

### **Disability Services Commissioner**

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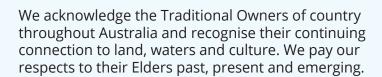
Disability Services Commissioner

# 2019-20 Annual Report

**Including** 

A review of disability service provision to people who have died 2019-20

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







11 September 2020

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

Dear Minister,

Pursuant to s19 of the *Disability Act 2006*, I am pleased to provide you with the Disability Services Commissioner annual report for the financial year 2019–20.

As requested by the Ministerial referral in June 2019, the *Review of disability* service provision to people who have died 2019–20 is included in this report.

Yours sincerely,

Treasure Jennings

Disability Services Commissioner

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### Abbreviations, acronyms and definitions

### The Act

Disability Act 2006.

### **ACR**

Annual Complaints Reporting.

### **Assessment**

The stage after a person has made a complaint and we have determined that the issues are within-scope. The Act allows us 90 days to assess whether a service provider is meeting their obligations and to try and resolve the issues raised in the complaint.

### **Cash out**

The process of transferring DHHS run disability accommodation (Supported Independent Living) and respite (Short Term Accommodation and Assistance) services to 5 non-government providers as part of the transition from state funded disability supports to the National Disability Insurance Scheme (NDIS).

### Complaint

An expression of dissatisfaction made to or about a disability service provider, relating to its products, services, staff or the handling of a complaint, where a response or resolution is explicitly or implicitly expected or legally required.

### Conciliation

A process that allows all participants to have their voices heard, understand each other's perspective, explore issues and, where possible, reach agreement about a way forward in a safe and facilitated meeting.

### CVB

Community Visitors Board.

### DHHS

Department of Health and Human Services.

### **Disability Royal Commission**

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability established on 4 April 2019.

### DSB

Disability Services Board.

### DSC

30

The Office of the Disability Services Commissioner.

### **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 DHHS, or a person or body registered on the register of disability service providers
- 'regulated service provider' means a contracted service provider, funded service provider or a prescribed service provider
- 'contracted service provider' means a person, organisation or registered body that has entered into a contract with the Secretary of DHHS under s.10 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 DHHS 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 DHHS 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 DHHS.

### **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 DHHS, State or the Community Visitors Board. This term also covers matters we refer onto other bodies such as the Mental Health Complaints Commissioner or the NDIA.

### The Secretary

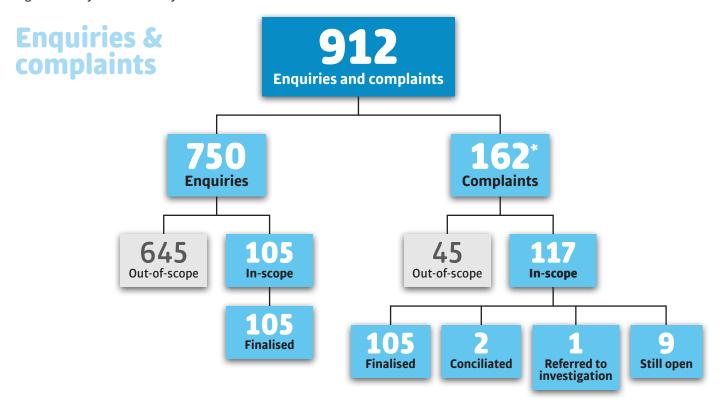
The Secretary of DHHS.

### **VDWC**

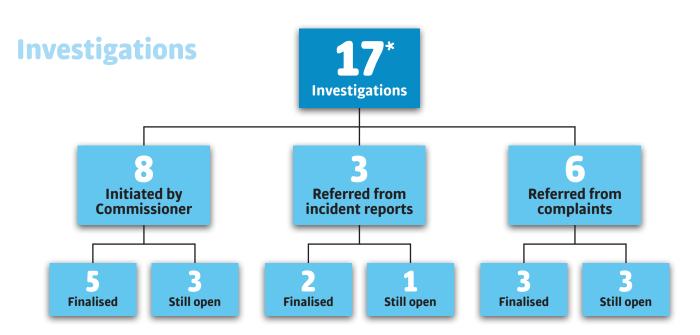
Victorian Disability Worker Commission.

# Our year in summary

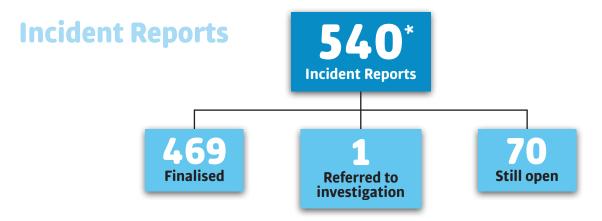
Figure 1: Our year in summary



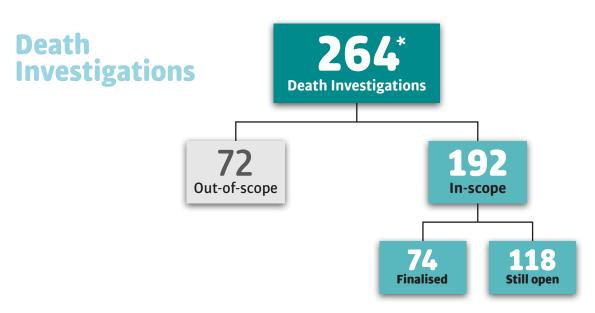
\* 118 received in 2019-20 + 44 carried over



\* 3 initiated in 2019-20 + 14 carried over



\* 372 received in 2019-20 + 168 carried over



\* 134 received in 2019–20 + 130 carried over

### Please note:

In our 2018–19 Annual Report and Review of disability service provision to people who have died 2018–19, there was a typographic error and a mis-categorisation whereby one death was counted as being in-scope and completed. In fact, the death was out-of-scope. These issues did not impact total death investigations (119). The correct data should have read: carried over 68, deaths reported 187, in-scope 99, out-of-scope 20, completed/closed 37 and still open 130.

# Message from the Commissioner

This year presented unique challenges and opportunities for people with disability, their families and the Victorian disability sector. The year saw the continuation of the significant changes that started in 2018, including the ongoing roll out of the National Disability Insurance Scheme (NDIS) and the transfer of group homes previously operated by the Department of Health and Human Services (DHHS) to non-government service providers. From 1 July 2019 the NDIS Quality and Safeguards Commission (NDIS Commission) started regulating quality and safeguards in Victoria for people who are participants in the NDIS, which has resulted in a reduced jurisdiction for the Disability Services Commissioner (DSC).

This year also saw opportunities presented by the commencement of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability (Disability Royal Commission) and unprecedented challenges from COVID-19.

For people not yet in the NDIS, and for services continuing to be funded by the Victorian Government, the key role of DSC continues to be resolving complaints and promoting the right of people with a disability to be free from abuse. DSC undertakes this role with a number of different approaches across the functions of the office: responding to enquiries and complaints, critical incident oversight including death investigations, commissioner-initiated investigations and capacity development projects.

In 2019 DHHS began the process of transferring over 500 government disability accommodation services to five nongovernment service providers. These providers are Aruma, Home@Scope, Life Without Barriers, Melba and Possability. DSC retains jurisdiction for state funded matters for as long as these transfer services remain funded by the Victorian Government through 'in-kind' arrangements. We also retain oversight of services which continue to be funded and contracted by DHHS such as disability justice and advocacy organisations, as well as clients in receipt of the Transport Accident Commission (TAC) funded disability services.

The Disability Royal Commission is hearing from people with disability, families, support people, organisations and the broader community to understand the extent and the impact of violence, abuse, neglect and exploitation of people with this disability. I was asked to appear at the Melbourne public hearing in December 2019 and we also prepared a written statement about what we have learnt at DSC. Details of our submission include recommendations based on our experience working within the disability services sector, and my statement to the Disability Royal Commission, can be found on our website, along with a Plain English version.

As an office we emphasise the importance and the right of speaking up. We encourage all people to share their story through the Disability Royal Commission public hearings, making submissions and responding to issues papers. It is imperative that the voices of people with disability are heard and that quality and safeguarding measures continue to be responsive into the future.

More recently, the disability sector has had to actively respond to the coronavirus (COVID-19) pandemic by adjusting services to comply with government advice and to ensure the safety and wellbeing of everyone.

In particular, the pandemic has highlighted the importance of ensuring accessible and clear information is available to assist people with disability in making informed decisions about their supports and services. Just as critical is that disability service providers ensure that whilst they prepare for and adapt to the new operating requirements, they continue to focus on the quality of the services they provide and on reducing the risk of people experiencing poor quality supports.

In our third year investigating deaths reported to our office by DHHS and the State Coroner,<sup>1</sup> it is disappointing to note that many of the issues that we highlighted in our inaugural Review are still evident.

There continue to be potentially preventable deaths attributed or provisionally attributed to choking on food or aspiration pneumonia. People who should have had mealtime support plans had not been assessed for these and did not have them, and some who had plans were not supported as they should have been. We are increasingly concerned that service providers and staff are not always aware of the serious risks people with disability can face at mealtimes, sometimes with terrible consequences, including potentially avoidable deaths.

Throughout the year I chaired a roundtable group to discuss this issue and strategies to reduce the number of avoidable deaths caused by choking and aspiration pneumonia. The results of this work included the development of a 'Safe Meal Times Poster' that is aimed at reminding workers of the key risks, and some simple steps to be aware of when supporting people with disability at mealtimes and a Service Flow Chart outlining the importance of all elements of the service system to ensuring a safer approach. You can view this material on our website, and on page 18 of this document.

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

More information about our work in this area, including actions we have taken to influence future supports and oversight, can be found in our *Review of disability service provision to people who have died 2019–20* included as part of this report. I urge all people with disability, families, carers, service providers and regulatory bodies to read this review to understand the issues of concern, and the actions that must be taken to improve the safety and wellbeing of all people with disability.

On 27 February 2020 we were informed that a single Commissioner would act in the roles of Disability Services Commissioner and Mental Health Complaints Commissioner. The two statutory offices will remain independent.

My term of office concluded on 30 June 2020. It has been a privilege to work with DSC staff to uphold our mission of protecting the rights of, and improving services for, people with disability. I thank all DSC staff for their dedication to protecting and advancing the rights of people with disability. In spite of the uncertainty which surrounded the future of the office, their professionalism and person-centred focus continues to ensure that the thoughts, feelings and voices of people with disability are listened to and incorporated in our daily practice and lead to service improvements across the sector.

I also want to acknowledge the positive and constructive relationship we had throughout the year with the Department of Health and Human Services and the NDIS Commission as we worked together on a smooth jurisdictional transition, and with the Victorian Disability Worker Commission as they prepared to commence from 1 July 2020.

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 board 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.

Finally, I want to offer my best wishes to Ms Treasure Jennings who was appointed as Disability Services Commissioner and Mental Health Complaints Commissioner.



Arthur Rogers Disability Services Commissioner 2019–20

# New Disability Services Commissioner from 1 July 2020

I am excited to commence in the inaugural role of Commissioner across both the Disability Services Commissioner and Mental Health Complaints Commissioner.

As the former Public Transport Ombudsman and Deputy Chairperson of the Independent Office for School Dispute Resolution Victoria, I am committed to improving services and safeguarding for people with disability.

At this time of significant reform in the disability sector, I look forward to supporting the final stages of transfer of services to the NDIS and ensuring that any remaining state-funded services are identified so that a comprehensive complaints mechanism remains in place.



Treasure Jennings Disability Services Commissioner 2020-21

# Message from the President of the Disability Services Board

Throughout the year the Disability Services Board (DSB) met regularly to consider issues facing people with disability and the wider sector. We worked closely with the Disability Services Commissioner (DSC) and other organisations to improve outcomes for people with disability, including ensuring appropriate safeguards were in place for people with disability while Victoria navigated the ongoing transition to the NDIS and implementing business continuity plans in response to COVID-19. We need to remain vigilant about maintaining relevant safeguards so no person with disability falls through the safety net.

This year, the DSB provided valuable insight into the various quality and safeguarding issues needing consideration as we prepare for the closure of the Office of the Disability Services Commissioner.

One issue of particular concern was the collaboration between Victoria and the Commonwealth Government regarding Victorians with complex disability service needs and there not being a 'provider of last resort'.

Other issues we provided insight and advice on included:

- The outcome of the Government's ongoing review of quality and safeguarding mechanisms in place for Victorians with a disability who access disability services which continue to be regulated under the Act
- The Disability Royal Commission, specifically regarding the Easy Read guide to the public to make submissions which originally included a statement 'not to lie'.

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 continued dedication to improving the safety and quality of Victorian disability services. The board members are:

Argiri Alisandratos Iill Linklater

Christian Astourian Rocca Salcedo Mesa Karen Cusack Professor Ruth Webber Glenn Foard Bryan Woodford OAM

Helen Kostiuk

I extend a special thanks to Chris Asquini who retired as a DSB member in 2020.

The board currently has 10 members. While the Act requires 11 people, the Minister has confirmed the vacancy will not be filled. This will not impede DSB's operations.

On behalf of the board I would like to thank Arthur for his support and collaboration with the board and for his ongoing dedication to improving the lives of people with disability. We wish him all the very best.

The board looks forward to working with Ms Treasure Jennings to ensure the oversight and safeguarding bodies throughout the human services sector work together to deliver consistent and comprehensive safeguards for all people.



**Georgina Frost** President Disability Services Board

# **Enquiries and complaints**

Whilst the jurisdiction of DSC has decreased, it is still important and relevant to identify the key themes coming out of the data.

This year we received a total of 750 enquiries and 118 complaints. In total, 21% were in-scope and 79% were out-of-scope. We also continued working on 44 complaints carried over from 2019-20.

Of the 750 enquiries, 105 were in-scope and 645 were out-of-scope for DSC.

Of the 118 new complaints, 73 were in-scope and 45 were out-of-scope.

In total, 750 enquiries and 162 complaints (118 new and 44 carried over) were addressed in 2019–20.

The in-scope complaints were assessed in accordance with the Act. One preliminary assessment took longer than the legislated 90-day period. The Commissioner considered that this was reasonable because of the complexity of the complaint including the involvement of Worksafe, the emerging COVID-19 restrictions, and because this complaint had already been reopened. This complaint has carried over into the 2020–21 reporting period.

Throughout the year, DSC finalised 105 complaints, with one complaint referred to investigation following assessment, two complaints finalised through conciliation, and six Notices of Advice being issued.

As shown in Figure 3, over 80% of in-scope complaints made to DSC were resolved or partially resolved (49% were resolved and 33% were partially resolved). DSC uses the Four As approach to respond to complaints and feedback. The Four As are:

- Acknowledgement
- Answers
- Actions
- Apology.

The most common complaint outcome achieved across the Four As categories related to actions taken to resolve the complaint (77%). Answers or explanations were provided to respondents in 47% of cases, whilst acknowledgment of a person's views occurred in 23% of cases. An apology was only used in 18% of cases. See Figure 4 for more information.

The issues raised through in-scope complaints were similar to previous years with the key areas of concern being:

- Service quality
- · Group supports
- Quality of communications
- · Staff related issues, and
- · Policy or procedures.

Figure 2: Proportion of new in-scope and out-of-scope enquiries

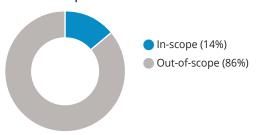


Figure 3: Resolution rates for finalised in-scope complaints\*

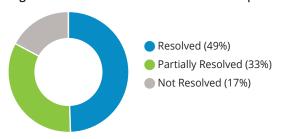
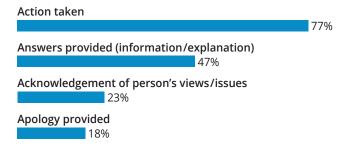
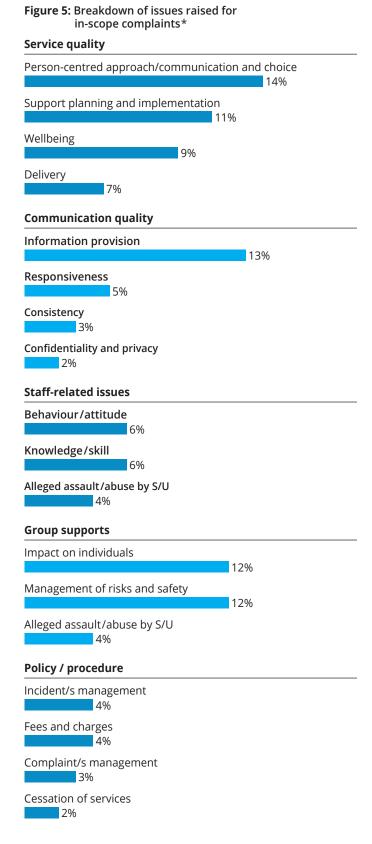


Figure 4: Top ways in-scope complaints were resolved using the Four As approach\*



<sup>\*</sup>As multiple issues are possible in an enquiry / complaint, the total percentages do not equal 100%.

# **Enquiries and complaints**



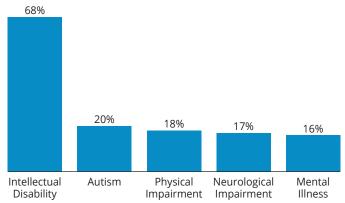
Who contacts us

Families, parents and guardians have continued to be the primary source of in-scope enquiries and complaints (52%), showing the important role that families play in supporting and safeguarding people with disability.

This year saw an increase in the number of staff members who contacted DSC 19%, up from 5% last year.

The percentage of enquiries and complaints coming directly from people with disability has come down from 25% in 2019 to 17% in 2020.

Figure 6: Top five primary disability types related to in-scope enquiries and complaints\*



<sup>\*</sup>As multiple issues are possible in an enquiry / complaint, the total percentages do not equal 100%.

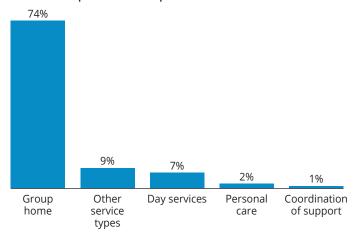
### Enquiries and complaints about group homes

Consistent with previous annual reports the service type that triggered the largest number of enquiries and complaints was group homes. Of the top five service types reported in in-scope enquiries and complaints, 74% were about group homes.

Group homes have consistently been one of the biggest sources of enquiries and complaints to DSC due to the whole-of-life nature of this service type, the complexities of living with others and the incorporation of workplace requirements. With the transition of disability services to the NDIS Commission, leaving the five transfer providers responsible for group homes in-scope for DSC, this has incurred an even higher group home representation for this year compared with last year.

DSC will continue to share our learning from people living and working in these homes with the NDIS Commission to minimise potential future disruption when regulatory oversight of these services is transitioned to the NDIS Commission.

Figure 7: Top primary service types raised for in-scope enquiries and complaints\*



In-scope enquiries related to COVID-19 included questions about the use of, or lack of use of, Personal Protective Equipment. We also received enquiries about visiting restrictions, issues of staff moving between houses, and day services closing.

### Enquiries, complaints and out-of-scope matters

Despite a reduction in the number of enquiries and complaints, DSC continues to respond to a substantial number of out-of-scope enquiries. Out-of-scope enquiries were approximately 86% of all 2019–20 enquiries and can require up to 45 minutes per call to support people through the complexities of the transitioning disability sector. DSC continues to receive many enquiries about NDIS, a majority of which are out-of-scope.

Of the out-of-scope complaints, DSC made 47 written referrals of complaints, including 32 to the NDIS Commission and 15 to other organisations including Victoria Police, the Office of the Public Advocate (OPA), the National Disability Insurance Agency (NDIA) and the Victorian Senior Practitioner.

In early 2020, modifications to DSC phone system enabled calls relating to the NDIS to be directly transferred to the NDIS Commission before speaking to a DSC staff member. This improvement strategy assisted people to access the correct service required at the start of their enquiry, and as a result has reduced the number of out-of-scope enquiries coming into DSC.

<sup>\*</sup>As multiple issues are possible in an enquiry / complaint, the total percentages do not equal 100%.

# Oversight of critical incidents

Through successive Ministerial Referrals, DSC has provided increasing levels of oversight into category one/major impact incident reports. From 2017 this has included the authority to inquire into and investigate any incidents relating to abuse or neglect in the provision of services, and the provision of disability services to people who have died.

In the past DSC received incident reports that related to services funded by DHHS and the NDIS. In 2019–20 only services funded by DHHS remain in the jurisdiction of DSC. From 1 July 2019 the NDIS Commission has oversight of reportable incidents for NDIS funded services.

DSC received 372 new incident reports in 2019–20. Of the new reports the top three issues were:

- 121 (33%) related to an injury
- 118 (32%) alleged physical abuse or assault
- 68 (18%) alleged poor quality of care.

Unexplained injuries, alleged sexual abuse or assault, and new incident types (such as incidents that do not fit into existing categories) each contributed between 2% and 10% of total incident reports.

DSC carried over 168 open incident report reviews from 2018–19. Of these, 2 were further carried over into the 2020–21 reporting year due to the complexity and nature of the incident.

In total, DSC dealt with 540 incident reports, referring one for investigation and closing 469.

70 incident reports remain open and will be reviewed in 2020-21.

Figure 8: Incident reports on deaths, alleged assaults, injuries and poor quality of care by gender

Alleged sexual abuse or assault	
58%	42%
Alleged physical abuse or assault	
36%	64%
Injury	
49%	51%
Poor quality of care	
50%	50%
Unexplained injury	
31%	69%
Death	
39%	61%
Incident types < 3%	
80%	20%
Female Male	

Table 1: Incidents relating to alleged physical or sexual assault\*

	2019-20
Alleged physical abuse or assault	
Client to client	26%
Client to other	2%
Client to staff	-
Other to client	8%
Staff to client	64%
Alleged sexual abuse or assault	
Client to client	42%
Client to other	-
Client to staff	-
Other to client	27%
Staff to client	31%

<sup>\*</sup>As multiple issues are possible in an enquiry / complaint, the total percentages may not equal 100%.

### Including people with disability in investigations

In reviewing incident reports DSC has identified gaps or poor practice by service providers when it comes to including people with disability in investigations following events requiring an incident report.

In particular, there have been instances where:

- the person with disability was not interviewed, or interviewed only after a considerable length of time had passed since the incident occurred
- inadequate communication supports were given to enable the person with disability to participate
- insufficient attention was given to the situation and experience of the person involved.

Unless addressed, these issues can mean that investigations into matters cannot be substantiated. This could compromise the wellbeing and safety of individuals and other residents by removing opportunities for practice and service improvement, and the risk of recurring abuse becomes substantially higher. DSC investigations have also evidenced similar themes of poor practice in not consulting with people with disability during internal investigation processes.

### Notice of Advice

In 2020, DSC received several incident reports from in-kind group home staff to DHHS, which outlined an event that took place at an NDIS funded day service or other program. The responsibility for leading a review of the incident or allegation sits with the service where the incident took place. In each of the reports to DHHS about incidents taking place other than at the group home, the home has appropriately provided care, support and took the person for medical appointments. The group home appropriately focussed on the wellbeing and needs of the person and completed all reporting requirements to DHHS.

DSC was concerned that not all incidents were reported to the NDIS Commission by the day service or other responsible third-party service provider including in-kind group homes.

Subsequently we issued a Notice of Advice to the five DHHS transfer/in-kind service providers. The Notice requested that the providers identify incident reports that relate to an incident that has occurred at a day service (or other NDIS funded service) and ensure that these and future incidents are reported to the NDIS Commission as well as DSC to ensure appropriate oversight of these incidents.

# Investigating disability services

Throughout 2019–20, DSC worked on 17 investigations in total, including three new investigations, with information being received through a variety of channels including incident reports and complaints.

We also continued working on 14 investigations carried over from 2018-19 including:

- 7 commissioner-initiated investigations (s128B)
- 5 referred from complaints (s118)
- 2 referred from incident reports (s128I).

Factors that help us determine if an investigation is required include the severity of the information referred to us including matters of abuse or neglect, and the number of incident reports associated with a service provider or site.

In 2019-20 a total of 10 investigations were finalised including:

- 5 commissioner-initiated (s128B)
- 3 referred from complaints (s118)
- 2 referred from incident reports (s128I).

The central themes across these investigations included:

- incident reporting issues
- person-centred care
- poor communication
- · behavioural supports.

As evidenced last year, DSC continues to take an educative approach in our investigations. Overall service providers continue to engage positively throughout the investigation process, often taking actions, addressing concerns and improving services before our investigation concludes resulting in fewer Notices to Take Action needing to be issued. Greater collaboration with external stakeholders such as Victoria Police, the Coroners Court of Victoria, OPA and the Community Visitors Board (CVB) also continues, enabling DSC to be more strategic in identifying and investigating potentially concerning situations and service providers.

We will carry seven investigations into the 2020-21 year in order to ensure service improvement and better practice by providers in supporting people with disability.

### **Authorised Officers**

DSC has authority to conduct announced and unannounced visits to service providers where there are concerns about abuse or neglect in the provision of services.

This year DSC conducted six Authorised Officer visits related to investigations.

### **Reviewing Community Visitor Board referrals**

In accordance with the Ministerial Referral, DSC receives referrals of matters relating to abuse and neglect from the CBV. These referrals and our collaboration with OPA, provide DSC with useful and specific information for consideration of complaints, incident reports and/or investigations. DSC acknowledge the hard work and support of the Community Visitors who provide an incredibly valuable insight into the sector

In 2019–20 DSC received 63 referrals relating to 15 service providers.

# Education, information and training

DSC continues to provide information to people with disability, families, advocates and the disability sector about the importance of speaking up as a means of improving disability services. The NDIS Commission and the Victorian Disability Worker Commission have also begun operating and promoting their services for Victorians with disability, service providers and the broader community.

This year DSC has assisted people to navigate the service landscape in acknowledgment of these new safeguarding mechanisms. We have also shared what we have learnt about who to contact with complaints about disability services, and the importance of building safe and respectful cultures to prevent violence, abuse, neglect and exploitation of people with disability. We continue to work on providing information that is evidence-based, accessible and reflective of the work undertaken by DSC to support improved practice across the sector.

Providing clarity about who and where to make complaints has been a key focus for DSC, spanning across all our communication channels including website, newsletter, and social media, through to resources and overall capacity building initiatives. Assisting people to navigate through the various systems can be challenging as people have expressed confusion about where to go for the right support, and not wanting to have to re-tell their story. We work on the basis that there is no wrong door and we provide 'warm' referrals to ensure people with disability feel listened to and heard in order to achieve best outcomes.

The trust we have developed over the years with people with disability, advocacy organisations, services, departments and statutory bodies is integral to our work. A foundational piece of our work is the Four As approach to successful resolution. It recognises that people who make a complaint are generally seeking one or more of these four outcomes: Acknowledgment, Answers, Actions and Apology. We are pleased that the NDIS Commission has included this approach as part of their effective complaint handling guidance.

DSC complaint handling resources are a valuable collection of tools for developing an effective person-centred 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.

Conveying the message that "It's OK to complain" and encouraging people to speak up about their experiences requires a multi-pronged approach in both resource development and delivery. DSC resources are offered in a variety of formats, with an emphasis on ensuring the content is accessible for people with disability and speaks to the specific audience. This has included providing resources in Rich Text Format, Tagged PDF, video, Easy English, Plain English, Auslan, in other languages by request, and when

possible guided by cultural Elders and members who understand their community best. We have delivered these messages via media, exhibitions, conferences (VicDAN), interactive workshops, meetings and sponsoring the VALID "Having a Say" conference.

It is imperative that information that seeks to empower people with disability is accessible. DSC has worked collaboratively with other organisations to ensure accessible information was available throughout the COVID-19 pandemic, including reminders that despite the impacts of the pandemic it was still important to speak up about their experiences in disability services.

We have collaborated and consulted with key experts in order to produce targeted and evidence-based resources. An example of this is the Safe Mealtime Poster (see page 18).

Management of dysphagia and mealtime supports are long-standing systemic issues. In response to the prevalence of choking and aspiration pneumonia as causes of death in people with disability, the Commissioner convened a multi-agency roundtable to identify key issues and develop actions to ensure that people with disability who have swallowing difficulties receive appropriate assessments and mealtime supports. The poster is aimed at disability support workers who offer mealtime assistance on a daily basis. It provides a simple stepped through process on what to do to make mealtimes safe and enjoyable. It also outlines what signs to observe with people who have swallowing difficulties and what action needs to be taken to ensure mealtimes are safe and do not contribute to deteriorating health and potential death.



**NDIS Plans** 

Speech and swallowing

Staff and provider knowledge

Mealtime supports

Free training modules including information on mealtime supports have been released by Disability Services Consulting (DSC)

Lobbying for change to Certificate IV

including allied health

National Commission to provide guidance to service providers

Safeguarding and quality review

 Training for support workers and carers on importance of following Mealtime Support Plans Speech Pathology Australia to review and publish more professional

development resources for members

 National Commission to use revised practice standards as part of accreditation review

Individual incidents are being followed up

Reflective practice

Person with disability

Focus on empowering participant to learn about dysphagia and helping design their mealtime management plan

•Guidance material for planners include information on how to

discuss dysphagia supports with participants

**Mealtime Supports Actions** 

 NDIS working on adding mealtime supports / dysphagia to its practice guidelines International Dysphagia Diet Standardisation Initiative

 Guidance materials for planners being prepared NDIA now funding disability related health supports

 Can now be included in the NDIS planning process and individual support plan

Some people with dysphagia will not be eligible for NDIS and will receive supports from the health sector

Assessments by speech pathologists are critical for forming the Mealtime Support Plan
 Focus on speech pathologist writing clear and accessible

 Ensuring workers communicate effectively about mealtimes with participants

 Guidance to support workers to accurately interpret Mealtime Support Plan information is important

 NDS Developing resources for practice leaders that will include information on mealtime supports

while eating or drinking Never leave people alone



# Always follow the person's mealtime support plan IF YOU OBSERVE

alert and sitting as upright as possible Check the person is unnecessary distractions Before you start remove any

amounts of food Offer small

Wait for food to clear from the person's offering more mouth before

> 000 Call ambulance

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

voice or breathing

1300 60 60 24 Nurse on Call

numbers Other important



### **Building Safe and Respectful Cultures**

Continuing on from 2018–19, the Building Safe and Respectful Cultures (BSRC) project aimed to understand the role culture has in promoting safety and wellbeing and look at the conditions that lead to violence, abuse and neglect in disability services.

Peta Ferguson was one of the BSRC researchers and presented at the 2019 Australasian Society for Intellectual Disability (ASID) Conference in Adelaide.



Peta Ferguson (left) with Deputy Commissioner Samantha Dooley

### Peta's reflection on BSRC and the ASID conference

As a person with a disability, a parent of a son who is in receipt of services and having many friends with and without disabilities I see it as imperative that I advocate for safe and respectful spaces for people with disability across the board. Although we were looking at the culture in disability services, much of what we learnt is relevant to how people with disability are treated in the broader community.

Safety and respect can be difficult to talk about if you don't know what that looks or feels like. We spoke with people in receipt of services, family members, staff and CEOs about how to build safe and respectful cultures. We listened to what was challenging and what people found useful.

At the start of this project I was surprised and concerned that everyone we spoke to felt stressed and unable to instigate positive change. People felt like others didn't understand what it was like to be in their shoes. Creating opportunities where people could spend time together and highlight similarities as opposed to differences seemed positive as the need for safety and respect is universal.

My experience as a researcher at DSC was extremely positive. Time was spent getting to know one another and identifying people's strengths. It did not feel like a tokenistic exercise and this made for a strong and respectful dynamic that continues to this day.

I have spoken at conferences before but mainly in relation to my work with Brain Injury Matters and broader advocacy work. Going to the ASID conference in Adelaide was a great opportunity for me to share what we learnt as part of the BSRC project, be visible and show that people with disability make a valuable contribution to the research process. I strongly believe that community researchers, or people with disability who also happen to be researchers, should be included in all aspects of research as we enriched the process and understanding for all involved.

Being a presenter at the conference was both validating and empowering as I received positive feedback that what we had produced was of a high calibre and of interest to others. It was hugely gratifying to have people listen. The mantra, nothing about us without us, needs to be enlivened and more people with disability should be leading this work.

We made some short films as part of the project and I remember saying that people with disability are merely asking to be treated like human beings, with equal value and to have their human rights respected. Sounds simple but I know on a personal basis and from the experience of others, that this is not always the case.

Sometimes this work is exhausting as ableism is so pervasive and relentless; however I will continue to educate and inform others about the importance of prevention, and how speaking up can help beyond measure.

The mantra, nothing about us without us needs to be enlivened and more people with disability should be leading this work.

# Annual Complaints Reporting (ACR) from the sector

Only service providers registered with DHHS were required to provide a complaint report to DSC for 2019–20.

### Complaints to disability service providers

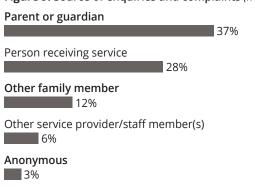
From 1 July 2019, the NDIS Commission began operating in Victoria with responsibility for handling complaints about NDIS funded services. DHHS wrote to the 559 service providers that provided only NDIS funded services and deemed them exempt from complying with s105 of the *Disability Act 2006* (where the annual complaints reporting requirements are located).

Only service providers registered with the DHHS were required to provide a complaint report to DSC for 2019–20. Disability service providers funded through DHHS are required to provide a complaints report that details the number, types and outcomes of complaints received, including how they were resolved. Reporting for these services covered clients who had not yet transitioned to the NDIS, services for people with a disability delivered through service systems outside the NDIS or which fell outside the jurisdiction of the NDIS Commission. The exemption of reporting complaints about NDIS services led to a significant reduction in the number of service providers reporting to DSC in 2019–20 and in the volume of complaints reported.

In 2019–20, 182 disability service providers submitted a complaint report to DSC. 70 of those service providers (representing 38% of all service providers required to report) submitted a total of 485 in-scope complaints. This included 358 new complaints and 127 complaints carried over from the previous year. More than half (112 providers or 62%) of service providers who submitted their reports indicated that they did not receive any in-scope complaints.

Almost all in-scope complaints (94%) were in relation to services funded by DHHS, with 4% in relation to TAC funded services and 2% in relation to complaints funded by other sources. For information about who made complaints see Figure 9.

Figure 9: Source of enquiries and complaints (n=452)\*



In 2019, as part of the transition to NDIS, the management of the Victorian Government's disability accommodation services were transferred to five non-government disability service providers. A total of 253 complaints were submitted by these five service providers, representing 52% of all complaints in 2019–20. As expected, almost all complaints (94%) from these five service providers were in relation to supported accommodation services. As a result, a large portion of all in-scope complaints received in 2019–20 were in relation to shared supported accommodation services (67%), followed by a much smaller proportion of complaints in relation to personal care services (7%). The breakdown of the top five complaint service types is shown in Figure 10.

The two most common issues raised in complaints were dissatisfaction with the quality of service (45%) and dissatisfaction with staff behaviour and attitude (41%), followed by complaints about communication by the service provider (26%)\*. An overview of the types of complaint issues is shown in Table 2.

Figure 10: Complaints by service type (n=468)\*

Supported accommodations (group or shared)

Personal care

7%

Participation in community, social and civic activities (non-Day Services)

6%

Coordination of support 4%

Anonymous

3%

<sup>\*</sup>As multiple issues are possible in an enquiry / complaint, the total percentages may not equal 100%.

Table 2: Complaint issues (n=478)\*

Service delivery and quality standards Dissatisfaction with quality of service provided Physical and psychological health and safety Perception of insufficient service or support provided Lack of choice of service or activities Other service delivery, quality or standards issues  Workforce and staff-related issues Staff behaviour and attitude Staff behaviour and attitude Knowledge and skill of workers High turnover of workers or staff rostering/attendance Discrimination, abuse, neglect, intimidation, assault or bullying Poor match between person and workers Other staff-related issues  Communication from service provider Insufficient communication Poor quality communication Poor quality communication Other communication issues  Relationships and compatibility Wait time to access services Cost of service or funding issues Transport issue(s) Request for service refused as not considered priority for access to services Other service access issues  Policy and procedures Concerns about policies or procedures The way complaints have been handled Privacy or confidentiality breach Other policy or procedure issues  Service access, access priority or compatibility Not compatible or poor relationships with other people sharing the services Discrimination, abuse, neglect, intimidation, assault or bullying Other		
Staff behaviour and attitude Knowledge and skill of workers High turnover of workers or staff rostering/attendance Discrimination, abuse, neglect, intimidation, assault or bullying Poor match between person and workers Other staff-related issues  Communication from service provider Insufficient communication Poor quality communication Poor quality communication Other communication issues  Relationships and compatibility Wait time to access services Cost of service or funding issues Transport issue(s) Request for service refused as not considered priority for access to services Other service access issues  Policy and procedures Concerns about policies or procedures The way complaints have been handled Privacy or confidentiality breach Other policy or procedure issues  Service access, access priority or compatibility Not compatible or poor relationships with other people sharing the services Discrimination, abuse, neglect, intimidation, assault or bullying	Dissatisfaction with quality of service provided Physical and psychological health and safety Perception of insufficient service or support provided Lack of choice of service or activities	21% 19% 9% 4%
Insufficient communication 14% Poor quality communication 12% Other communication issues 4%  Relationships and compatibility 12% Wait time to access services 3% Cost of service or funding issues 3% Transport issue(s) <1% Request for service refused as not considered priority for access to services Other service access issues 3%  Policy and procedures 10% Concerns about policies or procedures 5% The way complaints have been handled 3% Privacy or confidentiality breach 2% Other policy or procedure issues <1%  Service access, access priority or compatibility 10% Not compatible or poor relationships with other people sharing the services Discrimination, abuse, neglect, intimidation, assault or bullying	Staff behaviour and attitude Knowledge and skill of workers High turnover of workers or staff rostering/attendance Discrimination, abuse, neglect, intimidation, assault or bullying Poor match between person and workers	23% 11% 6% 6% 3%
Wait time to access services Cost of service or funding issues Transport issue(s) Request for service refused as not considered priority for access to services Other service access issues  Policy and procedures Concerns about policies or procedures The way complaints have been handled Privacy or confidentiality breach Other policy or procedure issues  Service access, access priority or compatibility Not compatible or poor relationships with other people sharing the services Discrimination, abuse, neglect, intimidation, assault or bullying	Insufficient communication Poor quality communication	14% 12%
Concerns about policies or procedures The way complaints have been handled 3% Privacy or confidentiality breach Other policy or procedure issues  Service access, access priority or compatibility Not compatible or poor relationships with other people sharing the services Discrimination, abuse, neglect, intimidation, assault or bullying	Wait time to access services Cost of service or funding issues Transport issue(s) Request for service refused as not considered priority for access to services	3% 3% <1% <1%
Not compatible or poor relationships with other people sharing the services  Discrimination, abuse, neglect, intimidation, assault or bullying  4%	Concerns about policies or procedures The way complaints have been handled Privacy or confidentiality breach	5% 3% 2%
Other 4%	Not compatible or poor relationships with other people sharing the services Discrimination, abuse, neglect, intimidation, assault	9%
	Other	4%

### Service providers responding to complaints

Consistent with 2018-19, the complaint outcome most frequently achieved in 2019-20 across the Four As outcome categories was an acknowledgement of the person's views or issues (57%). Action taken to resolve the complaint was the next most common outcome (47%). Where actions were taken to address the complaint, they were commonly in relation to disciplinary action or performance management (18%), change or improvement to communication (10%), and review or development of support plans (8%). The next most common outcome achieved across the Four As were answers or explanations provided to the person receiving service (40%). An apology from the service provider was the least frequent complaint outcome (23%) this outcome was half as frequent as in 2018-19 (47%). The proportion of complaints that did not have an outcome at the end of the financial year was higher (21%) than in 2018–19 (6%). Refer to Table 3 and 4 for more information.

Service providers reported that the vast majority (94%) of closed complaints have been resolved to at least some degree. Providers also indicated that 29% of all complaints (whether open or closed) had been raised with an agency or authority apart from their service, in particular with DSC (14%) or a DHHS Division (6%).

<sup>\*</sup>As multiple issues are possible in an enquiry / complaint, the total percentages may not equal 100%.

# Annual Complaints Reporting (ACR) from the sector

Table 3: Ways complaints were resolved using the Four As (n=452)\*

Acknowledgement - person's views/issues	57%
Action Taken	47%
Disciplinary action or performance management of staff	18%
Communication issues addressed	10%
Support plan or person-centred plan to be developed or reviewed	8%
Change to way in which support/service provided	6%
Change or appointment of worker	5%
Policy/procedural change proposed or made	5%
Referrals made by provider	4%
More choice	3%
Access to an appropriate service	3%
Change or review of decision	1%
Reimbursement, waiver or reduction of fees	1%
Other	13%
No outcome (yet)	21%
Answers provided – information/explanations	40%
Apology provided	23%

**Table 4:** Satisfaction with the management of complaints (n=445)\*

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Our service managed the complaint well	21%	45%	32%	2%	1%
The person who made the complaint was satisfied with how this complaint was managed	15%	31%	48%	5%	1%
The person who made the complaint was satisfied with the outcome of this complaint	14%	27%	51%	6%	2%
The complaint was straightforward to resolve	13%	31%	36%	14%	5%

# Feedback from service providers Effective communication

'The need for clear communication and reasonable timeframes when implementing changes to personal care services. This complaint arose from the decision to cease providing a particular type of support, and we may not have been clear or timely with communication to carers and families.'

Better understanding of and empathy towards client requirements and the importance of person-centred approach

'It is essential staff take the time to listen and be guided by the customer in how they would like their supports to be delivered. Staff must develop meaningful relationships that foster engagement and trust.'

Implementing a formal complaints process and highlight the importance of rigorous complaints investigation, including following-up complaints in a timely manner

'The importance of responding to concerns or complaints in a timely fashion and to take the time to listen and to acknowledge any concerns raised.'

'The earlier contact is made with the complainant the better, to explain what measures are being undertaken to resolve the issue.'

<sup>\*</sup>As multiple issues are possible in an enquiry / complaint, the total percentages may not equal 100%.



A review of disability service provision to people who have died 2019-20



# Introduction to the death investigation process

Our third annual review of disability service provision to people who have died is a timely reminder that urgent action is still required to ensure the safety, wellbeing and human rights of people with disability.

In 2017, DSC began investigations into disability service provision to Victorians with disability who have died. The aim of an investigation is to consider the quality and appropriateness of the disability services provided to the person who has died and to provide advice on necessary actions to address risks to other people with disability.

The first phase of the investigation process begins with a request for the disability service provider to provide a completed questionnaire and other documents about the person who has died.<sup>1</sup> This information includes file notes, incident reports, health plans and person-centred plans.

In August 2019, DSC introduced a revised process to ensure a more efficient and targeted approach in our work, and to enhance the capacity of service providers to identify and take early action in response to the death of a person with disability. In this new process, we ask service providers to first conduct their own internal review to identify any practice issues within service delivery and to develop an action plan to address these key risk areas. DSC requests a copy of this internal review.

We have found this collaborative approach to be more responsive in informing the capacity of service providers to make service improvements, thereby reducing potential risks to other people in receipt of disability services.

In this first phase of the investigation, DSC appraises the service provider's internal review and action plans, by comparing and contrasting them to our assessment of the information available. We determine 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. If we are satisfied that the service provider's review addresses the key risks, we ask service providers to report back to DSC on the outcomes of any improvement actions, prior to a final review and closure of the investigation.

Critically, where we disagree with the outcomes of a service provider's review, or we hold significant concerns about the safety and wellbeing of people with disability, we undertake a second phase of investigation. This involves further analysis of individual support documentation and organisational records in order to assess the adequacy of disability service provision to the person before their death. In this second phase, we also invite the family or key supporters of the person who died to share their perspective about the adequacy of disability service provision. We may also interview relevant staff of the service provider.

In situations where we identify deficiencies in service provision or risks to other people with disability, we issue the service provider with a Notice to Take Action requiring them to make service improvements and report back to us.

After completing the investigation, we also prepare a report outlining our findings for the service provider, the Secretary of DHHS, the Minister, the NDIS Commission, and for reportable deaths, the State Coroner. The Act does not provide for our reports to be made public; however, DSC is subject to the *Freedom of Information Act 1982*.

<sup>1</sup> If a DHHS-managed service has transferred to a non-government service provider subsequent to the death of a resident, DHHS is responsible for ensuring any requests are responded to and any actions carried out.

# Overview of deaths of people with disability in Victoria

In 2019–20, we have found that people with disability in receipt of disability services continue to die approximately 25 to 30 years younger than the general population of Victoria.<sup>2</sup> People with intellectual disability and who have multiple chronic health conditions are a high risk group.

Effective monitoring of mortality data is critical to understanding and shaping the development of targeted preventative health initiatives, and public policy.<sup>3</sup> 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.<sup>4</sup>

In this section we highlight data from investigations into the deaths of people with disability that were finalised by DSC in 2019–20. These finalised death investigations relate to cases that mostly occurred between 2017–2019. Data is principally obtained from an extensive 70-point questionnaire, completed by service providers to inform our initial risk assessment.

In 2019–20 our office finalised 74 investigations and issued 25 Notices to Take Action to service providers to improve their services. Authorised Officer visits were conducted in relation to two disability service providers. We carried over 130 open investigations from 2018–19 and have 118 investigations which will be carried over into 2020–21.

### Service provider and service type

Of the 74 investigations finalised by DSC in 2019–20, the primary service provider for people who died comprised DHHS-managed services (55%) and non-government community service organisations (CSO) (45%).

Shared supported accommodation, typically group homes, was the primary service type that represented the largest number of deaths (89%) investigated by DSC in 2019–20. There are a number of factors that contribute to deaths of people living in group homes, including but not limited to, a failure to manage key health risks.

Table 5: Finalised investigations by service provider type

CSO	Shared supported accommodation Individualised support packages Flexible support packages Outreach support Respite	26 3 1 1 2
DHHS	Shared supported accommodation Case management	40 1
Total		74

<sup>2</sup> Our data derived from 2019-20 finalised investigations into the deaths of people with disability who died while in receipt of disability services, demonstrates that people with disability had life expectancies that were 29.3 years and 27.7 years lower than that of Victorian females and males respectively.

### Age

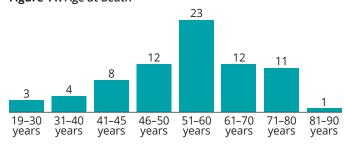
In our 2019–20 finalised investigations, the median age at death of people in receipt of disability services was 56 years for females and 54 years for males. Given Victoria has the equal highest female life expectancy at birth in Australia (85.3 years) and the highest male life expectancy (81.7 years),<sup>5</sup> this premature mortality is of significant concern.

In addition to premature death, people with disability may experience the ageing process at an earlier and faster rate, for example, in their 40s and 50s.<sup>6</sup> 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.

Pessimistic beliefs about ageing can contribute to older people with disability being less physically active than younger counterparts. Our 2019–20 investigations have also raised issues in relation to inadequacies of funding for supports for people with disability as they age, for example, to engage in appropriate physical activity or goals for community inclusion.

People with disability should be able to continue to live in their group homes and to participate and engage in the community as they age, however this can only practically happen so long as disability support workers are trained and able to support them.<sup>9</sup> DSC has observed efforts undertaken to upskill the departmental and transfer workforce including the Certificate IV in Disability and the department funded Comprehensive Health Assessment Program.

Figure 11: Age at death



<sup>5</sup> Australian Bureau of Statistics, *Life Tables, States, Territories and Australia* 2016-2018 (Catalogue No 3302.0.55.001, 30 October 2019). <a href="https://www.abs.gov.au/AUSSTATS/abs@.nsf/0/97E435FA3B82A89DCA2570A6000573D3?Opendocument">https://www.abs.gov.au/AUSSTATS/abs@.nsf/0/97E435FA3B82A89DCA2570A6000573D3?Opendocument</a>>.

<sup>3</sup> Carmela Salomon & Julian Trollor, 'A scoping review of causes and contributors to deaths of people with disability in Australia – Findings' (Department of Developmental Disability Neuropsychiatry UNSW, 19 August 2019) 4.

<sup>4</sup> Catalina Devandas Aguilar, Report of the Special Rapporteur on the rights of persons with disabilities, UN Doc A'HRC/73/161 (16 July 2018) [22].

<sup>6</sup> World Health Organisation, World Report on Disability (2011) 59.

<sup>7</sup> Carmela Salomon et al, 'A qualitative exploration of barriers and enablers of healthy lifestyle engagement for older Australian with intellectual disabilities' (2019) 6(2) Research and Practice in Intellectual and Developmental Disabilities 182, 188.

<sup>8</sup> Ruth Webber, Barbara Bowers & Christine Bigby, 'Confidence of group home staff in supporting the health needs of older residents with intellectual disability' (2016) 41(2) Journal of Intellectual & Developmental Disability 107, 107.

<sup>9</sup> Ibid 10

# Overview of deaths of people with disability in Victoria

### Gender

Of the death investigations finalised by DSC in 2019–20, 45% were female, and 55% were males. This higher male to female ratio of deaths in disability services has been evident in comparable state reviews in other jurisdictions.<sup>10</sup>

Issues in relation to sexual and reproductive rights impacting women and girls are typically not disclosed to DSC; however our 2019–20 finalised death investigations have highlighted specific issues of gender-based violence in group homes. For example, one woman with an intellectual disability had her menstruation suppressed for over thirty years to prevent her perceived distress at bleeding, without the trial of other less restrictive options or without seeking consent. This practice of chemical restraint can be shaped by incorrect assumptions that women and girls with disability are incapable of menstrual management.<sup>11</sup>

### **Cultural status**

Intersectionality helps us to understand how different sets of identities impact on access to rights and opportunities. People with disability comprise a heterogenous group. This diversity results in significant variability in the situation and support needs of different groups of people with disability.<sup>12</sup>

The capacity of DSC to use 2019–20 disaggregated data in our work to more deeply uncover intersectional issues is limited. In relation to people from a culturally and linguistically diverse (CALD) background, only two of 74 people who died were known to be born overseas, and four people spoke languages other than English.

In 2019–20, DSC did not investigate any deaths of First Nations people with disability. This low number of deaths impacting First Nations peoples in our data may reflect the low rate at which First Nations people with disability access mainstream disability services. The kinds of supports and accommodation available to people with disability, including in group homes, can be different to the whole-of-family and community models preferred by First Nations people with disability.<sup>13</sup>

### Type of disability

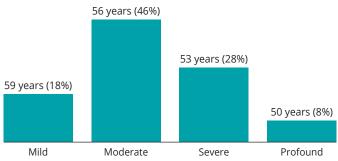
Of the finalised death investigations undertaken by DSC in 2019–20, the top five primary disability types were intellectual disability (51%), syndrome related (15%, mainly Down syndrome), neurological disability (12%), physical disability (12%, mainly cerebral palsy), and autism spectrum (7%).

The data shows that more than half of the people who died in receipt of disability services had an intellectual disability. People with intellectual disability are known to have a high occurrence of premature death, relative over-representation of deaths in young and middle-age groups, and have deaths that are potentially avoidable.<sup>14</sup>

Of our 2019–20 finalised investigations, people with a mild or moderate intellectual disability (64%) were more likely to have died compared to those with a severe or profound intellectual disability (36%). This may indicate that people with mild to moderate intellectual disability do not always receive the preventative strategies and supports that they require for their daily activities, such as at mealtimes or toileting.

It is imperative therefore that people with intellectual disability be supported to access holistic care, regular health monitoring and reviews, and early diagnosis and treatment to prevent or postpone the adverse effects of chronic health issues.<sup>15</sup>

Figure 12: Median age at death by level of intellectual disability



<sup>10</sup> Carmela Salomon & Julian Trollor, 'A scoping review of causes and contributors to deaths of people with disability in Australia – Findings' (Department of Developmental Disability Neuropsychiatry UNSW, 19 August 2019) 30.

<sup>11</sup> Beth Goldblatt & Linda Steele 'Bloody unfair: Inequality related to menstruation – Considering the role of discrimination law' (2019) 41(3) Sydney Law Review 293.

<sup>12</sup> Catalina Devandas Aguilar, Report of the Special Rapporteur on the rights of persons with disabilities, UN Doc A/HRC/34/58 (20 December 2016) [42].

<sup>13</sup> Australian Government, Australian Government plan to improve outcomes for Aboriginal and Torres Strait Islander people with disability (2017) 10.

<sup>14</sup> Julian Trollor et al, 'Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data' (2017) 7 BMJ Open 6.

<sup>15</sup> Simone Reppermund et al, 'Factors associated with death in people with intellectual disability' (2019) J Appl Res Intellect Disabil. (advance) 5.

### Health conditions

Consistent with other years, in 2019–20 we found multimorbidity to be a strong predictor of deaths in people with disability. Of our finalised investigations, 97% of people who died had identified health issues. The top five health conditions were urinary incontinence (66%), constipation (58%), epilepsy (44%), faecal incontinence (42%) and gastroosophageal reflux disease (23%).

In 2019–20, 23% of people with disability who died whilst in receipt of services had known mental health issues. The primary mental health concerns impacting people with disability were anxiety (14%), depression (10%), schizophrenia (10%) and bipolar disorder (10%). We anticipate that this data does not capture people who may have been experiencing a mental disorder that was undiagnosed as a result of diagnostic overshadowing.<sup>16</sup>

Our data from 2019–20 finalised investigations indicates that the majority of people with disability who had a mental illness consulted with a psychiatrist (74%). However, there were low levels of access to, and integration of, treatment through a psychologist (16%) or social worker (11%).

DSC is concerned that people with dual disability are not consistently supported to access multidisciplinary care and the full range of skills and strategies needed to treat their mental illness. Collaborative work across disability and health services, and access to professionals with specialist experience is critical to improving access, treatment and outcomes for people with intellectual disability and mental illness.<sup>17</sup>

### Support networks and supported decision-making

At the core of supported decision-making is the idea that all persons, except in very limited circumstances, have some level of decision-making ability, and that with appropriate support, they are able to make decisions.<sup>18</sup>

Family provided support for medical decision-making in 78% of the death investigations finalised by DSC in 2019–20. It is evident that family continue to occupy an important supportive role for people with disability in receipt of disability services, promoting and supporting their family member to have a voice and to exercise choice over their own lives.

When people with disability do not have family or other natural supports in their lives, there is the risk that they become wholly reliant on service providers or individual staff, to look out for their day-to-day wellbeing and rights. DSC continues to promote the importance of people with disability having access to independent advocates and active unpaid social networks.

<sup>16</sup> Erin Louise Whittle et al, 'Barriers and enablers to accessing mental health services for people with intellectual disability: A scoping review' (2018) 11 Journal of Mental Health Research in Intellectual Disabilities 69, 98.

<sup>17</sup> Ibid

<sup>18</sup> Australian Law Reform Commission, Equality, Capacity and Disability in Commonwealth Laws (Commonwealth of Australia, August 2014) 99.

# Overview of deaths of people with disability in Victoria

### Notifications of 2019-20 deaths

In 2019–20, DSC received 134 new notifications of people with disability who died whilst in receipt of disability services; 62 of these death notifications were in-scope and 72 out-of-scope for investigation.

It is important to note that there was a decrease in notifications of deaths in-scope for investigation in 2019–20, due to the reduction in our jurisdiction over 2019–20, and the commencement of the NDIS Commission in Victoria.<sup>19</sup>

The effect of the transition of government disability accommodation and respite services to five non-government providers is also reflected in the 2019–20 data for primary service provider and service type. For example, in 2019–20 the majority of new notifications were from non-government community service organisations (94%), as opposed to DHHS-managed services (6%).

In 2019–20, there were no new notifications of deaths of people with disability due to COVID-19 that were in-scope for investigation by DSC.

**Table 6:** Investigations by service provider and primary service type received

CSO	Shared supported accommodation Individualised support packages Respite Unknown Criminal justice services Information services	48 4 1 2 1
	Other	1
DHHS	Shared supported accommodation	4
Total		62

<sup>19</sup> Disability Services Commissioner, A review of disability service provision to people who have died 2018–19 (2019) 6.

### Cause of death

Regrettably, in 2019–20 people with disability in receipt of disability services continue to be over-represented in deaths due to respiratory and nervous system diseases (mainly epilepsy-related deaths).

Under DHHS incident reporting guidelines, deaths are categorised as either expected, such as where the person receiving disability services died because of the progression of a diagnosed condition or illness, or as unexpected, such as due to a seizure or choking.20

In our 2019–20 finalised investigations, 73% of deaths were unexpected, 20% of deaths were expected and 7% were unclassified. While people with disability may experience complex health conditions and co-morbidities that increase ill-health, it is clear that many of these deaths were potentially preventable.

The State Coroner provides a preliminary or confirmed cause of death for in-scope reportable deaths.<sup>21</sup> Using this information, we have categorised cause of death according to the International Statistical Classification of Diseases and Related Health Problems (ICD-10).<sup>22</sup>

In 2019–20, 56 of the investigations that were finalised by DSC were also in-scope for the State Coroner. Diseases of the respiratory system (mainly aspiration pneumonia) were the leading cause of death for 2019-20 investigations that were in-scope for the State Coroner.

The top five causes of death as categorised by the ICD-10 were: diseases of the respiratory system (38%), diseases of the circulatory system (14%), diseases of the nervous system (13%), neoplasms (13%) and external causes (7%).

This data aligns with research into how dominant causes of death differ between people with disability and the general population. For example, people with intellectual disability are over-represented in deaths related to diseases of the respiratory and nervous systems and under-represented in deaths due to age-dependent causes such as diseases of the circulatory system and neoplasms.<sup>23</sup>

In the category of nervous system diseases, epilepsy-related deaths were the leading cause of death in our 2019-20 finalised investigations. In our investigations, we observed that the majority of service providers played a critical role in ensuring people with epilepsy were able to access their neurologist for the assessment and management of their epilepsy, including through regular medication review.

However, in our 2019-20 finalised investigations, some service providers failed to monitor and chart seizures impacting the individual, contributing to under-reporting of seizures at specialist appointments. Delays to timely and expert assessment and management may be more likely when events are non-convulsive or low impact.<sup>24</sup>

In our 2019-20 finalised investigations, a number of people with Down syndrome and Alzheimer's disease died due to a seizure. Research shows new-onset epilepsy seems to occur early in the course of dementia in people with Down syndrome. It is therefore important to seek seizure control early for this group through medication, and to implement a comprehensive epilepsy management plan and strategies.<sup>25</sup>

The State Coroner identified Sudden Unexpected Death in Epilepsy (SUDEP)<sup>26</sup> as a cause of epilepsy-related death in four of the in-scope cases. Of the four SUDEP deaths, in each the person with a disability died during sleep; one person died in the afternoon and three died at night. A comparable state review in Queensland found individuals identified as having epilepsy were more likely to have a time of death during the night.<sup>27</sup>

Sleep is a significant risk factor for SUDEP, and the prone position may be a likely contributing factor.<sup>28</sup> While there is a need for further research to understand and reduce the harmful impact of epilepsy and SUDEP risks, DSC considers the sector should more fully consider policies and practice guidelines to mitigate the risks of SUDEP. This should cover the importance of comprehensive risk assessment, as well as the protective benefit of night supervision and monitoring systems for those at risk, such as the use of seizure detection smart watches or pressure mattresses.<sup>29</sup>

<sup>20</sup> Department of Health and Human Services, Client Incident Management Summary Guide (January 2020) <a href="https://providers.dhhs.vic.gov.au/cims">https://providers.dhhs.vic.gov.au/cims</a>>.

There remains a gap in our knowledge on the cause of death of people with disability in Victoria due to limitations of the definition of a 'reportable death' under the Coroners Act 2008, which does not require deaths in group homes managed by non-government service providers to be reported to the State Coroner, unless they are unexpected.

<sup>22</sup> World Health Organisation, International Statistical Classification of Diseases and Related Health Problems (ICD-10) <a href="https://www.who.int/classifications/icd/covid19/en/">https://www.who.int/classifications/icd/covid19/en/</a>

<sup>23</sup> Julian Trollor et al, 'Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data' (2017) 7 BMJ Open, 7.

 <sup>24</sup> Anna Firkin et al, 'Mind the gap: Multiple events and lengthy delays before presentation with a "first seizure" (2015) 56 *Epilepsia*, 1534, 1534.
 25 Taha Gholipour et al, 'The clinical and neurobehavioural course of Down syndrome and

dementia with or without new-onset epilepsy' (2017) 68 Epilepsy & Behaviour, 13

<sup>26</sup> SUDEP refers to a death without an obvious medical cause that happens unexpectedly and suddenly in an individual with a diagnosis of epilepsy

Office of the Public Advocate (Qld), Deaths in care of people with disability in Queensland

Ahmer Ali et al, 'Association of sleep with sudden unexpected death in epilepsy' (2017) 76 Epilepsy & Behaviour (advance) 1.

Office of the Public Advocate (Qld), Deaths in care of people with disability in Queensland

# Cause of death

 Table 7: Cause of death of in-scope reportable deaths by ICD-10 chapter\*

Cause of death	201	9–20
Respiratory system diseases	21	38%
Circulatory system diseases	8	14%
Neoplasms	7	13%
Digestive system diseases	3	5%
Congenital malformations, deformations and chromosomal abnormalities	1	2%
Nervous system diseases	7	13%
External causes of morbidity	4	7%
Genitourinary system diseases		
Injury, poisoning and certain other consequences of external causes		
Unascertained by the Coroner		
Unknown or non-reportable	5	9%
Total	56	100%

<sup>\*</sup>Total percentage does not equal 100% due decimal rounding rules.

# Key issues from death investigations

There is wide variability in how group homes are managed and whether they create an environment that is protective of human rights. People with disability have the right to make important decisions about their life, and to receive the supports they require to exercise this choice.<sup>30</sup>

The key practice issues identified in our annual report, *A review of disability service provision to people who have died 2018–2019*, continue to pose significant health risk for people in receipt of disability services in 2019–20. These factors included a failure to manage key health risks of choking and aspiration, constipation, and rapidly deteriorating health. This risk of premature death is further increased if a person is not supported to communicate their needs effectively.<sup>31</sup>

It is worth noting the issues of concern identified in our investigations do not always relate directly to the cause of death of a person with disability. However, they do impact upon the quality of supports provided to, and the quality of life outcomes experienced by, people with disability.

In this report, we broadly overview issues relating to health, specifically health promotion and prevention, however we principally highlight how people with cognitive disability may be denied their rights to decision-making.<sup>32</sup>

### Health promotion and prevention

Known areas of health risk need to be managed by disability service providers in a person-centred and proactive manner. People with disability require annual health assessments with a consistent general practitioner so that a comprehensive health record can be established, and emerging issues identified.

DSC has found that the annual health assessments and specific health management plans for people with disability are not consistently created, or up to date. This occurs despite known risks to an individual in areas such as choking and aspiration, chronic constipation and epilepsy. Other health issues may not be detected early; a situation exacerbated by financial disincentives for general practitioners to provide long consultations.<sup>33</sup>

In our 2019–20 finalised investigations, it was evident that often support workers were either unaware of, or did not follow, the preventative strategies detailed in a specific health management plan.

The effects of poor oral and dental health are frequently evident with people missing some or all of their teeth, and not seeing a dentist for years at a time. In one 2019–20 investigation, delays in preventative care contributed to an individual having 16 teeth removed due to cavities and periodontal disease. The service provider did not seek guidance or engage behavioural support specialists to proactively manage this person's reported distress during oral health routines.

People with intellectual disability are more likely than age-matched peers to be overweight or obese, and are less likely to be knowledgeable about healthy eating.<sup>34</sup> Low expectations of people with disability also contribute to inadequate support to lead healthy lifestyles through dedicated forms of physical exercise. In 2019–20, only 60% of people who died due to circulatory disease were considered to be very active or somewhat active. DSC has observed how people with disability may spend a lot of time in their own rooms engaging in sedentary activities such as watching television or listening to music.

### Supported decision-making

People with disability are not consistently provided with the support necessary to make, communicate, and participate in decisions that affect them, in accordance with legislative requirements, including s9 of the *Charter of Human Rights and Responsibilities Act 2006* (Vic) and s4 of the Act.

This may occur because of problems with the group home model itself. Group homes often replicate institutional living arrangements. For example, in this environment, people are rarely provided with opportunities to choose their service provider, with whom they live, which staff will be employed, and what supports will be prioritised.<sup>35</sup>

In group homes, everyday routines and structures are often determined by managers and staff. Service providers often make decisions about daily meal choices, scheduling of daily activities, social interactions, and the kinds of community access on offer to people with disability. In addition, the systems of support are often designed for the group rather than the individual.

People with disability are not inherently vulnerable, however they may be made vulnerable by social and environmental barriers.<sup>36</sup> For example, when people with disability are consistently denied the opportunity to make decisions through participation in daily activities and in the community, they may not develop or maintain the skills necessary to make those decisions.<sup>37</sup>

<sup>30</sup> Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) Article 12.

<sup>31</sup> Disability Services Commissioner, A review of disability service provision to people who have died 2018–19 (2019) 10.

<sup>32</sup> Cognitive disability includes people with intellectual disability, dementia, autism, acquired brain injury and other impairments that may affect cognition.

<sup>33</sup> Royal Australian College of General Practitioners, Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability – Health care for people with cognitive disability (April 2020) 9.

<sup>34</sup> Carmela Salomon et al, 'Get Healthy! A physical activity and nutrition program for older adults with intellectual disability: Pilot study protocol' (2018) 4 Pilot and Feasibility Studies. 144.

<sup>35</sup> Sally Robinson and Lesley Chenoweth, 'Preventing abuse in accommodation services: From procedural response to protective cultures' (2011) 15(1) *Journal of Intellectual Disabilities* 63, 66.

<sup>36</sup> Anna Arstein-Kerslake, 'Breaking down COVID-19 barriers for people with disability' <a href="https://pursuit.unimelb.edu.au/articles/breaking-down-covid-19-barriers-for-people-with-disability">https://pursuit.unimelb.edu.au/articles/breaking-down-covid-19-barriers-for-people-with-disability</a>.

<sup>37</sup> Anna Arstein-Kerslake, Restoring Voice to People with Cognitive Disabilities: Realising the Right to Equal Recognition before the Law (Cambridge University Press, 2017) 196-197.

### Key issues from death investigations

### Person-centred active support

Person-centred active support is an individualised approach to organising support for people with disability. It is underpinned by the idea that activities and relationships are an important way in which quality of life is achieved.<sup>38</sup>

We observed significant shortcomings in the quality of person-centred plans created for people with disability. In 2019–20, DSC found individualised plans completed by service providers were commonly incomplete, planning meetings did not always involve the individual or their supporters, and goals were not written in specific measurable terms or reviewed within clearly defined timelines.

Even when person-centred planning is of high quality, there can be an implementation gap. Support workers may prioritise doing household work over other activities that might be meaningful to the individual, such as spending time outdoors. Or Staff might assist people with daily activities, such as eating meals and dressing, however with low levels of engagement, for example, without asking what that person might want to eat or wear.

A lack of active support was evident in one 2019–20 investigation when a person with an intellectual disability and visual impairment was scheduled to be in bed each night at 7pm, without being afforded choice or control over their bedtime routine. When an occupational therapist recommended that this person be actively supported to participate in household activities, staff reported to DSC that they would 'pretend' to cook together.

This poor quality of active support does not develop an individual's capabilities and strengths for their meaningful participation and inclusion in the community.

DSC considers disability support workers require practical, hands-on training in active support. This is because research has shown that the implementation of active support is more effective if senior leaders of an organisation exercise practice leadership close to frontline service delivery, with coherence in their enactment of person-centred values and actions.<sup>39</sup>

### Positive behaviour supports

Restrictive practices involve the use of interventions and practices that have the effect of restricting the rights or freedom of movement of a person with disability.<sup>40</sup> Typically, these practices are used with people who display behaviours of concern. In Victoria, the use of regulated restrictive practices by disability service providers must be included in a Behaviour Support Plan and reported to the Victorian Senior Practitioner.<sup>41</sup>

DSC has completed multiple investigations where restrictive practices were not being administered in accordance with an approved Behaviour Support Plan, including a failure to consult with families about the actions taken and the use of an outdated plan. We have also found unauthorised use of mechanical restraint, chemical restraint, environmental restraint and isolation or seclusion.

In our 2019–20 finalised investigations, service providers sometimes attributed behavioural problems to a person's disability, without attempts to understand the underlying causes of the behaviour. For example, this diagnostic overshadowing occurred when support workers did not identify that severe constipation was a possible cause of distress to an individual who was non-verbal in their communication but who was vocalising loudly. To reduce the impact of loud vocalisations, staff wore noise-cancelling earmuffs, instead of addressing the underlying issue.

In another 2019–20 investigation, a service provider attempted to address behaviours of concern, such as faecal smearing, by compelling an individual to wear continence aids and a restrictive bodysuit in reverse. There was little effort to understand why the behaviours occurred and what other less restrictive alternatives could be used.

These practices, when unauthorised, infringe upon human rights, and can have a serious impact on an individual's health and wellbeing. It is not uncommon for dehumanising or restrictive practices to be justified on the grounds of protecting the rights and safety of staff, without a deep consideration of alternatives. We strongly agree that the positive behaviour support model is an alternative approach that respects the rights of people with disability, and similarly can prevent the behaviour of concern or 'hazard' from impacting staff. 43

<sup>38</sup> Christine Bigby et al, 'Quality of practice in supported accommodation services for people with intellectual disabilities: What matters at the organisational level' (2020) *Journal of Intellectual* & Developmental Disability (advance) 1.

<sup>39</sup> Christine Bigby et al, 'Quality of practice in supported accommodation services for people with intellectual disabilities: What matters at the organisational level' (2020) Journal of Intellectual & Developmental Disability (advance) 11.

<sup>40</sup> Jeffrey Chan 'Challenges to realising the Convention on the Rights of Persons with Disabilities (CRPD) in Australia for people with intellectual disability and behaviours of concern' (2016) 23(2) Psychiatry, Psychology and Law 207, 210.

<sup>41</sup> Disability Act 2006, s. 132ZQ. Regulated restrictive practices by registered NDIS providers must be included in an NDIS behaviour support plan prepared by an NDIS behaviour support practitioner and reported to the NDIS Commission.

<sup>42</sup> Jeffrey Chan 'Challenges to realising the Convention on the Rights of Persons with Disabilities (CRPD) in Australia for people with intellectual disability and behaviours of concern' (2016) 23(2) Psychiatry, Psychology and Law 207, 211.

<sup>43</sup> Ibid 210

### Medical decision-making

Under the supported decision-making model set out in the Australian Law Reform Commission's report, *Equality, Capacity and Disability in Commonwealth Laws*, supporters have a duty to ensure the will and preferences of the individual direct decisions that are made.<sup>44</sup>

Service providers often play an important role in the lives of people with disability who do not have consistent family involvement; for example, they may assume responsibility for coordinating medical appointments and health information.<sup>45</sup> However, this aspect of their role can cause problems. A repeated issue in our investigations is that attempts are not always made to involve the person with disability or their family in discussions at their medical appointments or about their medical treatment. In one 2019–20 investigation, a support worker attended some medical appointments on behalf of an individual, without their presence at the appointment, and without family consent.

In another example, we found that an individual was reviewed along with another resident by the same psychiatrist during the one appointment, with each remaining in the consulting room while the other individual was attended to. It is unacceptable that this was allowed to occur.

It is concerning that service providers do not routinely consider and respect the essential role and support of families and carers, in accordance with the Act.<sup>46</sup> Common issues include incorrect information on next-of-kin information and a failure to provide updated health information. In one 2019–20 investigation, the service provider did not communicate with the family that their family member was in an intensive care unit, despite a deterioration in health and hospitalisation six days earlier.

We have observed in our 2019–20 investigations, situations where the kinds of medical treatment on offer, or the decision to withhold treatment, has been made in relation to the family's or medical professional's perception of the person's best interests, rather than in relation to best practice procedures for the person's presenting conditions and treatment options.

This practice can be shaped by ableist assumptions that the quality of life of people with disability is very low, and that they will never live happy and fulfilling lives. Ableism leads to discrimination, including the denial of treatment on the basis of disability.<sup>47</sup>

### End of life care

The process of discussing and documenting end of life care preferences is referred to as advance care planning. Ideally advance care planning is undertaken as a slow process, as time is needed and should be used to assist people with disability to adjust to the changing situation and to make decisions step by step.<sup>48</sup>

However, in our 2019–20 finalised investigations we did not often observe a deliberate and considered approach to end of life care planning. Rather, this usually occurred in response to a person's rapidly deteriorating health. As a result, there was a narrowed medical emphasis in advance care plans such as the making of resuscitation orders and directives on life-sustaining treatments.

This lack of a proactive approach to advance care planning is a missed opportunity for people to consider and express their preferences, including about where they would like to die or their spiritual needs for dying (such as wishes for visitation).<sup>49</sup> In 2019–20, insufficient advance care planning contributed to unnecessary emergency department presentations for people with disability at the end of life.

An absence of formal arrangements for medical decision making can be problematic at the end of life. In 2019–20, some families were provided with the choice between actively treating or withholding treatment from an individual with an intellectual disability, despite not having a close and continuing relationship with the individual. Service providers may be aware of this tension, however, have not proactively requested the advice or intervention of the Office of Public Advocate (OPA).

It can be difficult for people with disability to self-advocate about issues that impact their health, wellbeing and quality of life. DSC considers that access to skilled independent advocates and other professionals can enable people with disability and their families to develop the capabilities to self-advocate across their whole-of-life, and to learn about and prepare for death and dying.

<sup>44</sup> Australian Law Reform Commission, Equality, Capacity and Disability in Commonwealth Laws (Commonwealth of Australia, August 2014) 116.

<sup>45</sup> Office of the Public Advocate (Qld), Deaths in care of people with disability in Queensland 2016, 59.

<sup>46</sup> Disability Act 2006, s. 5(3)(j).

<sup>47</sup> Catalina Devandas Aguilar, Report of the Special Rapporteur on the rights of persons with disabilities, UN Doc A/HRC/71/314 (9 August 2016) [31].

<sup>48</sup> Hille Voss et al, 'What is important for advance care planning in the palliative phase of people with intellectual disabilities? A multi-perspective interview study' (2020) 33 *J Appl Res Intellect Disabil* 160, 165.

<sup>49</sup> Michele Wiese et al, 'What is talked about? Community living staff experiences of talking with older people with intellectual disability about dying and death' (2014) 58(7) Journal of Intellectual Disability Research 679, 686.

# Key actions and future opportunities

Over 2019–20, we have been encouraged by developments in quality and safeguarding, which reaffirm to DSC the effectiveness of our death investigations in identifying and addressing barriers to the health, wellbeing and human rights of people with disability.

### Providing advice on systemic reform

Over the past three years, DSC has issued numerous Notices to Take Action to service providers to rectify practices that did not meet their obligations under the Act. As a result, government and disability service providers have improved their level of responsiveness to the needs and rights of people with disability.

In this 2019–20 reporting period, we observed the clear impact of death investigations in effecting systemic change, particularly in relation to falls prevention. For example, DHHS commissioned a practice advice on falls risk minimisation, providing strategies to assist support workers to reduce the falls risk of people living in group homes.

This systemic reform was influenced by the sustained work of DSC. For example, we had observed that people who were known to be at increased risk of falling, often did not have access to a falls risk assessment or management plan to mitigate the risk of falling. When the advice of allied health professionals for falls prevention was effectively sought by service providers, it was not consistently actioned.

We are encouraged that this DHHS practice advice has potential to promote collaborative working at the interface of disability and health, such as through enabling people with disability better access to preventative falls and balance clinics, and access to rehabilitation to support the transition from hospital to home.

### A human rights approach

Shared supported accommodation is a home for its residents, but it is also a workplace, with its associated routines, rules and regulations. We have found this can sometimes lead to a prioritisation of staff needs and preferences, over the human rights and needs of the residents. In turn, this can lead to a poor culture within services.

A lack of staff awareness about how to deliver supports with people's needs and human rights in mind, were a common and concerning issue in our 2019–20 finalised investigations. For example, in one investigation, we found that staff at a group home did not escalate to management their requests for the replacement of light bulbs, requiring residents to eat in the dark for two weeks.

Staff who have been neglectful may be identified as lacking training and to have a low level of competence in performing core supports. In one 2019–20 finalised investigation, a service provider was found to have offered supervision to staff only once during the year. Service providers have reported to DSC that inadequate funding levels have contributed to supervision that is infrequent and less focused on reflective practice.

The drafting of the *Convention on the Rights of Persons with Disabilities* provides a human rights-based alternative for service provision. It places people with disability at the centre of their own lives and ensuring opportunity for their active involvement in decision-making processes.<sup>50</sup> We consider that a human rights approach to training and education can help to better embed supported decision-making in the everyday practices of the disability sector.

<sup>50</sup> Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) Preamble.

### Change and the transfer of services

People with disability who have a prior history of institutionalisation, experience specific barriers to their right to health. Due to multiple changes in placement, information about people's lives can be lost or reproduced with inaccuracies. In one 2019–20 finalised investigation, we found that hearsay within a disability service informed an individual's health information.

It is important then, that a key objective in the NDIS transition and transfer of DHHS group homes to five non-government providers, is to ensure safety and consistency of individualised supports to people with disability, with residents largely being supported by staff who also transfer to the new providers.<sup>51</sup>

Indeed, over 2019–20 we have observed a keen willingness of many transfer service providers to ensure individualised supports and strategies are adequate to meet the health needs of people with disability in order to avoid preventable deaths. In this report, we have also called on service providers to reflect upon how they support people with disability to exercise choice and control in their daily lives.

At this critical juncture, maintaining continuity in systems of support for people with disability is undoubtedly important. However, DSC also considers it necessary that service providers critically question the status quo of the culture of a group home. The culture and practices of a group home are built upon shared staff values, beliefs, norms, patterns of behaviour and ways of working.<sup>52</sup>

We encourage service providers to review the report by DSC, *Building safe and respectful cultures*.<sup>53</sup> This research illustrates how the development of strong mutually rewarding relationships between people with disability, their families, disability support workers and management is critical to the realisation of a strong organisational culture, and to the creation of an environment that is protective of human rights.

### Quality and safeguarding during COVID-19

This report year of 2019–20 has brought to the fore an unprecedented level of focus on the issues impacting people with disability. This has occurred through the lens of the Disability Royal Commission and inquiries by the Joint Standing Committee on the NDIS, including into the NDIS Commission.

Further change is afoot for Victorians, as the Victorian Government prepares for changes to the Act, to reflect the changing role of government with the full implementation of the NDIS. As discussed, DSC as a state-based oversight body has already adapted to a considerable reduction in our jurisdiction.

We are optimistic that such inquiries can help to build community and political awareness of the numerous policy problems that restrict people with disability from their right to full participation and inclusion in the community, and to work through and implement possible solutions for transformative change.

The COVID-19 pandemic in particular has highlighted pressing human rights issues affecting people with disability, such as in relation to the extent that they receive safe and regular access to essential support services and access to health care. <sup>54</sup> Specific concerns about people with disability in group homes include the higher risk of infection, social isolation and closure of day services, and the risk of reduced safeguarding or oversight practices. <sup>55</sup>

Through the cumulative learning and evidence derived from our death investigations, our office has continued to contribute to service improvements and systemic reforms that have improved the lives of people with disability. In our oversight role for the forthcoming year, DSC will keep such longstanding and emergent issues impacting disability services in full view.

<sup>51</sup> The Victorian Government, Transfer of disability accommodation and respite services <a href="https://www.vic.gov.au/transfer-disability-accommodation-and-respite-services">https://www.vic.gov.au/transfer-disability-accommodation-and-respite-services</a>.

<sup>52</sup> Lincoln Humphreys, Christine Bigby & Teresa Iacono, 'Dimensions of group home culture as predictors of quality of life outcomes' (2020) J Appl Res Intellect Disabil (advance) 6.

<sup>53</sup> Sally Robinson et al, Building safe and respectful cultures in disability services for people with disability (Report for the Disability Services Commissioner, June 2019).

<sup>54</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Issues paper – Emergency planning and response (15 April 2020) <a href="https://disability.royalcommission.gov.au/publications/emergency-planning-and-response">https://disability.royalcommission.gov.au/publications/emergency-planning-and-response</a>> 5.

<sup>55</sup> Ibid 6.

# **Appendices**

### Appendix 1: Operations

### Financial statement for the year ended 30 June 2020

The Department of Health and Human Services (DHHS) provides financial services to the Disability Services Commissioner (DSC).

The financial operations of DSC are consolidated into those of DHHS 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 2019–20 is provided below.

## Operating statement for the year ended 30 June 2020

### Expenses from continuing activities

Total expenses	\$ 4,824,019
Indirect expenses (includes depreciation and long-service leave)	\$ 120,416
Supplies and consumables	\$ 290,457
Salary On-costs	\$ 570,031
Salaries	\$ 3,843,115

### Staffing for the year ended 30 June 2020

22.2 full-time equivalent (FTE) at 30 June 2020.

### 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*. DSC complies with this Act in its collection and handling of personal information.

DSC's privacy policy <a href="http://www.odsc.vic.gov.au">http://www.odsc.vic.gov.au</a> 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 DSC subject to certain exemptions. In 2019–20, DSC received 5 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 writing to:

Freedom of Information Officer Disability Services Commissioner Level 20, 570 Bourke Street Melbourne VIC 3000

Email: odsc.foi@odsc.vic.gov.au

Our website <a href="http://www.odsc.vic.gov.au">http://www.odsc.vic.gov.au</a> has more information about this process.

### 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 DSC, to act consistently with the human rights in the Charter.

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 DSC or its officers can be made verbally or in writing to:

Independent Broad-based Anti-corruption Commission GPO Box 24234

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

Melbourne Vic 3001

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

Anti-corruption Commission website:

<a href="http://www.ibac.vic.gov.au">http://www.ibac.vic.gov.au</a>

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

