

Off the record



Improve  
Experience Report  
Learn Change  
Avoid  
Inform Purpose  
Consult  
Ask Record  
Equal Analyse  
Prevent  
Include Monitor  
Involve  
Review Follow-up  
In(visible) Quality  
Research Culture Evaluate  
Check Transparent

## Investigation Report

An investigation into the Ministry of Health's collection, use, and reporting of information about the deaths of people with intellectual disabilities

July 2020

Peter Boshier  
Chief Ombudsman

 **Ombudsman**  
Tuia kia ōrite • Fairness for all

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## Foreword

In 2018, serious concerns were raised with me about the recent deaths of a group of people with intellectual disabilities receiving full-time residential support. The concerns primarily related to a lack of visibility surrounding the deaths. There were questions about whether the appropriate people and agencies were being informed and the necessary enquiries made, particularly following a sudden or unexpected death. There was a sense from those who contacted me that the deaths of these people were seen as not important and had been overlooked, including by the Ministry of Health.

I was troubled by what had been submitted to me. I understood that information about health outcomes for New Zealanders with intellectual disabilities is limited, but also that the data that does exist shows their overall health outcomes are poorer and their life expectancies significantly lower than the population at large. I was also aware of a real concern that the deaths of some people with intellectual disabilities may be premature or avoidable.

Reliable health and disability data is important for many reasons. It allows for the monitoring of changes over time in respect of particular events, conditions, impairments or diseases. It enables progress against goals to be measured. It is vital for evaluating the quality of services and interventions, and assessing the extent to which these are producing the desired outcomes. Good data helps make informed decisions about the future allocation of resources, and can help identify matters warranting further research or inquiry.

As Chief Ombudsman, I investigate the administrative conduct of government agencies. This includes investigations into serious or systemic issues, where I think my intervention has the potential to result in wider administrative improvement. In addition, I am one of three partners responsible for monitoring New Zealand's progress in implementing the United Nations Convention on the Rights of Persons with Disabilities (Disability Convention). This is a key international treaty for ensuring people with disabilities have access to the same rights and opportunities as everyone else. Ensuring that New Zealand meets its Disability Convention obligations is something I am passionate about.

I was also aware of a real concern that the deaths of some people with intellectual disabilities may be premature or avoidable.

The Ministry of Health (the Ministry) plans, funds, and purchases disability support services, including residential support services. As such, it is responsible for monitoring how the system performs, and for ensuring the quality of services. It is responsible for steering improvements that support people to live longer, healthier, and more independent lives. The Ministry cannot fulfil these responsibilities without good data.

This report presents the findings of my investigation into the Ministry's collection, use, and reporting of information about the deaths of people with intellectual disabilities receiving full-time residential support, drawing on a sample of deaths that occurred between January 2016 and June 2018.

I have found that the Ministry's arrangements for collecting information about the deaths of its service users were not adequate or robust. The Ministry's systems and processes did not support the collection of information that was complete, accurate, or sufficient. They did not provide a sound basis for staff to determine whether there was a need for further enquiry or other follow-up action. In the absence of clear guidance for staff, the follow-up that did occur appears to have been limited and inconsistent. To compound matters, there was no internal audit process that might have identified these issues and record-keeping was not adequate. Significantly, there was no evidence to indicate that the information the Ministry collected, or should have collected, was used to inform its own service or policy development, or shared with residential support providers in ways that might support their quality improvement efforts.

In making these findings, I am aware that the Ministry undoubtedly faces enormous challenges, including some that are specific to meeting the needs of people with intellectual disabilities, and others that relate more broadly to obtaining and making good use of data.

At the same time, there is good reason to be optimistic. Shortly before I commenced this investigation, the Ministry brought its disability-related functions together under one directorate.

At the same time, there is good reason to be optimistic. Shortly before I commenced this investigation, the Ministry brought its disability-related functions together under one directorate.

I anticipate this being a stronger basis for the development of a more cohesive approach to the Ministry's responsibilities for purchasing and monitoring disability services, and for actively managing the performance of disability services.

I am encouraged by the way in which the Ministry has engaged with my investigation. Commendable changes have already been made to remedy the deficiencies identified and the Ministry has signalled a clear willingness to make further improvements.

I look forward to continued engagement with the Ministry as it works through the implementation of my recommendations.

**Peter Boshier**

Chief Ombudsman

July 2020

## Acknowledgements

I would like to thank the Ministry of Health—in particular staff from the Disability Directorate—for their assistance and cooperation throughout this investigation.

My thanks also to the other individuals and organisations who contributed to this investigation, including:

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Chief Archivist

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Chief Coroner

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Deputy Commissioner Disability  
(Health and Disability Commissioner)

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Disability Commissioner (Human Rights Commission)

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Disability Support Network

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Dr Frances Hughes, ONZM

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Health Quality & Safety Commission

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IHC New Zealand

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Providers of residential support services

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People First New Zealand

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Sharon Brandford

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Sir Robert Martin, KNZM

Finally, but importantly, I acknowledge the people who were part of the sample group that was examined for this investigation, and whose information formed the basis for my findings and recommendations.

## A note about terminology

Language around disability is important. I acknowledge that people have differing views on the meaning, accuracy, and effects of particular terms. I have chosen to use the term 'intellectual disability' in this report.

There is no single definition of the term 'intellectual disability'. People with intellectual disabilities are a diverse group but they often have challenges understanding new or complex information, learning new skills, and living independently.

The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (ID(CCR) Act) defines an intellectual disability as a permanent impairment that:

- results in an IQ of 70 or less;
- results in significant deficits in adaptive functioning in areas such as communication, self-care, home living and social skills; and
- becomes apparent before a person reaches the age of 18.

The term 'learning disability' is also commonly used to refer to someone with an intellectual disability, especially by those in the disability community. (In some countries 'learning disability' is used to describe a person who may have difficulty with tasks such as reading or concentrating, and 'intellectual disability' refers to a person who has higher needs or needs greater support.)

In Te Ao Māori, 'tangata whaikaha hinengaro' may be used to refer to a person with an intellectual or learning disability.

The United Nations Convention on the Rights of Persons with Disabilities (which New Zealand has signed) refers to 'intellectual disability' as 'intellectual impairment'.

See **Appendix 1** for a glossary of other terms used in this report.

## Executive summary

### The investigation

New Zealanders with intellectual disabilities have overall poorer health outcomes compared to people without intellectual disabilities, despite higher than average use of health services. There are significant differences in life expectancy—people with intellectual disabilities can expect their lives to be shorter by an estimated 17-24 years compared to the general population. There is concern that the deaths of some people with intellectual disabilities may be premature or avoidable.

The Ministry of Health (the Ministry) is responsible for leading New Zealand's health and disability systems. It also funds, purchases, and monitors disability support services. These support services are provided by district health boards (DHBs) and community-based organisations, and include full-time residential support for more than 6000 people with intellectual disabilities.

People with intellectual disabilities are amongst the most marginalised members of society. Good data, used effectively is fundamental to improving their lives and life expectancy, reducing inequities, and promoting a more inclusive society.

The purpose of my investigation was to examine the Ministry's policies and practices in recording and reporting the deaths of people with intellectual disabilities receiving full-time residential support, in order to identify whether they were consistent with good administrative practice and accountability, and relevant international conventions including the United Nations Convention on the Rights of Persons with Disabilities.

My investigation examined the Ministry's systems of information collection, analysis, and reporting in relation to the deaths of people living in facilities run by DHBs and non-DHB providers. It included consideration of the Ministry's records relating to people with intellectual disabilities who died between 1 January 2016 and 30 June 2018, who had been receiving full-time, Ministry-funded residential support in the Auckland, Wellington, and Canterbury regions.

It included consideration of the Ministry's records relating to people with intellectual disabilities who died between 1 January 2016 and 30 June 2018, who had been receiving full-time, Ministry-funded residential support in the Auckland, Wellington, and Canterbury regions.

My investigation focused on Disability Support Services (DSS) as the service within the Ministry that was responsible for purchasing and monitoring services provided for people with intellectual disabilities, including residential support.

### **My opinion**

Overall, it is my opinion that for the period under review, the Ministry's systems for the collection, use, and reporting of information about the deaths of people with intellectual disabilities receiving residential support, and associated record keeping, were unreasonable.

### Information collection

The Ministry's systems did not support the collection of complete, accurate or sufficient information in the context of its fundamental responsibilities and obligations.

- The Ministry did not have systems and processes in place to ensure that DSS, as the service responsible for purchasing and monitoring residential support, was informed of all of the deaths of its service users. There was no arrangement to cross-check the death notifications received from providers with relevant information held by other Ministry services. Enquiries made in the course of this investigation revealed 10 people who met the criteria for my sample group but whose deaths DSS had been unaware of. This represented just over nine percent of my sample group.
- There was no clear process to ensure the information held by DSS about a person's cause of death was updated when additional information became available after receipt of the initial notification.
- As the funder and purchaser of residential support, the Ministry has an obligation to collect information to ensure providers are delivering quality services in accordance with their contracts. The information collected by the Ministry was insufficient for those purposes.

Enquiries made in the course of this investigation revealed 10 people who met the criteria for my sample group but whose deaths DSS had been unaware of.

- Furthermore, there was a lack of consistency among staff as to what constituted insufficient information and when further enquiries were required.

### Use and reporting of information

The Ministry did not use and report on the information it collected, or was mandated to collect, to meet its quality assurance obligations or for broader evaluative and decision-making purposes.

- Ministry staff responsible for reviewing death notifications were provided with no clear guidance for determining whether further information or follow-up action was necessary. This led to practice that was both inconsistent and at odds with senior management's expectations. There was no internal audit process that might have identified this. Of particular note were a number of cases in the records for my sample group where DSS was advised that the person had died suddenly and unexpectedly, but no further information was obtained in relation to whether the death may have been avoidable, or to determine whether any follow-up action was required.
- Some providers carried out their own reviews following the death of their residents, to consider whether they had been provided with appropriate care, treatment, and support, and whether anything could or should have been done differently. However, a number of providers carried out no such reviews. The evidence from my sample group indicated that even when a review was completed, the Ministry rarely obtained details of the findings and any recommendations, contrary to the expectations of DSS senior management.
- Some staff appeared to believe that if a person's death had been reported to a coroner, it was unnecessary for them to make further enquiries or take any follow-up action. It was also evident that, unless a coroner made a finding or recommendation specific to the Ministry (and this did not occur in any of the cases in my sample

group), information about the outcome of a coronial inquiry was rarely obtained by DSS.

- There was little evidence to indicate information was analysed or reported in ways that could be shared with the residential support providers to support their quality improvement efforts, or to inform future policy development and initiatives.

### Record keeping

The Ministry's record keeping was deficient, a fact brought into sharp focus by the difficulties it had locating information required for my investigation.

- Of particular note was the lack of records showing enquiries made or actions taken by DSS in relation to a death notification, an identified or potential concern, and the outcome of any enquiries or other actions. The records for my sample group simply did not reflect the level of engagement that relevant staff reported having with either their Ministry colleagues or providers.
- Some interactions that should have been documented were not. Some information was not saved, or not saved in a manner that allowed it to be readily located and retrieved.
- There was no shared or standardised process for recording and saving information.
- There was no clear and consistent process for ensuring the spreadsheet used by DSS to collate information about the deaths of service users was updated if and when additional information came to hand at a later date. There were gaps in the process for keeping track of cases where a concern or potential concern had been identified, and enquiries were being made or follow-up action taken.

There was no shared or standardised process for recording and saving information.

## Recommendations

The Ministry implemented a number of changes in the course of my investigation to improve its administrative processes, most notably with the Disability Directorate's introduction of a new standard operating procedure (SOP) for the management of death notifications for people accessing residential support.<sup>1</sup> This became effective on 1 July 2019. The SOP sets out the roles and responsibilities of relevant Ministry staff following the death of a service user and provides guidance on identifying and acting on any related concerns. It confirms the Ministry's expectations of providers when a death occurs. It also confirms an expectation that information will be analysed and reported to inform future decision-making and service development. I have considered these recent steps taken by the Ministry when formulating my final opinion and recommendations.

I recommend that the Ministry take the following additional actions:

1. review the system recently introduced by the Disability Directorate to cross-check its data with Mortality Collection data to ensure this includes information received from the coroner, including final coroners' findings;
2. review the implementation and operation of the 'Death notification and management' SOP introduced on 1 July 2019, including its operation with respect to disabled service users living in aged residential care facilities, and service users in hospital level secure services;
3. review and amend the death notification form to ensure it captures sufficient relevant information from providers following a death, in the context of Ministry's role and responsibilities;
4. undertake an audit of Disability Directorate records for a sample of the last 20 deaths notified to the Ministry between 1 July and 31 December 2019 to ensure that in accordance with the new SOP and good administrative practice:

The SOP sets out the roles and responsibilities of relevant Ministry staff following the death of a service user and provides guidance on identifying and acting on any related concerns.

<sup>1</sup> Following a restructure within the Ministry, responsibility for the work previously carried out by DSS now lies with newly established teams within the Disability Directorate.

- a. appropriate steps are being taken to identify and manage any quality issues;
  - b. relevant feedback is shared with providers; and
  - c. the necessary records are being made and stored;
5. establish a process for ongoing audits of Disability Directorate records for a sample of deaths on an annual basis;
6. develop a comprehensive, robust, and durable plan to engage with and support providers and other relevant stakeholders, including service users (through representative bodies/ organisations), in order to:
- a. ensure an appropriate level of review is undertaken following the deaths of all people with intellectual disabilities receiving Ministry-funded residential support;
  - b. ensure provider reviews are routinely supplied to and reviewed by the Ministry;
  - c. establish mechanisms for review learnings to be shared with providers and other relevant stakeholders;
  - d. ensure the Ministry's expectations in relation to provider reviews are reflected in its contracts/service specifications; and
  - e. explore options for establishing, in the longer term, a national independent review system;
7. engage and work with the Health Quality & Safety Commission to explore options for supporting providers to improve the quality of experience and the safety of the care and services their residents receive. This will be achieved through reporting, reviewing, and learning from adverse events and near misses, including by increasing compliance with the National Adverse Events Reporting Policy among non-DHB providers, and through supporting quality improvement projects to effect change;
8. confirm arrangements for undertaking in-depth analysis of information about the deaths of service users (eg when and

how often this will occur), and information from critical incident reports, and utilising that analysis to inform future policy and practice;

9. consider what actions can be taken to develop and implement an improved information management system that better supports Disability Directorate staff to capture, store, access, and utilise relevant information, and compliance with the Public Records Act 2005; and
10. review the measures currently in place to ensure relevant senior leaders have sufficient oversight of operational practice in relation to the Ministry's expectations and obligations following the death of a disabled service user.

The Ministry is required to report back to me on recommendations 1 to 10 by **3 October 2020**.

## Feedback

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The Ministry provided the following comment:

*Since the commencement of your investigation, the Ministry has taken steps to improve the collection and recording of information relating to the deaths of all disabled people in full-time residential care, as noted in your provisional opinion. The Ministry acknowledges there is still work to do and is committed to implementing the recommendations outlined in your report. The Disability Directorate will continue to proactively engage with your Office as it works through the implementation of the recommendations.*

In addition:

- The Health Quality & Safety Commission advised that its Patient Safety Team met with the Ministry to discuss recommendation 7. The Commission also advised it is well placed to assist with recommendation 8, and will approach the Ministry about this.
- The Chief Archivist advised that he agreed with my assessment and recommendations, and that *'Archives New Zealand will engage with the Ministry to ensure that recordkeeping best practice arises from the lessons outlined in the Ombudsman's recommendations'*.



## Why this investigation?

In 2018, concerns were raised with me by people working in the health and disability sectors about a lack of visibility in relation to the deaths of people with intellectual disabilities who receive residential support. There were questions about whether the appropriate people and agencies were being informed and the necessary enquiries made, particularly following a sudden or unexpected death. When I enquired more widely, it was clear to me there was reason to take a closer look.

The lack of reliable and up-to-date information about health outcomes for New Zealanders with intellectual disabilities is well recognised. Reports confirm they have significantly poorer health outcomes than people without intellectual disabilities, despite higher than average use of health services.<sup>2</sup> The disparity is at its most stark

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<sup>2</sup> Health and Independence Report 2017, Ministry of Health (2018). Available at: <https://www.health.govt.nz/system/files/documents/publications/health-and-independence-report-2017-v2.pdf>

## Why this investigation?

perhaps, for life expectancy. People with intellectual disabilities can expect their lives to be shorter by an estimated 17-24 years compared to the general population.<sup>3</sup> This is broadly consistent with the situation in comparable countries.<sup>4</sup>

The fact that people with intellectual disabilities tend to experience higher rates of certain serious health conditions will certainly be a contributing factor. However, questions are rightly asked about the extent to which some of the deaths among this population group may be premature or avoidable. Factors identified as relevant—both here and internationally—include difficulties with access to appropriate and timely health care, the nature and structure of service provision, socio-economic deprivation, and communication challenges. In order to properly understand and respond to this, information about the causes and circumstances of the deaths should be collected and analysed.

The Ministry of Health (the Ministry) is responsible for leading New Zealand's health and disability systems. It also funds, purchases, and monitors disability support services, including full-time residential support for more than 6000 people with intellectual disabilities, giving rise to obligations in relation to quality assurance and quality improvement. I commenced this investigation as it was not clear

People with intellectual disabilities can expect their lives to be shorter by an estimated 17-24 years compared to the general population.

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3 Figures from 2014-2016 show the life expectancy for males with intellectual disability was 63.0 years, compared with 79.9 years for all New Zealand males – a difference of 16.9 years. The life expectancy for females with intellectual disability was 59.3 years, compared with 83.4 years for all New Zealand females – a difference of 24.1 years.

4 See for example:

Heslop, P, P Blair, P, P Fleming P, M Hoghton, A Marriott, A, and L Russ, L. *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final Report*. Norah Fry Research Centre, University of Bristol, UK, 2013. Retrieved on 1 November 2018 from: <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

Trollor J, P Srasuebku, H Xu, S Howlett. 'Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data.' *BMJ Open* 7, no. 2 (January 2017). Retrieved on 8 July 2019 from: <https://bmjopen.bmj.com/content/7/2/e013489>. This study found that 38% of deaths in the group of people with intellectual disabilities were potentially avoidable, compared to 17% in the comparison group.

to me that, when it came to the collection, use, and reporting of information about the deaths of people with intellectual disabilities, the Ministry's practices were administratively sound, or consistent with its responsibilities and obligations to ensure providers are delivering quality care and support, and to reduce health disparities.

People with intellectual disabilities are amongst the most marginalised members of society. Good data, used effectively, is fundamental to improving their lives and life expectancy including by helping to prevent premature or avoidable deaths, reducing inequities, and promoting a more inclusive society.

### **United Nations Convention on the Rights of Persons with Disabilities (Disability Convention)**

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The Disability Convention is an international human rights treaty, which New Zealand signed in 2007, and ratified in 2008. Its purpose is to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. As Chief Ombudsman, I am part of New Zealand's Independent Monitoring Mechanism, responsible for protecting, monitoring, and promoting New Zealand's progress in implementing the Convention.<sup>5</sup>

The Disability Convention articles of particular relevance to this investigation are Article 10, which reaffirms the inherent right to life of all people, Article 25, which recognises the right of disabled people to enjoy the highest attainable standard of health without discrimination on the basis of disability, and Article 31, which requires the collection of appropriate data and statistical information.

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<sup>5</sup> This responsibility is accorded to me under Article 33(2) of the Disability Convention. The other Independent Monitoring Mechanism partners are the Disabled Person's Organisations' Coalition (a group of national disabled people's organisations) and the Human Rights Commission.

### Ombudsman's jurisdiction

Under the Ombudsmen Act 1975 (OA), I have the authority to investigate the administrative acts, decisions, omissions and recommendations of government agencies, including the Ministry of Health.<sup>6</sup> My role is to consider the Ministry's administrative conduct and form an independent opinion on whether that conduct was reasonable.<sup>7</sup>

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<sup>6</sup> An Ombudsman may investigate a specific complaint or 'of his own motion' (section 13(3)). An own motion or self-initiated investigation is usually prompted by serious or systemic issues, where the Ombudsman thinks their intervention has the potential to result in wider administrative improvement.

<sup>7</sup> Sections 22(1) and 22(2).



## What did I investigate?

On 26 October 2018, I formally notified the Ministry of my intention to investigate its administrative practices concerning the recording and reporting of deaths of people with intellectual disabilities receiving full-time residential support. I confirmed in the terms of reference<sup>8</sup> that:

- the purpose of my investigation was to examine the Ministry's practices in recording and reporting the deaths of people with intellectual disabilities in order to identify whether the Ministry's policies and practices are consistent with good administrative practice and accountability, and relevant international conventions including the Disability Convention;

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<sup>8</sup> Available in full at: <https://www.ombudsman.parliament.nz/resources/terms-reference-intellectual-disability-systemic-investigations> (including in Easy Read).

- my investigation would examine the Ministry's system of information collection, analysis, and reporting in relation to the deaths of people living in facilities run by district health boards (DHBs) and non-DHB providers; and
- my investigation would include consideration of the Ministry's records relating to people with intellectual disabilities who died between 1 January 2016 and 30 June 2018, who had been receiving full-time, Ministry-funded residential support in the Auckland, Wellington and Canterbury regions.

It is important to note at the outset that my investigation is focused on the Ministry's actions. I have not investigated individual deaths, or the services delivered by providers. Given that the providers are not subject to my legislation, I do not have authority to investigate their actions.<sup>9</sup>

This is one of two investigations I am conducting into issues relevant to the intellectual disability sector. My second investigation concerns the Ministry's oversight of facilities and services for people with intellectual disabilities with high and complex needs.<sup>10</sup> I will report on the outcome of my second investigation later this year.

It is important to note at the outset that my investigation is focused on the Ministry's actions. I have not investigated individual deaths, or the services delivered by providers.

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<sup>9</sup> I have authority to require information from providers as third parties for the purposes of my investigation (OA section 19(1)).

<sup>10</sup> The terms of reference for this investigation are also available at: <https://www.ombudsman.parliament.nz/resources/terms-reference-intellectual-disability-systemic-investigations>



## How did I investigate?

My investigation involved information gathering and analysis through:

- consideration of relevant international and national law, policy and procedure;
- initial meetings with senior Ministry staff;
- an initial information request to the Ministry and follow-up requests;
- meetings with and information requests to the Chief Coroner and the Deputy Health and Disability Commissioner (Disability);
- information requests to 14 providers;
- a review of relevant records held by the Ministry for 108 service users, and held by providers for 41 service users;
- information requests to 15 District Inspectors designated under the ID(CCR) Act;

- meetings with other stakeholders including representatives from People First New Zealand, IHC New Zealand, the Health Quality & Safety Commission, and the Disability Support Network;
- interviews with staff from the Ministry's Disability Support Services (DSS) and HealthCERT;<sup>11</sup> and
- external expert advice.

On 26 May 2020, my provisional report was provided to the Ministry for comment.

Relevant third parties were also consulted on my provisional findings and recommendations, and a number of changes have been made to incorporate their feedback.

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<sup>11</sup> Including current staff and staff who had left the Ministry within the previous year.



## Background

### The legal and policy framework

#### International obligations: the Disability Convention

As noted on page 21, the Disability Convention is an international human rights treaty designed to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. Articles 4(3), 10, 25, and 31 of the Disability Convention are of particular relevance to this investigation.

- Article 4(3) — Consultation and involvement

This article requires parties to closely consult with and actively involve persons with disabilities, through their representative organisations, in the implementation of the Convention and other decision-making processes relating to persons with disabilities.

- Article 10 — Right to life

This article reaffirms that every person has the inherent right to life, and the need to take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

- Article 25 — Health

This article recognises that persons with disabilities have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability. It requires persons with disabilities to be provided with the services they need specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities.

- Article 31 — Statistics and data collection

This article requires parties to collect appropriate data and statistical information to give effect to the Convention. Such data needs to be appropriately disaggregated or broken down, so parties can assess how they are fulfilling their obligations, and to identify and address barriers faced by persons with disabilities in exercising their rights.

New Zealand's first review by the United Nations Committee on the Rights of Persons with Disabilities (the Committee) was in 2014.<sup>12</sup> At that time, the Committee expressed its concerns on a range of issues including:

- the barriers that still exist preventing disabled people from fully accessing health care services;
- that Māori have the poorest health outcomes in New Zealand and that the prevalence of disability is higher among Māori as a result of poverty and disadvantages; and

Right to enjoy the highest attainable standard of health without discrimination on the basis of disability.

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<sup>12</sup> Available at: <http://docstore.ohchr.org>

- that government departments, crown entities, and local authorities do not always collect and publish disaggregated data on people with disabilities in their annual reports.

The Committee has asked the Government for a report on progress in advance of the next review including on the issues above, and on measures taken to collect data and information about indigenous peoples with disabilities along with the disaggregation, analysis, and dissemination of that data.

### New Zealand Public Health and Disability Act 2000

The statutory framework for New Zealand's health and disability system involves many pieces of legislation. Of particular importance is the New Zealand Public Health and Disability Act 2000, which established the current structure for the organisation of health and disability services and government funding.<sup>13</sup>

Under this Act:

- the Minister of Health must determine a strategy for health services to provide the framework for the Government's overall direction of the health sector in improving the health of people and communities; and
- the Minister responsible for disability issues must determine a strategy for disability support services to provide the framework for the Government's overall direction of the disability sector in improving disability support services.<sup>14</sup>

### New Zealand Health Strategy

The current health strategy, *New Zealand Health Strategy: Future Direction* (the Health Strategy), sets the direction of health services for the 10 years from 2016 to 2026, with the overall aim of improving

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<sup>13</sup> See Appendix 2 for an overview of New Zealand's health and disability system.

<sup>14</sup> Part 2, section 8.

the health of people and communities. It recognises people with intellectual disabilities as a high needs population. Within the Health Strategy, a 'Roadmap of actions' sets out actions to be taken in 27 work areas, under five themes.

- Action 4 relates to the 'people-powered' theme and proposes promoting '*people-led service design*'. This includes the development and implementation of an action plan to improve the health of people with learning/intellectual disabilities.
- Action 25 relates to the 'smart system' theme and proposes strengthening the national analytical capability. This is about increasing the quality of national data and analytical capability, to make the whole health system more transparent and provide useful information for designing and delivering effective services.

## New Zealand Disability Strategy

The current disability strategy, *New Zealand Disability Strategy 2016-2026* (the Disability Strategy), is designed to guide the work of government agencies on disability issues for the 10 years from 2016, and is identified as the government's vehicle for meeting our Disability Convention obligations. The vision of the Disability Strategy is for New Zealand to become a non-disabling society—

*a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen.*

The Disability Strategy identifies as key to its implementation:

- three sets of principles—Te Tiriti o Waitangi (the Treaty of Waitangi), the Disability Convention, and ensuring disabled people are involved in decision-making that impacts them; and
- two approaches—investing in our whole lives (a long-term approach), and specific and mainstream services (a twin-track approach).

The primary vehicle for implementing the Disability Strategy is the *Disability Action Plan* (DAP). The 2014-18 DAP set out 12 priorities.

The vision of the Disability Strategy is for New Zealand to become a non-disabling society.

Priority 9 was about making government services more responsive to disabled people, which includes increasing access to health services and improving health outcomes for disabled people, with a specific focus on people with intellectual disabilities. From this, a key policy objective was to strengthen data collection and information so that people with intellectual disabilities are visible in the health system, and their health needs can be met more efficiently and effectively.

The 2019-23 DAP was released in November 2019. It includes 25 work programmes, to be delivered by 14 agencies (including the Ministry of Health) and their partners. Improving disabled people's access to quality healthcare and health outcomes is again identified as a priority. In addition, government agencies have been asked to commit to two 'cross-cutting' issues: the collection of better data about disabled people, and greater involvement of disabled people in policy and service development.

Improving disabled people's access to quality healthcare and health outcomes is again identified as a priority.

## The Ministry of Health

The Minister of Health is principally supported by the Ministry of Health. In this section, I provide an overview of the role and purpose of the Ministry, a number of key plans and reviews, services within the Ministry that are particularly relevant to my investigation, and people and organisations outside the Ministry that are similarly relevant.

### Role and purpose

The Ministry of Health seeks to improve, promote, and protect the health and well-being of New Zealanders, through its leadership of our health and disability system. Its responsibilities include:

- advising the Minister of Health, the Government, and other stakeholders on health and disability matters;
- providing clinical and technical advice on a range of health and disability policies;
- directly purchasing and monitoring a range of national health and disability support services;

- administering legislation and regulations to ensure the safety of health products and services; and
- providing health sector information and payment services for the benefit of all New Zealanders.

As the agency with overall responsibility for the management and development of the health and disability system, the Ministry steers improvements that help people live longer, healthier, and more independent lives. It also seeks to reduce health disparities by improving the health outcomes of Māori and other population groups.<sup>15</sup>

The Ministry's leadership role needs to be seen in the context of a semi-devolved health and disability system, with leadership distributed amongst various layers. The Ministry is responsible for the overall strategic direction, setting expectations about service delivery, and funding. Many of the day-to-day functions and decisions occur at the local level, including by DHBs and non-DHB providers.

Given the complex array of institutional arrangements and the 'distributed leadership' model, the Ministry has a range of levers from formal (statutory) to informal (relationship management) to influence the health and disability system, giving rise to different levels of responsibility and accountability. In a practical sense, the Ministry has greater ability to control services it purchases directly, when compared to services funded through the twenty DHBs (which are required to plan, fund and provide health services).

In relation to the purchasing of disability support services, the Ministry enters directly into agreements with DHBs and a range of non-DHB community providers. While the providers are responsible for the day-to-day care and support of service users, the Ministry retains overall accountability, as the commissioner of those services. This differs from services funded through the twenty DHBs, and for which DHBs are accountable.

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<sup>15</sup> As noted earlier, the overall purpose of the Ministry and the organisational features of the health and disability sectors are determined largely by the provisions of the New Zealand Public Health and Disability Act 2000, in addition to the Health Act 1956.

The current Director-General of Health and Chief Executive, Dr Ashley Bloomfield, started in his role on 8 June 2018. A Ministry press release stated:

*[Dr Bloomfield] sees the Ministry's stewardship role as ensuring clear direction, delivering the best possible health outcomes – equitably for all groups – with the available resources, and robust planning for the future.<sup>16</sup>*

The Ministry has a current work programme focused on achieving equity in health outcomes. This work is ongoing but in February 2019, the Ministry formally adopted the following definition of equity:

*In Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust. Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes.*

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<sup>16</sup> <https://www.health.govt.nz/news-media/news-items/introducing-ashley-bloomfield>

## Key plans and reviews

There are a number of government reviews and plans of particular relevance to this investigation. These are listed in Table 1 below, with further details set out in Appendix 3.

**Table 1: Key reviews and plans**

Name	Purpose
Enabling Good Lives	An approach that stems from a 2011 report, which concluded a fundamental shift was needed in relation to disability support.
System transformation	A current initiative to transform the disability system.
Putting People First	A 2013 review of the performance and quality management processes for disability services purchased by the Ministry.
Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan	A culturally anchored approach to supporting Māori with disabilities (tāngata whaikaha) and their whānau.

### Key services and teams

#### The Disability Directorate

The Ministry's disability-related work was previously carried out by a number of services and teams sitting under different business units. In October 2018, following the appointment of Dr Bloomfield, a Disability Directorate was established to provide *'oversight of 'end-to-end' activities and functions for the disability community'*.

This includes purchasing disability support services for people with long-term impairments (physical, intellectual and/or sensory) who require ongoing government support to enhance their health and well-being, as well as advising on disability policy and ensuring disabled people receive the health care services they need. The Disability Directorate is led by a Deputy Director-General Disability, a position taken up by Adri Isbister in March 2019.

#### Disability Support Services

Disability Support Services (DSS) previously sat within the Service Commissioning business unit, and then became part of the Disability Directorate. A second phase of restructuring has recently occurred and DSS no longer exists in the same form as it did when I commenced my investigation.<sup>17</sup> It was, however, the service responsible for purchasing and monitoring services for disabled people, including residential support, throughout the period focused on in this investigation.

The teams/staff within DSS responsible for the work most relevant to this investigation were the Community Living Team, the Quality Team, and the Chief Advisor ID(CCR) Act.

- The Community Living Team had particular responsibility for managing the Ministry's approximately 700 contracts with providers of residential support services. This work was undertaken

A second phase of restructuring has recently occurred and DSS no longer exists in the same form as it did when I commenced my investigation.

<sup>17</sup> The Disability Directorate now includes a Strategy, Policy and Performance team, an Operational Performance team, a Chief Clinical Advisor, a Principal Advisor Māori, a System Transformation team, and a manager for the Office of the Deputy Director-General Disability.

by a team of contract relationship managers, each of whom had responsibility for managing specific contracts.<sup>18</sup>

- The role of the Quality Team was to provide assurance that Ministry-funded providers of disability support services are delivering quality services. The Quality Team remains responsible for managing incidents and complaints about disability support services, and for managing a programme of developmental evaluations for providers. It also provides advice and support on quality improvement.<sup>19</sup>
- The Chief Advisor ID(CCR) was responsible for oversight of the statutory processes under the ID(CCR) Act, which provides for the compulsory care and rehabilitation of people with intellectual disabilities who have been either found unfit to stand trial for, or convicted of, an imprisonable offence. This includes directing District Inspectors to conduct investigations where there are concerns about an individual's rights or wider service issues that require inquiry.<sup>20,21</sup>
- These teams/staff reported to a group manager, who in turn reported to the Director of Service Commissioning, and more recently to the Deputy Director-General Disability.

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18 The recent restructuring included changes to the role and function of contract relationship managers (now called 'portfolio managers'). They now sit within three regional teams, which are part of the Disability Directorate's Operational Performance team.

19 The Quality Team now sits within the Disability Directorate's Strategy, Policy and Performance team.

20 District Inspectors are appointed under the ID(CCR) Act and designated by the Director-General of Health to perform certain functions. They provide an independent monitoring function to ensure the rights of people subject to the ID(CCR) Act are upheld.

21 The recent restructuring has resulted in some changes to the role and function of Chief Advisor ID(CCR) (now Chief Clinical Advisor), and that person reports directly to the Deputy Director-General Disability.

- The majority of the Ministry's service users with an intellectual disability are supported through mainstream disability support services. In addition, the Ministry supports a group of approximately 320 service users under the 'High and Complex Framework'. This is a framework of interconnected specialised services for people whose needs are high and complex such that they cannot be supported by mainstream services. It includes people who are subject to court orders under the ID(CCR) Act and civil clients.<sup>22</sup>

### HealthCERT

HealthCERT sits within the Ministry and is a regulator, responsible for ensuring services such as hospitals and residential care facilities provide safe and reasonable levels of service for consumers as required under the Health and Disability Services (Safety) Act 2001.

Residential care provided in any premises (including aged care premises) for five or more people with an intellectual, physical, or sensory disability is required to be audited against New Zealand Health and Disability Services Standards by an independent designated auditing agency, and certified by HealthCERT.<sup>23</sup> Providers are audited on a regular cycle and certified for one to five years, depending on the audit findings.

It is not the role of HealthCERT to examine the circumstances in which a person living in a residential care facility has died.

Providers are audited on a regular cycle and certified for one to five years, depending on the audit findings.

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22 'Civil clients' is the term used to describe people who are not subject to orders under the ID(CCR) Act, but who meet the eligibility criteria for services under the High and Complex Framework.

23 It should be noted that although premises with fewer than five residents are not required to be audited against the Health and Disability Services Standards for the purposes of certification, the standards are mandatory for relevant service-based contracts that receive health funding. I note also that the current standards, Health and Disability Services Standards 8134:2008, are in the process of being reviewed. The review is expected to be completed by December 2020.

### **Mortality Collection**

The Ministry is also responsible for the Mortality Collection, which gathers and produces data on causes of death for New Zealand's vital statistics, and for public health research, policy formulation, monitoring the effectiveness of health programmes, and cancer survival studies. Mortality data is sent to the World Health Organization (WHO) each year to be used in international comparisons of mortality statistics.

The Mortality Collection is compiled by matching death and stillbirth registration data provided by Births, Deaths and Marriages with Medical Certificates of Causes of Death and coroners' reports.<sup>24</sup> Staff responsible for the Mortality Collection code the cause of death, using the WHO coding protocol.

Once a fortnight, the Mortality Collection team sends DHBs and other health service providers a list of people who have died, which they use to reconcile with their own cohorts of clients.<sup>25</sup>

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24 Births, Deaths and Marriages is a service managed by the Department of Internal Affairs.

25 The list shows the person's National Health Index number, date of death, and domicile.

### *Medical Certificate of Cause of Death*

In most cases when a person dies, a medical practitioner or nurse practitioner will certify the cause of death and complete a Medical Certificate of Cause of Death.<sup>26</sup> The practitioner records the direct cause of death, any antecedent and underlying causes, and other significant conditions that contributed to the death but which were not related to the disease or condition causing death.<sup>27</sup>

A correctly completed Medical Certificate of Cause of Death would identify a person as having an intellectual disability only if it was relevant to their cause of death. An intellectual disability should not be identified as the direct cause of death.

If staff responsible for the Mortality Collection are unable to code the cause of death on the basis of the information provided, they will seek clarification from the certifying practitioner.

It is noted that a 2015 report by the Law Commission, *Death, Burial and Cremation*, found fairly high levels of error in the recording of deaths.<sup>28</sup>

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26 Under section 46AA of the Burial and Cremation Act 1964, a body may not be buried, cremated or otherwise disposed of unless the person in charge of the disposal has been given either a certificate of cause of death or a coroner's authorisation.

27 The Medical Certificate of Cause of Death asks for:

- Part 1
  - (a) Direct cause: disease or condition directly leading to death;
  - (b) Antecedent causes: any morbid conditions giving rise to the above cause;
  - (c) Underlying cause: the disease or injury which initiated the train of morbid events leading to death
- Part 2 Other significant conditions contributing to the death but not related to the disease or condition causing death.

28 Available at: <https://www.lawcom.govt.nz/sites/default/files/projectAvailableFormats/NZLC-R134-Death-Burial-and-Cremation.pdf> (pages 49-50).

## Residential support services

In 2018, there were approximately 6160 people with intellectual disabilities receiving full-time Ministry-funded residential support. This represents just over 80% of the total number of disabled people in residential services.

According to a Ministry report from March 2018, 77% of disabled people accessing residential support are New Zealand European/other and 15% are Māori. Pacific and Asian populations are significantly under-represented in residential support settings compared with the general population (3% and 2% respectively).<sup>29,30</sup>

As outlined above, the Ministry purchases disability support services, including residential support services, from DHBs and a range of non-DHB community providers. Full-time residential support is provided in a number of different settings:

- **Community Residential Support Services (CRSS):** These are community-based homes contracted by the Ministry to provide full-time residential support. A CRSS may be a single home supporting fewer than five people, or a large organisation with multiple homes supporting several hundred people. In 2018, there were more than 5600 people with intellectual disabilities receiving this type of support. It should be noted that this includes a number of people with intellectual disabilities who live in CRSS homes contracted for people with a physical and/or sensory disability.

In 2018, there were approximately 6160 people with intellectual disabilities receiving full-time Ministry-funded residential support.

29 Where I Live; How I Live: Disability Support Services Community Residential Support Services Strategy 2018 to 2020, Ministry of Health (March 2018). Available at: <https://www.health.govt.nz/publication/where-i-live-how-i-live-disability-support-services-community-residential-support-services-strategy>.

30 According to Statistics NZ, results from the 2018 census show approximately 70% of New Zealanders identify with at least one European ethnicity, 17% identify as Maori, 15% identify with at least one Asian ethnicity, and 8% identify with at least one Pacific group. (People may identify with more than one ethnicity.) See: <https://www.stats.govt.nz/news/new-zealands-population-reflects-growing-diversity>

- **Regional Intellectual Disability Supervised Accommodation Services (RIDSAS):** These are community-based homes contracted by the Ministry to provide supervised accommodation for people under the High and Complex Framework, including people subject to orders under ID(CCR) Act, and eligible civil clients. In 2018, there were approximately 250 people receiving this type of support.
- **Regional and National Intellectual Disability Secure Services (RIDSS/NIDSS):** These are hospital-level secure facilities providing residential services and assessment beds. The Ministry contracts these services from five DHBs.<sup>31</sup> In 2018, there were approximately 70 people receiving this type of support.
- **Aged Residential Care (ARC):** These are rest homes and private hospitals providing residential care primarily for people over the age of 65. However, for a range of reasons a number of younger people with intellectual, physical and/or sensory disabilities live in aged residential care facilities. In 2018, this included more than 240 people with intellectual disabilities. Aged residential care providers are contracted by DHBs.

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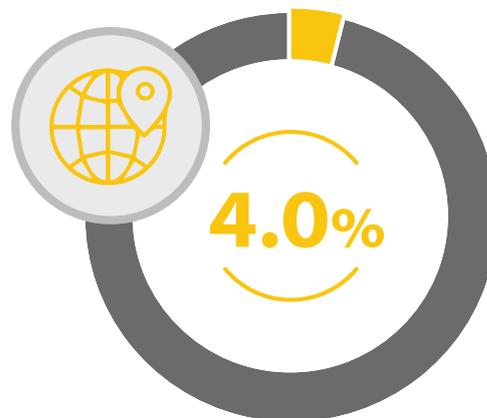
<sup>31</sup> Auckland, Waikato, Capital & Coast, Canterbury, and Southern.

People with intellectual disabilities in types of residential support settings

**Community Residential Support Services**



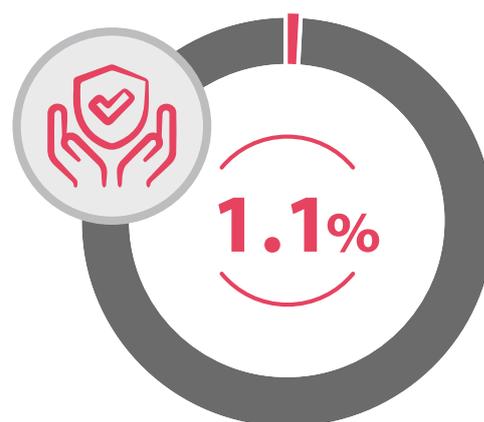
**Regional Intellectual Disability Supervised Accommodation Services**



**Aged Residential Care**



**Regional/National Intellectual Disability Secure Services**



## Other key people and agencies

There are a number of other people and agencies whose work is relevant to this investigation. These are listed in below, with further details set out in Appendix 4.

**Table 2: Other key people and agencies**

Name	Role
The Coroner	<p>The Coroner is a judicial officer (like a judge), who looks into certain deaths, including those that are unexpected, violent, or suspicious, to find out what happened. Deaths that must be reported to a coroner include:</p> <ul style="list-style-type: none"> <li>• those that appear to be without known cause, self-inflicted, unnatural, or violent;</li> <li>• those that were medically unexpected; and</li> <li>• those that occurred when the person was <i>'in official custody or care'</i> (which includes people detained under the Mental Health Act or the ID(CCR) Act).</li> </ul> <p>Sometimes the duty coroner will be contacted for advice as to whether a death is required to be reported.</p>
Needs Assessment and Service Coordination (NASC) agencies	<p>Organisations contracted by the Ministry to work with disabled people to identify their strengths and support needs, outline what disability support services are available, and determine their eligibility for Ministry-funded support (including residential support).</p> <p>NASC referrals, assessments, funded services, and key client details are recorded by NASC agencies in a central database known as Socrates. Data from Socrates is exported to the Ministry's Client Claim Processing System, so that providers of disability support services are paid. Providers are required to inform their local NASC when a person stops receiving a service (because they have died or for some other reason) so that payments are stopped.</p>

Name	Role
Health and Disability Commissioner	A person whose role it is to protect and promote the rights of health and disability services consumers, including through the investigation of complaints.
Health Quality & Safety Commission	The Commission's role is to lead and coordinate efforts to improve the quality and safety of health and disability services.
Human Rights Commission	The Commission promotes and protects the human rights of all people in New Zealand. It receives and helps resolve complaints about discrimination. The Disability Rights Commissioner has a specific role in promoting and protecting the rights of disabled people.
Office for Disability Issues	A strategic and whole-of-government focused policy team located within the Ministry of Social Development; the focal point within government on disability issues.



## Information collection, use, and reporting: what was happening?

Prior to my investigation, there had been some recognition within the Ministry that its systems and processes for collecting and using information about the deaths of people receiving residential support could be improved. However, no further work was undertaken and the matter was, it appears, put on hold due to other priorities. My investigation appears to have created impetus for reactivation of this work, and I have taken this into account when formulating my opinion and recommendations. In particular, I am aware that during my investigation, the Ministry made some specific improvements. Most notably, in July 2019 the Disability Directorate introduced a new standard operating procedure (SOP) for death notification and management. I will discuss this in more detail later.

In this section, I cover the arrangements that were in place when I commenced my investigation in October 2018. As noted earlier, I have drawn on data from a sample group: people with intellectual

disabilities who died between 1 January 2016 and 30 June 2018 and who had been receiving full-time residential support in the Auckland, Wellington, and Canterbury regions.

## What information was the Ministry collecting?

Information about the deaths of people with intellectual disabilities receiving residential support was collected by different services or teams within the Ministry for different purposes, as summarised below.

**Table 3: Summary of information about deaths collected by services/teams within the Ministry**

Team/service	Type of information collected	Purpose
Disability Support Services	Identifying data/key facts as per death notification form (and critical incident report if relevant), and additional information about the person's death as considered relevant	For contract performance monitoring, quality assurance, and quality improvement purposes
HealthCERT	Information about deaths that also meet the critical incident criteria (certified providers only)	For provider certification purposes
Client Claim Processing System (CCPS)	Date of death (date is input into Socrates database by NASC agency and exported to CCPS)	To stop payments to provider
Mortality Collection	Information about the person's cause of death, including date, and place of death	For New Zealand's vital statistics, public health research, policy formulation, monitoring the effectiveness of health programmes, and cancer survival studies

I have outlined in more detail below the systems and processes of DSS, as the key service within the Ministry responsible for purchasing and monitoring residential support services for disabled people.<sup>32</sup>

Information collected by HealthCERT for regulatory purposes, by the Mortality Collection team for statistical purposes, and through the Client Claim Processing System for payment purposes may be relevant to this investigation and, where that is the case, I have considered that information. However, it is important to note that there was no arrangement for information obtained by the Mortality Collection team to be shared with DSS. Furthermore, Mortality Collection data does not indicate whether a deceased person had an intellectual disability if it is not relevant to their cause of death, or whether the person received residential support. In addition, there was no process to ensure information obtained by the Client Claim Processing System about service user deaths was consistently shared with DSS.

Until recently, DSS relied almost entirely on disability providers for information about the deaths of disabled people receiving residential support.

Providers are contractually required to report the death of a service user to the Ministry *'as soon as practical within 48 hours'*.<sup>33</sup> This generally involves completing a death notification form and emailing it to DSS.<sup>34</sup> The form asks for identifying information such as the person's name and date of birth, along with the date and place of death, whether the person's family and GP have been advised, and whether the police and coroner are involved. There is a field for 'Details/Comments'. The form was amended last year to include the person's National Health Index (NHI) number and 'Cause of death'.<sup>35</sup>

Mortality Collection data does not indicate whether a deceased person had an intellectual disability if it is not relevant to their cause of death, or whether the person received residential support.

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32 As noted previously, those responsibilities now sit with the Disability Directorate's Operational Performance team and the Strategy, Policy and Performance team.

33 This includes supported and supervised residential services (ie CRSS and RIDSAS).

34 See: <https://www.health.govt.nz/our-work/disability-services/contracting-and-working-disability-support-services/reporting-critical-incidents-and-death-service>

35 The NHI number is a unique identifier assigned to every person who uses health and disability support services in New Zealand. A person's NHI number is stored on the National Health Index along with their demographic details.

The notification process is underpinned by the contracts between DSS and providers, and requirements set out in service specifications.<sup>36</sup>

The contracts and service specifications do not set out the specific information providers are required to supply following a death.<sup>37</sup> Depending on the information supplied, Ministry staff may contact the provider for further information. DSS advised that its staff take a *'relationship based approach with providers, to ensure they provide data and reporting as required under their contracts'* and that *'the focus for reporting compliance is on performance management'*.

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36 The contracting arrangement, known as the 'Streamlined Contracting Framework' involves:

- the 'Outcome Agreement', which is the overarching contract used across the Ministry;
- Tier One Service Specifications, which apply to disability support services purchased by the Ministry, irrespective of delivery setting;
- Tier Two Service Specifications, which define service specific requirements; and
- Tier Three Service Specifications, which set out additional requirements relevant to services for children and young people.

37 There are some differences in the death reporting requirements for the different types of service, as set out in the relevant Tier Two Service Specifications. For example:

- providers of CRSS are required to notify the NASC within 48 hours, the Ministry for payment purposes through the next information reporting cycle (and if a critical incident in accordance with relevant requirements for those), and their DSS contract relationship manager as soon as possible;
- providers of RIDSAS are required to notify the Ministry through a critical incident report (to be completed within 24 hours) and the Forensic Coordination Service; and
- aged residential care providers are required to notify the NASC within 48 hours, the Ministry for payment purposes through the next information reporting cycle (and if a critical incident in accordance with relevant requirements for those), and their DSS contract relationship manager as soon as reasonably practicable.

DSS advised further that it does not routinely collect or hold other health information about individual service users, and that this is generally held by health care providers, DHBs, disability support providers, family and individual disabled people.<sup>38</sup>

Under the Outcome Agreement, providers are also required to report all critical incidents to the Ministry as soon as practical within 24 hours. These reports were also sent to DSS.

A reporting template is available on the Ministry's website, which defines a critical incident as any sudden and/or unusual event that could:

1. be life threatening for the client or others
2. be dangerous, with the client at risk of grave harm
3. have significant consequences like the client being involved in criminal activity, absconding, or requiring emergency services or hospitalisation
4. be a serious crisis that may result in media or political attention.<sup>39</sup>

In addition, section 31 of the Health and Disability Services (Safety) Act 2001 requires certified providers<sup>40</sup> to notify the Director-General of Health of certain matters, including:

- a. any incident or situation ... that has put at risk, may have put at risk, puts at risk, or may be putting at risk the

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38 DSS staff initially expressed the view that its mandate to collect additional information was limited by privacy obligations. I note that the law—notably the Health Act 1956 and the Health Information Privacy Code (HIPC)—anticipates circumstances where it may be necessary for Ministry officials to collect health information from providers in order to perform its functions. Health information as defined under clause 4(1) of the HIPC is a broad term. It includes information about a person's disabilities, information about any health or disability services provided to a person, and information about a person that is collected before or in the course of, and incidental to, the provision of any health service or disability service.

39 Available at: <https://www.health.govt.nz/system/files/documents/pages/critical-incident-reporting-form-v06.pdf>

40 See page 37. Providers are certified under the Health and Disability Services (Safety) Act 2001, demonstrating that they meet relevant approved standards.

health or safety of people for whom the person was or is providing the services;

- b. any investigation commenced by a constable into any aspect of the services, their provision, or any premises in which they were provided; and
- c. any death of a person to whom the person was providing the services, or occurring in any premises in which they were provided, that is required to be reported to a coroner under the Coroners Act 2006.

Section 31 notifications are sent to HealthCERT. If a service user was harmed (or allegedly harmed) as a result of the incident, or caused the incident, providers are asked to include that person's NHI number but not their name.

Accordingly, some deaths and/or a preceding event may also be a critical incident, and some critical incidents must be reported to both DSS and HealthCERT.

As noted earlier, providers are also required to inform their local NASC agency of a person's death.<sup>41</sup> The NASC agency then updates the Socrates database, and payments to the provider made through the Ministry's Client Claim Processing System are stopped.

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<sup>41</sup> See Table 3, page 46.

## What did the Ministry do with the information?

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It became evident during interviews with Ministry staff that there were some changes to DSS processes around death notifications during the 2½ year period covered by our sample group (January 2016 to June 2018). It is understood that prior to 2016, for example, there was no process for collating death notification information into a central repository. Some minor changes were made to the death notification form. There were changes to the way that staff from the Quality Team, Community Living Team, and HealthCERT reviewed the notifications.

The diagram on the following page sets out the process that appeared to be in place when I commenced this investigation, following the receipt of a death notification form. In essence, details from the form were transferred into a spreadsheet. Additional columns were completed to show the DHB region, relevant contract relationship manager, and funding stream (that is, whether the person's primary disability was identified as physical or intellectual). The spreadsheet was then circulated to relevant staff. The information was reviewed by the contract relationship manager and Quality Team staff to determine whether further details were needed or whether the notification raised concerns warranting further action. Where an issue of concern or potential concern was identified and not addressed through initial enquiries, it could be escalated and logged on the Quality agenda. It remained on the agenda as a recurring item until the concern was resolved, at which point a closing statement was entered in the minutes.

It is understood that prior to 2016, for example, there was no process for collating death notification information into a central repository.

# Notification process following the death of a person receiving residential support (2018)



In terms of how the process worked in practice, DSS staff noted that providers less familiar with the process sometimes required guidance on who they needed to notify and how to do so. They would sometimes, for example, send the death notification form directly to the contract relationship manager and not to the DSS inbox, or complete a critical incident report instead of a death notification form, or notify the NASC, DHB, and/or HealthCERT but not DSS.

DSS and HealthCERT staff also observed a lack of consistency among providers in relation to critical incident reporting, with some providers over-reporting and others under-reporting.

Several staff commented that most of the items on the Quality agenda related to critical incidents (non-death related) and complaints, and that it was rare for death notifications to be escalated in this way.

The process for people with intellectual disabilities in aged residential care facilities was slightly different due to those providers being contracted by DHBs rather than the Ministry. The contract relationship manager with particular responsibility for DSS service users in aged residential care facilities advised that if, following a death, there were concerns requiring follow-up, those concerns would be managed by the relevant DHB in the first instance. The contract relationship manager would ask to be advised of the outcome and DSS would, in the interim, consider whether there was any reason to suspend further placements at that facility.

## How did the Ministry use the information?

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### Quality assurance

It appears that for the most part, DSS's actions following the death of a person receiving residential support can be seen as part of a quality assurance process. In general terms, quality assurance relates to activities focused on providing confidence that certain expectations in relation to quality are met. This is relevant in the context of the Ministry's:

- specific responsibilities for funding, purchasing, and monitoring disability support services;
- regulatory role in administering the Health and Disability Services (Safety) Act 2001, which requires providers of health and disability services subject to that Act to be certified against the Health and Disability Services Standards; and
- overarching role in leading New Zealand's health system to achieve the best possible health outcomes.

In response to my information request, the Ministry explained that on being notified of a death, DSS consider whether there are any *'extenuating circumstances'* that need consideration and that where there are exceptional or unusual circumstances surrounding a person's death *'the Ministry has a role to play in investigating if action needs to be taken to ensure other residents are safe, and to work with the provider to make safety improvements'*. I note that this explanation is included in the 2019 SOP, but does not appear to have been set out in any previous guidance, policy, or procedure. Interviews with staff from DSS's Senior Management Team indicated that they recognised the Ministry as having a broader level of responsibility, but were thinking further about exactly where that responsibility starts and ends and, consequently, their obligations in relation to service delivery.

In general terms, quality assurance relates to activities focused on providing confidence that certain expectations in relation to quality are met.

Contracts and service specifications set out the Ministry's expectations in relation to a range of matters, including what the service will entail (its 'components') and service quality. For example, under the Tier Two Service Specifications, providers of CRSS are required to ensure:

- their service users have access to the services of a general medical practitioner and to specialist assessments and services as required; and
- secure, physically safe internal and external environments that meet the person's particular mobility and safety requirements.

It should be noted that in general terms, the service specifications reflect the approach adopted by the Ministry over recent years to support people in ways that mean they have greater choice and control, and that respect their autonomy and independence.

The contracts and services specifications also set out how the Ministry will monitor and audit provider performance. This involves a range of mechanisms, including:

- periodic reporting on agreed performance measures;
- visits to the provider by their contract relationship manager;
- other email and phone contact with the provider as required; and
- routine and issues-based audits.

In addition, under the Tier One Service Specifications, all providers are required to:

*Develop, document, implement and evaluate a transparent system for managing and improving the quality of services, mitigating risks and ensuring quality management and governance to achieve the best outcomes for people.*

DSS and HealthCERT staff outlined a range of actions that may be taken if the death of a person raises concerns or potential concerns about the services provided. The actions taken will depend on the nature and seriousness of the concerns, and the provider's response to any matters raised with them.

In some cases, it may be a relatively straightforward matter of seeking further information, such as confirmation that there had been no delay in seeking medical assistance for a person who had become unwell. Or, a provider may be asked to take some form of corrective action, such as removing an identified hazard. These enquiries are generally undertaken by contract relationship managers in the first instance. If there are concerns about a provider's response, the matter may be escalated to involve relevant senior managers. Concerns and expectations may be discussed with the provider's senior management in person, and/or set out in writing.

Other possible actions include recommending that a developmental evaluation be scheduled for that provider, which involves assessing a provider against their contract and making recommendations for improvement. Each year, the Quality Team arranges developmental evaluations for a sample of providers.<sup>42</sup> Alternatively, an issues-based audit may be arranged. This is a focused audit, undertaken as a result of particular safety or quality concerns, complaints, or non-compliance.<sup>43</sup>

At the most serious end, where a provider fails to acknowledge an issue or take the necessary steps to rectify concerns, the Ministry may appoint a temporary manager or terminate its contract with that provider. The termination of a contract due to quality concerns is a last resort and this doesn't often occur, the last time being in 2015. The preference is always to work with a provider to resolve any concerns that may exist.

DSS's senior managers and contract relationship managers alike talked about the value of working in ways that build and maintain positive relationships with providers, and not being unnecessarily focused on wrong-doing or responding punitively. In this way, providers are more likely to be open about particular challenges

If there are concerns about a provider's response, the matter may be escalated to involve relevant senior managers.

<sup>42</sup> Specialist agencies are contracted to carry out developmental evaluations.

<sup>43</sup> An issues-based audit can occur with or without notice. If there are issues requiring quick action but there is no immediate risk to the health and safety of residents, the provider is given 10 days' notice. If the complaint, issue or allegation is very serious and there is a risk to residents' health and safety, the provider is given no prior notice.

or quality issues, and can be supported to address these. Ministry staff indicated that for the most part, they considered this to be an effective approach. The contracts, on the other hand, were considered to be comparatively weak levers in terms of quality.

## Quality improvement

In addition to quality assurance oversight, there is the issue of drawing on information about deaths for quality improvement purposes. This is about improving the quality of existing support services, and planning the shape of future services so as to improve health and other outcomes. A memo from Quality Team staff to DSS's Senior Management Team in January 2018 noted that DSS could review the way it manages death notifications '*to ensure they contribute to service and system improvements*', and that there was increasing interest in using this information in different ways.

However, no tangible evidence was provided to me to indicate that this was happening in the Ministry in a systematic or meaningful way. DSS staff noted that with limited resources, there had been little opportunity to do quality improvement work in relation to death data, although the Ministry did look to make small improvements where it was possible to do so.

## What records were kept?

Information from the death notification forms was collated into the death notification spreadsheet, which staff described as a fairly static document. It was occasionally updated if new information about a person's death came to hand, but it was not used to track enquiries made or follow-up action taken. As noted earlier, issues of concern or potential concern were logged on the Quality agenda and recorded in the minutes.

Staff explained that records relating to enquiries or follow-up actions were mostly held in DSS's main database, Lotus Notes. They commented that it is not an easy system to navigate. There are multiple places where information may be logged, with separate spaces for care recipients, mainstream service users,

providers of supervised and secure services, and providers of mainstream services.<sup>44</sup> There may also be several spaces for a larger provider, or where a provider has changed its name. The current system holds records from 2014, so accessing earlier records about a specific provider means retrieving these from an archived database.

The contract relationship managers interviewed by my investigators also described varying practices for recording and saving information. Their accounts, along with my review of the information provided for my sample group, indicated that:

- important emails and file notes about meetings or conversations are saved in Lotus Notes, but files notes may not have been made for all substantive interactions;
- some records were not saved centrally;
- there were inconsistent practices in updating provider management plans;
- it would be difficult for a new contract relationship manager to readily access records about a particular provider that they had become responsible for; and
- the IT system is *'barely fit for purpose'*, making navigation and access difficult.

It is perhaps not surprising, therefore, that when we requested certain information about the people in our sample group, the Ministry had considerable difficulty establishing exactly what information it actually held.

## What information was reported?

While it is understood that the Ministry collated and reported more information about the deaths of DSS service users than it did prior to January 2016, overall reporting remained limited.

The current system holds records from 2014, so accessing earlier records about a specific provider means retrieving these from an archived database.

<sup>44</sup> Care recipients are people with intellectual disabilities who are subject to orders under the ID(CCR) Act.

## Internal reporting

During the period January 2016 to June 2018, the Quality Team produced a number of reports for DSS's Senior Management Team for quality assurance, performance, and compliance purposes, details of which are set out in Appendix 5.

It should be noted that in each case, the report data relates to *all* DSS services (ie services for people with physical, sensory, and/or intellectual disabilities), and is not broken down by disability type.

It is also important to note that providers are required under their contracts to supply the Ministry with a report every six months. Providers report on their performance against specified 'Results Based Accountability' measures. Measures include the maintenance of residents' personal plans, the involvement of residents in their communities, levels of staff training, and staff turnover. None of the measures relate directly to deaths. A death-related issue could potentially be included in a provider report if it was also the subject of a complaint, or if a provider identified it as an issue they wished to bring to DSS's attention.

Provider reports are reviewed by the contract relationship managers. The contract relationship managers interviewed for this investigation had differing ways of reviewing the reports, and expressed differing views as to their usefulness. It was noted that there was a plan for the reports to be centrally collated and analysed with a view to identifying common issues and themes, but that this had not occurred as yet.

## External reporting

The Ministry advised there is no external reporting of the information it collects specific to service user deaths.

Two existing mechanisms were used by the Ministry to share general information and learnings with providers as a group.<sup>45</sup>

There was a plan for the reports to be centrally collated and analysed with a view to identifying common issues and themes, but this had not occurred.

<sup>45</sup> As distinct from any communication that Ministry staff may have had with an individual provider about a specific issue.

- Four or five times a year, DSS produces an e-newsletter for the disability sector. These contain information about changes within DSS, updates on disability projects and consultations, and information about other matters that may be relevant to disabled people, their families/whānau, and providers.<sup>46</sup> The newsletter has, on occasion, been used to remind providers of their obligations to notify DSS and HealthCERT of critical incidents and deaths. Once a year, DSS produces a 'special edition' of its newsletter, which highlights how people and organisations demonstrate innovative practice in disability support services.
- In recent years, DSS ran an annual provider forum in four or five main centres.

## What did our sample group show?

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- The Ministry was asked to provide me with information about people with intellectual disabilities who died between 1 January 2016 and 30 June 2018, and who had been receiving full-time residential support in the Auckland, Wellington, and Canterbury regions.<sup>47</sup>
- The confirmed sample group comprised 108 people.<sup>48</sup>

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46 For example, the most recent newsletter includes information about organisational changes within the Disability Directorate, updates on Enabling Good Lives projects in the Waikato and Christchurch, updates on pay equity and Funded Family Care, information about the forthcoming meetings being held by the DDG, and information about the current measles outbreak.

47 The Auckland region includes homes and facilities within the area covered by Auckland, Waitematā, and Counties Manukau DHBs. The Wellington region include homes and facilities within the area covered by Capital & Coast and Hutt Valley DHBs. The Canterbury region includes homes and facilities within the area covered by Canterbury DHB.

48 This represents an estimated 40% of the total deaths in New Zealand of people with intellectual disabilities receiving full-time residential support, between 1 January 2016 and 30 June 2018. This is an approximate figure as the data for the 159 deaths *outside* of the Auckland, Wellington and Canterbury regions was not cross-checked.

My analysis of the information showed:

- 67 (62%) were male and 41 (38%) were female.
- The average age at death was 57 years (male = 56 years, female = 58 years).<sup>49</sup>
- The oldest person was 91 years old and the youngest was 25 years old.
- Age at death:

**Table 4: Age profile**

Age range	Number of people
Younger than 30	4
30–39 years	5
40–49 years	20
50–59 years	29
60–69 years	30
70–79 years	16
80–89 years	3
90–99 years	1

- 45 (42%) died in hospital or in a hospice, and 63 (58%) died at or near their home.
- Residential support was delivered by 25 providers: one hospital secure care facility and 24 non-DHB providers. The non-DHB providers ranged from large organisations with multiple homes providing residential support to several hundred people, to small providers supporting fewer than ten residents. One person had

<sup>49</sup> As noted in footnote 3, figures from 2014–2016 show a life expectancy of 63.0 years for males with intellectual disability, compared with 79.9 years for all New Zealand males, and 59.3 years for females with intellectual disability, compared with 83.4 years for all New Zealand.

been living in an aged residential care facility, and four people in facilities contracted to provide support for people with physical and/or sensory disabilities, rather than intellectual disabilities.

- In terms of the most common causes of death:
  - aspiration pneumonia was the direct cause of death in 23 cases (21%), and an antecedent cause in a further three cases;<sup>50</sup>
  - the direct cause of death in 20 cases (19%) was cardiac-related;
  - pneumonia was the direct cause of death in 17 cases (16%);
  - sepsis was direct cause of death in 10 cases (9%);
  - Seven people died as the result of an accident (7%);
  - cancer was the direct cause of death in six cases (6%), and an antecedent or underlying cause in a further four cases;
  - the direct cause of death in six cases (6%) was a respiratory-related condition; and
  - bowel obstruction was the direct cause of death in one case, but an antecedent or underlying cause in a further five cases.
- Twenty-one (19%) of the deaths were reported to the coroner:
  - of these, inquiries were opened in respect of nine (including three in relation to the deaths of people in official custody or care);<sup>51</sup>
  - of the nine, five inquiries were conducted on the papers, two inquests were held, and two remain active; and
  - no inquiry was directed in relation to the remaining 11.<sup>52</sup>

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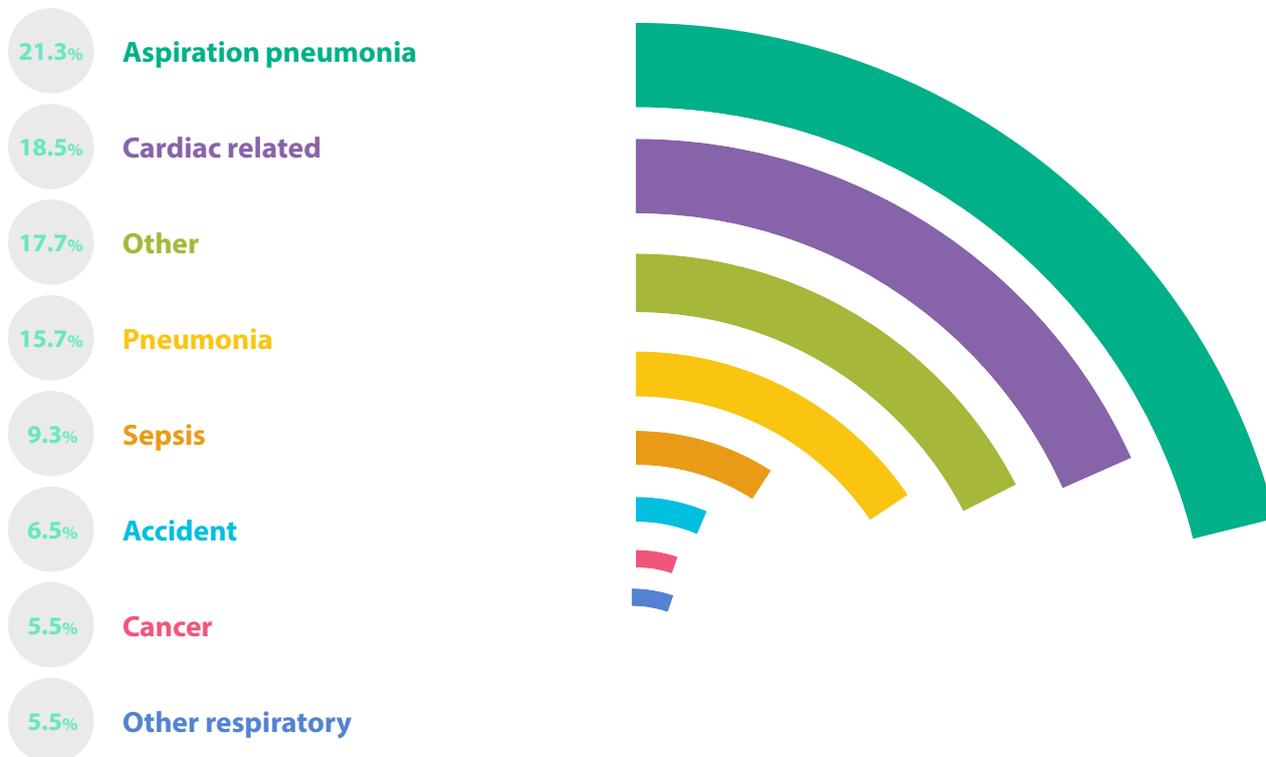
50 See footnote 27 for explanations of direct, antecedent and underlying causes.

51 As noted on page 43, deaths in 'official custody or care' include the deaths of people in police custody, and people detained under the Mental Health Act or the ID(CCR) Act.

52 In these cases, the coroners considered they were able to establish the matters required under section 57(2) of the Coroners Act 2006 without opening an inquiry. These include, as far as possible, the person's identity, where and when they died, the cause of death and the circumstances in which they died.

- The duty coroner was contacted in a further 17 cases (16%) and it was determined that the death was not reportable.
- On the Medical Certificates of Cause of Death for the 87 people in my sample group not reported to the coroner:
  - there was no reference to intellectual disability in just over 41% of cases;
  - intellectual disability or a specific condition such as Down Syndrome was identified as a Part II significant contributing condition in just over 40% cases; and
  - intellectual disability or a specific condition such as Down Syndrome was identified as a Part 1 antecedent or underlying cause in almost 19% of cases.
- There were complaints to HDC in respect of four people, two of which related to care provided to the person in the period leading up to their death.

## Most common causes of death



## Further examination of smaller sample

Following an initial review of the information provided by the Ministry, I sought information from 14 service providers for a subset of the sample group, comprising 41 people. The purpose was essentially to review the type of information held by providers in relation the deaths of their residents and compare that with information held by the Ministry.

The subset of 41 was a selected sample. I was interested in those cases where the information held by the Ministry seemed particularly limited. I also ensured representation in terms of region, where the person died, provider size, and provider type.

## Information from providers

As noted previously, this investigation concerns the actions of the Ministry. I have not investigated individual deaths, or the services delivered by providers. I have, however, considered information held by providers relating to the deaths of their residents in order to fully understand relevant processes that occur following the death of a person receiving residential support, the nature of the information generated as a result, and how the Ministry's monitoring and oversight arrangements operated in practice.

I would note that overall, the information held by providers relating to the deaths of their residents was variable. In some cases, the records clearly set out the care, treatment, and support the person had needed and received in the days, weeks, or months prior to their death, and exactly what had occurred following their death. In other cases, this was rather more difficult to ascertain.

Of particular interest were the records relating to actions taken by providers after the person had died. In 25 of the 41 cases for which I obtained provider records, there was evidence that the provider had conducted some form of review following the person's death.

In most of the review reports, the reviewer identified learnings of some description: things that could have been done better or improvements needed, whether for individual staff who had been involved in supporting the person, or more generally for the provider. In some cases, the findings were described as incidental, not directly related to the events leading to the person's death. In other cases, there were findings that were potentially directly relevant to the person's death. Examples of the concerns identified by providers and the actions proposed to remedy those concerns are set out in text box 1 below.

For the most part, it appears that the review reports were not requested by, or supplied to, the Ministry. I will explain later why I consider this to be problematic.

I have not investigated individual deaths, or the services delivered by providers.

## 1 — Concerns and learnings identified by providers

- S was in their fifties and died following a fall. The reviewer noted that staff who were present correctly recognised that S needed to be checked by a medical professional and arranged a GP appointment, but that staff may benefit from additional guidelines on when to contact emergency services. Accordingly, the provider undertook to review its policy guidelines.
- C was in their forties and died of aspiration pneumonia. The reviewer concluded that C was at high risk of this due to their disabilities, and all preventative measures had been in place to minimise this risk. However, it was noted that when staff had found C unresponsive, they focused their attention on summoning assistance from the on-call manager and emergency services, and did not consider performing CPR.
- L was in their sixties and died suddenly. L had been discharged from hospital a few days earlier, following treatment for an infection. The reviewer identified concerns around communication at the time of discharge from hospital. It was proposed that a memorandum of understanding between the DHB and the provider in relation to discharge planning be considered.
- K was in their sixties and their death was heart related. K had had an unwitnessed fall a few days earlier. The provider identified the need for a tool to assist staff to make informed decisions following the reporting of an incident, and a revised incident reporting and response system.

In my view, these concerns and learnings that had been properly identified by the providers was information that the Ministry should have been collecting and reviewing, for reasons I will explain later.<sup>53</sup>

53 See 'Lack of attention to provider reviews' (pp 82-88) and 'Use of information for service development and shared learning' (pp 94-96).



## My concerns

I have identified the following concerns about the collection, use, and reporting of information about the deaths of people with intellectual disabilities receiving full-time residential support.

### Incomplete information

The first significant issue I identified is that the Ministry's arrangements for collecting information simply did not ensure DSS was apprised of all service user deaths.

Enquiries made in the course of this investigation revealed 10 people who met the criteria for our sample group but whose deaths DSS had been unaware of. Seven of these people were part of a wider group of 27 from one provider, which DSS did not know about.<sup>54</sup>

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<sup>54</sup> The remaining 20 people lived in other regions or did not receive full-time residential support.

The Ministry suggested that its email security system may have blocked the relevant emails from the provider. If this were the case, it would raise serious issues about the capacity and monitoring of the IT system.

In the case of the three other people, the providers' records included death notification forms but the DSS had no record of receiving these. In only one case was the provider also able to provide a 'sent' email to confirm the form was actually emailed to DSS. In that case, it had been sent directly to the contract relationship manager and either not forwarded to the Quality Team, or forwarded but not logged.

There were a further three deaths that DSS was aware of but that were initially omitted from the sample group, because they had not been centrally logged.

This was one of several factors that contributed to a protracted process during my investigation of confirming my sample group and obtaining relevant information about their deaths. The Ministry provided an initial list in December 2018. It was necessary for my staff to seek clarification on several occasions as to whether particular people had been correctly included or excluded. While I understand Ministry staff were endeavouring to locate and supply the relevant information promptly, it seems their ability to do so was impeded by their information management systems and processes. The final information about the people in my sample group was not received until August 2019.

The Ministry relies on providers to report deaths by completing a death notification form. It appears that, in most cases forms were submitted to DSS, albeit with varying levels of detail. However, a more robust system was clearly required to ensure all of the deaths came to the attention of DSS. That this did not exist was particularly surprising given the other services or systems within the Ministry that routinely receive death data. I refer in particular to the Ministry's system for paying providers, and the Mortality Collection data.<sup>55</sup>

This was one of several factors that contributed to a protracted process during my investigation of confirming my sample group and obtaining relevant information about their deaths.

<sup>55</sup> See page 38 for information about the Mortality Collection and page 50 for information about the payment system.

The Ministry has already taken steps to rectify this. The Disability Directorate is now included on the list of agencies/services that receive fortnightly updates from the team responsible for the Mortality Collection, and a data-matching process has been put in place. The Ministry has confirmed that this is providing improved information.

In addition, since my investigation started, a process has been implemented for staff from the Quality Team to cross-check information on its death notification spreadsheet with Socrates on a fortnightly basis. It is understood that previously DSS staff provided the staff responsible for Socrates with a list of services users whose deaths they had been advised of, but there was no process in place for the reverse to occur (ie for Socrates staff to provide DSS with a list), although this did occur on an informal basis from time to time.

### Insufficient information collected

Assessing the information collected by the Ministry in relation to the deaths of the people in the sample group has been somewhat difficult, as it appears some information was either not documented by DSS or not stored in a manner that allowed for it to be identified and retrieved. I have commented on this further below (see 'Record keeping').

While I accept that the Ministry likely collected more information than it has been able to provide for this investigation, ultimately I must rely on the evidence that exists. And, on that basis, I consider the information that the Ministry collected and stored in a retrievable manner in relation to the deaths of its service users was insufficient, given the significant purposes for which that information was required.

As outlined above, DSS staff reviewed the information received when a provider reported a death in order to identify whether there were any extenuating circumstances that need to be considered. DSS staff explained during interview that matters they were looking to confirm when advised of a death include that:

While I accept that the Ministry likely collected more information than it has been able to provide for this investigation, ultimately I must rely on the evidence that exists.

## My concerns

- there are no issues in terms of the safety and well-being of other residents;
- the appropriate agencies/people have been informed;
- the provider in no way contributed to the person's death;
- the provider is delivering good quality care in accordance with their contract; and
- where a provider had undertaken a review, they will let DSS know what they have found, what they have done, and confirm that any necessary improvements have been implemented.

In addition, there was an intention to use the information to identify broader trends, which has not to date translated into practice.

A senior DSS manager acknowledged that the death notification form is '*pretty high level*'. Although the Ministry may seek further information from a provider if it is considered necessary to do so, evidence from my review of records for the sample group suggests that occurred in only a handful of cases. Staff confirmed during interview such enquiries were not common.

In my view, the death notification form is not adequate, even as a tool for determining whether further information is required.

NOTIFICATION OF DEATH IN SERVICE REPORTED TO DISABILITY SUPPORT SERVICES												
Name of Client	NHI No.	Date of Birth	Date of Death	Provider Name	Date MoH Advised	Place of Death	Details / Comments	Cause of Death	Family Advised (Y/N)	GP Advised (Y/N)	Police Involved (If yes, please explain)	Coroner Involved (If yes please explain in detail the process being followed, is there going to be a report?)

Figure 1: Death Notification form (Ministry of Health)

I do not consider the form facilitates the collection of enough information in the context of what the Ministry is looking to establish. Providers are not, for example, asked whether they are undertaking a review of the person's death. While a provider may volunteer that they are doing so—this occurred in just one of the 108 cases in our sample group—there is nothing to indicate that is something the Ministry is interested in. Providers are given no indication as to why the information is being sought so as to elicit the necessary level of detail. A provider may choose to include information about a specific quality of care issue but again, the form does little to encourage providers to supply information of this nature.

The current version of the death notification form includes a field for *'Details/Comments'*, with a separate field for *'Cause of Death'*. A previous version had a single field for *'Details (include cause of death)'*. For the most part, providers appear to understand that what the Ministry is asking for here is information about the cause and/or circumstances of the person's death. However, the level of detail providers included in the notification forms for my sample group was variable. Some included a fairly detailed summary, with the provider outlining when the person was first observed to have become unwell, when medical assistance was sought and what other actions staff took, what treatment was provided, and what the family/whānau involvement was, as well as the cause of death. In other cases, the information was minimal—*'cancer'*, *'waiting for death certificate'*, *'unknown'*, *'died of natural causes'*, for example.

A provider may not be in a position to advise the cause of death at the time of notification. That does not preclude them from providing information about what happened before (and after, if relevant) the person's death. It is clear that the Ministry needs to give providers more guidance on exactly what it wants to know, so that the necessary level of detail is provided as a matter of course rather than by exception.

The level of detail required will vary to some extent depending on the circumstances, including whether the person's death was or may have been avoidable. Preventability is of course crucial. But the Ministry also has a broader interest in knowing that providers are

For the most part, providers appear to understand that what the Ministry is asking for here is information about the cause and/or circumstances of the person's death.

delivering good quality care. As such, it could also be said to have an interest in information about deaths regardless of preventability—whether a terminally-ill person received appropriate end-of-life care, for example.

I acknowledge that the Ministry will be cognisant of the administrative ‘burden’ its reporting requirements impose on providers. However, we are talking here about a small number of deaths of a highly vulnerable population group. Furthermore, the provision of a relatively small amount of additional information need not be onerous. And, if providers understand why the information is needed and see the value of this for them and their service users—in terms of receiving aggregated information, analysis, and learnings about preventable deaths—any resistance to providing more information at the time of notification should be minimal.

### Lack of consistency as to what is ‘insufficient’ information

DSS staff explained that where the information provided in relation to a particular person’s death was incomplete or considered insufficient, providers would be asked for more details. Such enquiries would generally be undertaken by the contract relationship manager. However, following on from the lack of clarity as to what was required in the initial form, there was a lack of consistency as to exactly what might constitute insufficient information. Staff talked about anything on the form that raises ‘alarm bells’ or ‘a red flag’, or ‘looks a bit questionable’. Some contract relationship managers reported that if the notification form indicated that the person had died of natural causes or it was an expected death, but provided no further detail about the circumstances or actual cause of death, they would make no further enquiries. Others said that in such situations they would definitely ask for more information. A senior DSS manager talked about getting notifications with ‘*the level of detail appropriate for the concern it raises*’. In the case of an accident, she explained, she would expect to see a reasonable amount of detail to show what was done both before, and in response to, the accident. It could be difficult with a person who becomes ill and is admitted to hospital, but she would

Following on from the lack of clarity as to what was required in the initial form, there was a lack of consistency as to exactly what might constitute insufficient information.

still expect to see information indicating that the person's GP been contacted within the appropriate timeframe, that the family had been made aware, and that anything to do with the environment had been dealt with.

Even allowing for a greater level of interaction between providers and the contract relationship managers than the records reflect, the evidence points to the Ministry not consistently obtaining sufficient information in each case to obtain the assurances that were expected.

Of particular concern were a number of cases where DSS was notified of a person's death and the notification form indicated that the person had died suddenly and unexpectedly, but no further information appears to have been obtained or other follow-up action taken by DSS (see text box 2). This is important in terms of both quality assurance concerns relating to the deaths individually, and understanding any broader patterns and trends for quality improvement purposes. I will comment further on this later.<sup>56</sup>

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<sup>56</sup> See 'Use of information for service development and shared learning' (pp 94-96).

## 2 — Minimal information about sudden and unexpected deaths

There were a number of cases in my sample group where the only information held by DSS was a death notification form, and where the information on that form indicated clearly that the person had died suddenly and unexpectedly.<sup>57</sup> For example:

- F was in their forties. The provider advised DSS that staff had heard a noise and found F had fallen onto the floor in another room. F was unconscious. Emergency services were called but F was unable to be revived.
- B was in their sixties. The provider advised DSS that according to staff, B appeared well at meal time and for a period afterwards. However, when B was checked a short time later they were found unconscious on the floor and were unable to be revived.
- R was in their thirties. The provider advised DSS that R had been found unresponsive that morning and the death was unexpected.
- J was in their sixties. The provider advised that their staff had found J unresponsive on the floor. Staff attempted resuscitation and called emergency services, but J was unable to be revived. It was noted that J's death appeared to have been a medical event but it was unexpected. J had been on antibiotics but was otherwise thought to be in good health.

Each of these people lived in a CRSS. There is no evidence that the Ministry made any further enquiries about events leading to their deaths or took any other follow-up action. In each case, DSS was advised that the death had been referred to the coroner. However, there was no mechanism in place for DSS to obtain coronial findings and that rarely occurred.<sup>58</sup> DSS therefore collected no other information regarding the circumstances or causes of these people's deaths.

Given the nature of the information provided in these cases, I would have expected the Ministry to have obtained further information about the circumstances surrounding the deaths of these people.

57 As outlined previously, DSS was the key service within the Ministry responsible for purchasing and monitoring residential support services for disabled people. Information was held by other Ministry teams and services—notably the Mortality Collection and the Client Claim Processing System. However, there was no arrangement for information obtained by the Mortality Collection team to be shared with DSS. Furthermore, Mortality Collection data does not indicate whether a deceased person had an intellectual disability if it is not relevant to their cause of death, or whether the person was receiving residential support. There was no process for ensuring information obtained by the Client Claim Processing System about service user deaths was consistently shared with DSS.

58 See page 76.

There was also a small number of cases where the provider supplied even less information (see text box 3).

### 3 — No information about cause or circumstances of death

In a small number of cases in my sample group, the only information held by DSS was a death notification form with little or no information as to the circumstances in which the person had died, whether the death was expected, or any indication of the possible cause. For example:

- D was in their thirties and lived in a CRSS for people with physical disabilities. The provider indicated that D's death had been referred to the coroner, but provided no details about the cause of death, previous health status, or events leading to the death.
- P was in their forties and lived in a CRSS for people with physical disabilities. The provider advised that P had been sent to hospital by ambulance due to them being unwell and that the death had not been referred to the coroner, but provided no further details.

Again, I consider there was a clear and definite need for the Ministry to obtain additional information before deciding whether any follow-up was necessary.

## Inaccurate or incomplete information about cause of death

Often it is the circumstances surrounding a person's death that are more relevant in terms of preventability and quality of care than the actual medical cause of death. Generally speaking though, reducing the incidence of preventable deaths relies on knowing medically what people are dying of. Reducing inequalities relies on knowing about differences in common causes of death between different population groups.

Providers are expected to inform the Ministry of a person's death within 48 hours, or within 24 hours if the death is also a critical incident. They can only advise on the basis of the information they

have at that time. Sometimes they will have a confirmed cause of death, but at other times they may only have information suggestive of a probable cause, or the cause may be wholly unknown. If cause of death is important, however, there needs to be an effective process for relevant Ministry teams or services to obtain both accurate information, and information not available at the time of notification.

The information DSS obtained about cause of death was summarised by staff from the Quality Team and reported on internally within DSS. This was intended to provide DSS's senior managers with an overview of numbers and potentially any patterns or trends. However, as detailed above, there were a number of deaths simply not included in DSS's records. In addition, cause of death information from providers was variable, and there was no process to obtain and record information that became available only after the initial notification, including information held by other Ministry services, namely the Mortality Collection, or the Coroner. Accordingly, the accuracy and completeness of the information reported, and therefore the extent to which DSS senior management could rely on this, is questionable.

I note some examples in text box 4 below.

### **4 — Differences between reported and confirmed cause of death**

- E – The provider advised DSS that E was in fragile health and a palliative care plan was in place. The Medical Certificate of Cause of Death held in the Mortality Collection showed the confirmed cause of death was asthma related.
- A – The provider advised DSS that A had been discharged from hospital some days earlier and was under a palliative care team. The Medical Certificate of Cause of Death held in the Mortality Collection identified the direct cause as lung related, and a stroke as the antecedent cause.
- T – The provider advised DSS that T had died peacefully at home after a short period of illness for which they were hospitalised. The coroner's report showed T's confirmed cause of death was aspiration pneumonia.
- G – The provider advised DSS that it understood G to have died due to complications of their specified disability but that the coroner was awaiting further test results. The coroner's report identified G's disability as an antecedent cause, but aspiration pneumonia as the direct cause.
- M – The provider advised DSS that M was seen by their GP due to a bad cold and was diagnosed with, and treated for, a chest infection, but had collapsed and was unable to be resuscitated. The coroner's report showed the direct cause as a flu related respiratory infection.

I consider the Ministry needs a process that:

- ensures DSS, in the context of its particular functions and responsibilities relating to residential support, receives from providers any information held at the time about the cause of the person's death, and an indication as to the basis for the information (for example, whether this was confirmed by a completed Medical Certificate of Cause of Death, or verbal advice from a hospital clinician or family member);

- enables DSS to obtain accurate cause of death information when this became available after the initial notification; and
- ensures DSS's records relating to cause of death were added to or corrected when additional information (including from the Coroner) was obtained at a later date.

Information of this nature is also relevant in terms of decision-making on the need for further enquiries or follow-up action, for quality assurance purposes.

### Lack of guidance for follow-up enquiries and action

DSS senior managers interviewed by my investigators expressed a high level of confidence that where a concern or potential concern about a provider was identified, the Ministry acted promptly to address this. While I am pleased to hear this, I regret that this was not reflected in the evidence before me.

As outlined previously, on the basis of the information for my sample group I have concerns about the adequacy and completeness of the information staff relied on to determine whether the Ministry needed to ask or do anything further. There are few records to indicate providers were asked for additional information, even when the person's death was identified as sudden and unexpected. The fact that a person died suddenly and unexpectedly does not of course mean their care was necessarily lacking. It is, however, reason to find out more. The evidence from my sample group suggests that in the majority of cases that did not occur.

In only two of the 108 cases I looked at was a concern recorded in the Quality minutes, and in both cases that was the result of a complaint rather than a result of a proactive enquiry.<sup>59</sup> In one case, the complaint was made to Health and Disability Commissioner (HDC). The matter remained open with DSS for approximately 18 months,

The fact that a person died suddenly and unexpectedly does not of course mean their care was necessarily lacking. It is, however, reason to find out more. The evidence from my sample group suggests that in the majority of cases that did not occur.

<sup>59</sup> An item was recorded in the Quality minutes in respect of one other person in my sample group, but this related to a complaint about the care that person received prior to their death.

but was closed pending the outcome of HDC's enquiries. HDC wrote to DSS with the outcome four months after that. In the other case, the complaint was made to the agency that had recently completed an audit of the facility. In that case, DSS arranged for a further audit.

A number of staff made the point that it is not the role of the Ministry staff to clinically assess a person's care or treatment, and nor are they necessarily qualified to do so. Staff do, however, need to obtain sufficient relevant information and assess this in order to meet the Ministry's obligations in relation to quality assurance including, critically, to ensure providers are meeting their contractual obligations to ensure the provision of timely, competent, and appropriate services. If advice is needed beyond the expertise of the staff responsible for these tasks, there should be a means to obtain this.

The contract relationship managers interviewed by my investigators talked about the value of knowing their providers well when it came to determining the need for further enquiries or follow-up action on particular issues, whether death-related or otherwise. They know, they said, which providers need closer attention.

It is part of a contract relationship manager's skillset to manage the potential tension between their role in building and maintaining supportive, trust-based relationships with their providers, and ensuring contract compliance. While a contract relationship manager's previous experience of a provider is certainly relevant, there are risks if this is relied on too much.

In my view, what was missing here were clear policies and guidance for staff on the kinds of matters they needed to seek assurance on, and when further questions needed to be asked. In the absence of this, staff described varying levels of intervention, while the written records indicate the overall level of enquiry was low. Too much was left to individual determination and discretion.

In addition, it appears there was no internal quality audit process, which would have enabled any omissions or inconsistencies to be identified and rectified.

In my view, what was missing here were clear policies and guidance for staff on the kinds of matters they needed to seek assurance on, and when further questions needed to be asked.

It is not possible to say whether, if further information had been obtained in respect of the individual cases, it would have provided the necessary assurance, or whether it would have raised concerns warranting some kind of follow-up action (such as requiring the provider to undertake an internal review, more regular monitoring by the contract relationship manager, or additional reporting for a period). My review of the sample of 41 provider records suggests that in some cases at least, there were matters that should certainly have been followed up on by the Ministry. Further enquiries may also have generated information about issues relevant to the future care and support of other service users.

## 5 — N

DSS was notified of the death of N, who was in their fifties and had been living in a supervised residential service. The provider advised DSS via the death notification form that N had been admitted to hospital with gastric issues, specifying several symptoms. The provider said further that N had abdominal surgery but subsequently died of suspected pneumonia. The provider noted that they did not know whether N's death had been referred to the coroner.

The death notification form was the only information held by DSS in relation to N's death. There is no information to indicate that the Ministry sought any further information from the provider or that there was any other follow-up.

Provider records showed that a fortnight after N's death, the provider wrote to the Forensic Coordination Service to inform that service about N's hospitalisation.<sup>60</sup> The provider outlined in some detail the circumstances leading up to N's admission to hospital and death. It also identified some concerns about the actions of its staff, including delays in seeking medical assistance, and a lack of documentation that made it difficult to know whether N's condition had improved or deteriorated following a GP visit. The provider noted the steps it was taking to rectify the concerns identified. While N's death was included in the Forensic Coordination Service's quarterly report to DSS, there was no reference to the concerns the provider had identified about its own service, and no evidence to indicate DSS was otherwise aware of these.

In my view, DSS needed to know about the review undertaken by the provider, its findings, and the steps the provider proposed taking to remedy the concerns identified—not least so that staff could confirm those remedial actions were taken. It needed to know whether N's death was in fact reported to the coroner and, if so, the coroner's findings.

<sup>60</sup> The Forensic Coordination Service provides comprehensive needs assessment and intensive service coordination for people under the High and Complex Framework (see page 37).

### Lack of attention to provider reviews

The death of a person may be reviewed in different ways, for different purposes, and by different agencies or entities. At a national level, New Zealand currently has five mortality review committees. These are dedicated to reviewing deaths of children and young people, babies and mothers where death is caused by pregnancy or childbirth, deaths resulting from family violence, deaths associated with surgery, and deaths by suicide.<sup>61</sup> Broadly speaking, the purpose is to learn how to best prevent these deaths.

Health and disability providers may review a person's death if it is considered to be a serious 'adverse event'—that is, if it is not related to the natural course of an illness and differs from the immediate expected outcome of care and management.<sup>62</sup>

Providers of residential support services may review the death of a resident because it was a serious adverse event, for another specific reason (eg in response to a complaint), or because it is their practice to review the deaths of all of their residents. A provider review is essentially an opportunity to consider whether the person who died had been provided with appropriate care, treatment, and support, and whether anything could or should have been done differently. Crucially, this could be about identifying avoidable deaths so as to prevent or minimise the risk of similar deaths in the future. It may be about ensuring that the end-of-life care provided was as it should have been. It can also be about providing families/whānau with reassurance that their family member received good quality care.

A provider review is essentially an opportunity to consider whether the person who died had been provided with appropriate care, treatment, and support, and whether anything could or should have been done differently.

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61 The mortality review committees were established under sections 11 and 18 of the New Zealand Public Health and Disability Act 2000, but became statutory committees under section 59E of the amended New Zealand Public Health and Disability Act in April 2011. They report to the Health Quality & Safety Commission Board.

62 See the Health Quality & Safety Commission information in Appendix 5 for further information about adverse events. As noted, under the National Adverse Events Reporting policy, health and disability service providers are 'expected' to report serious adverse events to HQSC. Some providers, such as DHBs, are contractually obliged to do so.

As noted earlier, in 25 of the 41 cases for which I obtained provider records, there was evidence that the provider had conducted a review following the person's death.

In terms of the information collected by the Ministry about these reviews, I note the following from my sample:

- In only one case out of the 108 did the Ministry's records include a provider's internal investigation report.
- In one other case, there is evidence from the provider that an internal investigation report was sent to DSS. However there was no apparent record of it with the Ministry.
- In three further cases, records show that the provider had advised the Ministry it was undertaking an investigation. There is no evidence in these cases that the Ministry followed up with the provider to ensure the investigation was actually carried out, to obtain the investigation findings, or to obtain a copy of the full report.

I have two concerns here. First, that even when an investigation or review was completed, the Ministry rarely appeared to obtain copies of the review report or details of the findings and any recommendations. This is in spite of reviews being a pivotal source of information about the quality of that provider's service (including its ability to self-evaluate), its compliance or otherwise with its contract, and about potential risks it would have been appropriate for the Ministry to know about for both quality assurance and quality improvement purposes.

That this did not occur would appear to be inconsistent with the expectations of DSS's senior managers, who advised that they would normally expect staff to see any provider reviews of the quality of care delivered to a person, and follow up to ensure any recommendations coming out of those reviews are implemented. As one senior manager explained:

*Our expectation is when things go wrong, as they sometimes do, that provider will do their own investigation and let us*

Even when an investigation or review was completed, the Ministry rarely appeared to obtain copies of the review report or details of the findings and any recommendations.

*know what they've found and what they've done and they'll implement improvements to make sure it doesn't happen again.*

Secondly, I am concerned that in a significant number of cases, the Ministry took no action to ensure an investigation or a review was carried out by or on behalf of the provider. I note that the factor most likely to determine whether a review was or was not undertaken, was unconnected to the circumstances of the death and was simply the size of the provider (the larger providers being most likely to undertake reviews).<sup>63</sup>

It has been suggested that not all deaths need to be reviewed, and that a review is unnecessary if the person died of a known and natural cause, for example. Some Ministry staff initially suggested that a person who dies in residential care has died 'in their home' and, as such, proposed that their death should be no more subject to an investigation or review than that of a person living independently in the community—to do otherwise would be intrusive and inconsistent with the push for disabled people to have greater choice and control in all that they do. I would note that while some people spoken to in the course of this investigation identified this as a tension, ultimately everyone, including representatives from the disability community, appeared to agree that there is a difference.

At issue here are the deaths of people whose needs are such that they require full-time, government-funded residential support, including support to access health care. They are part of a population group known to have poorer health outcomes than the general population. Their ability to communicate may be limited, and they may not have family/whānau support and/or advocacy. As Sir Robert Martin KNZM put it, *'People can't always tell you when something's up'*.<sup>64</sup> As such, it seems to me that it is of the utmost importance for someone with

At issue here are the deaths of people whose needs are such that they require full-time, government-funded residential support, including support to access health care.

63 As noted on page 24, the services delivered by providers are not the subject of this investigation.

64 Sir Robert Martin made history in 2016 as the first person with a learning disability elected onto a United Nations Treaty Body, when he was elected onto the Committee on the Rights of Persons with Disabilities.

the relevant skills, expertise, and experience to turn their mind to the questions of what happened, whether there was anything that could or should have been done differently, and whether there is anything to be learned or changed as a result. I do, however, acknowledge that not all deaths require the same type or level of review.

Accordingly, I entirely support the Ministry having included in the new SOP a specific expectation that when someone receiving residential support dies, the provider will conduct an internal inquiry. This requires an assessment of whether the person's death could have been prevented, whether there is any ongoing risk for other service users, whether action by the provider may prevent or minimise the risk of a similar death, and whether the immediate response could be improved in the case of a future death.

There would also be benefit in the Disability Directorate providing guidance in terms of when an internal review is sufficient, and when it may be more appropriate to arrange for this to be carried out by an external party. While this is relevant for all providers, it is important to acknowledge the particular challenge for smaller providers, who are less likely have the necessary staff or infrastructure for an internal review to be undertaken by someone with a degree of independence (eg someone who was not directly involved in the person's care).

I note there was an acknowledgement by some staff that given the Ministry's broader responsibilities in terms of health, it should be giving providers more guidance. As one person commented:

*I think part of the culture of DSS at the moment is that we expect you to do all of these good things, but we're not going to show you how ... We expect you to do this thing ... but we're not going to tell you what we mean by that.*

In short, I consider the Ministry could and should have been looking more closely at providers' own review information where this existed, and taking steps to support those providers not carrying out such reviews to begin doing so.

I note by way of example, the examples of H, W, and O set out in text boxes 6, 7, and 8 below. In each case, the only information held by DSS was a death notification form or a critical incident report.

I consider the Ministry could and should have been looking more closely at providers' own review information where this existed, and taking steps to support those providers not carrying out such reviews to begin doing so.

In the third case, however, there was good evidence that the provider had in fact undertaken a comprehensive review of their resident's care, the report for which could have been of value for the Ministry.

### 6 — H

DSS received a critical incident report about the death of H, a person in their fifties who had been living in a CRSS. It was noted that H had been admitted to hospital the day before they died after staff had noticed unwellness and a distended abdomen, and had been diagnosed with a bowel obstruction. H's death had not been referred to the coroner.

According to the care plan, H was non-verbal and relied on body language and facial expressions to communicate their needs. H had a significant intellectual disability and required a high level of support, but was usually well. The plan identified several alerts or signs of unwellness for H, including choking and constipation. It was noted that H's food intake should be monitored and staff should be alert to signs of pancreatitis or abdominal obstruction.

There is no information to indicate that the provider undertook a review of any kind following H's death.

The critical incident report is the only information held by DSS in relation to H's death. The provider's records indicate a death notification form was also sent to DSS. There is no information to indicate that following H's death, DSS sought any further information from the provider or took any other follow-up action. I find it difficult to see how, in this case, DSS had sufficient information to be satisfied that the provider was meeting its contractual obligations.

The Medical Certificate of Cause of Death confirmed bowel obstruction as the direct cause of H's death, with their specified disability and chronic constipation as antecedent causes.

## 7 — W

DSS received a critical incident report about the death of W, who was in their sixties and had been living in a CRSS. It was noted that staff had found W that morning, the death was unexpected, police and the ambulance service had attended, and a coroner's inquest was possible but this was being discussed by the coroner, GP, and police.

According to the care plan, W was independent with some daily living activities and able to express their needs and wants openly. In addition to an intellectual disability, W had periods of mental unwellness and a month prior to their death, was admitted to a mental health unit. The provider's daily records following W's discharge from the unit indicate a decline in health and well-being over the following few weeks, although there is little information as to the cause of that decline.

The critical incident report is the only information held by DSS in relation to W's death. The provider's records indicate a death notification form was also sent to DSS. There is no information to indicate that following W's death, DSS sought any further information from the provider or took any other follow-up action. Again, the lack of information collected by DSS is concerning.

Records from the coroner show that the duty coroner was contacted and provided advice, but no referral was made. The Medical Certificate of Cause Death identified W's direct causes of death as uncertain natural causes and diabetes. W's mental health condition was noted as an underlying cause.

## 8 — O

O was in their fifties and had lived in a CRSS for many years. O had previously been independent with many tasks, but a deterioration in health over the previous 2-3 years meant O was needing a higher level of support.

DSS was notified of O's death. The provider advised on the death notification form that O had been admitted to hospital following an episode of shortness of breath, and an x-ray had confirmed fractures to several ribs. O was diagnosed with aspiration pneumonia, but did not respond to antibiotics and died six days after admission. The provider explained further that O had been taken to an Accident & Emergency clinic several days prior to the hospital admission after complaining of pain in the rib area. The diagnosis at that time was bruising, possibly due to an unwitnessed fall.

The death notification form is the only information held by DSS in relation to O's death. There is no information to indicate that DSS sought any further information from the provider or took any other follow-up action.

The provider's records include an initial report on the death of O, and a follow-up report completed by one of the provider's regional advisors. The advisor noted the purpose of the report: to check whether anything of relevance had been missed in the initial report; to consider any underlying health issues that may have contributed to the fractures, to reflect on possible scenarios leading to the fall or other cause of the fractures, and to reflect on and recommend any further learning from the case.

The advisor's report included details of the review methodology, a summary of relevant information about O's background, and comment on environmental and potential scenarios that may possibly have contributed. While there was no conclusive finding as to the cause of the fractures, the advisor made a number of observations. These included comment on the importance of health advocacy at both planned and unplanned medical appointments, especially when the person is not known to the medical professional they are seeing, and the need for strong advocacy with the NASC when there has been a new diagnosis and change in need. The advisor also noted some issues with the bathroom at the home and suggested modification for better accessibility may be indicated, depending on the needs of future residents.

In this case, the provider undertook a comprehensive review of events leading to O's death. However, there is no evidence to indicate DSS was aware of the review or its findings.

## A national review system?

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Aside from provider reviews, there is also the broader question of whether New Zealand should have some kind of independent national review system. One such system is the Learning Disabilities Mortality Review (LeDeR) Programme in the United Kingdom. This was set up in 2015, following the 2013 Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), which looked at the avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews.<sup>65</sup> The Inquiry panel's recommendations included the routine collection and review of data providing intelligence about the mortality of people with learning disabilities, and the establishment of a body to take forward the reviews of deaths of people with learning disabilities, in order to learn from experience and continue to provide a driver to reduce inequalities in care for this vulnerable population.

The LeDeR Programme has encountered a number of challenges, including difficulties ensuring the timely completion of mortality reviews to a recognised standard. The extent to which it has, or will, drive the desired change remains to be seen, but there can be little doubt that it has contributed significantly to a much stronger evidence base. The question of whether such a programme is either feasible or desirable for New Zealand is one that warrants further consideration. I certainly consider there are some compelling arguments in its favour, although I do not doubt that were such a programme to be introduced here, it would be fundamentally different in concept and design.

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<sup>65</sup> The aim of the CIPOLD inquiry was to review the patterns of care people received in the period leading up to their deaths, identify errors or omissions contributing to the deaths, show evidence of good practice, and improve the evidence on avoiding premature death.

## Involvement of a coroner

Ministry staff expressed differing views on the extent to which the involvement of a coroner affected their follow-up enquiries and actions. Some staff suggested that while it was important to be aware of coroner involvement, any necessary enquiries would still be made. Other staff, however, appeared to see coronial involvement as reason for the Ministry to step back entirely. They talked about not being able to do anything while the coroner is looking at the matter or, as one person put it, *'the basic rule is if someone else is investigating, it's not our business'*.

It is certainly important that coronial (or police) inquiries into a person's death are in no way compromised by any enquiries, reviews, or investigations undertaken by the Ministry or the provider. However, I do not see that the involvement of a coroner in determining the cause of a person's death and surrounding circumstances precludes either the Ministry or the provider from looking at aspects of what happened and whether steps should be taken immediately to prevent or minimise the risk of a similar event—even if a full understanding of what happened may not be possible until the coroner issues their findings.

It was also evident that, unless a coroner made a finding or recommendation specific to the Ministry (and this did not occur in any of the cases in our sample group), DSS rarely obtained information about the outcome of coronial inquiries.<sup>66</sup> DSS senior managers initially expressed the view that their service had no mandate to do so. However, under the Coroners Act 2006, a coroner must provide a copy of the completed and signed certificate of findings, together with any recommendations to all *'interested parties'*, defined as *'any person or organisation that the responsible coroner considers has an interest in the death or suspected death (apart from any interest in common with the public)'*. The Chief Coroner

Some staff suggested that while it was important to be aware of coroner involvement, any necessary enquiries would still be made.

<sup>66</sup> As outlined previously, coronial findings are obtained by the Mortality Collection but there was no mechanism for that information to be shared with DSS.

advised my Office that for coroners to be aware that a party should be recognised as an interested party, there needs to be a mechanism to alert the coroner to the party's involvement.

As noted earlier, 19% of the deaths in our sample group were reported to a coroner. These included those deaths that resulted from an accident and a number of others identified as sudden and unexpected. For the most part, the only information DSS held about the deaths of these people was that contained in the death notification form. Coronial inquiries can take some time to complete. Nevertheless, DSS should, in my view, have had a process in place to obtain information about the outcome of coronial cases. Without this, the accuracy and completeness of its reporting on the deaths of its service users is further compromised.

### 9 — U

DSS was notified of the death of U, who was in their forties and who had been living in a supervised residential service. The provider advised that U had collapsed at home and CPR was administered until the paramedics arrived, but U was unable to be revived. The provider confirmed that the police and coroner were involved.

DSS supplied two other documents that referred to U's death, both of which were provided to DSS some weeks after U had died.

For privacy reasons, I am unable to outline further details about the information provided to DSS regarding the circumstances leading to U's death. However, in this case also, I am concerned about the dearth of information held by the Ministry in relation to U's death, and the apparent lack of any follow-up enquiry or action.

In addition, the provider in this case advised they had not undertaken any kind of internal review or investigation, due to the involvement of the coroner and the police.

I am seeking further information from the Ministry in relation to this particular case.

## Record keeping

Most of the staff interviewed for this investigation, including senior managers, acknowledged that DSS's record keeping is *'not as good as it could be'*, a fact brought more sharply into focus through the protracted process of locating information for both this and my other current investigation concerning the Ministry and intellectual disability.<sup>67</sup>

Of particular note is the lack of records showing enquiries made or actions taken by DSS in relation to a death notification, an identified or potential concern, and the outcome of any enquiries or actions. The records for my sample group simply did not reflect the level of engagement that staff reported having with either their Ministry colleagues or providers.

I note that under the Public Records Act 2005, the Ministry is required to:

*create and maintain full and accurate records of their affairs, in accordance with normal, prudent business practice, including the records of any matter that is contracted out to an independent contractor.*<sup>68</sup>

In addition, records must be maintained in an accessible form until their disposal is authorised by the Chief Archivist.

My specific concerns in relation to record keeping are as follows.

- Some interactions were simply not documented. I am not suggesting that there should be a detailed file note for every telephone conversation between a provider and a contract relationship manager. However, where the Ministry has asked for and/or been provided with additional information from a provider in relation to a person's death, I would certainly expect there to be some record of that. Similarly, where staff discuss a matter identified as potentially concerning and conclude further enquiry

The records for my sample group simply did not reflect the level of engagement that staff reported having with either their Ministry colleagues or providers.

<sup>67</sup> See page 24.

<sup>68</sup> Section 17.

or action is not warranted, there should be some record of the decision and the reasons.

- Some information was not saved, or not saved in a manner that allowed it to be readily located and retrieved. There is little value in information that is not accessible.
- There was no shared or standardised process for recording and saving information. Staff described different practices in terms of what information they recorded, and what and where information was saved. Aside from the difficulties this created for my investigation, staff noted it could be problematic when it came to responding to official information requests, and for new staff looking to get up to speed with recent issues that may have been raised with or by a provider.
- The death notification spreadsheet is the means by which DSS collates information from the death notification forms. There was no clear or consistent process for ensuring the spreadsheet was updated if and when additional information came to hand at a later date.
- There were gaps in the process for keeping track of cases where a concern or potential concern had been identified, and enquiries were being made or follow-up action taken. Where a serious concern or potential concern was identified, the matter was logged in the Quality minutes and then followed through until staff were satisfied the matter was resolved. Of the 108 people in my sample group, this occurred in only two cases. There was no process, however, to keep track of matters that had not been escalated in this way but where enquiries were being made.
- I note that a number of staff identified the lack of an appropriate case management system as contributing to the sub-optimal record keeping.

## Use of information for service development and shared learning

Health and disability data has a number of purposes. It allows for the monitoring of changes over time in respect of particular events, conditions, impairments or diseases. It enables progress against goals to be measured. It is vital for evaluating the quality of services and interventions, and assessing the extent to which these are improving desired outcomes. Good data helps make informed decisions about the future allocation of resources, and can help identify matters warranting further research or inquiry.

As a member of People First said, *'How can we plan for the future with no understanding of where we are, or without a platform to move forward?'*

The Ministry has long been aware of the need for better data about the health status and health care utilisation of New Zealanders with intellectual disabilities.<sup>69</sup>

Some efforts have been made to address this. In 2011, a project team led by the Ministry reported on a selection of health status and health care utilisation indicators for New Zealanders with and without an intellectual disability. In terms of the overall results, the team found that:

*[for] all of the indicators examined ... people with an intellectual disability were more disadvantaged in terms of their health and life expectancy, compared to people without intellectual disability. The group with intellectual disability experienced higher rates of specific health conditions, and they also used health services more (apart from preventive screening services).*

Health and disability data is vital for evaluating the quality of services and interventions, and assessing the extent to which these are improving desired outcomes.

<sup>69</sup> It was, for example, highlighted in *'To Have and 'Ordinary' Life'*, a 2003 study by the National Advisory Committee on Health and Disability, available at: [http://www.moh.govt.nz/notebook/nbbooks.nsf/0/01C3D18A8584E882CC257A17000604BE/\\$file/ToHaveOrdLifeBkgrdPapers.pdf](http://www.moh.govt.nz/notebook/nbbooks.nsf/0/01C3D18A8584E882CC257A17000604BE/$file/ToHaveOrdLifeBkgrdPapers.pdf)

Concern about health outcomes for people with intellectual disabilities is of course not limited to those who receive residential support. There is the much larger group of people who access non-residential support, and undoubtedly a further group who for one reason or another receive no Ministry-funded support. However, people receiving full-time residential support are generally those needing high levels of support. Of this group of more than 6000 people, a small proportion—between 1.5% and 2%—can be expected to die each year.<sup>70</sup> As the Ministry states, death is a significant event. Aside from the question of the Ministry's responsibilities for looking at these deaths individually for quality assurance purposes, there is also the question of whether the deaths have been reported in a manner that is useful for broader evaluative and decision-making purposes.

Had the Ministry's administrative arrangements ensured the collection of complete, accurate, and sufficient information, and had that information been fully analysed and reported, it could have been used to inform the Ministry's own policy and service development. Information used for these purposes needs to be both sufficiently comprehensive and appropriately broken down. I acknowledge the small numbers involved may limit the extent to which significant patterns or trends could be identified. I would, however, suggest the Ministry's internal reporting on the deaths of people accessing full-time residential support should be further broken down to include disability type and ethnicity.

In addition, there may be value in this information in terms of learnings able to be shared with providers collectively, to support their quality improvement efforts for the benefit of service users. This could, for example, include information about the identification of particular risks, common themes from provider reviews, or examples of good practice. Information used for this purpose would of course need to be aggregated and/or anonymised.

I would, however, suggest the Ministry's internal reporting on the deaths of people accessing full-time residential support should be further broken down to include disability type and ethnicity.

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<sup>70</sup> As noted on page 40, in 2018 there were approximately 6160 people with intellectual disabilities receiving full-time Ministry-funded residential support.

I note the comments from one provider on both the value of sharing information and its view of the Ministry's role in facilitating this:

*Historically, and certainly in recent years, we have requested sector engagement and guidance led by the Ministry in relation to particular deaths and related health and safety risks (such as drowning and choking). We are aware that other service providers have also sought such guidance and engagement from the Ministry. To date, the Ministry has not been willing to take such an approach, and no such engagement has occurred. We are also not aware of any analysis or shared learnings or related discussions occurring external to the Ministry regarding service user deaths. In our view, it would be beneficial for the Ministry to take more of a leadership approach in terms of developing guidance and common practice for managing these risks based on learnings from past cases, as well as taking a leadership role in encouraging sector engagement and sharing of information.*

The Ministry should be a key player in creating and maintaining a learning culture amongst disability providers, in order to maximise safety and quality, and ensure improved future health outcomes.

Ultimately, there is a need for more comprehensive, robust data on the deaths of people with intellectual disabilities in New Zealand irrespective of what Ministry-funded services they may use. However, I consider the Ministry should have made better use of the data it collected, or was mandated to collect, about its residential support service users. It should have looked more closely at how that information could inform its own policy and service development, and how it could be shared with providers to support their quality improvement efforts. This is relevant also in the context of New Zealand's obligations under the Disability Convention.

## Changes to collection and recording made in July 2019

As previously noted, prior to my investigation, there had been some recognition by the Ministry that its management of death notifications to DSS could be improved. A review was proposed, and approved by DSS senior management in January 2018. The review did not take place, and although some minor changes were made during 2018, progress effectively stalled. It would appear this was due to other work taking priority at a time when resources in this area were limited.

The first half of 2019, however, saw the matter firmly back on the agenda. The Ministry acknowledged that my investigation had served as a prompt to action, and it appears that the investigation process itself highlighted gaps in its arrangements for managing death notifications, as well as opportunities to fill those and make improvements. Changes have already been implemented, the most significant of which are captured in two new SOPs: 'Death notification and management (residential services only)' and 'Critical incident management (all DD funded services)'. These became effective on 1 July 2019.

The SOP for death notification and management begins by setting out the purpose and scope of the procedure, along with the background to its introduction. In terms of the purpose, the SOP states:

*The process and guidance aim to:*

- a. *provide a consistent way of gathering, assessing and filing information about deaths*
- b. *ensure [Disability Directorate] quality assurance functions are implemented appropriately and consistently, so that actions taken:*
  - i. *are fair, risk-based and justifiable*
  - ii. *uphold the rights of disabled people and their family/whānau*

The Ministry acknowledged that my investigation had served as a prompt to action, and it appears that the investigation process itself highlighted gaps in its arrangements for managing death notifications, as well as opportunities to fill those and make improvements.

- iii. *provide assurance that deaths are managed appropriately by providers*
- iv. *are consistent with our role and functions, and complement other government agencies' processes (e.g. the Coroner, the Police, HQSC)*
- v. *inform Ministry of Health (MoH) actions to improve the health and well-being of disabled people.*

The SOP then summarises the death notification process, which is also captured in a series of process charts (see Appendix 6). It also sets out the roles and responsibilities of relevant staff, and provides guidance on identifying and acting on concerns.

More specifically, the SOP:

- provides guidance to staff responsible for triaging death notifications, including guidance on identifying deaths unlikely to be avoidable, possibly avoidable, and likely avoidable (and/or high profile);
- confirms the responsibilities of the Quality Team and contract relationship managers for assessing the available information to determine whether there could be a quality issue relating to the death (with examples of deaths that could indicate poor quality care);
- confirms new processes for cross-checking DSS information about deaths with information logged in Socrates and held in the Mortality Collection, to ensure no death is missed and to improve data quality;
- provides guidance for DSS staff in relation to recording quality concerns and filing that information; and
- confirms changes to the death notification spreadsheet to improve data quality, and to ensure any concerns identified are recorded and tracked.

The guidance also sets out the Ministry's expectations of providers in relation to the management of a person's death. These include that service users are supported to access healthcare (including palliative care) in a timely and appropriate manner, that the immediate response following a death is managed appropriately, and that following a death, the provider will conduct an internal process to assess:

- i. *whether the death could have been prevented by some action or inaction by the provider or other party, and/or if there is any ongoing risk for other clients*
- ii. *whether action by the provider may prevent or minimise the risk of a similar death, such as:*
  1. *re-training or further training of workers*
  2. *practice improvements*
  3. *improving policies and procedures*
  4. *changes to the environment in which supports or services are provided*
  5. *changes to the way supports or services are provided*
- iii. *the immediate response could be improved in the case of a future death.*

This SOP is certainly a positive move in the right direction and represents a solid start to putting in place appropriate administrative arrangements for the collection and use of information about the deaths of people in this group.

The process now in place, whereby the Disability Directorate cross-checks the information it receives from providers with data from the Mortality Collection and Socrates should result in its cause of death data being more complete and accurate. The guidance for staff on identifying and responding to possible provider quality issues should ensure more thorough and consistent quality assurance activity. If used as intended, the SOP will also significantly improve record-keeping.

The guidance for staff on identifying and responding to possible provider quality issues should ensure more thorough and consistent quality assurance activity.

It is of course important that the changes outlined in the SOP are in fact carried out in practice. My recommendations are therefore focused on ensuring that occurs, and the other areas that, in my view, require further work—namely ensuring provider reviews are carried out, using data to inform policy, sharing learnings with providers, and external reporting.

## Conclusion

As outlined at the start of this report, people with intellectual disabilities have poorer health outcomes than the general population, including significantly lower life expectancies.

The Ministry of Health funds, purchases, and monitors disability support services, including full-time residential support for more than 6000 people with intellectual disabilities. It is also responsible for leading New Zealand's health and disability systems. This gives rise to certain obligations and responsibilities.

It is evident from the people I spoke to and the information I looked at, that in its effort to achieve better health outcomes for people with intellectual disabilities, the Ministry faces a number of challenges. These are not necessarily new, nor specific to residential support services.

While there is a general trend away from full-time residential support in favour of community-based options, an increasing number of people with intellectual disabilities have higher and more complex needs, requiring higher levels of support. There are ongoing questions around how best to strike the right balance between arrangements and measures that maximise people's autonomy and those that provide for an appropriate level of support, to ensure the delivery of safe, quality services. Such questions now need to be considered in the context of the current programme to transform the disability system—the extent to which the new structures and processes can and should be extended into residential support, and how this might look. A number of people my investigators talked to in the course of this investigation raised serious concerns about the barriers that people with intellectual

It is evident from the people I spoke to and the information I looked at, that in its effort to achieve better health outcomes for people with intellectual disabilities, the Ministry faces a number of challenges.

disabilities encounter when it comes to accessing appropriate and equitable health care, including hospital care. There are funding pressures. In terms of data, there are challenges arising from current data collection systems and arrangements generally, which do not readily enable the creation of datasets about the health status and health care utilisation of people with intellectual disabilities.

The importance of good data should not be underestimated. The purpose of this investigation was to examine the Ministry's policies and practices in recording and reporting the deaths of people with intellectual disabilities receiving full-time residential support, in order to identify whether they were consistent with good administrative practice and accountability, and relevant international conventions, particularly the Disability Convention.

Overall, in my opinion the Ministry's arrangements in relation to the collection, use, and reporting of information about the deaths of people with intellectual disabilities receiving Ministry-funded residential support were unreasonable.

There are some important differences in terms of the requirements that apply to providers of different types of residential support. However, all providers are required through their contracts to deliver services that meet certain expectations and standards (including the Health and Disability Services Standards). They are required to have systems in place to manage and improve the quality of the services they provide. For its part, the Ministry is responsible for ensuring providers deliver services in accordance with the terms of their contracts. It has a clear mandate to collect information relevant to that obligation.

It became evident in the course of my investigation that the Ministry's arrangements for collecting information about the deaths of its service users were not adequate. Its systems and processes did not support the collection of information that was complete, accurate, or sufficient. They did not provide a sound basis for staff to determine whether there was a need for further enquiry or other follow-up action. In the absence of clear guidance for staff, the follow-up that did occur appears to have been limited and inconsistent. There was no internal audit process that might have identified this.

Overall, in my opinion the Ministry's arrangements in relation to the collection, use, and reporting of information about the deaths of people with intellectual disabilities receiving Ministry-funded residential support were unreasonable.

Record keeping was deficient and not consistent with the requirements of the Public Records Act. There was no evidence that the information the Ministry collected, or should have collected, was used to inform its own service or policy development, or shared with providers in ways that might support their quality improvement efforts.

Commendable changes have already been made to remedy the deficiencies identified. My recommendations are focused on supplementing these changes where necessary and ensuring they have been effectively implemented and are achieving the intended outcomes. I am also recommending further engagement with potential to improve health outcomes for people with intellectual disabilities including through the identification and prevention of avoidable or premature deaths.



## Recommendations

In light of the changes that have already been made, I recommend that the Ministry takes the following actions:

1. review the system recently introduced by the Disability Directorate to cross-check its data with Mortality Collection data to ensure this includes information received from the coroner, including final coroners' findings;
2. review the implementation and operation of the Death notification and management SOP introduced on 1 July 2019, including its operation with respect to disabled service users living in aged residential care facilities, and service users in hospital-level secure services;
3. review and amend the death notification form to ensure it captures sufficient relevant information from providers following a death, in the context of Ministry's role and responsibilities;

4. undertake an audit of Disability Directorate records for a sample of the last 20 deaths notified to the Ministry between 1 July and 31 December 2019, to ensure that, in accordance with the new SOP and good administrative practice:
  - a. appropriate steps are being taken to identify and manage any quality issues;
  - b. relevant feedback is shared with providers; and
  - c. the necessary records are being made and stored;
5. establish a process for ongoing audits of Disability Directorate records for a sample of deaths on an annual basis;
6. develop a comprehensive, robust, and durable plan to engage with and support providers and other relevant stakeholders, including service users (through representative bodies/ organisations), in order to:
  - a. ensure an appropriate level of review is undertaken following the deaths of all people with intellectual disabilities receiving Ministry-funded residential support;
  - b. ensure provider reviews are routinely supplied to and reviewed by the Ministry;
  - c. establish mechanisms for review learnings to be shared with providers and other relevant stakeholders;
  - d. ensure the Ministry's expectations in relation to provider reviews are reflected in its contracts/service specifications; and
  - e. explore options for establishing, in the longer term, a national independent review system;
7. engage and work with the Health Quality & Safety Commission to explore options for supporting providers to improve the quality of experience and the safety of the care and services their residents receive. This will be achieved

through reporting, reviewing, and learning from adverse events and near misses, including by increasing compliance with the National Adverse Events Reporting Policy among non-DHB providers, and through supporting quality improvement projects to effect change;

8. confirm arrangements for undertaking in-depth analysis of information about the deaths of service users (eg when and how often this will occur), and information from critical incident reports, and utilising that analysis to inform future policy and practice;
9. consider what actions can be taken to develop and implement an improved information management system that better supports Disability Directorate staff to capture, store, access, and utilise relevant information, and compliance with the Public Records Act 2005; and
10. review the measures currently in place to ensure relevant senior leaders have sufficient oversight of operational practice in relation to the Ministry's expectations and obligations following the death of a disabled service user.

The Ministry is required to report back to me on recommendations 1 to 10 by **3 October 2020**.



## Feedback

The Ministry provided the following comment:

*Since the commencement of your investigation, the Ministry has taken steps to improve the collection and recording of information relating to the deaths of all disabled people in full-time residential care, as noted in your provisional opinion. The Ministry acknowledges there is still work to do and is committed to implementing the recommendations outlined in your report. The Disability Directorate will continue to proactively engage with your Office as it works through the implementation of the recommendations.*

In addition:

- The Health Quality & Safety Commission advised that its Patient Safety Team met with the Ministry to discuss recommendation 7. The Commission also advised it is well placed to assist with recommendation 8, and will approach the Ministry about this.
- The Chief Archivist advised that he agreed with my assessment and recommendations, and that *'Archives New Zealand will engage with the Ministry to ensure that recordkeeping best practice arises from the lessons outlined in the Ombudsman's recommendations'*.

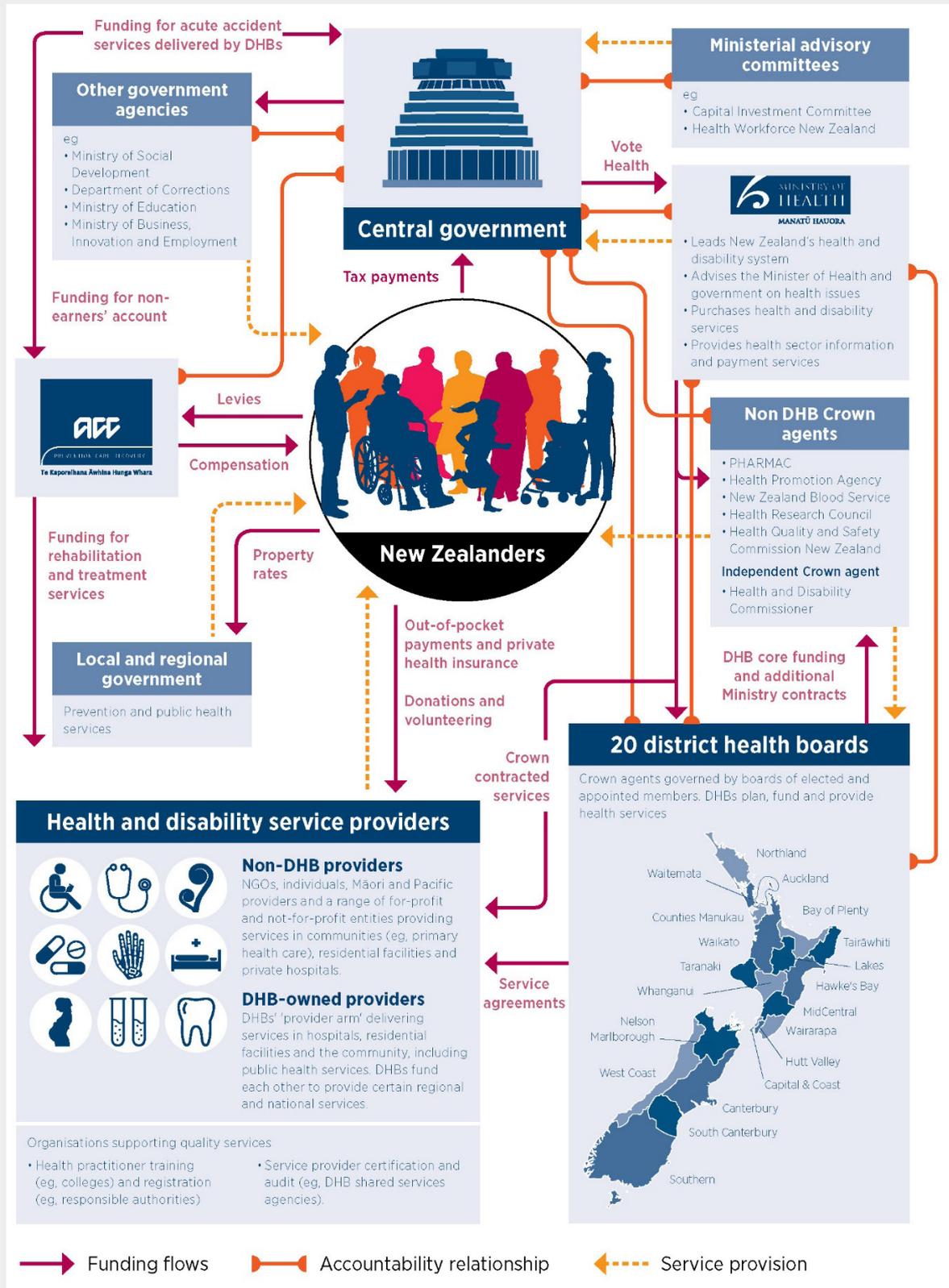
## Appendix 1. Glossary

Term	Meaning
Community Residential Support Services (CRSS)	Community-based homes providing 24-hour residential support for disabled people.
Coroner	A judicial officer (like a judge), who looks into certain deaths, including those that are unexpected, violent, or suspicious, to find out what happened.
District Inspector (ID(CCR) Act)	A lawyer designated under the ID(CCR) Act 2003 to monitor, protect, and give effect to the rights of people receiving compulsory care and rehabilitation.
Disability Directorate	The section of the Ministry of Health responsible for providing oversight of 'end-to-end' activities and functions for the disability community (established October 2018).
Disability Support Services (DSS)	The service within the Disability Directorate responsible for purchasing and monitoring services for disabled people (up until late 2019, when the Directorate was restructured).
Health and Disability Commissioner (HDC)	A person whose role it is to protect and promote the rights of health and disability services consumers, including by resolving complaints about health and disability service providers.
Health Quality & Safety Commission (HQSC)	The Commission's role is to lead and coordinate efforts to improve the quality and safety of health and disability services, as set out in section 59B of the New Zealand Public Health and Disability Act 2000.
HealthCERT	A business group within the Ministry of Health responsible for ensuring services such as hospitals and residential care facilities provide safe and reasonable levels of service, as required under the Health and Disability Services (Safety) Act 2001.

Term	Meaning
High and Complex Framework	A framework of interconnected specialised services for people whose needs are high and complex such that they cannot be supported by mainstream services. This includes people who are subject to orders under the ID(CCR) Act.
Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (ID(CCR) Act)	A law that provides for the compulsory care and rehabilitation of people with intellectual disabilities who have been either found unfit to stand trial on, or convicted of, an imprisonable offence.
Ministry of Health	The government agency responsible for leading New Zealand’s health and disability systems.
Needs Assessment and Service Coordination (NASC)	Organisations contracted by the Ministry of Health to work with disabled people to identify their strengths and support needs, outline what disability support services are available, and determine their eligibility for Ministry-funded support (including residential support).
National and Regional Intellectual Disability Secure Services (NIDSS/RIDSS)	Hospital-level secure facilities providing residential services and assessment beds. NIDSS are provided by the Auckland and Wellington District Health Boards (DHBs), and RIDSS by the Auckland, Waikato, Capital & Coast, Canterbury and Southern DHBs.
Providers	The Ministry has contracts with a range of disability support service providers—that is, people and organisations providing services to support people with disabilities. These include day services, home and community services, equipment, and residential services. Unless stated otherwise, the term ‘provider’ in this report refers specifically to people or organisations contracted by the Ministry to provide full-time residential support for people with intellectual disabilities.

Term	Meaning
Quality assurance	Activity focused on providing confidence that a service meets expected quality requirements.
Quality improvement	Activity focused on changes that will lead to better outcomes.
Regional Intellectual Disability Supervised Accommodation Services (RIDSAS)	Community-based homes providing supervised accommodation for people under the High and Complex Framework, including people subject to orders under ID(CCR) Act.
Service users	For the purposes of this report, the term 'service users' is used to describe people with intellectual disabilities who access Ministry-funded residential support.
Standard Operating Procedure (SOP)	A set of written instructions to help staff complete certain tasks.
United Nations Convention on the Rights of Persons with Disabilities (Disability Convention)	An international human rights agreement intended to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.

## Appendix 2. Overview of NZ's health and disability system



From Ministry of Health Annual Report for the year ended 30 June 2019.

## Appendix 3. Key Ministry strategies and reviews

### **Enabling Good Lives and system transformation**

In 2007, a Social Services Select Committee inquiry heard that people with disabilities often felt they had little control over the services they received. Funding was also found to be relatively inflexible.

In 2011, a group of people from the disability sector reviewed day options for disabled people and concluded that a fundamental shift was needed. Their report, entitled 'Enabling Good Lives' (EGL), identified the need for a number of changes including:

- a new approach to supporting disabled people, which offers greater choice and control over the supports they receive so they can plan for the lives they want;
- a partnership between disability sector and government agencies, aimed at long-term transformation of how disabled people and families are supported to live everyday lives; and
- an initiative to bring funding from the Ministries of Health, Education and Social Development together in a single package that can be used flexibly.

The principles of EGL are identified as: self-determination, beginning early, person-centred, ordinary life outcomes, mainstream first, mana enhancing, easy to use, and relationship-building.

Ministers agreed change was needed and gave approval for the EGL approach to be tested through 'demonstrations' in Christchurch and Hamilton. The initiatives were reportedly well received and evaluations showed they led to improvements in people's lives, enabling them to achieve better outcomes. EGL can be described as a partnership between the disability sector and government agencies, aimed at long-term transformation of how disabled people and families are supported to live everyday lives.

During 2016, a group of Ministers discussed the future direction of disability support and proposals were developed for transforming the system. Based on the vision and principles of EGL, a team was set up to develop the high-level design that was to be the basis of the transformed system. A prototype of the transformed system, known as Mana Whaikaha, was launched in the MidCentral DHB region in October 2018. The Ministry is due to report back to Ministers at the end of 2020. Cabinet will then decide on extending to other regions.

At its simplest, the vision is for disabled people to have greater choice and control.

### **Whāia Te Ao Mārama 2018 to 2022**

In March 2018, the Ministry issued Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan. The plan is based on the principles of Te Tiriti o Waitangi and reflects New Zealand's Disability Convention obligations. It is aligned with the vision and principles of EGL and system transformation.

The plan sets out six goals, including that by 2022, tāngata whaikaha will receive disability support services that are responsive to Te Ao Māori. One of the actions for realising this goal is a commitment by the Ministry to drive service improvements using data and evidence.

### **Putting People First**

In 2013, the Ministry commissioned an external review of the performance and quality management processes for disability services purchased.

It made a number of recommendations, grouped into four key areas:

- Support service providers to offer high quality care and supports that place disabled people at the centre of their service.
- Give disabled people a voice—the ability to speak out when unsafe, including support to do this if they are unable to do so on their own.

- Ensure the processes that capture complaints, incidents, and issues do so in a way that (i) keeps disabled people safe, and (ii) resolves the complaint.
- Ensure performance management systems are effective, responsive, and undertaken regularly enough, so little opportunity exists for people to fall through the cracks.

The review panel commented on the relationship between the Ministry and providers, and how providers could be supported to perform well. It noted that providers are susceptible to the Ministry's view of them, as the funder and purchaser of services. If the Ministry focuses on wrong-doing, therefore, providers will make an effort to not be seen doing wrong and may act to cover up poor performance. The review panel suggested better outcomes could be achieved by placing emphasis on what's working well, and what constitutes good performance:

*While monitoring for poor performance is one method of ensuring the required standards are met, supporting providers to achieve high levels of performance and people-centered services, is likely to have greater impact on the day-to-day well-being of disabled people.*

## Appendix 4. Other key people and agencies

### The Coroner

In some situations, the medical or nurse practitioner does not complete a Medical Certificate of Cause of Death, and the practitioner or police will report the death to a coroner.<sup>71</sup> Deaths that must be reported to a coroner include:

- those that appear to be without known cause, self-inflicted, unnatural, or violent;
- those that were medically unexpected; and
- those that occurred when the person was *'in official custody or care'* (which includes people detained under the Mental Health Act or the ID(CCR) Act).

Sometimes the duty coroner will be contacted for advice as to whether a death is required to be reported.

When a death is reported to a coroner, they will decide whether to open an inquiry. Inquiries enable the coroner to find out more about who the person was, as well as where, when, and how they died. They also help coroners make recommendations or comments that might prevent a similar death happening in the future. A coroner may ask for another investigation, such as a post mortem, to help them decide whether to hold an inquiry. Sometimes, they may decide they can make a finding without opening an inquiry. If an inquiry is opened, the coroner will decide whether to conduct this 'on the papers', by reading the evidence, or whether to hold an inquest so they can hear from witnesses. Until 2016, it was mandatory to hold an inquest into the death of any person in official custody or care. That requirement was removed under the Coroners Amendment Act 2016.

Each year, coroners accept jurisdiction for approximately 3600 deaths

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<sup>71</sup> Reporting requirements are set out in Part 2 of the Coroners Act 2006.

in New Zealand.<sup>72</sup> This represents approximately 10% of the total number of deaths each year. The Chief Coroner advised that only a very small proportion of those that are reported—approximately 3%—proceed to inquest. In approximately 57% of coronial cases, the death is found to be from natural causes.

The Law Commission report also identified *'significant confusion' among doctors as to when a death should be reported to the coroner.*<sup>73</sup>

### **Needs Assessment and Service Coordination agencies**

Needs Assessment and Service Coordination services (NASCs) are organisations contracted by the Ministry to work with disabled people to:

- identify their strengths and support needs;
- outline what disability support services are available; and
- determine their eligibility for Ministry-funded support services (including residential support).

There are 15 NASCs across the country. In addition, the Forensic Coordination Service acts as a NASC for people under the High and Complex Framework.

NASC referrals, assessments, funded services, and key client details are recorded by NASCs in a central database known as Socrates. Data from Socrates is exported to the Ministry's Client Claim Processing System, so that providers of disability support services are paid. Those providers are required to inform their local NASC when a person stops receiving a service (because they have died or for some other reason) so that payments are stopped. Aside from this, the Ministry does not require specific reporting from NASCs about the deaths of individuals and NASCs have no specific responsibility for monitoring deaths.

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<sup>72</sup> Annual Report 2018-2019 Office of the Chief Coroner of New Zealand, available at: <https://coronialservices.justice.govt.nz/assets/Documents/Publications/Chief-Coroners-Annual-Report-2018-2019.pdf> (pages 8-9).

<sup>73</sup> See footnote 28, page 39.

### Health and Disability Commissioner

The purpose of the Health and Disability Commissioner (HDC) is to promote and protect the rights of consumers, as set out in the Code of Health and Disability Services Consumers' Rights, including by resolving complaints about health and disability service providers.

Under the Health and Disability Commissioner Act 1994, HDC has a range of options for dealing with complaints, including by:

- referring a complaint to an agency involved in the health and disability sector (including to the Director-General of Health) if it appears that failures or inadequacies in the systems or practices of the provider concerned may harm the health or safety of members of the public;<sup>74</sup> and
- referring a matter to an appropriate person or authority if the Commissioner considers it is necessary or desirable in the public interest to do so.<sup>75</sup>

HDC is also responsible for the Nationwide Health and Disability Advocacy Service, which provides independent support for consumers with concerns or complaints about health and disability providers.

HDC's Deputy Commissioner Disability has a specific focus on increasing disabled consumers' awareness of their rights as set out in the Code and ensuring that HDC is accessible and responsive to all consumers, including those less able to speak up for themselves and more susceptible to abuse and neglect. The current Deputy Commissioner Disability advised that from time to time, HDC meets with key Ministry staff, namely the Chief Advisor, ID(CCR) Act, the Quality Team, and HealthCERT for general discussions about specific issues or concerns arising from complaints received. Where appropriate, HDC refers complaints to the Ministry, HealthCERT and, on occasions, to a DHB.

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74 Section 34(1)

75 Section 59(4)

The death of a person with an intellectual disability receiving residential support may come to the attention of HDC if a complaint is made about the services that person received. Another agency or authority may also bring the matter to HDC's attention.

### **Health Quality & Safety Commission**

HQSC's role is to lead and coordinate efforts to improve the quality and safety of health and disability services.

HQSC's Patient Safety Programme aims to support the health and disability sector and consumers in improving patient safety and system resilience, to reduce harm associated with healthcare to consumers and their families/whānau.

The Adverse Events Learning Programme (AELP), which sits within the Patient Safety Programme, aims to reduce preventable harm and uses the National Adverse Events Reporting Policy 2017 to drive the identification, reporting, reviewing, and learning from adverse events.

HQSC defines an adverse event as:

*An event with negative or unfavourable reactions or results that are unintended, unexpected or unplanned (also referred to as 'incident' or 'reportable event'). In practice this is most often understood as an event which results in harm or has the potential to result in harm to a consumer.<sup>76</sup>*

A death may be an adverse event if it is not related to the natural course of an illness and differs from the immediate expected outcome of care and management.

The role of the programme is to promote a nationally consistent approach to reporting, review, and learning, and to share lessons learned nationally and across the health and disability sector. The intention is to encourage an open culture of reporting, where people can learn from what happened and put in place systems to reduce the risk of similar events occurring in the future.

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<sup>76</sup> National Adverse Events Reporting Policy 2017, available at: [https://www.hqsc.govt.nz/assets/Reportable-Events/Publications/National\\_Adverse\\_Events\\_Policy\\_2017/National\\_Adverse\\_Events\\_Policy\\_2017\\_WEB\\_FINAL.pdf](https://www.hqsc.govt.nz/assets/Reportable-Events/Publications/National_Adverse_Events_Policy_2017/National_Adverse_Events_Policy_2017_WEB_FINAL.pdf)

A key component of the programme is the National Adverse Events Reporting Policy, which applies to all health and disability providers with obligations under the Health and Disability Services (Safety) Act 2001, as well as those providers not covered by that Act but which voluntarily comply.<sup>77</sup>

Under the policy, health and disability service providers are 'expected' to report serious adverse events to HQSC. Some providers, such as DHBs, are contractually obliged to do so. Providers are required to rate adverse events from one (most serious) to four (least serious) using a Severity Assessment Code (SAC) tool. They must then:

- report rated SAC 1 and SAC 2 adverse events to HQSC within 15 working days of being reported to the provider;
- formally review SAC 1 and SAC 2 rated adverse events, develop recommendations to improve the safety of the system, and develop a pathway to oversee the implementation and operation of those recommendations; and
- send a summary of the review findings and recommendations to HQSC within 70 working days from the date the event was reported to the provider.

The death of a person with an intellectual disability should, therefore, be reported to HQSC if it resulted from a SAC 1 or SAC 2 rated adverse event that occurred while they were under the care of a DHB (eg if they were a hospital inpatient or in a secure hospital-level residential service). In addition, any death may be reported if the person was under the care of a provider that has chosen to report.

In practice, the vast majority of reporting to HQSC is by DHBs. Of the 916 adverse events reported between 1 July 2018 and 30 June 2019, 798 were reported by DHBs (including from the mental health and addiction sector), and only five by 'other providers', the category that

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<sup>77</sup> Under the Health and Disability Services (Safety) Act 2001, health and disability services include services 'provided to people with disabilities or people who are frail (whether because of their age or for some other reason), for their care or support or to promote their independence'.

could potentially include providers of residential support for people with intellectual disabilities.<sup>78</sup>

In its 'Learning from adverse events' report for 1 July 2018 to 30 June 2019, HQSC states:

*The national policy is designed to be relevant to all providers of health and disability services. It is of concern that, except for private surgical hospitals and emergency ambulance providers, there is little visibility of adverse events that are occurring outside the DHB hospital system. Over the past year we have worked with some general practices, primary birthing units and disability support services to help them incorporate the national policy into their local systems and processes. We are happy to work with any other providers at an individual level who would like assistance in implementing the national policy. We will also be working with quality improvement networks at the sector level.<sup>79</sup>*

### **Human Rights Commission**

The Commission promotes and protects the human rights of all people in New Zealand. It receives and helps resolve complaints about discrimination. The Disability Rights Commissioner has a specific role in promoting and protecting the rights of disabled people.

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78 The remaining 113 adverse events were reported by members of the New Zealand Private Surgical Hospitals Association (100), ambulance services (7), the primary care sector (5) and Hospice (1).

79 Available at: <https://www.hqsc.govt.nz/our-programmes/adverse-events/publications-and-resources/publication/3889/>

### Office for Disability Issues

The Office for Disability Issues is a focal point in government for disability issues. It supports the implementation of the Disability Convention and the Disability Strategy.

The Office for Disability Issues is administered by the Ministry of Social Development, and its annual work programme is agreed directly with the Minister for Disability Issues.

Key areas of responsibility include:

- supporting the Minister for Disability Issues;
- coordinating and reporting on implementation of the Disability Convention, the Disability Strategy and the DAP;
- providing advice to government agencies on disability issues;
- sharing ideas and growing the understanding of issues that are important to disabled people;
- helping to facilitate an effective working relationship between the disability sector and government agencies; and
- providing secretariat support to the New Zealand Sign Language Board and Fund.<sup>80</sup>

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<sup>80</sup> <https://www.odi.govt.nz/>

## Appendix 5. Internal reporting

The Ministry provided me with the following internal reports for the relevant period.

- *Monthly Dashboards*: In May 2017, the Quality Team began producing 'Monthly Dashboard' reports. These are intended to provide management with a snapshot of complaints, critical incidents, death notifications, quality concerns, and audit and evaluation reports from the previous month. In terms of the data about deaths, the first reports showed high level statistical information about the number of notifications, whether this was an increase/decrease on the previous month, and the names of the providers. Later reports include a graph showing the number of deaths per month for the previous 12 months, and some information about causes of death (if known).
- *6-monthly Quality Report for July-December 2017*: In 2017, DSS's Senior Management Team agreed the Quality Team would produce a report every six months which, with the Monthly Dashboard reports, would provide the Ministry with:
  - a. assurance that DSS funded providers are delivering supports that safeguard disabled people; and
  - b. information and analysis to support quality improvement of services provided by DSS funded providers.

In terms of information about deaths, the report for July-December 2017 included the total number of people in residential services who died, the percentage of males/females, and the average age of the deceased. It also included a breakdown by cause (using categories of causes such as respiratory, accidents, cancer, disability-related), and the number of deaths with police or coroner involvement.

DSS confirmed that no further six-monthly reports were produced after the July-December 2017 report and the analytical and reporting focus was directed instead on the monthly dashboards.

- *DSS Quality: Annual report:* In January 2018, the Quality Team produced a 'Quality Report' for DSS 2016/2017. This was an analysis of complaints, incidents, death notifications, and the findings of a small sample of audits and evaluations undertaken in 2016/2017. In relation to deaths, the report included the same type of data as the six-monthly report and made a number of observations in relation to cause of death. It was noted that information submitted by providers indicated that the main cause of death was related to respiratory issues, which could be related to the person's disability (eg accidental aspiration pneumonia) or a non-disability related chest infection. It was also noted that:
  - some providers had recorded '*unexpected deaths of unknown causes*', with coroner involvement in most such cases; and
  - the numbers showed an increase in deaths reported to the coroner from 9% in 2015/2016 to 24% in 2016/2017, which may reflect changes to reporting requirements brought in by the Coroners Amendment Act 2016.

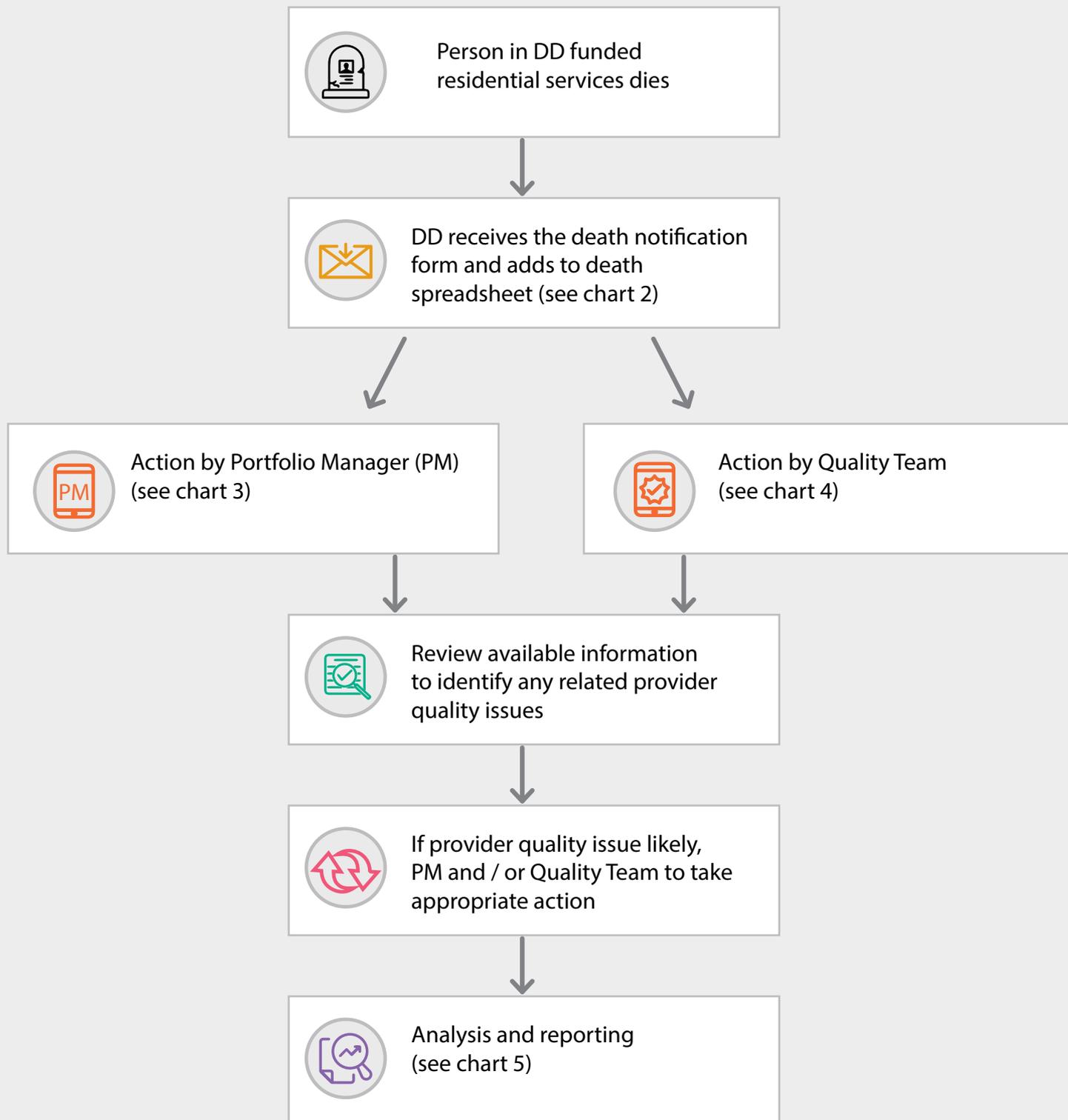
## Appendix 6. Revised processes following the death of person receiving Ministry-funded residential support

The following charts show the Disability Directorate's revised and current processes following the death of a disabled person receiving Ministry-funded residential support, as set out in the standard operating procedure for death notification and management (residential services), effective from 1 July 2019.

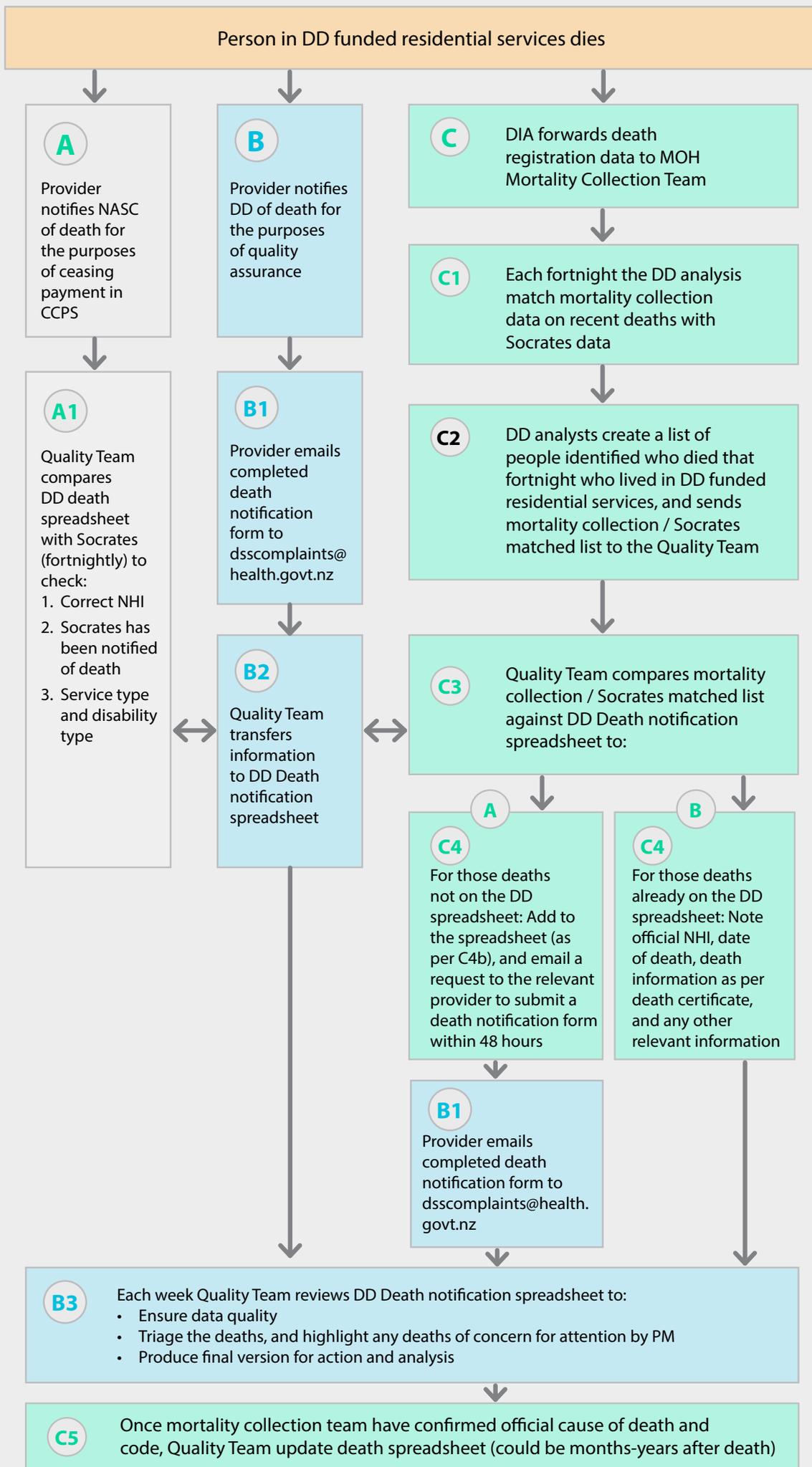


# Chart 1 DD Death notification process: Process overview

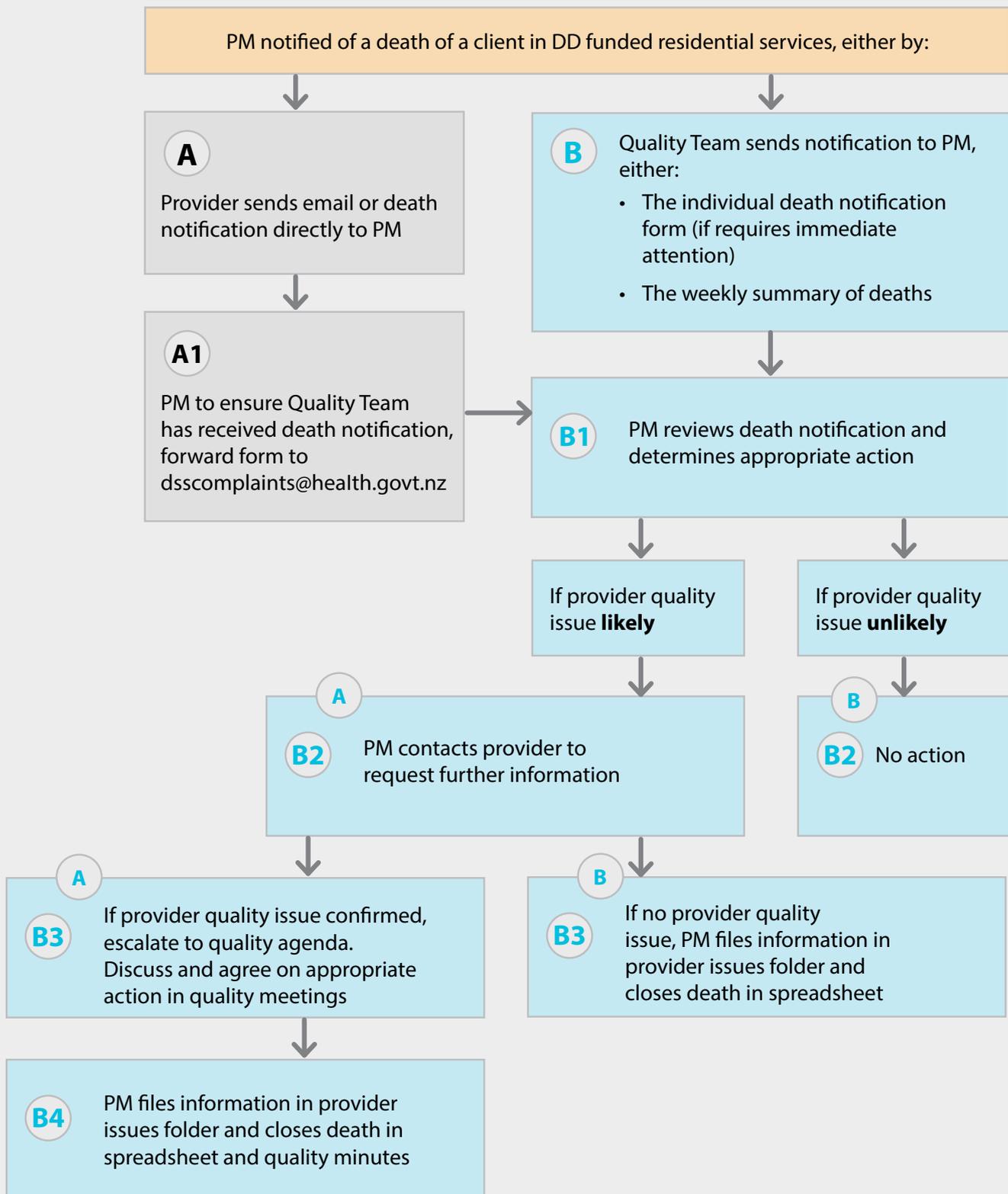
Effective 01 July 2019



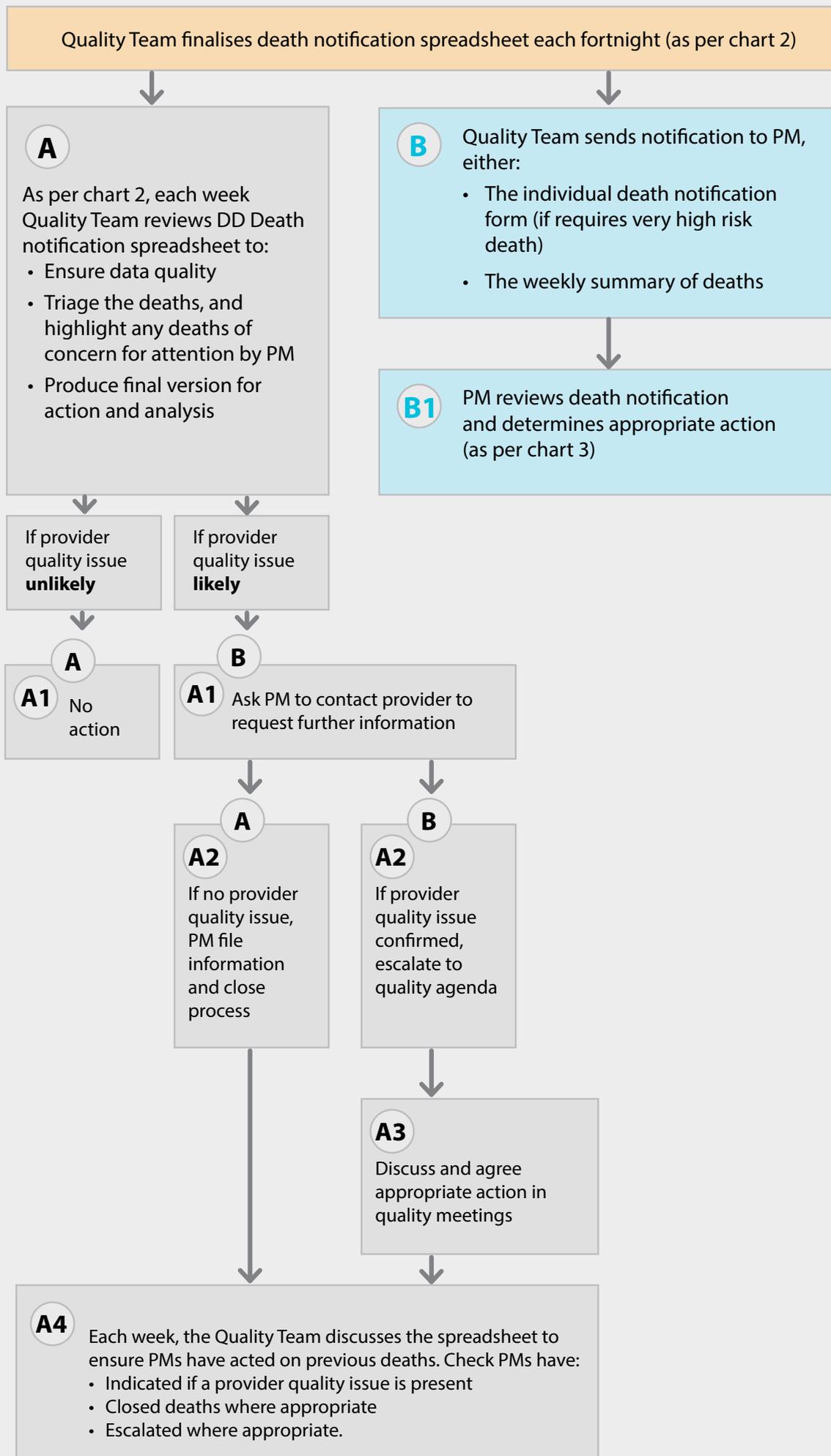
**Chart 2** DD Death notification process: Receiving the notification form



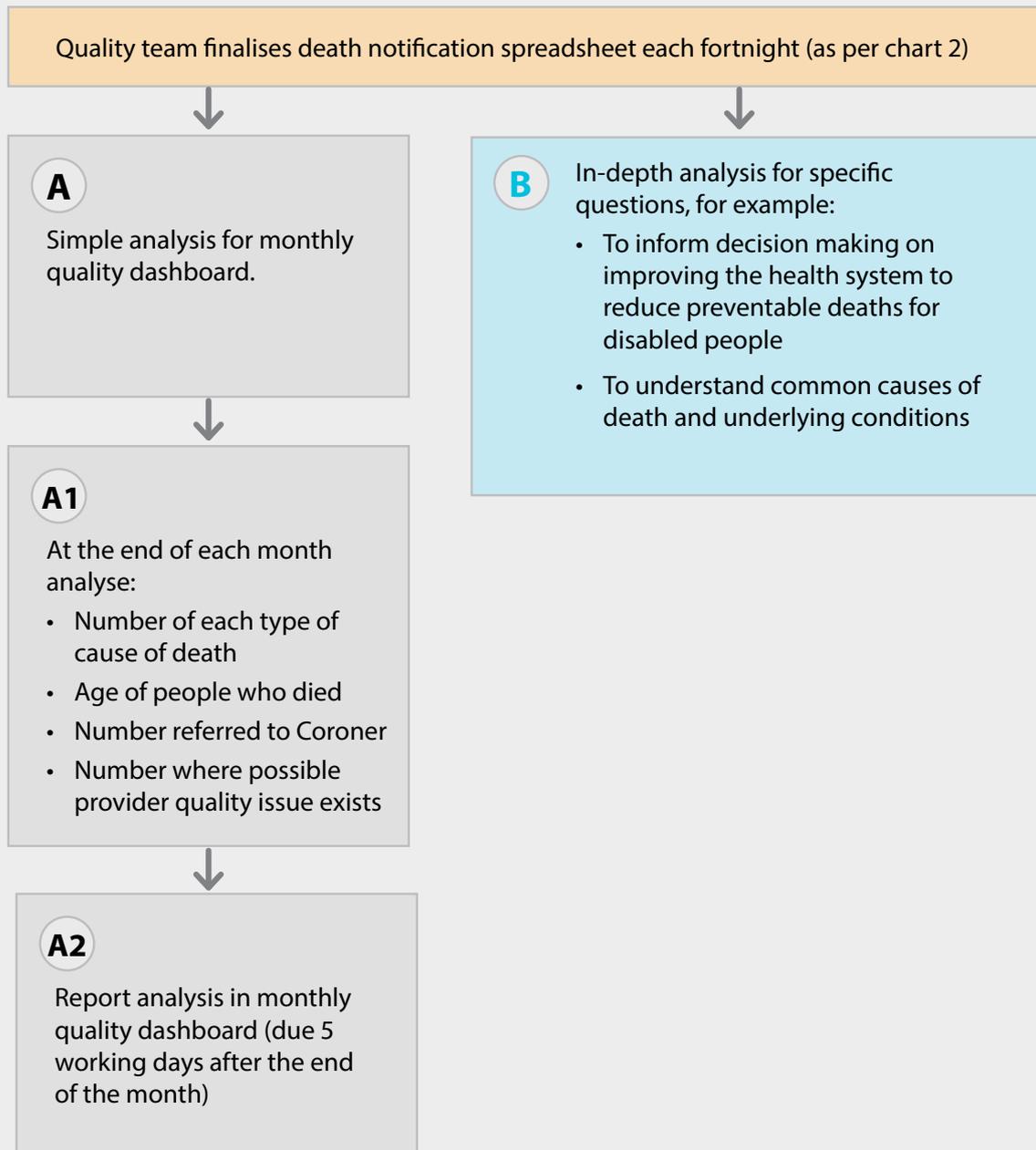
**Chart 3** DD Death notification process: Action by Portfolio Manager (PM)



**Chart 4** DD Death notification process: Action by Quality Team



## Chart 5 DD Death notification process: Analysis and reporting





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