Disability Services Commissioner

2020-21 Annual Report

Including

A review of disability service provision to people who have died 2020-21





Disability Services Commissioner

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A review of disability service provision to people who have died 2020–21

The Disability Services Commissioner is an independent oversight body resolving complaints and promoting the right of Victorians with disability to be free from abuse

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.



9 September 2021

The Hon. James Merlino MP Minister for Disability, Ageing and Carers Level 22, 50 Lonsdale Street Melbourne VIC 3000

Dear Minister,

Pursuant to s. 19 of the *Disability Act 2006*, I am pleased to provide you with the Disability Services Commissioner annual report for the financial year 2020-21.

As requested by the Ministerial referral in June 2020, the *Review of disability* service provision to people who have died 2020-21 is included in this report.

Yours sincerely,

Treasure Jennings

Disability Services Commissioner

Disability Services Commissioner

L30, 570 Bourke Street Naarm/Melbourne VIC 3000

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Disability service

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

Disability service providers

Refers to 'disability service providers' and 'regulated service providers' as defined in the Act. The Act defines these as follows:

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

Enquiry

Where a person contacts us seeking information or advice about their concerns. This is not a complaint.

Finalised

A matter that has been completed or closed.

Group Homes

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

Incident reports

Matters referred to us from DFFH as per the referral from the Minister.

In-kind supports

Services to people with disability that continue to be funded by the Victorian Government until such time as those services and supports fully transfer to the NDIS. These supports are known as 'in-kind' supports.

In-scope

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

The Minister

Minister for Disability, Ageing and Carers.

NDIA

National Disability Insurance Agency.

NDIS

National Disability Insurance Scheme.

NDIS Commission

NDIS Quality and Safeguards Commission.

Notice of Advice

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

Notice to Take Action

A Notice to Take Action (NTTA) can be individual or systemic. It is a direction to take action that we have issued to a disability service provider, the Secretary and/or the Minister after an investigation.

This notice specifies actions that are required to be undertaken to resolve issues identified during the investigation and improve services and/or prevent abuse and neglect.

Open

A matter still active or in progress.

Out-of-scope

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

Resolved

Where the person who made the complaint decides that the issue/s have been addressed.

Review

An inquiry into or consideration of a matter or incident. The process includes seeking further information or documentation, and determining what actions we, or another person or entity should take, if any, to address or respond to a matter or whether to investigate the matter

Referrals

Matters referred to us from a variety of sources including the Minister, the Secretary of DFFH, State or the Community Visitors Board. This term also covers matters we refer on to other bodies.

Safeguarding body

Any agency or organisation with responsibility to oversee supports and services provided to people with disability.

The Secretary

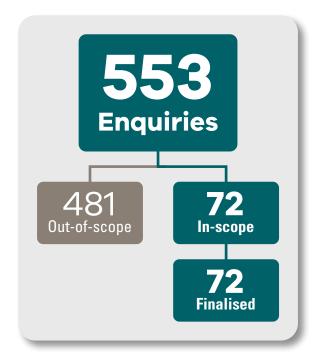
The Secretary of DFFH.

VDWC

Victorian Disability Worker Commission.

Our year in summary

Figure 1: Our year in summary





*103 received in 2020-21 + 9 carried over from 2019-20



*7 carried over from 2019-20





*404 received in 2020-21 + 70 carried over from 2019-20



***95** received in 2020-21 + **118** carried over from 2019-20

Message from the Commissioner

It is with great pleasure that I present my first report as Victoria's Disability Services Commissioner and it is a privilege to be appointed to this role.

This year has again been one of significant changes, challenges, and opportunities for people with disability, their families, and the Victorian disability sector. The impact of COVID-19 and the extended lockdown periods in Victoria throughout this year cannot be overlooked, with many people with disability reaching out to my office expressing distress at, and seeking clarification of, the measures being undertaken by the Department and providers. Information about the complaints and enquiries we received in relation to COVID-19 can be found throughout this report.

The year also saw the culmination of significant changes with the finalisation of the transfer of the five remaining group home providers operating under 'in-kind' arrangements with the Department of Families, Fairness and Housing (DFFH) throughout February to May 2021. The NDIS Quality and Safeguards Commission (NDIS Commission) continued regulating quality and safeguards in Victoria for people who are participants in the NDIS. This final transfer to the NDIS now means that there is a significantly reduced jurisdiction for the Disability Services Commissioner (DSC) from June 2021.

The remaining role of the DSC continues to be resolving complaints and promoting the right of people with a disability to be free from abuse. We retain oversight of DFFH funded and contracted services such as disability justice and advocacy organisations. We also take complaints about DFFH registered service providers who are delivering supports to TAC funded clients.

As part of ensuring the knowledge gained by the DSC continues to impact and influence system improvements, I undertook to release a third Occasional Paper from this office on our work reviewing and investigating the circumstances of people with disability who have died and were reported to our office by DFFH and the State Coroner. More information about this paper is outlined on page 31 of this report. In reviewing this work of the DSC over three and half years of undertaking these reviews, we learned that understanding how a person lived was just as important as understanding how they died in ensuring quality care and safety. This year, the DSC has issued 14 Notices to Take Action from our work reviewing deaths and I believe that there is still a role for this level and type of review to continue.

I encourage service providers, regulators, families and carers to review this Occasional Paper along with the annual reporting of these reviews on <u>pages 21–31</u> of this report, so further work can continue to improve safety of care, particularly in relation to mealtime support, and that qualitative improvements can continue to be realised.

Complaints to my office suggest people continue to speak up and seek to improve the NDIS system, and I welcome the Federal government decision to review the role of Independent Assessments. Additionally, the extension to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability (Disability Royal Commission) will ensure that as many voices as possible can be heard and views considered before recommendations are delivered. It is vital that the experiences and voices of people with disability are heard, and that quality and safeguarding measures continue to be responsive into the future.

The Victorian Disability Worker Commission (VDWC) commenced operation from 1 July 2020. Strengthening oversight of Victorian disability services and staff is a shared responsibility and we have continued to value the highly constructive relationships we have forged with the VDWC, the newly formed Department of Families, Fairness and Housing and the Victorian branch of the NDIS Commission. I acknowledge that the transition to, and development of, new oversight bodies can be confusing for everyone, however the collective approach of the Commissioners has been one of supporting people with their enquiries and offering referral options as much as possible, as well as sharing learnings and insights.

I thank the Minister for Disability, Ageing and Carers, the Hon. Luke Donnellan MP, as well as Georgina Frost, President of the Disability Services Board, and members, for their continued support of the work of this office. I acknowledge their commitment to improving safeguards and increasing opportunities for people with disability. I also acknowledge the ongoing collaborative relationship with the State Coroner and the Public Advocate in the work of the DSC, and thank their staff for their ongoing professionalism and commitment.

Finally, I want to thank the DSC team, and especially the Acting Deputy Commissioner, Samantha Dooley, for their continued high standard of work and ongoing care of, and committment to, people with disability, their families, and carers. Operating the office remotely is extremely challenging. The largely seamless way the DSC has functioned this year is testament to their professionalism, integrity and strong sense of purpose.



Treasure Jennings *Disability Services Commissioner*

Message from the President of the Disability Services Board

The Disability Services Board (DSB) met regularly to consider quality and safeguarding issues facing people with disability in the Victorian disability service sector, particularly wider sector issues with the final transfer of in-kind group homes to the NDIS, and the newly formed Department of Families, Fairness and Housing (DFFH).

Throughout the year we worked closely with the DSC and other organisations to improve outcomes for people with disability, including implementing plans to ensure the activities of the DSB could continue, despite the ongoing impacts of COVID-19.

In performing its role, the board consulted with various stakeholders including the DFFH, NDIA, NDIS Commission, VDWC and the Minister for Disability, Ageing and Carers to influence system improvements and to ensure no Victorian with disability fell through the safety net.

Part of this work included monitoring Victoria's transition to the NDIS during the cash out process. We continued to work with other safeguarding bodies and provided guidance on key issues such as safer mealtime supports. The DSB also raised emerging issues and trends with Minister Donnellan to ensure any future change to disability legislation strengthens safeguards on key issues, especially preventable deaths of people with disability.

We received regular briefings from DFFH regarding the regulatory reform to the disability sector. We also commenced a process to review and evaluate the efficacy of the DSB and to consider what learnings could be used by the social services sector when the DSC winds back and safeguarding is moved to other bodies.

On behalf of the board, I would like to thank Treasure Jennings, and congratulate her on her first full year as Disability Services Commissioner.

The term of the DSB has been extended to coincide with Victoria's transition to the NDIS and DSC's continued role. I thank my fellow board members for their ongoing dedication to improving the safety and quality of Victorian disability services.

The board members are:

Argiri Alisandratos

Christian Astourian

Karen Cusack

Glenn Foard

Helen Kostiuk

Jill Linklater

Rocca Salcedo Mesa Professor Ruth Webber

Bryan Woodford OAM



Georgina Frost President, Disability Services Board

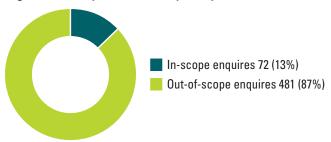
Enquiries

An enquiry is recorded by the DSC when a person contacts us seeking information or advice about their concerns. An enquiry can take up to 45 minutes to support people through the complexities of the transitioning disability sector.

In 2019-20 we had a total of 750 enquiries.

This year we received 553 new enquiries; 72 were in-scope and 481 were out-of-scope.

Figure 2: In-scope / out-of-scope enquires



Why have enquiries reduced?

The DSC jurisdiction decreased dramatically as new safeguarding bodies increased their influence in Victoria. The new safeguarding bodies, including the NDIS Commission and the VDWC, increased the promotion of services to Victorians, and so more people became aware of who else may help with their enquiry.

With most providers already transferred to the NDIS, and the final transfer of in-kind providers scheduled for February to May in 2021, the DSC expected that a high number of enquiries would still relate to NDIS funded services, and so be out of our jurisdiction. Understanding this trend, the DSC updated our phone system so that callers could self-select to be transferred to the NDIS Commission if their call related to a NDIS funded service. These calls were not counted in our total number of enquiries.

401 calls were diverted to the NDIS Commission through our updated phone system.

Why have our enquiries continued?

The disability sector is undergoing significant changes and there are now multiple safeguarding bodies in Victoria. Despite efforts by safeguarding bodies to promote their role and jurisdiction, some confusion remains as people are sometimes unsure about where they should go with their enquiry. Because the DSC has been active in the Victorian disability sector since 2007, many people are aware of our organisation and trust our ability to help. In many cases, people who have previously raised issues with us contact us again to seek advice and information about how to solve a problem they are facing.

Out-of-scope enquiries

Where have we directed people

A majority of enquiries (87%) are out-of-scope, meaning the DSC does not have the legislative authority to deal with enquiries we receive. Enquiries may relate to other state or territory jurisdictions who have their own safeguarding bodies in place.

This year the DSC provided the contact information for a broad range of safeguarding bodies on 478 occasions. The DSC commonly directed enquiries to:

Table 1: Top three Commonwealth bodies we referred to*

NDIS Commission	98
Commonwealth Ombudsman	29
National Disability Insurance Agency	25

^{*} Some enquiries involve directing people to contact more than one safeguarding body.

Table 2: Top four Victorian bodies we referred to*

Victorian Equal Opportunity and Human Rights Commission	35
Victorian Ombudsman	22
Health Complaints Commissioner	20
Victorian Disability Workers Commission	14

^{*} Some enquiries involve directing people to contact more than one safeguarding body.

Enquiries and COVID-19 State of Emergency

The DSC handled many enquiries relating to the impact of the COVID-19 pandemic from people with disability or their families. We directed people to the relevant pages on government websites and shared information about the topics they spoke about.

These enquiries were about:

- getting different or additional support and the impacts of isolation
- services closing, reducing, or imposing restrictions or limits
- wearing masks
- requirements for disability support workers to limit the number of locations where they work
- utilising funds in different ways and wanting approval
- visiting and keeping in contact with loved ones in group homes
- access to vaccine and experiences at vaccine centres.

In-scope enquiries

When dealing with in-scope enquiries we talk to people about our complaint handling processes and answer their questions. Many people contact the DSC for a discussion when they are preparing to raise their concerns with the service provider. Our coaching and suggestions always encourage the person to be clear with the service about the issues of concern, and where possible, think about the outcome they are seeking through the complaint process. We talk about the 'Four As' as a framework for resolution of complaints and ask people to consider if they are looking for:

- Acknowledgement
- Answers
- Actions
- Apology

If the person wished to make a complaint through the DSC, or was unable to resolve it with their provider, we would proceed to handle their concerns as a complaint.

CASE STUDY

In-scope enquiry

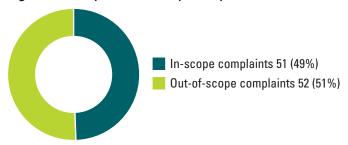
A mother rang the DSC about the situation for her son who was receiving personal care from a disability service provider still in-scope for DSC. She wanted to prepare for a meeting the next day with the provider, and she used the phone call with the DSC to develop clear points that she wanted to raise. The DSC also helped her to explore what she wanted to achieve for her son, which was to develop clear instructions and training for new team members coming onto her son's care program. At the end of the discussion she stated that she felt more confident about how best to raise her concerns directly with the provider.

Complaints

Similar to last year, we have had a further reduction to the jurisdiction and the number of complaints has reduced accordingly.

This year we received a total of 103 new complaints; 51 in-scope and 52 out-of-scope.

Figure 3: In-scope / out-of-scope complaints



This year the DSC carried over 9 complaints from 2019-20 and we will carry over 7 complaints into 2021-22.

Last year the total number of new complaints was 118, with 73 in-scope and 45 out-of-scope.

In-scope complaints were assessed in accordance with the Disability Act 2006 (the Act). Two preliminary assessments took longer than the legislated 90-day period. The Commissioner considered that this was reasonable because of the complexity of the complaints and COVID-19 restrictions including lockdown measures making it difficult for service providers to complete the required actions. These complaints remain open and have been carried over into 2021-22.

Table 3: Who contacts us - top three complaint contacts

Service user	22	21%
Family	38	37%
Staff	7	7%

The percentage of complaints coming directly from people with disability has gone up from 17% in 2019-20, to 21% in 2020-21.

Families, parents, carers and guardians have continued to be the primary source of complaints (37%), showing the important role that families play in supporting and safeguarding people with disability.

This year saw a decrease in the number of staff members who contacted the DSC regarding complaints about service providers or situations to 7%, down from 19% last year. We also noticed a reduction in contact from Support Coordinators seeking guidance about how to navigate the system.

Out-of-scope complaints

We formally escalated 52 out-of-scope complaints in 2020-21.

Due to their serious nature, the DSC determined that is was appropriate to refer these complaints to another body to ensure the matter was addressed promptly.

Figure 4: Steps involved with DSC referral process

- DSC checks if this is related to a previous contact, and if this complaint is in our jurisdiction.
- 2 DSC communicates with the complainant and seeks consent to consult and make a referral.
- DSC consults with the organisation/s that may be best to deal with the complaint.
- DSC makes a referral in writing and asks for confirmation of acceptance in writing.

 DSC lets the complainant know a referral has been made and accepted.

Out-of-scope issues that required referral to another body

- serious issues
- may involve allegations of abuse and neglect
- the complainant may have spent a lot of time working through the details of their concerns
- the complainant had contacted numerous places before reaching the DSC and had not found someone to address their concerns
- the complainant has been identified as vulnerable through marginalisation or requiring additional support.

Where we have directed out-of-scope complaints

Of the 52 out-of-scope complaints we received, we made 70 written referrals this year, with 21 going to the NDIS Commission. Last year, we made 47 written referrals of which 32 were to the NDIS Commission. We attribute our improved phone system and the NDIS Commission's ongoing engagement activities with the reduction this year in direct referrals from the DSC to the NDIS Commission.

An out-of-scope complaint may require a written referral to more than one safeguarding body. Where relevant, the DSC ensures each body is aware of multiple referrals from a single complaint.

Table 4: Written referrals made to another body

NDIS Commission	21
DFFH – Disability services (including IST)	12
Victorian Disability Worker Commission	8
Other	8
National Disability Insurance Agency	6
DFFH – Supported Residential Services	5
Mental Health Complaints Commissioner	3
Health Complaints Commissioner	3
Office of the Public Advocate	2
Victorian Senior Practitioner	2

Of note, the DSC recognises the importance of the role and work of the DFFH Intensive Support Team (IST). We made a number of referrals to this team in 2020-21 where additional coordination was needed between multiple providers in complex situations.

In-scope complaints

What types of complaints have been in-scope for the DSC?

There have been 51 new in-scope complaints this year.

The majority of in-scope complaints have been about the in-kind group homes prior to their transfer to the NDIS. Other topics included complaints about Forensic Disability Programs and TAC funded disability services.

Of the 51 new in-scope complaints we handled, 34 were about in-kind services, 15 about Community Service Organisations and two about DFFH.

Table 5: Top in-scope complaint issues*

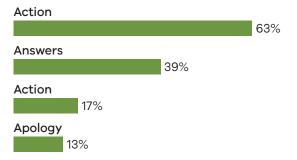
Service quality	24	46%
Group supports	14	27%
Policy/procedure	10	19%
Communication quality	9	17%
Staff related issues	6	11%

^{*} A complaint can contain more than one issue

How have complaints been resolved?

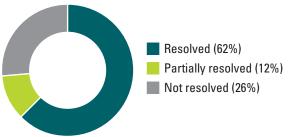
This year, 62% of complainants indicated they accepted their complaint as resolved, 12% of complaints were partially resolved and 26% indicated they were not satisfied that their matter had been resolved. Not resolved complaints include those that were withdrawn or referred to another body for further review. Overall these rates of resolution are similar to those of previous years.

Figure 5: Top ways in-scope complaints were resolved using the Four As approach*



^{*}Multiple responses are possible so figures may not add up to 100%

Figure 6: Resolution rates for finalised in-scope complaints



^{*}When percentages do not add up to 100% this is due to rounding.

CASE STUDY

In-scope complaint COVID-19 impact

practices in a service aimed at keeping residents safe during the COVID-19 pandemic. The complaint highlighted inconsistent practices between staff in infection control measures and use of personal protective equipment (PPE). In response to the complaint, the service undertook a review at the specific group home and recognised specific improvements. They also implemented an audit across all of their group homes so they could remind staff of expectations and address any service-wide inconsistencies.

Notices of Advice from complaints

This year the DSC issued four Notices of Advice compared to six last year. In two complaints a Notice of Advice was provided to the service provider and complainant.

These Notices covered issues relating to collaboration with health services, incident management and the procedures for investigation and root cause analysis.

The DSC also issued a Notice of Advice to a provider where there was an opportunity to improve the providers internal complaints system. The DSC asked the provider to use the following two resources within their review process for their complaints system:

- 10 useful tips for an effective complaints policy and procedure
 - www.odsc.vic.gov.au/resources/educational-materials/
- Effective Complaint Handling Guidelines for NDIS Providers

www.ndiscommission.gov.au/document/1081

Both resources were identified as the provider works across both state and Commonwealth jurisdictions.

Within the DSC Notice of Advice, the provider will be asked to report back with details of the actions they have taken within a set timeframe. When the DSC has confirmation about the actions taken, a final review occurs to ensure the actions meet the expectations set in the Notice of Advice.

Oversight of Incidents

Through successive Ministerial Referrals, the DSC has had a role in oversight into category one/major impact incident reports. This year only services funded by DFFH remained in the DSC jurisdiction for incident reviews.

The DSC received 404 new incident reports in 2020-21. Last year DSC received 372 new incident reports.

This year DFFH submitted a batch of 48 incident reports which related to incidents that happened in 2019-20. There was a delay in processing by DFFH and these reports were classified as historical. The delay in the DSC receiving these reports impacted the capacity of the DSC to follow up with the service provider in a timely manner. These incidents have been reviewed and included in the overall number of incidents reviewed for this year.

To prevent any similar delays occurring, the DSC worked with DFFH to create a safeguard mechanism whereby there were monthly check-ins on all incident reports. This ensured all incident reports were reviewed in a timely manner.

In addition to the 404 new incident reviews, the DSC carried over 70 reviews from last year making a total of 474 incident reviews to be managed this year. At the completion of the year, we finalised 429 reviews, ensured 2 out-of-scope reviews were notified to the NDIS Commission and will carry over 43 reviews into next year.

Of the 402 new in-scope reviews, the top three categories were:

- injury 45% (injury and unexplained injury together)
- physical abuse or assault 27%
- poor quality of care 24%

Allegations of abuse or assault with a sexualised nature make up a small number of incidents reviewed by the DSC. This equated to less than 6% of the incidents received.

Consulting with the Victorian Senior Practitioner

In a number of incident reviews, the DSC consulted with the Victorian Senior Practitioner (VSP). The DSC can ask VSP to review a Behaviour Support Plan. On occasion their review can lead to a Behaviour Support Plan Quality Evaluation II (BSP-QEII) or a full review of the person's behaviour support.

Consulting with the Victorian Disability Worker Commission (VDWC)

With incidents relating to poor quality of care or allegations of assault that involve a worker, the DSC will ask the provider if they have considered or made a notification to the VDWC. When the DSC receives a copy of a Quality of Support Review (QoSR), and the outcome of the investigation finds allegations against a staff member is substantiated, the DSC will consult with the VDWC to confirm that a notification has been made prior to finalising our review process.

CASE STUDY

Involvement of Victorian Senior Practitioner

Two residents of a group home were involved in a physical altercation. The incident report described that staff were unable to successfully implement any behaviour strategies to de-escalate the situation. This resulted in staff retreating and isolating themselves, leaving all residents in the house without support.

The DSC consulted with the VSP to understand if there were Behaviour Support Plans (BSP) in place and if a BSP-QE II had been undertaken. The VSP assessed the plans and decided that they would conduct a clinical review.

Consulting with the NDIS Commission and NDIA about incidents

When the DSC received out-of-scope incident reports we ensured that the incident had been reported to the NDIS Commission.

In one review, the provider's follow up actions resulted in recommendations including the engagement of specialised services for a resident. The DSC alerted the NDIA to the incident and asked them to consider the recommendations in the NDIS plan review process that was already underway. These recommendations were made to better support the resident and add further protection to other residents at the house.

PRACTICE CHALLENGE

Investigation processes where the staff are from another agency

The DSC has seen a number of situations where incidents and allegations may involve staff from another agency who have been contracted to work in a group home for a shift. In many cases the resident will request that the agency staff not return to the group home. The service may decide to not have that agency staff member back to their service at all.

The agency staff member is not always included in the service provider's investigation. It is not always clear that the agency is alerted to the seriousness of the incident. This increases the risk that an allegation of abuse or poor quality of care will be unsubstantiated, not investigated appropriately and other services will be unaware of any previous allegations against that staff member.

The DSC reminds all service providers and safeguarding bodies to adhere strictly with state and Commonwealth reporting requirements so that no oversight gaps exist across the sector in investigating matters relating to quality and safeguarding.

Higher number of injury reports

Of the 402 in-scope incident reports reviewed by the DSC, 159 (40%) related to injury. This can be compared to 121 (33%) the year before.

Many of these incidents described falls which occurred in the group home or whilst the person was being supported in the community. The injuries sustained included bruising, sprains, laceration requiring sutures and various fractures.

Falls charts were used by some service providers, usually for older people with disability, where the person had experienced numerous falls or sustained a significant injury, but not for isolated incidents.

The DSC refers to the practice advice when reviewing incidents related to falls and confirms either with the service provider, or in consultation with DFFH, that the service providers have implemented falls minimisation strategies as part of their intended follow-up actions. The DSC checks that declining mobility in a resident is documented and that the decline is addressed with the appropriate health professionals.

In early 2021, DFFH published practice advice on falls minimisation for disability support workers supporting residents in group homes.

https://providers.dffh.vic.gov.au/practice-advice-falls-minimisation-disability-support-workers-supporting-residents-group-homes-word

CASE STUDY

Falls risk and prevention

Bram* had a seizure and fell hard on the floor of his group home. Bram's thumb was injured. Staff immediately applied first aid for the bleeding and called paramedics who transported him to hospital. Surgery was needed for the thumb injury.

After the incident an Occupational Therapist review was organised, a falls risk assessment was completed and all staff were updated regarding his changing support needs. An appointment with Bram's neurologist was also booked as it was noted this type of fall following a seizure was rare for him. The DSC reviewed these actions and was satisfied the service provider had followed up appropriately.

Reviewing Community Visitor Board referrals

In accordance with the Ministerial Referral, the DSC receives referrals of matters relating to abuse and neglect from the Office of the Public Advocate's (OPA) Community Visitor Board (CVB). These matters are in addition to our 402 new in-scope incident reports.

This year we received 51 CVB referrals relating to five service providers. The providers were the in-kind services that had yet to transition to the NDIS. This compares with 63 referrals relating to 15 service providers in the previous year.

In 2020-21 these referrals were rated by the CVB as:

- 19 high risk
- 14 medium risk
- 18 low risk

The information contained in these referrals was considered in any related DSC complaint, incident report or investigation.

Importantly, one of these CVB referrals led to the DSC making a referral to the DFFH Intensive Support Team so that the resident could receive additional support to explore accommodation options.

Another CVB referral lead to the DSC consulting with the Victorian Senior Practitioner who agreed to review the quality of a resident's behaviour support plan in order to seek opportunities for improvement and address concerns about incidents between residents in the group home.

In another referral the DSC sought further information from the CVB program which lead to DFFH undertaking a review of a group home's incident reporting and categorisation. This resulted in a number of reports being upgraded and further attention given to a sequence of injuries sustained by a resident.

The DSC and OPA have continued to meet and discuss actions on referrals and changes in the sector during 2020-21.

The DSC acknowledge the contribution of the Community Visitors who provide an incredibly valuable insight into the sector.

^{*} Names and details have been changed

Investigations

Investigations continued to be an important and valuable part of our work. Our investigations relate to either complaints of a serious nature that are not suitable for conciliation, matters identified during our review of critical incidents, or where there are allegations of persistent or recurring systemic abuse or neglect in the provision of disability services.

This year, the DSC continued to work on seven investigations carried over from last year. Five of these were finalised:

- Two Commissioner Initiated Investigations (s. 128B)
- Two complaint investigations (s. 118)
- One referred from incident review (s. 1281)

Due to the decrease in jurisdiction, no new investigations were commenced. A contributing factor to this reduction is likely because the service providers that remained within jurisdiction continued to establish internal investigation processes and quality units, including the use of external investigators when appropriate, as they prepared to transfer fully to the NDIS. Additionally, all transfer providers have had a high level of oversight not only from the DSC but also from both the DFFH, the NDIS Commission and the VDWC throughout the year.

Of the investigations finalised, all contained issues related to service quality and individual supports. Incident management, poor communication, and poor staff supervision and training were also prominent in 60% of these matters.

Investigations assessed the quality of support and services in 24 homes across five service providers.

Investigation methodology in 2020–21

In conducting investigations, the DSC reviewed all processes to ensure compliance with the necessary COVID-19 requirements, should Authorised Officer visits be required. While no Authorised Officer visits were conducted in this time, more than 30 direct interviews with people with disability, their families/carers, staff, service providers and expert advisors were held via a combination of face-to-face, telephone conference or online methods to inform finalised investigation outcomes.

Investigation partners

Quality and safeguarding requires a multi-service approach. In finalising our investigations, the DSC continued to consult with our external partners including the Office of the Public Advocate (OPA) and the Community Visitors Board, the Coroners Court of Victoria, and the Transport Accident Commission (TAC).

Investigations in 2021–22

We will carry over two investigations into next year:

- One Commissioner Initiated Investigation (s. 128B)
- One referred from incident review (s. 1281)

Investigation outcomes

A single Notice to Take Action (NTTA) was issued for only one investigation and the DSC continued to take a practical and responsive approach with providers. This included working with service providers to identify issues requiring immediate actions concurrent with the investigation process, hence reducing the number of final NTTAs needing to be issued.

Investigation outcomes included the development of extensive service improvement plans as a result of three investigations, which recognised the long-term investment required to ensure systemic improvement. Additionally, specific staff training to address essential individual support needs was delivered in two investigations.

CASE STUDY

Person-centred interviews

Hearing the perspective of the individual is critical in any investigation. With the support of a communication specialist familiar with residents in a group home, the DSC met directly with each of the residents to gain their views and perspectives on the issues raised in our investigation. A variety of communication tools were used so that individuals felt calm and understood that they could end the interview at any time. In preparing for these interviews, the following questions were considered:

- has the person with disability been asked about their experience and supported to tell their story?
- have they been asked what they need to feel supported and safe?
- have they had their experience acknowledged?
- has their experience of trauma been acknowledged?
- has their history, including any history with police that may further impact them, been acknowledged?
- has the support plan been reviewed for any reference to related issues or supports?
- who is able to speak for and make decisions on their behalf, if they are unable to?
- what should be the involvement of family members or advocates.

Education, information and training

This year, the DSC continued to take an active role in providing information to people with disability, families, advocates and the Victorian disability sector about the importance of speaking up as a means of improving disability services during a time of ongoing sector change and COVID-19 challenges.

The DSC maintained strong working relationships with other safeguarding bodies, meeting regularly to discuss emerging issues and trends, and to ensure responsive communication between organisations.

We continue to work on providing information that is evidence-based, accessible and reflective of the work undertaken by the DSC to support improved practice across the sector. In 2020-21 we were pleased to see the finalisation and distribution of our 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, and the ongoing promotion work for the Safe Mealtimes Poster.

The DSC were also active in sector meetings, working with other bodies to help develop and promote new resources.

DSC complaint handling resources are a valuable collection of tools for developing an effective personcentred complaints resolution system. We continue to work alongside and share these resources with people with disability, families, national peak bodies, service providers and advocacy organisations as a sound practice approach that they can tailor to suit their needs.

Sharing resources and learnings

Through our engagement with people with disability, their families, supporters, carers and others, the DSC is continuing to evolve the way we distribute our content to ensure the key message 'It's OK to complain!' is heard and seen by as many people in the disability sector as possible.

Providing clarity about how and where to make complaints has always been a key focus for the DSC, spanning across all our communication channels including website, newsletter, and social media.

We distributed our digital newsletter to approximately 3000 people involved in the disability sector and while the role of the DSC is reducing, we have sought to promote information about important activities in the sector including:

- the VDWC
- in-kind group home transfer to the NDIS
- Accessible parking permit changes
- Disability Royal Commission updates.

CASE STUDY

Coaching family to be involved

Mark* is a 61-year-old man with a moderate intellectual disability, who is unable to communicate verbally but expresses himself through facial expressions and vocalisation. He lives in a group home in Melbourne where he has lived for over ten years. His brother John lives a few hours drive away and is his closest living relative. Despite living far away, John visits Mark as regularly as he can, at least twice a year.

After their mother died, John took on the role of advocate and next of kin for Mark. This role was complicated by John living in a different region during the COVID-19 lockdowns which prevented him from visiting Mark in 2020.

John called the DSC with concerns about a recent diabetes diagnosis his brother had received. John was concerned because he had received conflicting information from staff at the house when he called there to check on Mark.

After confirming the house was still in jurisdiction, the DSC followed up with the service to confirm the updated medical diagnoses, and any outcomes such as changes to care needs for Mark, and encouraged the service provider to follow up with John about his concerns.

John wanted answers, including information about how Mark was diagnosed, if there were any changes in his behaviour in the lead up to the diagnosis, and what allied health assessments (such as a dietician) were provided. John asked for an apology based on the amount of time left with unanswered questions about the change to his brothers' health.

The service provider of the group home responded quickly to John with a letter of apology, a detailed timeline about the situation leading up to the diagnosis, details about when and how the diagnosis was confirmed and their immediate response to it, including follow-up actions such as allied health treatment.

Before closing this case, the DSC checked in with John to ensure his concerns had been addressed. He remained concerned about his brother as he only saw him twice a year, and though he is non-verbal, he shows recognition of his voice. The DSC provided John with coaching about what he could do to be a bigger part of Mark's life.

Part of the coaching included details on his rights to have copies of service agreements, be updated on any changes such as injury or illnesses or participation in new activities, or if Mark has a new interest in something. John is now noted as a primary contact in Mark's file and is kept updated on anything new in his life.

To help John increase his contact with Mark while travel was not an option, the service provider arranged for Mark to get an iPad so the brothers could still catchup virtually. The group home also used the iPad to send John photos of new activities Mark participated in so he could use these as a conversation point.

John provided positive feedback to the DSC and explained that he is very pleased with the communications with the home, who now call him with updates, and have created set times for video calls. John noted that he's really happy to be more involved in Mark's life. In particular he notes that Mark shows joy when on the iPad with him and John can talk about and use visual prompts about the activities and hobbies in which Mark is participating.

^{*} Names and details have been changed

Annual Complaints Reporting (ACR) from the sector

This part of our report covers what disability service providers told us about the complaints made directly to them. These complaints are not about NDIS services. The complaint information submitted to the DSC through the ACR process was for services funded by DFFH or TAC.

Which services needed to complete an **Annual Complaint Report this year?**

Only service providers registered or regulated by DFFH were required to provide a complaints report to the DSC in 2020-21. For this year there were 228 providers included in the ACR data collection process.

There were approximately 80 providers who had their registration with DFFH lapse or revoked during the 2020-21 cycle. Those providers with registration for part of the cycle were still required to report for the part of the year they held registration.

The DFFH Secretary wrote to 48 additional service providers, as they were deemed to be exempt from complying with s. 105 of the *Disability Act 2006* which meant that they did not have to participate in ACR reporting.

What information were disability services required to report?

Disability service providers were required to provide a complaints report that detailed the

- number
- types
- outcomes of complaints received, including how they were resolved.

What were the numbers reported?

This year 223 disability service providers submitted a complaints report to the DSC. Of those service providers, 113 (representing 50% of all service providers required to report) submitted a total of 460 in-scope complaints. This included 284 new complaints and 176 complaints carried over from the previous year.

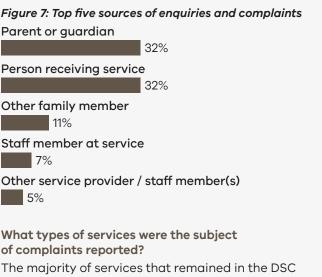
Ten per cent of complaints reported were in relation to TAC funded supports. This is up from 4% last year.

Why were there so many providers with a NIL report?

Many providers told the DSC that although they remain registered, they were not funded to provide disability services by DFFH during 2020-21; 110 disability service providers submitted a NIL report.

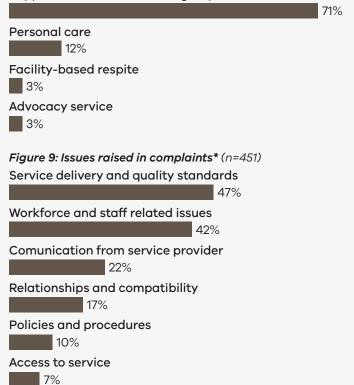
Who made complaints to their service provider?

In 2020-21, parents or guardians and the person receiving the service were the most common sources of complaints (both 32%). Similar sources of complaints were recorded in 2019-20, with 37% of complaints made by a parent or guardian and 28% made by the individual receiving service.



jurisdiction in this cycle were the five transfer providers who took over the group homes formally operated by DFFH.

Figure 8: Top four complaints by service type* Supported accommodation (group or shared)



^{*} Multiple responses are possible so figures may not add up to 100%

What outcomes were achieved from complaints and how were they resolved?

The ACR process is guided by s. 105 and s. 106B of the Disability Act 2006. As a result of conducting the ACR process for 14 years, the DSC has consistently gathered longitudinal complaints data which has allowed us to identify trends and areas of improvement'. The DSC has used this information to:

- look at themes from complaints across the sector
- develop and share resources for the sector
- deliver training and information for people with a disability, their families and staff working at all levels of the disability services sector
- provide advice about how to safeguard people's right to be free from abuse and neglect.

The continued increase in the number of complaints reported by the in-scope service providers is evidence that the proactive provision of training and information by the DSC in response to complaints has improved the complaints culture of service providers who participated in ACR. It also reinforces the importance of the sustained education and training program for service providers undertaken by our office.

Moving forward, it is vital that service providers continue to review their complaints data and use the information provided by clients to improve the experience of those using their services. It is equally important that services invest in promoting a positive complaints culture, where clients are encouraged to provide feedback and complaints directly to the service. If service providers do not invest in their complaints culture, it becomes very hard to deliver quality person-centred disability support as the process for obtaining feedback is effectively removed from those using the service. The DSC encourages services to consider learning from complaints as an essential part of quality improvement.

"A provider must be willing to engage and learn from feedback and complaints in order to be able to work towards best practice in caring for people using their service."

Feedback from a service provider.

Figure 10: Primary ways complaints were resolved using the 4As* (n=401)

Acknowledgement of person's views or issue	57%
Action	46%
Disciplinary action or performance management of staff	15%
Communication issues addressed	11%
Support plan or person-centred plan to be developed or reviewed	9%
Change to way in which support or service was provided	6%
Change or appointment of worker	6%
Answers provided – information or explanations	42%
Apology provided	25%

Table 6: Satisfaction with the management of complaints

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Our service managed the complaint well	23%	44%	31%	2%	<1%
The person who made the complaint was satisfied with how this complaint was managed	14%	33%	47%	5%	1%
The complaint was straightforward to resolve	12%	35%	37%	12%	4%
The person who made the complaint was satisfied with the outcome of this complaint	14%	31%	49%	5%	2%

^{*} Multiple responses are possible so figures may not add up to 100%

Disability Services Commissioner

A review of disability service provision to people who have died 2020-21

Introduction to the death investigation process

The DSC's fourth annual review of disability service provision to people who have died in Victoria is occurring in a time of significant change for people with disability and the sector more broadly.

The introduction of two safeguarding bodies, the NDIS Commission and the Victorian Disability Worker Commission, along with the Disability Royal Commission, the impacts of COVID-19, and changes to the NDIS itself, has had an impact on people in receipt of disability services, families, advocates, disability support staff and service providers. Navigating these times of change and uncertainty can be challenging, however it is imperative that the rights of people with disability are upheld and that continuous improvement remains at the forefront of service provision. Through reviewing a person's death, the DSC is uniquely placed to gain insights into the person's life and provide advice to improve disability services for others.

Why is the DSC jurisdiction decreasing?

The Commissioner's oversight jurisdiction in relation to reviews of disability service provision to people who have died is predicated on service providers being registered under the *Disability Act 2006*. Services that have transitioned to the NDIS are now subject to the oversight of the NDIS Commission.

While the DSC oversight role has decreased, we continue to ensure that appropriate investigative, safeguarding and improvement mechanisms are in place for services that were in-scope prior to transitioning to the NDIS Commission. In accordance with the recently extended Ministerial Referral, we will continue to review deaths that occur within residual disability services provided by the Victorian Government.

The DSC approach and outcomes

In undertaking a death investigation, the DSC considers the quality and appropriateness of the disability services provided to the person who has died. The DSC looks at the way services were provided and how the services may have impacted on the person's health, wellbeing and human rights.

The DSC focuses on providing positive outcomes for people with disability and can direct service providers through Notices to Take Action (NTTA) or Notices of Advice to take necessary steps to address risks to other people who remain in receipt of services. This informs the broader systemic work undertaken by the DSC.

Reviewing disability service provision to people who have died in Victoria commenced in the latter part of 2017 and we have sought to continually improve the DSCs internal processes.

In 2019-20 the DSC introduced a process whereby service providers were asked to undertake their own internal service review. This aimed 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.

This year we sought to further streamline this process by introducing a more responsive and proactive triaging method that includes a priority allocation for high-risk concerns. This update to our process has encouraged immediate action by the service provider, prior to an investigation being conducted by the DSC.

In this financial year the DSC finalised and closed 86 investigations and provided a further 5 finalised investigation reports with a Notice to Take Action to all pertinent parties including the Minister for Disability, Ageing and Carers, Secretary of the Department of Families Fairness and Housing, the State Coroner and the relevant disability service provider. The DSC does not close a case until we are satisfied that the service provider has acquitted all necessary actions. We are reporting on 91 cases in this 2020-21 cycle.



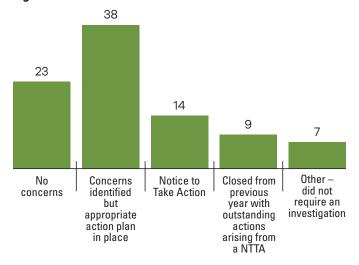
Importantly, in 23 finalised investigations the DSC found that disability services were provided in a manner that sufficiently promoted the rights, dignity, wellbeing and safety of the person who had died.

Additionally, a further 38 investigations were reviewed as having implemented service improvements or had a plan to do so. Therefore, no action by the DSC was required and a NTTA was not issued.

This demonstrates a consolidation of improved practice and a commitment from service providers to continuous quality improvement. It also reflects that we are now working with service providers who are familiar with issues raised in previous investigations and understand concerns in service delivery that require urgent attention and consideration.

The DSC issued 14 NTTAs in this cycle and closed a further nine investigations with outstanding NTTAs 27from the previous year.

Figure 11: Cases finalised and closed



While not all death investigations lead to NTTAs being issued, we found that there is still work to do to improve outcomes for people in receipt of disability services and prevent potentially avoidable or premature deaths. It is a timely reminder that more needs to be done to ensure the safety and wellbeing of people with disability.

The key issues of concern in our finalised investigations were:

- service quality communication supports, mealtime supports, bowel management, behaviour supports
- managing specific conditions health plans, illness prevention and monitoring
- managing deteriorating health
- record keeping.

The DSC aims to honour the lives of people who have died by learning from their lives. This year we prepared our 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. This paper outlines the valuable insights the DSC has gained through death investigations including a summary of the key issues and highlights the importance of an ongoing death review function.

Notifications of 2020-21 deaths

In 2020-21 the DSC received 95 new notifications; 44 of these death notifications were in-scope and 51 out-of-scope for investigation.

Last year (2019-20) we received 134 notifications; 62 of these death notifications were in-scope and 72 out-of-scope for investigation.

Table 7: Notifications of deaths

	2020-21	2019-20
In-scope for DSC	44 (46%)	62 (46%)
Out-of-scope for DSC	51 (54%)	72 (54%)
Total	95 (100%)	134 (100%)

This decrease in the number of notifications reflects the reduction in our jurisdiction, however we note that the percentage of in-scope deaths remained the same as last year.

The last services to transition to the NDIS were group homes previously operated by DFFH, transferred to five non-government service providers, commonly referred to as in-kind service providers. The residents of these group homes remained in the jurisdiction of the DSC until transitioning to the NDIS between February and May 2021. Given group homes were the last to transition to the NDIS it was not surprising that all new death notifications were from accommodation services.

Importantly, services already transitioned to the NDIS continue to work on service improvements if the person who died was in-scope for DSC at time of death.

We are relieved to note there were no notifications of deaths of people with disability due to COVID-19 in jurisdiction. The DSC remained informed of changes such as closure of day programs, visiting rules and increased requirements in relation to infection control. The DSC death investigations did not identify factors determining the impact of the pandemic and associated restrictions on the lives of people with disability living in accommodation services who had died.

The Ministerial referral that directs our work is due to cease on 30 June 2022. This extension will enable the DSC to work towards completion of the 76 carry over investigations, and any new death investigations, to ensure people with disability who are not eligible for the NDIS are provided with an appropriate safeguarding response.

Overview of deaths of people with disability in Victoria

This section provides an overview of data and information we have collected on the deaths of people with disability that were investigated by our office and finalised in this cycle. Data is obtained primarily from the following sources:

- an extensive 70-point questionnaire completed by the service provider
- an internal service provider review that encourages services to identify risks and take appropriate action
- additional documentation we request from service providers within the first month of establishing an investigation to inform our initial risk assessment
- relevant Coronial documents if the death is in-scope for the Coroner
- further information requested from service providers or external bodies to assist throughout the investigation period
- internal DSC documents relating to that person and/or service provider.

If the DSC is provided with an internal service provider review that identifies issues and concerns and outlines how these risks will be addressed through an accompanying action plan, this may lead to a more timely closure of an investigation.

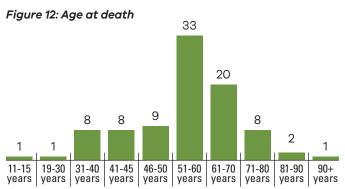
If the DSC receives an action plan and identifies additional opportunities for service improvement, we can request further information, conduct interviews and meet with relevant persons, and ultimately may direct or recommend actions to be taken through a Notice to Take Action or Notice of Advice.

Authorised Officer visits to group homes were not undertaken this year due to COVID-19 restrictions, however virtual interviews were conducted by Senior Review Officers.

Age and gender

In our finalised investigations we found that people with disability in receipt of disability services died approximately 24-28 years younger than the general population of Victoria.

The median age at death for people in receipt of disability services was 55 years for males and 57 years for females, a slight increase from previous years. This data is consistent with Australian and international research and confirms that people with disability in receipt of disability services have a significantly lower life expectancy than the general population. The Australia Bureau of Statistics (ABS) data in relation to deaths registered and received in 2019 shows that the median age at death was 81.7 years (78.8 for males, 84.8 for females). 1



Of the 91 finalised investigations 56% were male, 43% were female, and 1% identified as transgender.

ABS statistics show for deaths registered and received in 2019 that 52.2% of deaths were male and 47.8% of deaths were female. 2

Table 8: Gender

	2020-21	2019-20	2018-19
Male	51 (56%)	41 (55%)	22 (59%)
Female	39 (43%)	33 (45%)	15 (41%)
Transgender	1 (1%)		

Service provider and service type

Of the finalised investigations, the primary service provider for people who died comprised in-kind service providers (41%), non-government community service organisations (CSOs) (34%) and DHHS/DFFH managed services (25%). This data reflects in part the transfer of government-managed supported accommodation services to the non-government sector.

In-kind service providers are the most significant proportion as they remained in our jurisdiction over the 2020-21 cycle.

This year shared supported accommodation, typically group homes, was the primary service type that represented the largest number of deaths (88%) investigated by the DSC.

Table 9: Deaths by primary service provider type

In-kind service providers	37 (41%)
Community Service Organisations	31 (34%)
DHHS/DFFH	23 (25%)
Total	91 (100%)

Type of disability

Of the finalised investigations the top four primary disability types requiring most support from service providers were intellectual disability (49%), neurological disability (20%), physical disability (14%, mainly cerebral palsy) and syndromes (11% mainly Down Syndrome). This was the largest number of finalised cases attributed to neurological disability since the DSC began undertaking death reviews.

Table 10: Primary identified disability type requiring most support*

Intellectual disability	49%
Neurological (grouped)	20%
Physical (grouped)	14%
Syndrome (grouped)	11%
Autism	2%
Anxiety	1%
Dementia	1%
Unknown	1%

The data shows almost half of the people who died in receipt of disability services had an intellectual disability. People with mild or moderate intellectual disability (56%) were more likely to have died compared to those with severe or profound intellectual disability (44%).

¹ www.abs.gov.au/statistics/people/population/deaths-australia/latest-release, accessed 27 July 2021

² www.abs.gov.au/statistics/people/population/deaths-australia/latest-release, accessed 27 July 2021

^{*} When percentages do not add up to 100% this is due to rounding.

Health conditions

Consistent with other years the data shows multiple morbidities to be a strong predictor of death in people with disability. On average people with disability had three to five health issues present.

The DSC investigations revealed that 96% of people who died had identified health issues. The top five health conditions were urinary incontinence (66%), faecal incontinence (56%), constipation (56%), epilepsy (45%) and respiratory infection (30%).

Jurisdiction and reportable deaths

Under DHHS (now DFFH) incident reporting guidelines, deaths are categorised as either expected, where the person receiving disability services died because of a diagnosed condition or illness, or unexpected, such as due to a seizure or choking. Most deaths finalised this year by the DSC continue to be unexpected (71%). Expected deaths comprised 15% of total reportable deaths, and unclassified deaths (13%) noted where the service provider did not provide a response in the questionnaire or who stated they were unsure.

Table 11: Incident reports received from DHHS*

	2020-21	2019-20
Expected death	14 (15%)	15 (20%)
Unexpected death	65 (71%)	54 (73%)
Unclassified	12 (13%)	5 (7%)
Total	91	74

^{*}When percentages do not add up to 100% this is due to rounding.

There is a significant gap in knowledge on the cause of death of people with disability in Victoria in receipt of disability services when a death is not reported, or not in-scope for the Coroner. Of the 91 finalised investigations there were 55 deaths in-scope for investigation that were reported to the State Coroner. This gap is partly due to limitations of the definition of what constitutes a 'reportable death' under the Coroners Act 2008, with non-government service providers only required to report deaths that were unexpected and met the criteria for a reportable death.

Mandatory reporting to the State Coroner regardless of circumstances of death includes a person placed in 'custody or care' and this is inclusive of a person who was under the control, care or custody of the Secretary of the DFFH. This includes people in receipt of disability accommodation services administered by DFFH under the Act. One potential impact for group homes previously operated by the DFFH, transferring to nongovernment service providers was that the jurisdiction for the State Coroner was technically reduced as residents were no longer officially considered in the 'custody or care' of the Secretary. Fortunately, the DSC experience is that all five in-kind service providers have continued to report deaths in accordance with previous state government reporting guidelines. In addition, 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 service provider, where the death was deemed expected and while not a 'reportable death' to the Coroner, was required to be reported to the DSC under DFFH's incident reporting guidelines.3

As most service providers have transitioned to the NDIS, their clients may no longer be in the Coroner's purview and opportunities to understand and potentially address factors that may have contributed to the deaths of people with disability will be significantly reduced.

³ DSC Occasional Paper No.3 – Learning from reviews of Victorian disability service provision to people who have died 2017-2021 - A reflection for future safeguarding. pp11-13

Cause of death

The State Coroner provided a preliminary and later, a confirmed cause of death for 55 in-scope reportable deaths.

We utilise this information to categorise cause of death according to the International Statistical Classification of Diseases and Related Health Problems. (ICD-10). The top three causes of death in 2020-21 finalised investigations as categorised by the ICD-10 were: respiratory diseases (45%), neoplasms (16%) and nervous system diseases (15%).

Table 12: Cause of death of in-scope reportable deaths by ICD-10 chapter

Respiratory system diseases	25 (45%)
Neoplasms	9 (16%)
Nervous system diseases	8 (15%)
Circulatory system diseases	4 (7%)
External causes of morbidity	3 (5%)
Injury	3 (5%)
Unascertained	3 (5%)

Please note: When percentages do not add up to 100% this is due to rounding.

Of the 91 finalised investigations there were 55 deaths in-scope for investigation that were reported to the State Coroner.

Key issues from investigations

It is important to note that issues identified by the DSC investigations do not always relate directly to the cause of death of a person with disability. We consider a person's life and not just how they died.

By reviewing lives, the DSC have been able to focus on broader disability service provision and the quality of supports that we would not have otherwise known.

The DSC has experienced services being receptive to investigations and findings that draw attention to areas of practice that need strengthening, and make recommendations for service improvements. This leads to better and safer support for those still in receipt of services.

Key practice issues relating to service provision that required improvement were:

- service quality communication supports, mealtime supports, bowel management and behaviour supports
- managing specific conditions health plans, illness prevention and monitoring
- managing deteriorating health
- record keeping.

The following case studies highlight the complexity and interconnectedness of these practice issues and demonstrates that there is no single solution or quick fix to how these need to be addressed.

A robust approach is required if the sector is to identify and address the full range of contributors to the deaths of people with disability. The DSC have been able to gain valuable insight into practice issues that may not have been raised through complaints or incident reporting due to unequal power relations that typically characterise service provider relationships.4 It may be limiting to adopt an approach that is strictly based on compliance and regulation. The DSC considers that safeguarding responsibilities are an opportunity to continually strive for better practice. It is imperative that deaths of people with disability are systematically reviewed to readily identify causes of death, and to meaningfully assess possible links between a death and the adequacy of care being provided to the deceased before their death.

CASE STUDY

Mario

Mario* was a 52-year-old man, who enjoyed drawing, listening to music, shopping at Bunnings and was an avid Collingwood supporter. He had lived in his group home for over ten years and was remembered as a chatty, happy person, liked by all residents and staff. He had a close relationship with his family who visited him regularly.

Mario had a moderate intellectual disability and a diagnosis of depression/anxiety for which he was prescribed medication. He received assistance from group home staff for all aspects of his personal care, including supervision while eating.

Two years prior to his death he was also prescribed an antipsychotic medication ordinarily used to treat behavioural disorders, however there was minimal recording of why it was prescribed or if it was ever administered.

There was documentation by a speech pathologist that Mario required mealtime support and a modified diet. Mario had also been advised by a nutrition expert and speech pathologist to avoid certain foods. His GP noted him having had an allergic/adverse reaction to certain foods. Two days prior to his death Mario was provided with food that was a noted allergen and the following morning his health began to deteriorate. While this was not the cause of death, it did impact on his quality of care.

Our investigation found that there were no specific health management plans for Mario's mealtime, dietary or mental health support needs. The purpose of a health plan is to ensure health issues are not overlooked and that specific health management requirements are implemented. We also found that there was poor record keeping and monitoring in relation to his specific health needs and medication charting.

We issued a Notice to Take Action to the service provider. The range of measures that required implementation to improve services included:

- an audit of all resident files to determine all relevant health issues
- that each person with swallowing or eating difficulties was to obtain a speech pathologist assessment and have a comprehensive mealtime support plan in place
- provision of training to ensure mealtime supports and dietary needs were understood and implemented consistently by disability support staff
- ensuring all residents were supported to access appropriate health professionals for their health needs on a regular basis, including mental health needs
- review of all medications in conjunction with relevant health professionals
- ensuring all documentation pertaining to health needs was clear and complete, and that contemporaneous record keeping practices were embedded in daily practice.

⁴ Disability Services Commissioner, Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, June 2020. p.30.

^{*} Names and details have been changed

CASE STUDY

Tina

Tina* was a 54 year old woman, who enjoyed shopping, watching movies, and going to her day service. She had lived at her current group home since 2005 and had been living in various accommodation settings since she was a child. Her father visited her on a fortnightly basis and was her medical decision maker.

Tina had Down Syndrome and cerebral palsy. She used a wheelchair for mobility and required support for all personal care activities. She did not communicate verbally and relied mainly on facial expressions and basic signs to express herself. Her medical conditions included epilepsy, constipation and incontinence. She had swallowing difficulties, but the service provider we investigated was adamant that she did not have dysphagia.

Tina's day service raised their concerns to the group home staff that on several occasions she had been observed as 'not eating safely.' There was no documentation to indicate that the group home followed up on these concerns. The service did not have a speech pathologist assessment, swallowing assessment or mealtime support plan in place.

Records indicated that Tina had a history of constipation. Inconsistent file notes were used to track her bowel movements as opposed to a formalised bowel care management plan 'that included clear instructions on how and when to record bowel movements'. After an admission to hospital, Tina was found to have faecal loading and was treated for this condition. She was discharged with specific instructions for the administration of laxative medication. These instructions were not adhered to and Tina did not have a bowel motion for nine days. The service did not work with her medical treatment decision maker and her health service providers to develop and implement an adequate bowel care management plan.

Tina was said to have episodes of 'yelling' in the 12 months prior to her death. There was no indication that staff considered that she may have been communicating that she was in pain or discomfort. The service provided the DSC with a communication diary that was undated and did not appear to have had input from a speech pathologist. The DSC considers that a communication dictionary does not constitute a communication plan and that a speech pathology assessment was required to support her communication needs.

We issued a Notice to Take Action to the service provider in relation to these issues and requested that they implement the following:

- conduct an audit of supports for all residents to ensure all of their health needs are being met and appropriate plans are developed and implemented
- ensure each resident who requires communication support has a current communication assessment and comprehensive communication plan that includes how the person communicates pain or discomfort, which is understood and implemented consistently by all staff
- that all staff are provided with supervision and training relating to the provision of support to residents with chronic constipation. Such training to include signs and symptoms of constipation, risk factors for constipation, potential impact and seriousness of constipation, the complexity of chronic constipation in people with disability, and monitoring and recording requirements.

^{*} Names and details have been changed

Future safeguarding considerations

Death investigations effecting systemic change

Since the commencement of this function in 2017 it has been vitally important to provide systemic recommendations from what the DSC has learnt. A Notice of Advice may highlight a particular issue and provide a series of recommendations that are critical to service improvement and improved quality of life for people with disability. It may derive from a specific investigation or from trends we see emerging from a number of investigations. Responding to the DSC's recommendations requires time, planning, support and resources. The DSC are pleased to see that work on the following system-wide issues has continued this year despite the many challenges faced by the sector.

Falls prevention advice and guidelines

Falls prevention resources suitable for people residing in group homes were developed by the department in partnership with Monash University and provided to the five in-kind service providers in February 2020. This included practice advice and a checklist on the identification of falls risks and the implementation of risk strategies in residential group homes. There were delays with the implementation of the resources due to the impacts of COVID-19. A Community of Practice meeting and regular engagement with service providers confirmed that this has led to an increased awareness by disability support workers of the risk associated with falls and practice requirements to prevent and manage falls risks for residents more effectively.

Managing deteriorating health

The advice on managing deteriorating health is in progress. The department is working in partnership with the DSC to develop a poster for disability group home staff to raise awareness of the signs and symptoms of deteriorating health and what action a support worker should take when a person's health deteriorates. It will be based on information contained in the Residential Services Practice Manual (RSPM) and consultation with the in-kind service providers has already taken place. Resource development such as this, continues to be a key driver of the DSC's continuous improvement perspective when reviewing deaths.

Mealtime supports

Mealtime supports and associated risks may result in people with a disability being placed at significant risk of health complications or death. Since the DSC convened our first 'Safe Mealtimes Roundtable' in 2019, there have been projects and initiatives each year to address these pressing concerns and this recommendation is in its final stages of delivery. This year the DSC is pleased to see that there has been increased collaboration between DFFH and the NDIS Commission to achieve improved outcomes for people with disability through the 'Co-creating Safe and Enjoyable Meals for People with Disability and Dysphagia: Training, Implementation and Evaluation project' funded primarily by the NDIS Commission and led by the University of Technology Sydney (UTS). The aim is to co-create a training course for people with disability, direct support workers, family members and NDIS service providers to meet registration requirements in relation to the delivery of safe enjoyable meals, while also reducing the risk of choking death and increasing the nutritional benefit of the meal. As people who live in group homes are at increased risk of aspiration and choking, DFFH were active participants on a steering group to ensure the experiences of group homes were being heard.

Subsequently, DFFH funded UTS to deliver the training to all five in-kind service providers, most of that funding was given to the service providers to enable them to attend the training. Eleven workshops were held in April and May of this year training 102 staff in a wide range of positions from Direct Support Workers to Operations Managers from across the five organisations. Feedback from training attendees has been overwhelmingly positive. The UTS project is now in the evaluation phase and is expected to by finalised by September 2021. The resources will become widely available to the sector after the evaluation and will assist organisations to meet their obligations under the NDIS Rules and Practice Standards.

Resident incompatibility

The advice on resident incompatibility is in progress. A review of the department's vacancy coordination and tenancy management processes has taken place. The review's recommendations aim to support better compatibility matching though the vacancy process and outline clearer processes on how the Supported Independent Living (SIL) service providers and the department will work together to resolves issues where incompatibility between residents may impact on quality of life, safety, continued accommodation or independence. Key activities stemming from the review are expected to be largely concluded by the end of 2021.

Supporting a resident in hospital

The 'Supporting a resident while in hospital' advice included the need to evaluate relevant policies and procedures for currency, provide relevant training and supervision, and outline expectations for visitation of people with disability when hospitalised. Due to the emergence of COVID-19 this required modification as some people with disability are at greater risk of more serious illness if infected by COVID-19. Reasons for this include chronic health conditions or a weakened immune system, physical distancing being difficult or impossible for people who rely on support and assistance for their daily support needs, barriers to implementing basic hygiene measures and safely wearing masks.5

The DSC recommendations focused on open communication across and between the service provider, the resident's medical decision maker and hospital staff. It also highlighted the need for residents in hospital to receive regular visits from a familiar person providing comfort and non-medical related support, however this was not always possible due to COVID-19 restrictions.

To address this advice the department reviewed the guidance contained in the RSPM, sought views of in-kind service providers to better understand their roles and responsibilities when a resident is hospitalised and distributed the NDIS Commission Practice Alert: Transitions of care between disability services and hospitals.⁶ The Practice Alert addresses potential problems in transition of care arrangements, the risks associated for people with disability and outlined key steps in accessing appropriate supports before, during and after hospital admissions. The Victorian Government also funded the establishment of the Disability Liaison Officer Project (DLO Project). The project aims to make health services more accessible by having a Disability Liaison Officer on-site to support the needs of people with disability at key transition points when navigating health services. A Community of Practice meeting was held in early 2021 and a representative from the DLO Project informed in-kind service providers about the program and how it could be accessed. The NDIS Practice Alert and its implications for service provision was also discussed.

Menstrual suppression

Menstrual suppression as a form of chemical restraint was previously highlighted in a DSC death review investigation where a woman with an intellectual disability had her menstruation suppressed for over 30 years without considering less restrictive options or seeking informed consent. According to the Disability Act 2006 menstrual suppression is a reportable chemical restraint if it is used to stop behaviours of concern and is not treatment for an underlying health issue. It is also considered a chemical restraint under the NDIS (Restrictive Practices and Behaviour Support) Rules 2018. The menstrual suppression project was undertaken to report on the factors associated with menstrual suppression use for females with a disability reported to the Victorian Senior Practitioner. This report contains data from the Restrictive Intervention Data System (RIDS) of females subject to menstrual suppression, results of legislative compliance audits of females subject to menstrual suppression and discussion of known risks and implications involved in menstrual suppression. The Victorian Senior Practitioner made a series of recommendations on the menstrual management of women with disabilities, this closely aligns with the DSC's advice to the Secretary in this area. The final report is available from the Office of Professional Practice.7

It is worth noting that advice in relation to sexual and reproductive rights of women and girls would not have come to the DSC's attention without reviewing disability service provision to women who have died.

⁵ www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/ advice-for-people-at-risk-of-coronavirus-covid-19/coronavirus-covid-19-advicefor-people-with-disability

⁶ www.ndiscommission.gov.au/document/2431#:~:text=services%20and%20 hospitals-.Practice%20Alert%3A%20Transitions%20of%20care%20between%20 disability%20services%20and%20hospitals,of%20harm%20to%20NDIS%20 participants.

⁷ www.dhhs.vic.gov.au/sites/default/files/documents/202008/Use%20of%20 menstrual%20suppression%20Report%20by%20the%20Victorian%20Senior%20 Practitioner%202020_.pdf

Occasional Paper No.3: Learning from reviews



Reviewing Victorian disability service provision to people who have died will not cease completely now that all in-kind service providers have fully cashed out and transferred to the NDIS and NDIS Commission. While the NDIS Commission will consider deaths of all NDIS participants through their reportable incident mechanisms, the DSC will continue our role in Victoria on a very reduced scale to state funded disability services, and until such time as the *Disability Act 2006* is amended and proposed Social Services Regulatory Reform is undertaken.

In reviewing and investigating deaths since 2017, 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.

Our recent 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 highlights these lessons and proposes eight recommendations and four potential gaps to be considered for any future state-based death review function.

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

To learn more about this Occasional Paper, go to the DSC website: odsc.vic.gov.au

Appendices

Appendix 1: Operations

Financial statement for the year ended 30 June 2021

The Department of Families Fairness and Housing (DFFH), formerly the Department of Health and Human Services, provides financial services to Disability Services Commissioner (DSC).

The financial operations of DSC are consolidated into those of DFFH and are audited by the Victorian Auditor-General's Office. A complete financial report is therefore not provided in this annual report. A financial summary of expenditure for 2020-21 is provided below.

\$ 3,682,943	
-28,272	
\$171,306	
139,397	
548,322	
2,852,190	

Staffing for the year ended 30 June 2021

14.2 full-time equivalent (FTE) as at 30 June 2021.

Appendix 2: Compliance and accountability

Privacy and Data Protection Act 2014

DSC is an organisation bound by the provisions of the Privacy and Data Protection Act 2014. The DSC complies with this Act in its collection and handling of personal information.

The DSC privacy policy http://www.odsc.vic.gov.au explains how we deal with personal and health information.

Freedom of Information Act 1982

Victoria's Freedom of Information Act 1982 (FOI Act) allows the public a right of access to information held by the DSC subject to certain exemptions. In 2020-21, the DSC received 4 requests under the FOI Act.

Only one FOI request required an extension to the legislated timeframe.

Applications for access to information can be made in

Freedom of Information Officer Disability Services Commissioner Level 30, 570 Bourke Street Naarm/Melbourne VIC 3000 Email: odsc.foi@odsc.vic.gov.au

Our website has more information about this process: www.odsc.vic.gov.au

Charter of Human Rights and Responsibilities Act 2006

The Charter of Human Rights and Responsibilities Act 2006 sets out the basic rights, freedoms and responsibilities of all people in Victoria. It requires all public authorities, including the DSC, to act consistently with the human rights in the Charter.

The DSC complies with the legislative requirements outlined in the Charter and uses a human rights approach when dealing with enquiries and complaints, conducting reviews and investigations, and delivering education and information to the sector.

Protected Disclosure Act 2012

Disclosures of improper conduct by the DSC or its officers can be made verbally or in writing to: Independent Broad-based Anti-corruption Commission GPO Box 24234

Melbourne Vic 3001 Phone: 1300 735 135 Fax: (03) 8635 4444 Email: info@ibac.vic.gov.au

More information about Victoria's Protected Disclosure Act 2012 is available from the Independent Broad-based

Anti-corruption Commission website:

www.ibac.vic.gov.au

As of January 2020, we complied with the updated Public Disclosures Act.

Disability Services Commissioner

L 30, 570 Bourke Street Naarm/Melbourne VIC 3000

Enquiries and complaints: 1800 677 342 (free call from landlines)

Office enquiries: 1800 677 342 (local call)

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