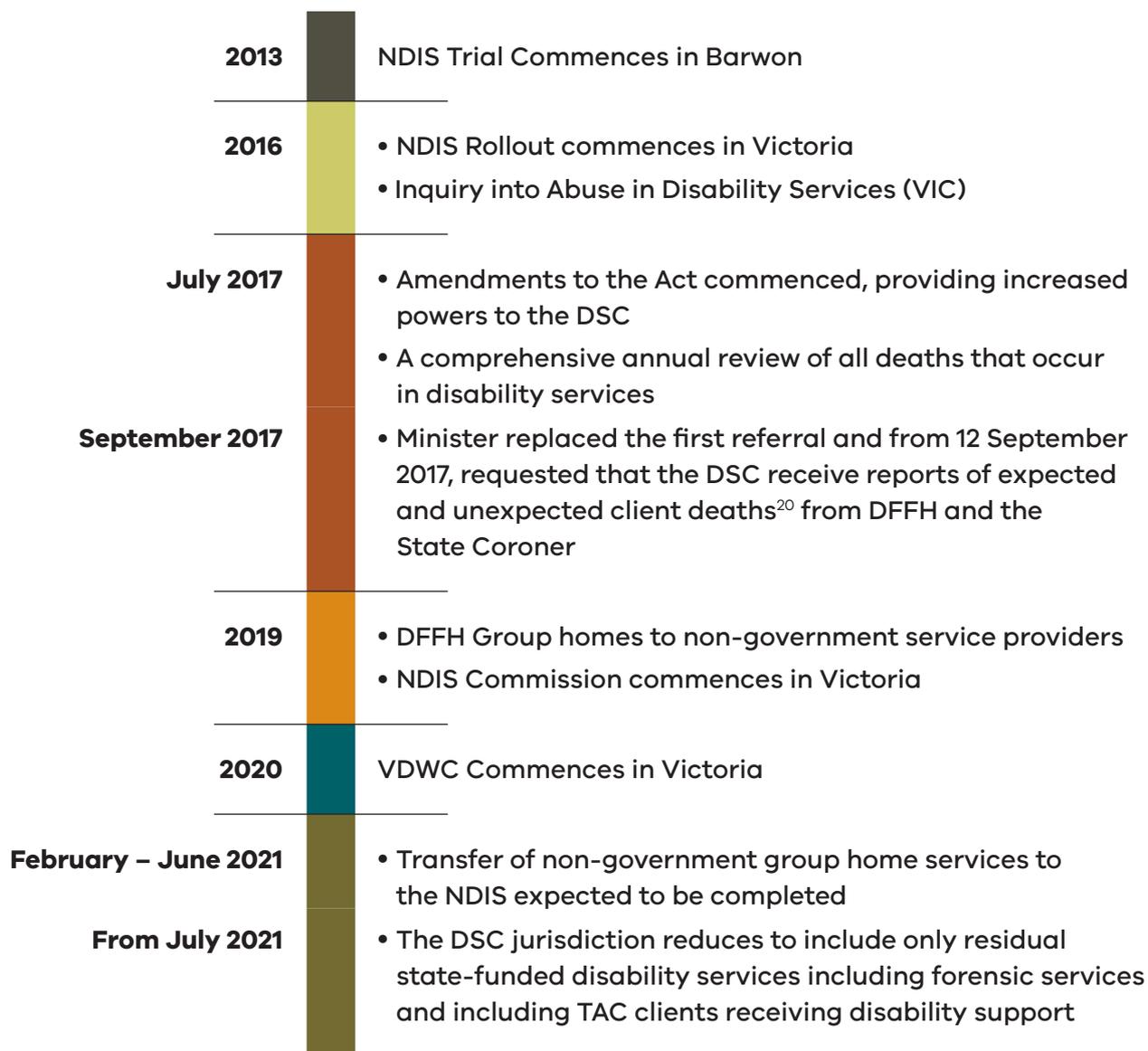
18 <https://www.coag.gov.au/sites/default/files/agreements/bilateral-agreement-between-the-commonwealth-of-australia-and-victoria-on-the-national-disability-insurance-scheme-PM-Premier-signed-17-June-2019.pdf>

19 VDWC website, <https://www.vdwc.vic.gov.au/>

Summary

In 2016 the Inquiry determined that there was a clear need for processes in Victoria to systematically review deaths, to identify leading causes of deaths and meaningfully assess possible links between a death and the adequacy of care. In partnership with the State Coroner, the DSC has performed this role and will continue to do so up until the full transition of state funded disability service provision to the NDIS whereby the NDIS Commission will assume responsibility for regulating quality and safeguards, including the review of deaths as a reportable incident, for people who are participants in the NDIS.

Timeline



²⁰ Disability Services Commissioner, *A review of disability service provision to people who have died 2017-18*, p.6. 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.

Part A: Partnerships, jurisdiction and processes

Memorandum of Understanding with the Coroners Court of Victoria (State Coroner)²¹

In accordance with recommendations from the Inquiry, the DSC 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. Unlike the State Coroner, our investigations do not determine cause of death – our focus is on the quality and appropriateness of services provided to the person who died.²²

Since 16 August 2017, the DSC has maintained a memorandum of understanding (MoU) 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.²³

The current MoU is scheduled to cease on 30 June 2021.

We have continued to work closely with staff from the Coroners Court of Victoria, specifically the Coroner's Prevention Unit (CPU), to exchange information about deaths of people with disability that are in-scope for our investigation. The State Coroner provides us with records and essential information including but not limited to 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' pursuant to the *Coroners Act 2008* (Coroners Act).²⁴

²¹ Disability Services Commissioner, *A review of disability service provision to people who have died 2017-18*, p.9.

²² Disability Services Commissioner, *A review of disability service provision to people who have died 2018-19*, p.4.

²³ Disability Services Commissioner, *A review of disability service provision to people who have died 2017-18*, p.9.

²⁴ Ibid.

Jurisdiction and reportable deaths

The DSC has never investigated the deaths of all Victorians with disability. In-scope deaths are those where the person was in receipt of disability services as defined in the Act and that are reportable to our office under DFFH incident reporting guidelines. Section 3 of the Act defines disability services as those services provided specifically for a person with disability where the disability service provider is the Secretary of DFFH or is a person or body registered on the register of disability service providers.²⁵ By this definition, deaths of people in receipt of DFFH services were in-scope for the DSC whether expected or unexpected.

We also investigate deaths that are considered 'reportable deaths' and referred to us by the State Coroner. Under the 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, 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
- 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
- the deceased person was immediately before their death, placed in custody or care. A person placed in custody or care includes a person who was under the control, care or custody of the Secretary of DFFH. This includes people in receipt of disability accommodation services administered by DFFH 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*
- the deceased person was under the control, care or custody of the Secretary of the Department of Justice or a police officer
- 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*
- the identity of the deceased person is unknown
- 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
- 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
- the death is of a prescribed class of person
- the death occurs in prescribed circumstances.²⁶

²⁵ Disability Services Commissioner, *A review of disability service provision to people who have died 2018-19*, p.4.

²⁶ Disability Services Commissioner, *A review of disability service provision to people who have died 2017-18*, p.12.

By this definition, non-government disability service providers were only required to report deaths that were unexpected and met the criteria for a 'reportable death'.

One potential impact for group homes previously operated by the DFFH and transferring to non-government service providers was that the jurisdiction for the State Coroner was technically reduced as residents were now no longer officially considered in the 'custody or care' of the Secretary of DFFH. While the DSC's experience is that all in-kind providers have continued to report deaths in accordance with previous state government reporting guidelines, we have noted that the State Coroner has not clarified the criteria that determines when a death of a person in an in-kind group home is considered a notifiable death, and when they are not. The DSC is aware the State Coroner has sought to review this definition and understands that a submission is currently being considered by State Government, however details of this definition are not known to the DSC at the time of writing this report.

It must also be noted that some deaths in-scope for the DSC have not been in-scope for the State Coroner. These have historically related to deaths where the person was receiving state-funded disability services, provided by a non-government provider, where the death was deemed expected and while not a 'reportable death' to the Coroner, was required to be reported to our office under DFFH's incident reporting guidelines.

Reporting implications of potentially avoidable deaths

In 2016, the Inquiry noted that the Parliamentary Committee received evidence that neglectful practices within disability services can, and have, led to the deaths of people with disability in Victoria.²⁷

Referred to as potentially avoidable deaths, including potentially preventable and potentially treatable deaths²⁸, Australian research in 2017 indicated that the proportion of potentially avoidable deaths remained higher for people with an intellectual disability compared with the general population.²⁹ Examples of the causes of potentially avoidable deaths may include respiratory system diseases such as aspiration pneumonia, or external causes including choking on food.³⁰

Critically, research undertaken in the United Kingdom showed that potentially avoidable deaths of people with an intellectual disability had been found entirely amenable to good quality health care.³¹ It is this fact that has reinforced the processes and practices of the DSC in ensuring that all in-scope incidents reports relating to a person's death are reviewed alongside other information in order to accurately assess service quality and identify any potential areas for improvement.

27 Parliament of Victoria, Family and Community Development Committee 2016, Inquiry into abuse in disability services: final report, State Government of Victoria, Melbourne, pp.xv.

28 Salomon C, and Trollor J, A scoping review of causes and contributors to deaths of people with disability in Australia: Findings, Report of the Department of Developmental Disability Neuropsychiatry, Faculty of Medicine, University of New South Wales, 19 August 2019, p.58.

29 Trollor J, Srasuebkul 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, p.5; Heslop P, Blair PS, Fleming P, Hoghton 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.

30 Salomon et al. 2019, op cit., p.60.

31 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., p.892.

Additionally, differentiating between potentially avoidable, preventable and treatable is important, especially if this relates to causes that may be deemed as 'natural'. Aspiration pneumonia may be considered a 'natural cause' thereby not automatically requiring the State Coroner to comprehensively investigate the death. However, the DSC considers aspiration pneumonia as potentially avoidable and requiring investigation into mealtime support practices, staff training and quality of care. If these deaths were only reported to the State Coroner, and not also to the DSC, then there would have been far less examination since 2017 of the standards of meal supports provided to the person who died.

A further challenge noted by the DSC while completing our work in reviewing deaths, is the interpretation of what constitutes a reportable death for a person with a disability. We have seen examples where a person living in a disability group home has passed away in hospital after being admitted due to symptoms relating to aspiration pneumonia, choking or epilepsy and their death has been recorded as 'expected' and not deemed reportable. Alternatively, a person who was previously living in a state-funded group home prior to their admission to hospital for a potentially preventable condition, may be interpreted as not being in the 'custody and care' of the State at the time of their death should their admission be long in duration, again resulting in their death being recorded as 'expected' and not deemed reportable. The implication from these scenarios is that certain deaths may not be reported to the State Coroner and therefore fail to offer opportunity to accurately record the cause of death and review the quality of service provision to the person prior to their death for possible service and systemic improvement.

Processes for inquiring into and investigating deaths

Preparing for death investigations

In determining our processes and approach to reviewing deaths in disability services, the DSC was informed by the experience and findings of other state and national jurisdictions including the Victorian Commission for Children and Young People (CCYP), the New South Wales Ombudsman and the Queensland Office of the Public Advocate, as well as international research and data to ensure suitable benchmarking.

Legislation and practice guidelines

The DSC adopted a person-centred and human rights based 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* (UNCRPD), in assessing the adequacy of disability service provision in our investigations³².

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

- DFFH Residential Services Practice Manual (RSPM)
- DFFH Human Services Standards
- DFFH Critical client management instruction, technical update 2014
- DFFH Client incident management guide: client incident management system 2017
- NDIS Quality and Safeguards Practice Standards and Quality Framework.

Investigations

The aim of DSC investigations has always been to consider the quality and appropriateness of the disability services provided to the person who has died and to recommend or provide advice on necessary actions to address risks to other people with disability. Over the past three and a half years, the DSC processes for investigating deaths have evolved in accordance with the Victorian context and the number of deaths reported (See Table 1).

Table 1: Death Investigations (1 July 2017 to 31 December 2021)

	2017-18	2018-19	2019-20	2020-21 6 month data only	Total 3.5 years
New deaths reported annually	103	119	134	52	408
Out-of-scope deaths	15	20	72	22	129
In-scope deaths	88	99	62	30	279
Investigations finalised	20	37	74	25	156
Carryover per year	68	130	118	123	123

³² Disability Services Commissioner, *A review of disability service provision to people who have died 2017-18*, p.9.

Establishment (2017-18)

In 2017-18, the DSC set about establishing the death review processes for information gathering and data collection to inform how we triage, undertake risk assessment and prioritisation for investigation:

1. **Notification** – Upon receipt of a death notification, all in-scope deaths were established as an investigation and the service provider notified by letter.
2. **Request for information** – Service providers were requested to do the following:
 - Questionnaire – Complete an extensive 70-point questionnaire to gather data and information about important factors relating to the person who died including:
 - details of death
 - general demographic information
 - health
 - wellbeing
 - disability service provision
 - Information and documentation provision – seek a range of documents from the service provider from at least three and up to 12 months prior to the person’s death.
3. **Step One** – Following the receipt of completed questionnaires and documentation from the service provider, the DSC undertook a detailed desktop review of the information to assess the adequacy of disability service provision.
4. **Step Two** – In cases that determined an investigation would benefit from additional enquiries, we applied other methodologies that may include site visits, either through exercising our Authorised Officer powers or by pre-arrangement with the service provider. We conducted interviews with family members, next of kin and staff from disability service providers or made requests for additional information.³³
5. **Investigation Report** – The Act requires that upon completion of an investigation, we provide a report to the Secretary of DFFH and the Minister. There is no prescription in the Act as to the form of this report, except for referral investigations (s 132ZE (3)) where the report must be in writing. We provide the investigation report to the service provider to promote continuous improvement. Additionally, we provide the completed investigation reports to the State Coroner, where the death was a ‘reportable death’ and within scope for the Coroner to review. It is important to note that the Act does not allow for Investigation reports to be made publicly available.³⁴
6. **Adverse comments** - If the investigation report makes an adverse comment or opinion about an individual person or about a service provider, in accordance with our obligations and procedural fairness, we provide the individual or provider with an opportunity to comment on our findings or opinions prior to finalising the report.³⁵

33 Ibid.

34 Ibid.

35 Ibid.

7. **Notice to Take Action (NTTA)** - At the completion of an investigation the DSC may determine that an action should be taken to improve the services investigated. In such cases, a Notice to Take Action (NTTA) is issued to the service provider outlining the decision, the reasons for the decision, and the actions required to improve the services being investigated. A penalty may be imposed on any service providers who fail to report to the DSC on their required actions from the NTTA.³⁶

8. **Advice to the Minister, Secretary of DFFH or service providers** – In addition to a NTTA, the Act also allows the DSC to provide recommendations or give a Notice of Advice (NoA) of a systemic nature to the Minister or Secretary of DFFH on improvements that can be made to the services that were investigated.³⁷

The DSC commenced its first investigation on 13 November 2017 and in that financial year prioritised the finalisation of 20 investigations. Investigations were prioritised based on potential and immediate risk, and implications for other residents.

Consolidation (2018-19)

In 2018-19, the DSC continued these established processes and practices with the result that in our first full 12-month operating period we finalised 37 investigations.

Continued consolidation allowed for the collection of additional data and information, resulting in richer thematic content and a better understanding of trends as described in Part B of this report. In addition to the consolidation of data and information, our internal practices matured, noting the initial expectation that the DSC would commence decommissioning as of 1 July 2019 with the introduction of the NDIS Commission. The result of the potential decommissioning of the DSC meant specialist staff would often accept more secure roles elsewhere, impacting on the DSC's capacity to conduct all investigations in a timely manner.

Review and Refinement (2019-20)

In 2019-20, with 130 outstanding death review investigations from the previous year, the DSC was extended until the full transition of services to the NDIS had been completed. The DSC reviewed and streamlined practices and improved completion rates. Procedural changes were made to address key challenges:

- **Challenge:** A barrier to the completion of timely reports was the precedent of providing full reports for each individual matter, even where it was found that service provision posed no risk to people in receipt of registered and/or regulated disability services. Additionally, concurrent cases with the State Coroner were subject to lengthy processes in terms of information exchange and provision.
- **Solution:** In consultation with the State Coroner, the DSC introduced the process of shorter investigation reports (otherwise known as Close by Letters) where no risks were identified, and the quality of service provision was deemed sufficient.

³⁶ Ibid., p.14.

³⁷ Ibid.

- **Challenge:** Due to the higher than anticipated number of in-scope deaths, and the considerable time required to complete some death investigations, there was a growing delay in the DSC completing investigations and communicating feedback to service providers in a timely manner to support their internal service improvements.
- **Solution:** The DSC introduced internal service reviews or self-assessments to enhance the capacity of service providers to identify service issues and take early action in response to the death of a person with disability. Further to our established practice of early contact with service providers should the death be considered to pose an immediate and high risk, this improved process directed service providers to conduct their own internal review to identify any practice issues within service delivery. Providers develop an action plan to address these key risk areas and the DSC requests a copy of this internal review.

This collaborative approach is more responsive in enhancing the capacity of service providers to make service improvements, thereby reducing potential risks to other people in receipt of disability services.

The DSC appraises the service provider's internal review and action plans and determines if the service provider complied with relevant legislation and practice guidelines, or if there is evidence of violence, abuse or neglect in the provision of services. Upon satisfaction that the service provider's review addresses the key risks or issues, we ask service providers to report back on the outcomes of any improvement actions, prior to a final review and closure of the investigation³⁸

- **Challenge:** Upon commencing death investigations in 2017, the DSC established a separate manual system and database to our existing complaint database which ultimately proved unsatisfactory in cross-referencing and managing our data.
- **Solution:** In improving these processes in 2019-20, it was determined that all data would be transferred onto the DSC complaints database.

The introduction of these new procedures improved the efficiency rate of matters, resulting in the DSC finalising 74 investigations in 2019-20.

Finalisation (2020-21)

The DSC's focus in 2020-21 is to maintain our legislative responsibilities for complaints regarding in-kind providers until they transition to the NDIS, and to finalise approximately 118³⁹ outstanding death review investigations. The DSC aims to work with the NDIS Commission in developing information-sharing processes, whereby essential follow-up information arising from our work can be considered by the NDIS Commission where they have subsequent jurisdiction to do so. We also hope to work with the NDIS Commission in transferring data that may subsequently be used in their reportable incident and oversight process.

³⁸ Disability Services Commissioner, *A review of disability service provision to people who have died 2019-20*, p.24.

³⁹ As at 30 June 2020, as reported in the Disability Services Commissioner, *A review of disability service provision to people who have died 2019-20*, p.7.

Summary and recommendations

1. Key partnerships

Partnership with the State Coroner has provided the DSC with essential information regarding a preliminary or confirmed cause of death, as well as additional medical or police reports and coronial findings, all of which assist in assessing service provision to individuals before they passed away. Feedback from the State Coroner affirms the value of the DSC investigation reports when completing coronial inquiries to understand the quality and appropriateness of the disability services provided to the person who has died. Importantly, the definition of 'custody and care' within the context of reportable deaths has ensured that the lives of individuals in supported accommodation services have received a level of scrutiny by both the DSC and the State Coroner.

Other partnerships with state and federal agencies have also played an important role in supporting the DSC's death review function. Our investigations have identified the occurrence of potential crimes, receipt of poor healthcare or generally poor service provided by someone outside our jurisdiction. Our investigative role and powers have allowed us to refer to and support collaborative partnerships with other organisations and entities to facilitate action in other areas.

Recommendation 1A

That any future state-based death review function, continues in primary partnership with the State Coroner.

- To assist this partnership, the DSC supports that the definition of 'in custody and care' is considered as broadly as possible for people with disability to ensure that safeguards are not only afforded to those who are participants in the NDIS, but to others in receipt of state-funded services and supports more broadly to ensure the review of any possible links between a person's death and their service quality.
- Additionally, strengthening a specific unit within the State Coroners office, such as the DSC's current partner unit of the Coroner's Prevention Unit (CPU), would support a stronger investigative focus on gathering qualitative data regarding targeted groups including disability, mental health, children and young people and ageing, beyond NDIS participants.

Recommendation 1B

That any future state-based death review function be afforded legislation with broad investigative powers to strengthen coordination with other state regulatory bodies and organisations such as the VDWC, the CCYP, the Health Complaints Commissioner (HCC), Victoria Police, Office of the Public Advocate (OPA) and the Australian Health Practitioner Regulations Agency (AHPRA) in order to complete practice-informed investigations of service provision with the expectation that this would inform broader systemic improvement, recognise sector expertise and reduce service silos.⁴⁰

⁴⁰ DHHS, Community services quality governance framework - Safe, effective, connected and person-centred community services for everybody, every time, 2018., p.7.

2. Timeframes

It has been the experience of the DSC that the process for investigation must be thorough enough to ensure the person's death is properly assessed against appropriate criteria, and efficient enough that providers are receiving timely feedback.

Importantly, any actions to be undertaken to improve services should be highlighted and initiated within the shortest possible time after the death has been reported to ensure meaningful and ongoing quality and safety improvements.

The average expected time taken for an investigation to be completed by the DSC from the time of acceptance to the issuing of NTTAs is three and a half months. Due to the challenge of maintaining a stable workforce during a time of expected closure, the unexpected number of in-scope investigations, and the initial DSC review process being too inflexible, the DSC has recorded multiple instances of investigation reports taking in excess of 18 months to finalise.

It has been the experience of the DSC that where service changes are required, the length of time taken to complete investigations means that we may be seeking a positive improvement that the provider has already initiated or completed, and that other issues go unaddressed.

The service provider's self-assessment is a practical and effective process; however, we are aware that sometimes significant practice matters may not be addressed until a full investigation is completed by the DSC and an NTTA is issued. This highlights the importance of adequate resourcing and efficient processes to systematically review deaths and meaningfully assess the quality of service provision.

Recommendation 2

That any future state-based death review function adhere to specified timeframes. We recommend the following:

- Responsive triaging processes should include a priority allocation in order to expedite cases that raise immediate concerns regarding violence, abuse, neglect or exploitation. An immediate actions framework⁴¹, supported by robust and responsive legislative powers, would assist in requiring immediate service and practice changes prior to a full investigation.
- Death review inquiries should be effectively triaged within six weeks; closing those matters which demonstrate sufficient care and support immediately, while progressing investigations of matters which raise concerns.
- Ideally, the time from acceptance of a routine investigation to initial findings should be three months, with complex investigations being completed in no more than six months. This ensures timely feedback to providers and safeguarding.
- Under current legislative timeframes, in addition to having 14 days to respond to adverse comments from a draft investigation report, providers are given up to 45 days to respond to NTTA's, with a further 15 days upon request. The DSC believes this timeframe is appropriate to maintain procedural fairness and develop improvement actions, and recommends that these timeframes remain part of any new death review and safeguarding function.

41 Australian Health Practitioner Regulation Agency (AHPRA) Immediate action process viewed at <https://www.ahpra.gov.au/Notifications/How-we-manage-concerns/Immediate-action.aspx>

3. Workforce

Reviewing deaths and assessing the quality of service provision to inform and implement enduring systemic change takes expertise, time and resources. The DSC finds that reviews and investigations of a person's death, including the analysis of a provider's internal service review and supporting documentation, particularly the analysis of health, medical and sector information, is a skilled task that requires training and experience. Issues relating to the DSC's capacity to retain staff in a climate of expected decommissioning has impeded on staff development and arguably diminished the effectiveness of the function.

Recommendation 3

That any future state-based death review function would need to be established and staffed in a manner that develops and retains the appropriate level of expertise to perform the role. At a fundamental level this includes committing to a dedicated staffing and operational model which is supported to meet the recommended timeframes, monitoring requirements and undertake expert analysis of a provider's initial self-assessment and documentation to ensure proper categorisation and action of each review.

Part B: Data, themes and systemic change

Data

Effective monitoring of mortality data is critical to understanding and shaping targeted preventative health initiatives and public policy. It is particularly important for people with disability, who are more likely to experience health inequalities due to neglect, poor treatment, and failure to undertake routine health promotion and prevention activities.⁴²

Over the past three years the DSC Questionnaire completed by service providers has assisted us to gather detailed information and comparative data relating to key individual characteristics, provider information, intersectional trends and causes of in-scope reportable deaths.

Furthermore, our investigation into these deaths have provided an opportunity for in-depth analysis of service provision allowing us to identify key themes requiring practice improvement, which subsequently informs our NTTAs or broader Notices of Advice (NoA).

Finalised investigations to date have provided rich information about the support needs and individual characteristics of people receiving disability services, as well as information regarding service providers. See **Appendix A** for a full comparative summary of key data from investigations finalised between 2017 and June 2020.

Our 2019-20 Annual Report noted that, consistent with other research, people in receipt of disability services continue to die approximately 25 to 30 years younger than the general population. In reviewing the 131 finalised investigations from 2017 to June 2020 (Table 2), we see that almost 50% of deaths related to people aged between 51 to 70 years of age.

Table 2: Age at death as at June 2020 – by financial year closed

Age at death	2017-18	2018-19	2019-20	Total
6–18 years	2	2	–	4
19–30 years	1	1	3	5
31–40 years	2	4	4	10
41–45 years	1	5	8	14
46–50 years	2	3	12	17
51–60 years	6	7	24	37
61–70 years	5	12	11	28
71–80 years	1	2	11	14
81–90 years	–	–	1	1
Unknown	–	1	–	1
Total	20	37	74	131

Furthermore, our data allows us to profile the experience of people who have died while in receipt of disability services. For example, a gender analysis tells us that of the 131 finalised investigations until 30 June 2020, 41% were female and 59% male.

⁴² Disability Services Commissioner, *A review of disability service provision to people who have died 2019-20*, p.25.

Female profile

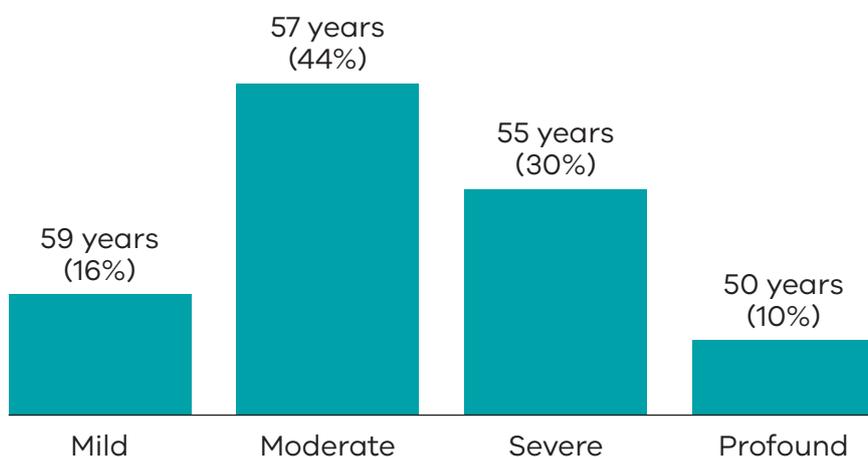
The majority of females lived in shared supported accommodation (81%), those in shared supported accommodation often had an intellectual disability (93%) and at least one or more health condition(s) (79%) such as epilepsy (41%), incontinence (68%) or constipation (63%). Females in shared supported accommodation with an intellectual disability died with a median age of 56 years from a variety of causes with the main causes being diseases of the respiratory system (22%), circulatory system (15%) or neoplasms (12%).

Male profile

The majority of males also lived in shared supported accommodation (86%), those in shared supported accommodation often had an intellectual disability (83%) and at least one health condition (80%) such as epilepsy (47%), incontinence (64%) or constipation (53%). Males in shared supported accommodation with an intellectual disability died with a median age of 55 years from a variety of causes with the main causes being diseases of the respiratory system (35%) and circulatory system (18%).

Strikingly, data regarding the median age at death by level of intellectual disability (Figure 1) denotes that 40% of people who died were diagnosed with a severe to profound intellectual disability and 60% of people who died had a mild to moderate intellectual disability. It is the cohort of mild to moderate disability who are potentially most at risk of deteriorating health and changing support needs. In 2019–20, our investigations highlighted that disability support workers may not necessarily understand the changes associated with age-related chronic diseases and conditions, such as dementia. For example, cognitive or mobility decline may be viewed as a manifestation of lifelong intellectual disability, rather than recognised as a sign of ageing.⁴³

Figure 1: Median age at death by level of intellectual disability and proportion of people with intellectual disability (July 2017 to June 2020)



⁴³ Ibid.

Themes and trends from data are critical in informing disability service quality and systemic improvement. Data is one part of the story of real people, with meaningful lives to live and who require funded supports to do this.

Data and information gathered from investigations inform the DSC’s NTTA to service providers to ensure better supports for people in direct receipt of disability services and strengthens our capacity to monitor systemic provider improvement. Key data and the associated themes also have the capacity to provide broader benefits to the 1.1 million Victorian’s with disability⁴⁴ and support the work of the State Disability Plan 2021-2024 as it seeks to make Victoria more inclusive, so that people with disability live satisfying everyday lives⁴⁵.

Key themes

The DSC death investigations consider whether the disability service provision was delivered in a manner that sufficiently promoted an individual’s rights, dignity, wellbeing and safety where there was evidence of appropriate and quality disability supports in these areas.

Based on three years of reviewing deaths (Table 3), it is significant to note that the DSC has issued NTTAs in 43% of finalised investigations to address system failings, rectify poor practice and inform ongoing service improvement.

Table 3: Notices to Take Action issued (1 July 2017 to 30 June 2020)

	2017-18	2018-19	2019-20
Investigations finalised	20	37	74
NTTAs issued to providers (% of reports with NTTA issued)	8 (40%)	23 (57.5%)	25 (34%)

Our data collection and in-depth analysis of key themes for the past three years has so far identified the following areas of concern:

Table 4: Notices to Take Action - Key themes (1 July 2017 to 30 June 2020)

2017-18	2018-19	2019-20
<ul style="list-style-type: none"> • Safe mealtime assistance • Communication needs and support • Quality and existence of health plans • Quality of record keeping 	<ul style="list-style-type: none"> • Choking and aspiration risks • Bowel management • Managing health needs • Staff support and training 	<ul style="list-style-type: none"> • Supported decision-making • Health promotion and prevention • Person-centred active supports • Positive behaviour supports • Medical decision-making • End of life care

44 Consultation paper for state disability plan 2021–2024, p.4.

45 Ibid., p.1.

The key themes highlight two interconnected and higher-level categories of health-related and rights-related risk. The initial themes for 2017-18 provided foundational priorities for immediate practice improvement and were communicated to the sector via a Notice of Advice.⁴⁶ Subsequent annual reports have addressed additional themes and risks that have continued concurrently with foundational priorities, with the aim to continually drive service improvement and ensure that changes lead to better and safer supports for those still in receipt of the services.

The following stories from past Annual Reports reflect the experience of real people (*names and details have been changed). These stories highlight the equally important aspects of health and rights related risks in the context of service provision, and why mechanisms for independent in-depth scrutiny of the quality of disability support provided to people with disability remains essential.

Some people's deaths are potentially avoidable

Truc*

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

Truc had lived in her group home for six years, after moving from her family home. For over a decade, Truc attended a day program five days a week. Truc communicated using some words, gestures and a photo book. Truc required assistance from support workers for personal care and daily living activities.

Truc had a moderate intellectual disability, epilepsy and gastro-oesophageal reflux disease. She also had a history of choking.

Our investigation found that Truc's group home had not communicated important information about her choking risk and mealtime supports to her day program. This meant the day service provider did not have enough information to provide Truc with appropriate support during mealtimes. As a result, support workers did not always assist her to eat at a safe pace, ensure her mouthfuls were appropriately sized, or ensure that all her food was fully chewed. We also found the information that the group home held about Truc's mealtime support needs was contradictory and outdated.⁴⁷

46 As viewed at <https://www.odsc.vic.gov.au/2018/11/26/notice-of-advice-systemic-issues-arising-from-the-review-of-disability-service-provision-to-people-who-have-died/>

47 Disability Services Commissioner, *A review of disability service provision to people who have died 2018-19*, p.9.

Some people's deaths highlight poor quality of care and lack of fundamental human rights

Sandra*

Sandra was a 45-year-old woman who had lived in the same group home since she was 17 years old.

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

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

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

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

We also found that staff had been using a range of strategies to seclude and isolate Sandra within her group home, none of which had been authorised and were therefore unlawful. Our investigation found that the treatment Sandra received from her group home constituted abuse and neglect, including the violation of her human right to communicate.⁴⁸

48 Ibid., p.15.

Some people's deaths highlight unsafe and inconsistent practices by workers

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. Ricardo died at the age of 65.

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.

The DSC initiated an investigation into disability services provided to Ricardo. The investigation found that while Ricardo had a mealtime management plan, records 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.⁴⁹

These stories, along with the many others reviewed by the DSC, highlight the importance of reviews which consider a person's life and not just how they died. By reviewing lives, we have been able to require services to act and improve. It is the DSC's experience that services have welcomed our analysis and commentary on their service delivery and see it as an important input into their continuous improvement processes.

49 Disability Services Commissioner, *A review of disability service provision to people who have died 2017-18*, p.29.

The recent Disability Royal Commission – Interim Report has highlighted the importance of empirical evidence and useful data⁵⁰, and identified similar key themes to that of the DSC in relation to healthcare and services for people with disability.⁵¹ *Public Hearing 4 - Health care and services for people with cognitive disability*, identified similar key themes including:

- quality health care
- attitudes, assumptions and culture
- communication and information sharing
- health system challenges
- lifetime health care
- integration of the health and disability service sectors
- reduction of distress and trauma
- training and education of health professionals
- collection of data and research initiatives to improve health care.⁵²

Insights from our review of deaths in Victoria echo the Disability Royal Commission's findings regarding the critical intersection between disability and health sectors.

Identifying systemic issues

As highlighted, while the DSC death investigations focus on the circumstances of an individual's death, we broaden our assessment to include the provision of appropriate and quality disability supports leading up to the death. This informs subsequent recommended actions to ensure disability service providers make the necessary service improvements for the benefit of those who continue to receive their services.

Examples of systemic advice from our review of deaths:

- **Notice of Advice to the sector in November 2018** – the DSC issued advice to all registered providers alerting them to the key systemic issues arising from the review of disability service provision to people who have died in 2017-18, and provided a resource identifying key themes, implications and why this is important for service provision.⁵³
- **Falls risk advice** – As a result of the DSC issuing a Notice of Advice to DFFH in 2018, the Department, in conjunction with Monash University, developed practice instructions on falls prevention and supporting guidelines for use in disability group homes. These instructions were distributed to all in-kind providers in April 2020.
- **Safe Mealtimes advice (Appendix B)** – In 2019 the DSC convened a Safe Mealtimes Roundtable Forum involving 13 key state and federal organisations. As a result of this collaboration, the DSC developed the Safe Mealtimes Poster and guidance on how to best promote the importance of mealtime support to disability support workers. This has been disseminated to all in-kind providers, advocacy groups and providers that have previously had a death within their service investigated by the DSC.⁵⁴

50 Disability Royal Commission Interim Report, p.9.

51 Ibid., p.267.

52 Ibid., p.270.

53 Disability Services Commissioner, *Key themes and implications for service provision from the inaugural Review of disability service provision to people who have died 2017-18*.

54 Safe Mealtimes Poster viewed at <https://www.odsc.vic.gov.au/2020/09/15/safe-mealtimes/>

- **Deteriorating health advice** – As a result of the DSC issuing a Notice of Advice to DHHS in 2019, the Department has commenced developing practice guidance for use in disability group homes to raise awareness of recognising and responding to deteriorating health when supporting people with disability. This work continues despite delays due to COVID-19.

Summary and recommendations

4. Data and information

The DSC began the death review process by using a combination of manual processes and multiple databases to record and manage cases. Retaining suitably qualified and skilled staff to manage and analyse data has been an ongoing challenge, further impacted by limited resources. Since 2019 we have been retrospectively transferring and consolidating all death review data onto a single complaints database system which allows for more consistent data extraction and monitoring across all functions of the DSC.

The DSC's data has proven to be consistent with national and international research outcomes and offered valuable information to the NDIS Commission when considering their own practice in the area of reviewing deaths as part of their reportable incident function.⁵⁵ Our investigations are rich in information and details, and considerable insight can be gained into the safety and quality of the service provided.

Additionally, a death review is a window into the life of the person and how well that person lived. There is much to be learned about the qualitative aspects of a person's life through undertaking a death review and how services can achieve higher standards of care, dignity, and participation. A Victorian Disability Deaths Registrar or similar could provide a broad and robust dataset on which to base conclusions and recommendations. An example of this can be seen in the State Coroner's Victorian Suicide Register⁵⁶ and accompanying review⁵⁷.

While the DSC's database system remains adequate for our current purposes, it has to date proven to limit our data analysis capability and the use of sound business intelligence tools for data analysis is highly recommended.

Recommendation 4

That any future state-based death review function will require a robust data collection and analysis system to maximise the benefit from undertaking this work to uncover systemic failures, develop corrective actions, and monitor ongoing practice particular to the Victorian community services context.

⁵⁵ Salomon et al. 2019, op cit., p 6.

⁵⁶ As viewed at <https://www.coronerscourt.vic.gov.au/forms-resources/request-coronial-data>

⁵⁷ Sutherland G, Milner A, Dwyer J, Bugeja L, Woodward A, Robinson J and Pirkis J., Implementation and evaluation of the Victorian Suicide Register, Australian and New Zealand Journal of Public Health. 2017.

5. Compliance vs Continuous Improvement

While the DSC's processes and data collection have benefited from the introduction of the providers internal service review it has always been our intention to do more than just achieve a minimum standard of care. By taking a 'deeper dive' into a person's life and death, the DSC seeks to promote more than a minimum standard of care by seeking to improve practices at a fundamental human rights level. Initially it could be said that the DSC's key themes in 2017-18 focused primarily on the basic requirements of physiological needs and safety – the need to eat safely, communicate wants and needs, and receive adequate daily support – all of which are able to be assessed for compliance and adherence. However, key themes from the following years have identified higher level needs and a human rights based approach which encompasses psychological and self-fulfilment needs such as supported decision-making, the right to individualised and personalised support, and the right to be included in medical and end of life decision-making.⁵⁸

Like our broader approach to complaints, conciliation and oversight, the DSC's approach to the death review process has sought to integrate legislative hierarchical governance with relational governance that promotes the importance of human agency through active engagement with providers and focuses on the day-to-day experience of the person who has died.⁵⁹ Consistent with the *Victorian Community Services quality governance framework*, the DSC believes it is essential to shift the focus beyond pure compliance, which does not necessarily promote high quality care, to a focus on continuous improvement which highlights the importance of "listening directly to the voices of the people who use our services".⁶⁰

Consistent with past research into the UK health-care system, the DSC supports that quality and safeguarding requires collaboration and that, "[transformational] governance should not emphasise the separate responsibility of institutions, groups or individuals but rather focus on their interrelatedness and shared monitoring responsibility".⁶¹

Recommendation 5

That any future state-based death review function be intentionally incorporated in a broader quality and governance model, as a critical component of ongoing monitoring, evaluation and improvement practices⁶².

58 Maslow AH., A Theory of Human Motivation (1943), Originally Published in *Psychological Review*, 50, 370-396.

59 Bodolica V, Spraggon M and Tofan G., A structuration framework for bridging the macro-micro divide in health-care governance, *Health Expectations*. 2016 Aug 19(4): 790-804

60 DHHS, Community services quality governance framework - Safe, effective, connected and person-centred community services for everybody, every time, 2018.

61 Bodolica et al. op cit., 2016.

62 Ibid.

6. Quality of life analysis

In many instances, our work, although focused on a person's death, provides rich insights into how a person lived. The DSC believes that any ongoing death investigation function must also collect, analyse and make assessments on the quality of a person's life, including the qualitative aspects of a person's engagement in areas including health, education, communications, community and other rights based areas.

This approach is not specific to disability services only, but rather has the capacity to translate into the context of other state-funded social services supporting people with disability such as Supported Residential Services (SRSs) and Out-of-home care. In performing this function since 2017, the DSC has provided a sound functional platform on which to build a mature and broad state-based review process to determine adequacy of service provision, identify targeted service-based improvements, and inform widespread systemic improvements across a broad range of community services.

Recommendation 6

That any future state-based death review function consider adopting a broad 'quality of life' approach that captures contemporaneous data, including health-related and rights-related risks, to inform the broader systemic improvement of Victorian community services.

7. Continuity and co-design in Victoria

The maturity of the DSC Death Review process, in combination with our established and well regarded stakeholder relationships in the sector, provides a solid foundational base on which future state and federal models of quality and safeguarding may consider building upon in order to achieve real improvement of services for people with disability. Taking the time and applying the resources necessary to appropriately review and investigate deaths, has provided the DSC with the opportunity to provide both individual and systemic advice to providers and the sector in order to promote human rights based approaches in service provision that promote effective policies, practices, and practical realities.⁶³

Recommendation 7A

That any future state-based death review function consults extensively with all stakeholders, including people with disability, families/carers and disability providers to ensure practice continuity and confidence in monitoring ongoing systemic and individual service improvement in Victoria.

Recommendation 7B:

That any future state-based death review function considers including an advisory model that represents the experience and voice of disability consumer groups in receipt of services⁶⁴.

⁶³ Australian Human Rights Commission viewed at <https://humanrights.gov.au/our-work/rights-and-freedoms/human-rights-based-approaches#:~:text=A%20human%20rights%20based%20approach,barriers%20to%20realising%20their%20rights.>

⁶⁴ DHHS, Client voice framework for community services, October 2019

8. Primary prevention

Primary abuse prevention has always been a priority for the DSC, in order to address essential factors including culture, attitudes and relationships within services to build cultures of respect.⁶⁵ In response to the Inquiry's recommended state-wide prevention and risk management workforce strategy for disability services,⁶⁶ the DSC's legislative powers were broadened to include abuse prevention. In 2019, the DSC launched a co-designed pilot program that looked specifically at the culture of services for people with disability, *Building safe and respectful cultures in disability services*.⁶⁷ The project considered practical ways to create safe environments within disability services. In reviewing deaths, while our NTTA, NoA and annual reports seek to raise awareness about potential risks and the importance of quality service provision, it is clear that ongoing and intentional primary prevention initiatives will be required to ensure better practice in the future.

Recommendation 8

The DSC recommends that any future state-based death review function consider co-designed prevention, education and positive practice strategies that support quality improvement and service accountability.

65 Coulson Barr, L. (2012). Safeguarding people's right to be free from abuse: Key considerations for preventing and responding to alleged staff to client abuse in disability services. In D. S. C. Laurie Harkin (ed.), Occasional paper No 1. Melbourne: Office of the Disability Services Commissioner.

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

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

Part C: The future of reviewing deaths in Victoria

By 1 July 2021, once all in-kind disability services transition to the NDIS and come under the jurisdiction of the NDIS Commission, the powers of the DSC to inquire into and investigate the provision of disability services to people who have died will be reduced to only a small number of residual state-funded disability services. Oversight of disability support workers will continue to be provided by the VDWC through processes of notifications and complaints.

Unlike the DSC, neither the NDIS Commission nor the VDWC/DWRB have a specific and dedicated death review function.

While the VDWC are yet to fully establish their intention in relation to reviewing worker practice regarding service provision to people with disability who have died, the NDIS Commission, in preparing for full transition, engaged Professor Julian Trollor (Chair, Intellectual Disability Mental Health, Faculty of Medicine, Department of Developmental Disability Neuropsychiatry at the University of New South Wales) to undertake research to review the causes and contributors to deaths of people with disability, and to identify population mortality trends and risks concerning the deaths of people with disability.⁶⁸ In August 2019, Professor Trollor and Dr Carmela Salomon presented their findings in, *A scoping review of causes and contributors to deaths of people with disability in Australia*⁶⁹ which included data provided by the DSC.

The DSC welcomed this scoping review, and acknowledges that in response the NDIS Commission has reviewed and/or developed compliance and enforcement requirements, as well as aligning reportable incident and practice advice, and that further regulatory work by the NDIS Commission continues in this area⁷⁰.

It is also encouraging to note that all key themes identified by the DSC relating to health and rights-related risks are regulated by the Commission in accordance with the NDIS Code of Conduct and NDIS Practice Standards and Quality Indicators⁷¹ including high-intensity skills descriptors for delivering complex supports safely⁷² and provider practice alerts.⁷³

However, it is important to note that the approach to reviewing deaths by the DSC is different to that of the NDIS Commission. In comparing approaches it is essential to recognise the legislated and operational differences between organisations which inform these approaches:

68 Research: Causes and contributors to deaths of people with disability in Australia – NDIS Commission’s response to recommendations viewed at <https://www.ndiscommission.gov.au/causes-and-contributors-deaths-people-disability>

69 Salomon et al. op cit., p.60.

70 NDIS Commission’s response to recommendations viewed at <https://www.ndiscommission.gov.au/causes-and-contributors-deaths-people-disability>

71 NDIS Practice Standards and Quality Indicators. January 2020 (Version3)

72 NDIS Practice Standards: skills descriptors - Information for auditors and providers, July 2018 (Version 1)

73 NDIS Commission’s Resources viewed at <https://www.ndiscommission.gov.au/resources>

Table 5: The DSC and NDIS Commission approaches to reviewing deaths

	The DSC practice approach to reportable deaths:	NDIS Commission practice approach to reportable deaths:
Jurisdiction	<ul style="list-style-type: none"> • State 	<ul style="list-style-type: none"> • National
Legislation	<ul style="list-style-type: none"> • <i>Disability Act 2006</i> (currently under review) • Ministerial Referral 	<ul style="list-style-type: none"> • <i>NDIS Act 2013</i>
Focus	<ul style="list-style-type: none"> • Compliance and broader service quality relating to death and prior to death • Systemic reform mechanism for reducing potentially avoidable deaths 	<ul style="list-style-type: none"> • Compliance, regulation and service quality specific to death • Systemic reform mechanism for reducing potentially avoidable deaths
Approach	<ul style="list-style-type: none"> • Micro to macro – Focus on reviewing the quality of life and death of all people in receipt of disability service provision to inform service improvement 	<ul style="list-style-type: none"> • Macro to micro – Focus on whether service quality caused/contributed to the death or as a result of service provision to inform service improvement
Notification	<ul style="list-style-type: none"> • Reviews deaths via a specific death review and reporting function by means of the Ministerial Referral 	<ul style="list-style-type: none"> • Reviews deaths as part of a Reportable Incident function – No specific death review function within the NDIS Act
Process	<ul style="list-style-type: none"> • Receive incident reports relating to deaths within 24 hours • Requests additional information from provider including questionnaire, relevant documentation and providers complete internal service review • Assess adequacy of service provision within 6 weeks of notification • Further investigation may be commenced if required 	<ul style="list-style-type: none"> • Receive Reportable Incident reports relating to deaths within 24 hours • Assess adequacy of service provision within 24 hours of notification based on information provided at time of reporting. May request additional information if immediate concerns are identified • Additional compliance, enforcement or investigation may be commenced if required
Compliance and enforcement powers	<ul style="list-style-type: none"> • While the <i>Disability Act 2006</i> provides some provision for penalty points to providers for non-compliance with NTTAs, the DSC are not the funding body and do not have powers to independently revoke registration • Powers to compel witnesses or required information 	<ul style="list-style-type: none"> • NDIS Act provides the NDIS Commission with a broad and extensive suit of compliance, registration and enforcement powers that enable revocation of registration and/or banning orders where appropriate

Like the DSC's jurisdiction, not all deaths of people with disability will be within the jurisdiction of the NDIS Commission. While the commencement of the NDIS offers significant social reform as it assists approximately 412,543⁷⁴ Australians to access disability supports, the NDIS does not support all people with disability given that the estimated number of Australians with disability is 4.4 million.⁷⁵ In Victoria, approximately 1.1 million Victorians have a disability⁷⁶ and 108,630 people are NDIS participants.⁷⁷ This indicates that only 9.9% of people with disability in Victoria would be considered within the jurisdiction of the NDIS Commission. Rightly, much collaborative energy on a state and federal level has been invested to ensure the successful establishment of the NDIS and its quality and safeguards. However, in Victoria consideration must be made as to any potential gaps that may exist once the review of deaths transfers predominantly to the NDIS Commission.

Summary and potential gaps

It is essential to note that the DSC has always enjoyed a positive and responsive relationship with the NDIS Commission. Both organisations have respected the differing approaches of the other and in the past the NDIS Commission have welcomed the readily shared resources and information provided by the DSC. Since commencing in Victoria on 1 July 2019, both organisations have invested heavily in ensuring that jurisdictional matters are referred as efficiently as possible between organisations in acknowledgement of the complexity of multiple oversight bodies until such time as the cash-out process is completed. Both now and into the future, the DSC is confident that both organisations will continue to work effectively together to achieve the shared goal of improving the quality and safety of service provision and empowering people with disability to live fulfilling lives.

Despite this collaborative relationship, the DSC is concerned that the following gaps exist in relation to the future of reviewing deaths in Victoria.

Opportunity gaps

The DSC reviews and investigates the life and death of a person, not just the death. In addition to investigating whether service quality caused or contributed to the death of a person in receipt of disability services, the DSC takes the unique opportunity to review the quality of support provided to ensure that the person was supported to be "healthy, safe and able to lead the life they value"⁷⁸. As stated previously, very often the death may be expected and the quality of service provision may not have directly contributed to the persons cause of death. However, with over 43% of the DSC investigations up until 30 June 2020 requiring a NNTA, the opportunity to review a person's quality of life through a rights based approach is a critical element of service improvement that a general audit or light-touch review would not necessarily identify.

74 NDIS Quarterly Report to disability ministers 30 September 2020., p.7.

75 Australian Bureau of Statistics. *Disability, Ageing and Carers, Australia: Summary of Findings*, Reference period 2018, released 24/10/2019.

76 Consultation paper for state disability plan 2021–2024, p.4.

77 NDIS Quality and Safeguards Commission, ACTIVITY REPORT – 1 July 2019 to 30 June 2020.

78 Victoria State Government, Department of Families, Fairness and Housing (DFFH), Capabilities Framework, as viewed at <https://intranet.dhhs.vic.gov.au/building-our-capabilities>

Oversight gaps

While the regulation, compliance, and enforcement powers of the NDIS Commission are far more significant than those of the DSC, current experience indicates that the NDIS Commission does not intend to mirror the same approach to death reviews and investigations as the DSC. Additionally, the sheer number of matters being dealt with by the NDIS Commission, including reportable incidents relating to deaths, means that there are growing pressures on the NDIS Commission to process and complete this work. The DSC remains concerned that at best there will be a gap in the time it will take the NDIS Commission to achieve the current in-depth standard of reviewing and investigating deaths currently delivered by the DSC, albeit via a different approach to that taken by the DSC. At worst the NDIS Commission's process for reviewing deaths will only ever take a regulatory approach and will rely more on reactive rather than preventative approaches to drive better practice and achieve ongoing quality service improvement.

Information gaps

Once all in-kind services transition across to the NDIS, requests for detailed state-related data regarding deaths of people with disability will be reliant upon information from the NDIS Commission and what is captured via notifications to the State Coroner. Currently, the DSC gathers critical information relating to a broad cross-section of personal and provider characteristics to better profile potential risk cohorts in Victoria. In combination with the State Coroner, the DSC death reviews and investigations document service quality and actions required for continuous improvement, which are always provided to both the Minister and the Secretary of DFFH as funder and regulator. Such regular and detailed investigation reports will not be provided by the NDIS Commission.

Additionally, appropriately stringent commonwealth information sharing legislation means that limited information can be shared by the NDIS Commission to the states, further exacerbating the potential gap between information available to the State in order to inform future social services reform, regulation and oversight more broadly.

Systemic gaps

The combination of gaps in opportunity, oversight and information ultimately culminates in system gaps. Where there is a lack of an active and contemporaneous understanding regarding service quality and data, there is the potential for ongoing risk. While significantly reduced, Victoria will continue to provide some disability services in the future including funding for disability advocacy and delivery of disability forensic services. Oversight arrangements are currently being reviewed and developed to ensure that these services continue to meet Victorian standards of quality and safeguarding, however effective sharing of national data and information is required to further enrich service quality.

Poor quality in one sector, for example disability services, has the potential to be replicated in other sectors including aged care, children's services and health. Gaps in approaches to oversight and information sharing increases the challenge in identifying and monitoring patterns of risk and poor practice, as well as reducing the opportunity to spotlight best practice methodologies that could be replicated in other social and

community services. In relinquishing the role of the DSC in reviewing deaths, Victoria loses the window of opportunity to fully explore the quality of someone's life and death which has the potential to require the improvement of not only disability services but the broader social services including health, allied health, education, guardianship, housing and palliative care.

Conclusion

Learning from reviewing Victorian disability service provision to people who have died will not cease completely once all in-kind providers have fully cashed-out and transferred to the NDIS and NDIS Commission. The DSC expects to continue this role in Victoria, on a very reduced scale, until such time as the *Disability Act 2006* is amended and any proposed Social Services Reform is undertaken. In the meantime the question remains – what processes, if any, will be implemented in Victoria to systematically review deaths in disability services and readily identify leading causes of death, or to meaningfully assess possible links between a death and the adequacy of care being provided to a person before their death?

Appendices

Appendix A:

Finalised investigation data from completed reviews 2017 to June 2020

Overview

Table 6: Reported deaths as at 30 June 2020 – In-scope / Out-of-scope

	2017-18		2018-19		2019-20	
In-scope for the the DSC	57%	20	65%	37	51%	74
Out-of-scope for the DSC	43%	15	35%	20	49%	72
Total	100%	35	100%	57	100%	146

Table 7: Incident Reports received from DFFH – Expected / Unexpected

	2017-18		2018-19		2019-20	
Expected death	30%	6	30%	11	19%	14
Unexpected death	70%	14	65%	24	73%	54
Unclassified			5%	2	8%	6
Total	100%	20	100%	37	100%	74

Services provided

Table 8: Investigations by service provider and primary service type

Service Provider (group)	Service Activity	2017-18	2018-19	2019-20
CSO	Shared Supported Accommodation	5	14	26
	Individualised Support Packages	2	1	4
	Case Management	1	1	
	Flexible Support Packages	3	1	
	Outreach Support	1	1	1
	Respite	1		2
DHHS	Shared Supported Accommodation	7	18	40
	Individualised Support Packages		1	
	Case Management			1
Total		20	37	74

Demographics

Figure 2: Gender and age at death between 1 July 2017 and 30 June 2020

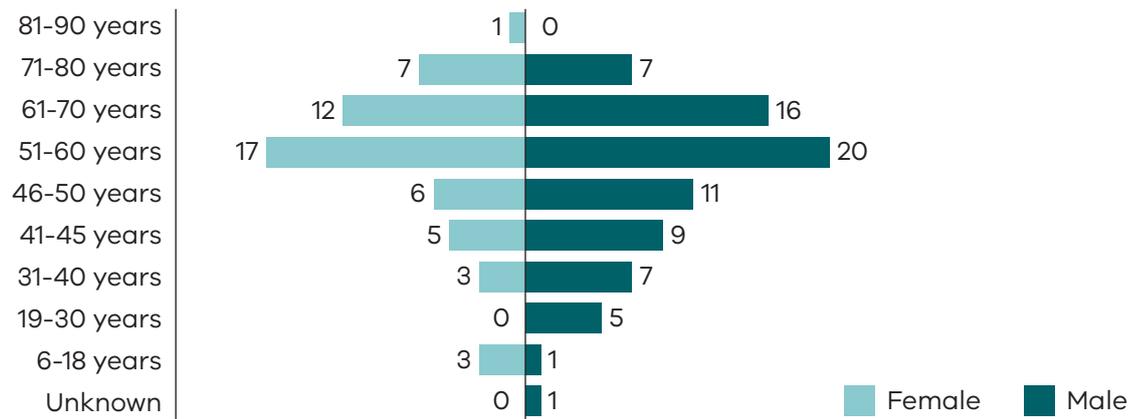


Table 9: Gender

	2017-18		2018-19		2019-20	
Male	70%	14	59%	22	55%	41
Female	30%	6	41%	15	45%	33

Table 10: Median age

	2017-18	2018-19	2019-20
Female	47.5	56	55
Male	56	52	54

Table 11: Median age by support needs*

		2017-18		2018-19		2019-20		Total	
		Median age	No. of cases						
Mobility	No mobility issue	52	3	52	11	53	23	52	37
	Walking frame	64.5	4	67	5	61	6	65	15
	Walking stick			54	1	45	1	49.5	2
	Wheelchair	47.5	10	52	19	55	37	55	66
	Mobility – other	54	4	54	4	56	30	56	43
Self-care	Could provide self-care independently	51.5	4	71	3	60	5	58	12
	Required assistance to dress	54	14	52	28	55	60	54	102
	Required assistance to prepare meals and drinks	56	15	54.5	35	55	68	55	118
	Required assistance to toilet	55.5	12	49	26	54	60	54	98
	Required assistance to wash/bathe	56	15	53	31	55	68	55	114
Social support	Social support advocate			55	1	60	6	55	7
	Social support family	56	19	52	30	55	62	54.5	111
	Social support friends	52	14	50.5	18	55	41	55	73
	Social support none			59.5	2	68	2	61.5	4
	Social supports other	47	3	54	5	55.5	20	55	28

* Multiple responses recorded

Representation of First Nations and Culturally and Linguistically Diverse (CALD) communities

Table 12: Identifies as Aboriginal and Torres Strait Islander **

Aboriginal and Torres Strait Islander status (group)	2017-18		2018-19		2019-20	
Neither Aboriginal nor Torres Strait Islander origin	13%	17	29%	37	49%	63
Unknown	2%	3			7%	9
Total	16%	20	29%	37	56%	72

** Missing questionnaire data for two cases (2019-20 reports – 72/74)

Table 13: Spoken languages**

Year of closed date	Other languages spoken (group)	Country of birth (group)	
2017-18	Languages other than English spoken	Australia	1
	No languages other than English spoken	Australia	17
		Unknown	2
2018-19	Languages other than English spoken	Australia	1
		Eastern European	1
	No languages other than English spoken	Australia	33
		Indo-European	1
Scandinavian		1	
2019-20	Languages other than English spoken	Australia	4
	No languages other than English spoken	Australia	64
		United Kingdom	2
		Unknown	2
Total			129

** Missing questionnaire data for two cases (2019-20 reports – 72/74)

Disability

Table 14: Primary identified disability type requiring most support**

Primary disability detail (group)	2017-18		2018-19		2019-20	
Intellectual disability	6	30%	17	46%	37	51%
Down syndrome	1	5%	2	5%	8	11%
Cerebral palsy (including spastic quadriplegia)	5	25%	3	8%	7	10%
Autism					5	7%
Acquired brain injury (ABI)	1	5%	4	11%	4	6%
Multiple sclerosis (MS)	2	10%			1	1%
Muscular dystrophy			1	3%	1	1%
Schizophrenia			1	3%	1	1%
Tourettes			1	3%		
Fragile X	2	10%	1	3%		
Other	3	15%	7	19%	8	11%
Total	20	100%	37	100%	72	100%

** Missing questionnaire data for two cases (2019-20 reports – 72/74)

Communication**

Table 15: Preferred communication modes

Communication modes (group)	2017-18		2018-19		2019-20	
Verbal language only, no support required	65%	13	46%	17	43%	31
Non-verbal multiple modes of communicating with aides or gestures	35%	7	51%	19	42%	30
Unable to communicate			3%	1	15%	11
Total	100%	20	100%	37	100%	72

Table 16: Communication plans in place

Communication plan (group)	2017-18		2018-19		2019-20	
No	55%	11	70%	17	50%	36
Yes	40%	8	30%	19	50%	36
Unknown	5%	1				11
Total	100%	20	100%	37	100%	72

** Missing questionnaire data for two cases (2019-20 reports – 72/74)

Mental Health**

Table 17: Recorded mental health / Psychosocial supports

Mental illness flag	2017-18		2018-19		2019-20	
Yes	30%	6	45%	17	24%	17
No	45%	9	37%	14	67%	48
Null	25%	5	18%	7	10%	7
Total	100%	20	100%	38	100%	72

Table 18: Recorded diagnosis of Depression

Depression	2017-18		2018-19		2019-20	
True	15%	3	32%	12	10%	7
False	85%	17	68%	26	90%	65
Total	100%	20	100%	38	100%	72

Table 19: Recorded diagnosis of Anxiety

Anxiety	2017-18		2018-19		2019-20	
True	15%	3	16%	6	14%	10
False	85%	17	84%	32	86%	62
Total	100%	20	100%	38	100%	72

** Missing questionnaire data for two cases (2019-20 reports – 72/74)

Social support and decision-making**

Table 20: Social support and decision-making

Social support	Decision-making capacity (group)	2017-18	2018-19	2019-20
No social support	A combination of the above			1% 1
	Independently made decisions		3% 1	
	Support required to make decisions		3% 1	1% 1
Social support from family, friends or advocate	A combination of the above	15% 3	8% 3	19% 14
	Independently made decisions	25% 5	19% 7	3% 2
	Legal guardianship arrangement in place	10% 2	19% 7	13% 9
	Support required to make decisions	35% 7	43% 16	58% 42
	Unanswered by SP	10% 2		1% 1
Unanswered by SP	Legal guardianship arrangement in place		3% 1	
	Support required to make decisions	5% 1	3% 1	1% 1
	Unanswered by SP			1% 1
Total		100% 20	100% 37	100% 72

** Missing questionnaire data for two cases (2019-20 reports – 72/74)

Table 21: Social support, decision-making and medical treatment consent**

Decision-making capacity	Consent for medical treatment provided by	Social support	2017-18				2018-19				2019-20			
			%	n	%	n	%	n	%	n	%	n		
A combination of the above	Family	Social support from family, friends or advocate	10%	2	3%	1	15%	11						
	Legal guardian	Social support from family, friends or advocate			3%	1	1%	1						
	Other	Social support from family, friends or advocate			3%	1								
	Self	Social support from family, friends or advocate	5%	1			3%	2						
Independently made decisions		No social support					1%	1						
	Family	Social support from family, friends or advocate	5%	1	3%	1								
	Other	Social support from family, friends or advocate	5%	1										
	Self	Social support from family, friends or advocate	15%	3	16%	6	3%	2						
Legal guardianship arrangement in place		No social support			3%	1								
	Advocate	Unanswered by SP			3%	1								
	Family	Social support from family, friends or advocate			16%	6	8%	6						
	Legal guardian	Social support from family, friends or advocate	5%	1	3%	1	4%	3						
Support required to make decisions		Social support from family, friends or advocate	5%	1										
	Advocate	Social support from family, friends or advocate					1%	1						
	Family	Social support from family, friends or advocate	30%	6	41%	15	51%	37						
		No social support			3%	1	1%	1						
Unanswered by SP		Unanswered by SP	5%	1	3%	1	1%	1						
	Other	Social support from family, friends or advocate			3%	1	6%	4						
	Self	Social support from family, friends or advocate	5%	5										
	Null	Unanswered by SP					1%	1						
Total	Family	Social support from family, friends or advocate	10%	2			1%	1						
	self	Social support from family, friends or advocate					1%	1						
Total			100%	20	100%	37	100%	72						

** Missing questionnaire data for two cases (2019-20 reports – 72/74)

Cause of in-scope reportable deaths

Table 22: Cause of in-scope reportable deaths by ICD10 Chapter

In-scope for CCOV	CORR cause of death (group)	2017-18	2018-19	2019-20	Total
Not indicated	Unknown or non-reportable			4 100%	4 100%
No	Respiratory system diseases			2 13%	2 5%
	External causes of morbidity		1 6%	1 6%	2 5%
	Unknown or non-reportable	7 100%	15 94%	13 81%	35 90%
Yes	Respiratory system diseases	5 38%	6 29%	20 37%	31 35%
	Circulatory system diseases	5 38%	7 33%	8 15%	20 23%
	Neoplasms		2 10%	6 11%	8 9%
	Digestive system diseases		1 5%	3 6%	4 5%
	Congenital malformations, deformations and chromosomal abnormalities		1 5%	1 2%	2 2%
	Nervous system diseases	1 8%	1 5%	7 13%	9 10%
	External causes of morbidity			4 7%	4 5%
	Genitourinary system diseases		1 5%		1 1%
	Injury, poisoning and certain other consequences of external causes		1 5%		1 1%
	Unascertained by the Coroner	2 15%	1 5%		3 3%
	Unknown or non-reportable			5 9%	5 6%
Total		20 100%	37 100%	74 100%	131 100%

Deaths relating to respiratory disease, choking or aspiration of food

Table 23: Living arrangements

Service activity	2017-18		2018-19		2019-20	
Shared supported Accommodation	80%	4	100%	6	90%	18
Respite	20%	1			5%	1
Individualised Support Packages					5%	1
Total	100%	5	100%	6	100%	20

Table 24: Gender

Gender	2017-18		2018-19		2019-20	
Female	20%	1	33%	2	40%	8
Male	80%	4	67%	4	60%	12
Total	100%	5	100%	6	100%	20

Table 25: Age

Age	2017-18		2018-19		2019-20	
10–19 years	20%	1				
20–29 years	80%	1				
30–39 years			17%	1	5%	1
40–49 years			33%	2	25%	5
50–59 years	40%	2	33%	2	50%	10
60 years and over	20%	1	17%	1	20%	4
Total	100%	5	100%	6	100%	20

Table 26: Recorded assessment of intellectual disability

Intellectual disability flag (group)	2017-18		2018-19		2019-20	
No intellectual disability recorded	40%	2			5%	1
Yes, intellectual disability recorded	60%	3	100%	6	95%	19
Total	100%	5	100%	6	100%	20

Table 27: Recorded mealtime support needs

Eating assistance (group)	2017-18		2018-19		2019-20	
Always require assistance with eating or drinking	60%	3	33%	2	60%	12
No feeding issues, could eat independently	20%	1	50%	3	15%	3
Sometimes required assistance with eating or drinking			17%	1	20%	4
Unknown	20%	1			5%	1
Total	100%	5	100%	6	100%	20

Safe Mealtimes

Always follow the person's mealtime support plan

Before you start remove any unnecessary distractions

- 1 Check the person is alert and sitting as upright as possible
- 2 Offer small amounts of food
- 3 Wait for food to clear from the person's mouth before offering more

Never leave people alone while eating or drinking



IF YOU OBSERVE

- Difficulty swallowing
- Choking or gagging
- Persistent coughing
- Bringing food back up
- Wet 'gurgly' sounding voice or breathing

**Call ambulance
000**

**Nurse on Call
1300 60 60 24**

**Other important
numbers**

Let's talk about Safe Mealtimes

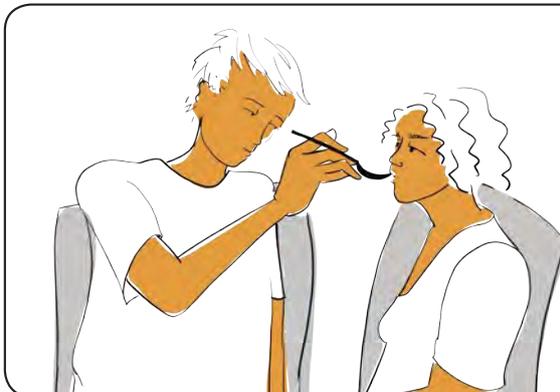
Remember it is always better to be safe than sorry
If you see the signs you must do something, your actions could save a life.

1. Does everyone have a mealtime support plan? If not, do you know who needs one?
2. Do you know where to find a person's mealtime support plan?
3. Who needs to have access to the person's mealtime support plan?
4. Is there anything getting in the way of you following the steps in the Safe Mealtime poster?
5. Have you noticed anything different or something that concerns you when supporting someone during mealtimes?
6. Is it time to review their mealtime support plan?
7. Who would you talk to about this?
8. What action would you take next and how would you document this?
9. How would you make sure actions have been followed up?

Actions:

..... / /

NOTE: This is an important area of support. Consider further training or professional development by a speech pathologist.



Always follow the person's mealtime support plan

1. Check the person is alert and sitting as upright as possible
2. Offer small amounts of food
3. Wait for food to clear from the person's mouth before offering more



Let's talk about safe mealtimes

Remember it is always better to be safe than sorry.

If you see the signs you must do something - your actions could save a life.

1. Does everyone have a mealtime support plan?
If not, do you know who needs one?
2. Do you know where to find a person's mealtime support plan?
3. Who needs to have access to the person's mealtime support plan?
4. Is there anything getting in the way of you following the steps in the Safe Mealtime poster?
5. Have you noticed anything different or something that concerns you when supporting someone during mealtimes?
6. Is it time to review their mealtime support plan?
7. Who would you talk to about this?
8. What action would you take next and how would you document this?
9. How would you make sure actions have been followed up?

NOTE: This is an important area of support. Consider further training or professional development by a speech pathologist.



Date of the meeting:	
Follow up actions	Who