MINISTRY OF HEALTH
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12 JUN 2019

Kirsty Johnston
Reporter
New Zealand Herald

By email: Kirsty.Johnston@nzme.co.nz
Ref: H201902527

Dear Ms Johnston

Response to your request for official information

Thank you for your request for information under the Official Information Act 1982 (the Act) to the Ministry of Health (the Ministry) on 15 April 2019, for information regarding the deaths of intellectually disabled people in forensic and residential care.

As per the email sent to you on 13 May 2019, the information for this response has been provided from January 2016. This is because prior to this date, death records and information were not held in a central location, but were stored across multiple systems. In order to provide information from this period, substantial collation and research would be required.

For the sake of clarity, I will address each of your questions in turn below.

- *Any reports, briefings or memos sent to/from the Ministry about the deaths of intellectually disabled people in forensic and residential care from January 2016.*

The Ministry has not identified any documents on this subject. As such, this part of your request is refused under section 18(e) of the Act as the information requested does not exist or, despite reasonable efforts to locate it, cannot be found.

- *Any data held on those deaths from January 2016.*

When a person with a disability dies in a residential disability setting funded by the Ministry, the provider is contractually required to advise the Ministry of their death. The purpose of this reporting is for service quality, assurance and compliance monitoring. Other agencies, such as the Police and the Coroner, may investigate individual deaths.

Please see the table overleaf showing the number of deaths of people with an intellectual disability who were living in residential care, as reported to the Ministry by providers, from 1 January 2016 to 8 May 2019. Further information held regarding these individuals which would be likely to identify those concerned has not been included in this table. This information is withheld under section 9(2)(a) of the Act in order to protect the privacy of natural persons.

Calendar Year	Deaths (intellectual disability only) across New Zealand
2019 (to 8 May 2019)	32
2018	82
2017	110
2016	112

In addition to this, three excerpts of documents have been identified as containing data regarding the deaths of intellectually disabled people in residential care. These are itemised in Appendix 1 and are outlined below.

The first attachment is a table containing the relevant information drawn from the '*DSS Monthly Dashboard*' between May 2017 and April 2019. The '*DSS Monthly Dashboard*' was introduced in May 2017 in order to provide a regular update on the Disability Support Services area, including any deaths of intellectually disabled people in residential care reported by providers. Please note that the deaths shown in the table include all deaths that have been reported to the Ministry by community residential disability providers, and also includes data about people with a physical disability who died while living in a community residential service. The information contained in the table is that reported by providers, and this may not be the official cause of death.

Attachments two and three consist of excerpts from the 2016/2017 DSS Quality Report and the DSS Quality 6 monthly report for July to December 2017 respectively. Both of these documents provide a high level update on a range of elements of Disability Support Services. The relevant information contained in these documents is provided in full.

- *Any reports on prevention of deaths of intellectually disabled people in forensic and residential care from the last ten years.*

Much of the Ministry's work relates, indirectly, to the prevention of deaths, including of intellectually disabled people in forensic and residential care. No reports, however, have been identified by the Ministry specifically on the subject of the prevention of these deaths.

It is possible that some information on this subject is held by another agency or organisation, such as Coronial Services, the Health and Disability Commissioner, the Ombudsman, and the United Nations.

- *Any media plans or communications strategies around those deaths from January 2016.*

No media plans or communications strategies regarding the deaths of intellectually disabled people in forensic and residential care have been identified. As such, this part of your request is refused under section 18(e) of the Act as the information does not exist or, despite reasonable efforts, cannot be found.

- *How the data was held prior to 2016 and what prompted the change in data collection.*

Prior to 2016, no centrally located database of relevant data existed. In January 2016, the Ministry identified the need to ensure that relevant data is kept centrally in order to enable the Ministry to better track any patterns or changes that may occur. There was no specific prompt for this change, however the Ministry is continually seeking to improve its processes and practices, including with regards to record-keeping.

I trust that this information fulfils your request. Please note that this response, with your personal details removed, may be published on the Ministry of Health website (if applicable).

Under section 28(3) of the Act you have the right to ask the Ombudsman to review any decisions made under this request.

Yours sincerely

Adri Isbister
Deputy Director-General
Disability

Appendix 1: List of documents proposed for release

#	Date	Title	Decision on release
1	May 2017 to April 2019	Details from DSS Monthly Dashboard	Excerpts released in full
2	Undated	Excerpt from the 2016/17 DSS Quality Report	Excerpt released in full
3	Undated	Excerpt from the DSS Quality 6 Monthly Report Jul-Dec 2017	Excerpt released in full

Attachment 1: Excerpts from the 'DSS Monthly Dashboard'

Month	**Number of death notifications reported by month to Disability Support Services**	**Comments and additional information about deaths reported in each monthly dashboard**
May 2017	11 death notifications received.	No deaths were referred to the coroner for May 2017.
June 2017	11 death notifications received.	Two deaths were referred to the coroner in June 2017
July 2017	10 death notifications received.	1 death was referred to the coroner. **Please note that the graph shown in the February 2018 row of this table depicts that 16 deaths occurred during July 2017. The number shown in the graph is incorrect and DSS records show that 10 deaths were reported to us in August 2017.**
August 2017	8 death notifications received.	1 death was referred to the coroner. **Please note that the graph shown in the February 2018 row of this table depicts that 9 deaths occurred during August 2017. The number shown in the graph is incorrect and DSS records show that 8 deaths were reported to us in August 2017**
September 2017	10 death notifications received	Four deaths were referred to the coroner. Age of the deceased: • 40-50y: 1 • 50-60y: 5 • 60-70y: 3 • >70y : 1 **Please note that the graph shown in the February 2018 row of this table depicts that 11 deaths occurred during September 2017. The number shown in the graph is incorrect and DSS records show that ten deaths were reported to us in September 2017.**
October 2017	14 death notifications received.	1 death was referred to the coroner. Age of the deceased: Age Group/n • 30-40y: 1 • 40-50y: 2 • 50-60y: 5 • 60-70y: 4 • >70y: 2

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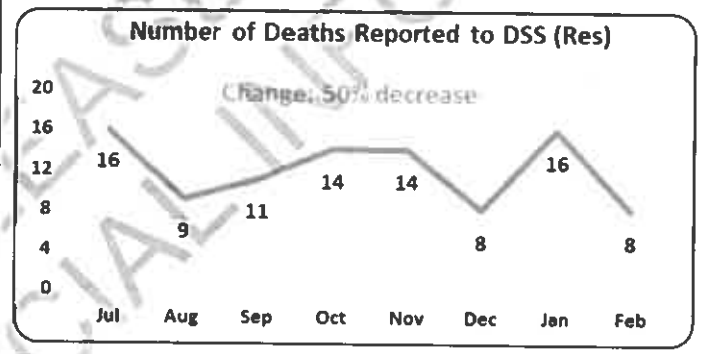
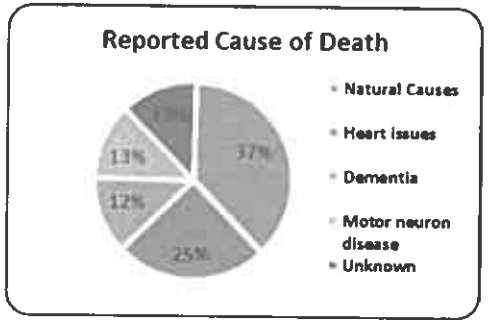
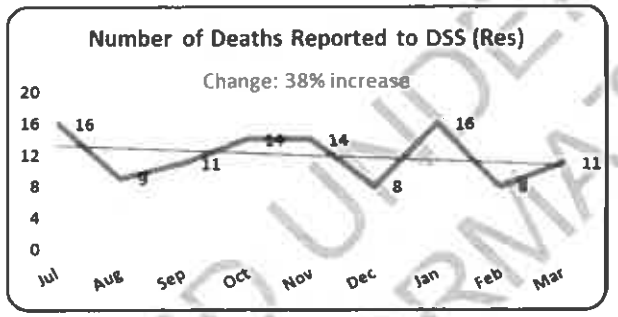
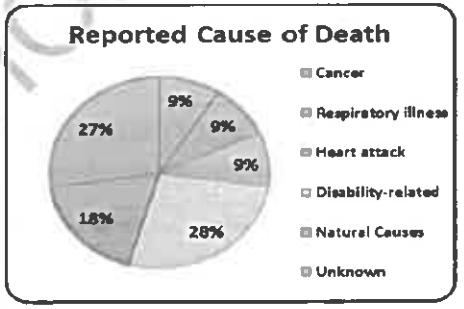
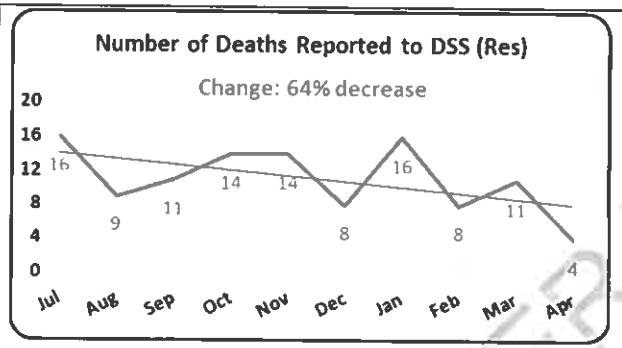
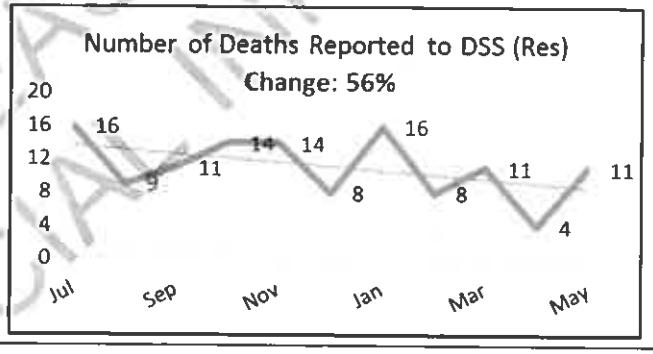
November 2017	14 death notifications received.	Age of the deceased: Age Group/n • 30-39y: 2 • 40-49y: 1 • 50-59y: 4 • 60-69y: 6 • >70y: 1
December 2017/January 2018	22 death notifications received.	4 referred to Coroner Age of the deceased: Age Group/n (n=22) • 40-49y: 5 • 50-59y: 5 • 60-69y: 7 • 70-79y: 3 • >80: 2 **Please note that the graph below shows that across December 2017/ January 2018 there were 24 deaths. The number shown in the graph is incorrect and DSS records show that ten deaths 22 reported to us over December 2017/January 2018**
February 2018	8 death notifications received.	Comments: • No trend in the number of deaths, no death involved coroner, one involved the police. One death of unknown cause but no concerns, as the person had a history of clinical illnesses and was being followed up with by the GP.  

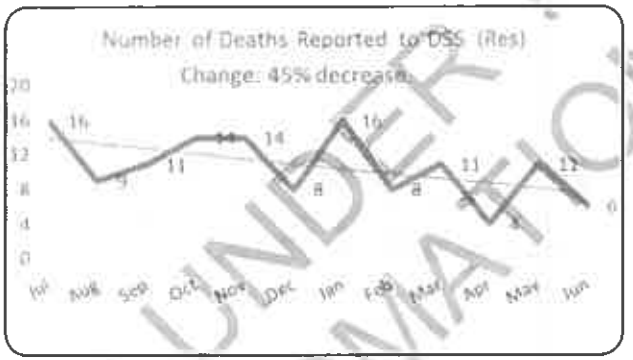
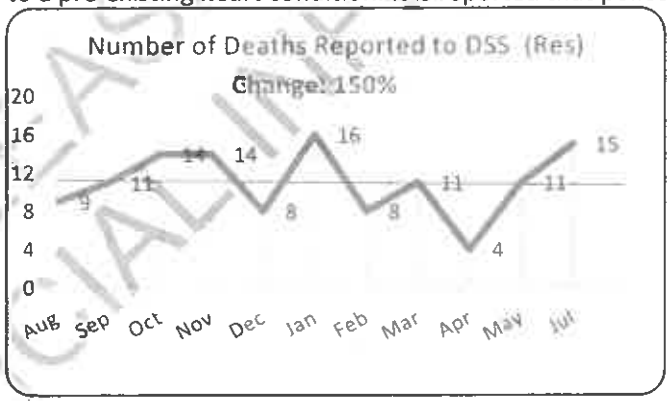
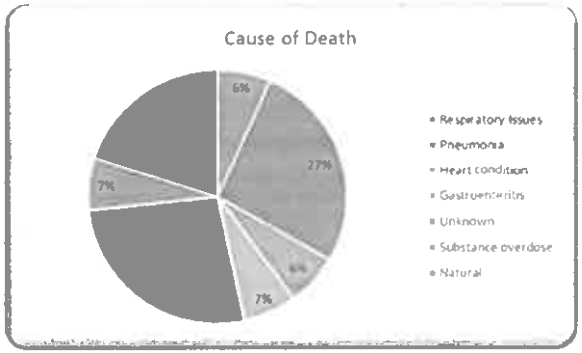
Attachment 1: Excerpts from the 'DSS Monthly Dashboard'

March 2018	11 death notifications received.	Comments: • There is a slight decreasing trend in the number of deaths received to date in this financial year. • Three deaths were of unknown cause. Two of these are of no apparent concern, as the people had been hospitalized for several weeks before their passing. For the other one, provider is still waiting for the death certificate to determine the cause of death. • One death involved the police, as they found the person deceased after they activated an emergency alarm. The likely cause of death was a heart attack. • No death involved the coroner.  
April 2018	4 death notifications received.	Comments: • There was a 64% decrease in the number of reported deaths this month. • Two deaths were of unknown cause: one person was found unconscious in the bathroom after an uneventful evening (police and coroner involved in this death) and another person died at the family home while on weekend leave. The actual cause of death in both cases was not known by the provider when the death notification form was submitted to DSS. • The other two deaths were for medical issues (heart attack and bowel obstruction).

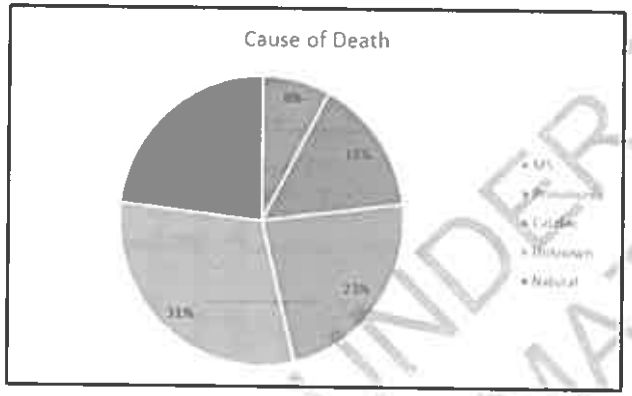
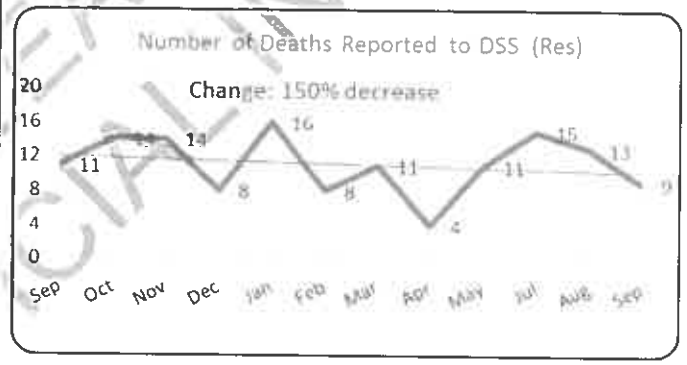
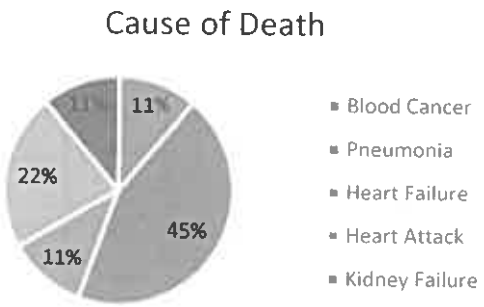
Attachment 1: Excerpts from the 'DSS Monthly Dashboard'

		
May 2018	11 death notifications received.	Comments: • There was a 56% increase in the number of reported deaths this month. • One death was of unknown cause: The provider only advised NASC on the 15/05/18 upon annual review. The client passed away 14/02/18. DSS did not receive the cause of death. • 2 deaths were due to natural causes. • 2 deaths were due to palliative care. • 3 deaths were due to respiratory failure. • Other causes included: MND, Spinocerebellar Ataxia and a vehicle accident (this was also the only death referred to the coroner this month). 

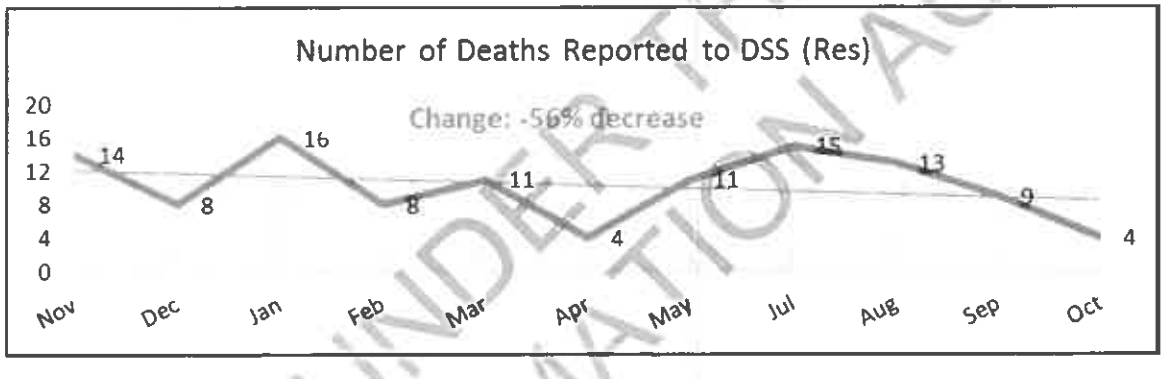
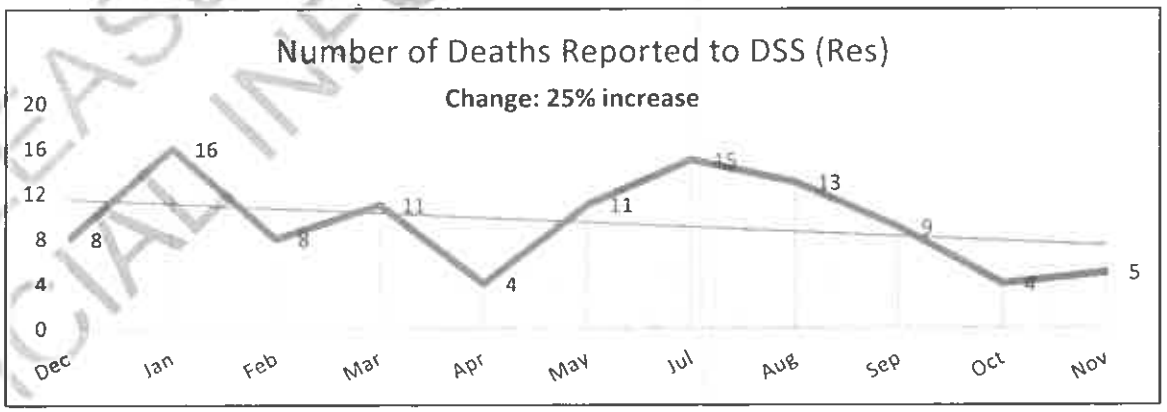
Attachment 1: Excerpts from the 'DSS Monthly Dashboard'

June 2018	6 death notifications received.	Comments: - There was a 45% decrease in the number of reported deaths this month. - 1 was due to pneumonia* - 2 were due to unknown causes* - 3 were due to progression of condition* *Cause of death as stated on death notification form 
July 2018	15 notifications received.	There was a 150% increase in the number of deaths reported in the month of July. Out of the 15 deaths reported to the Ministry, three were referred to the coroner. One of the three families where the coroner was involved, also involved the police. The family have since been informed that the cause of death was due to a pre-existing heart condition. It is reported that police was involved in six of the 15 death notifications.  

Attachment 1: Excerpts from the 'DSS Monthly Dashboard'

August 2018	13 notifications received.	From the 13 death notifications received we are aware of only one being referred to the coroner. A further two deaths did not specify whether the coroner will be involved. One service user passed away while in hospital and another notice of death was picked up in the Timaru herald. 
September 2018	9 notifications received.	From the 9 death notifications received none were referred to the coroner. Police were involved in only one death where the cause of death is yet to be confirmed. It is suspected to be a heart attack as the client had a history of heart related issues and was recently also diagnosed with renal failure.  

Attachment 1: Excerpts from the 'DSS Monthly Dashboard'

October 2018	4 death notifications received.	Police were involved in the death of one client who was found by his support worker who could not rouse him. One death was related to Huntington's disease and another client suffered a stroke. The fourth death seems to be linked to advancing pneumonia. 
November 2018	5 death notifications received.	Police were involved in the death of two clients this month. One service user was found deceased on his couch by his support worker. The other collapsed to the floor at the service from what they thought was a 'minor stomach upset'. Both of these cases have been referred to the coroner. Two deaths were related to pre-existing conditions and one due to natural causes. 

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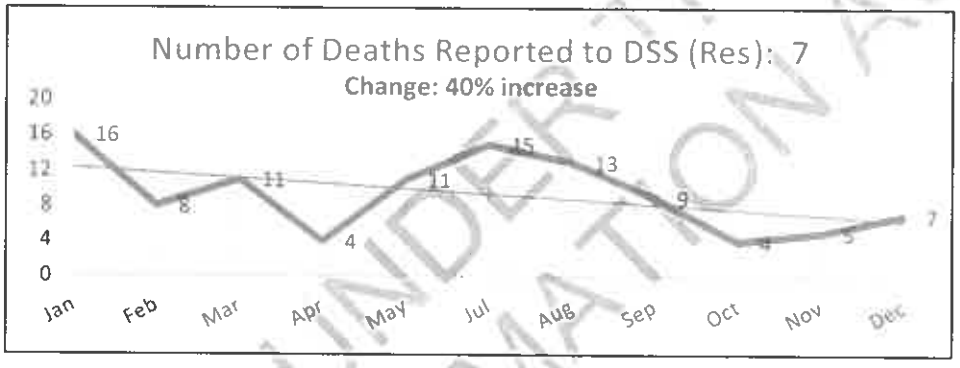
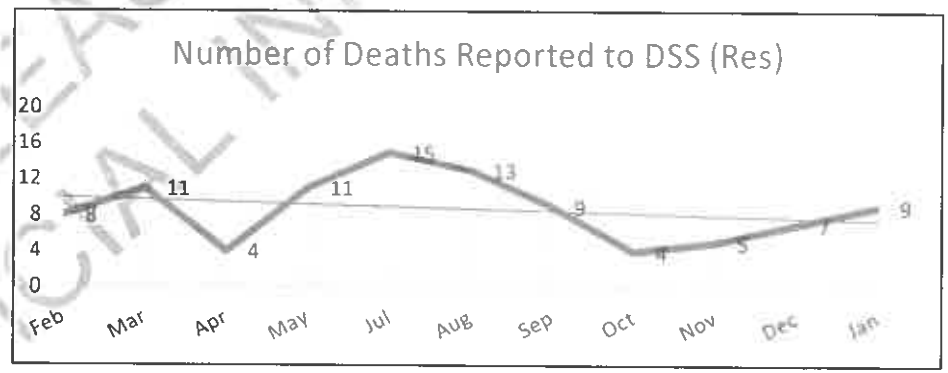
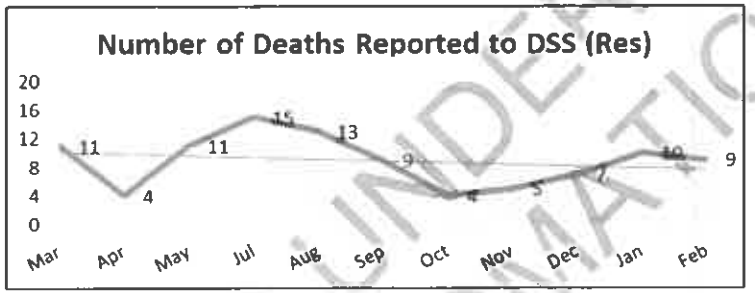
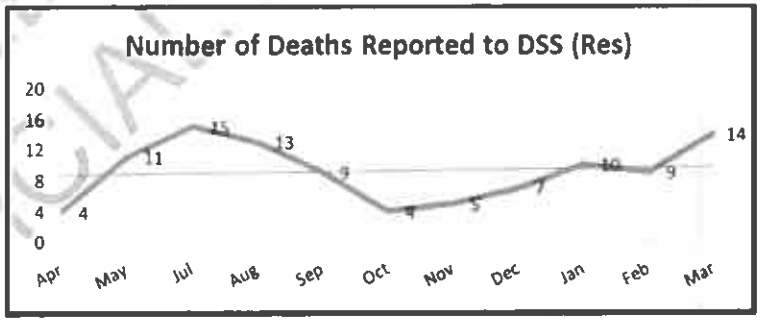
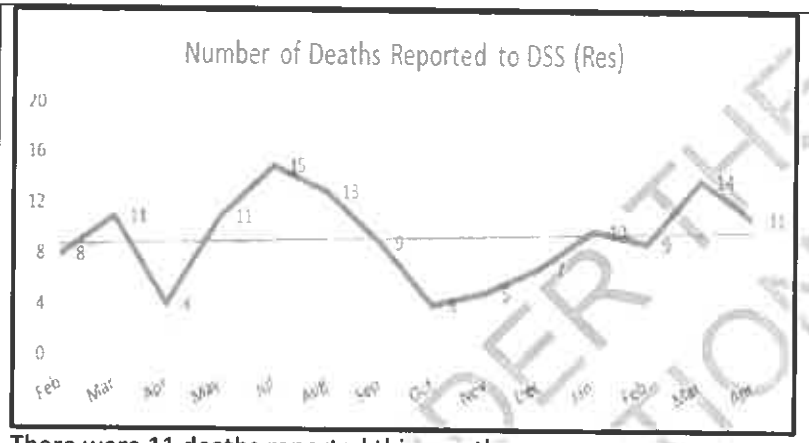
December 2018	7 death notifications received.	There was a 40% increase in the number of reported deaths this month. • 4 were due to pneumonia • 1 was due to progression of condition • 1 was due to an unknown cause which has been referred to the coroner and police to investigate • 1 was due to a brain haemorrhage. 
January 2019	9 death notifications received.	There were 9 deaths reported this month, representing a 29% increase compared to December 2 due to kidney failure 1 due to MS 3 due to natural causes 2 due to pneumonia 1 due to sepsis 

Attachment 1: Excerpts from the 'DSS Monthly Dashboard'

February 2019	9 death notifications received.	There were 9 deaths reported this month: • 1 due to kidney failure • 1 due to heart attack • 1 due to natural causes • 3 due to pneumonia • 1 due to brain haemorrhage • 1 due to stroke • 1 due to respiratory failure 
March 2019	14 death notifications received.	• 4 due to natural causes • 1 due to cancer • 1 due to choking • 1 due to injuries resulting from a car crash • 1 due to pneumonia • 1 due to stroke • 1 due to dementia • 4 due to unknown causes 

Attachment 1: Excerpts from the 'DSS Monthly Dashboard'

April 2019	11 death notifications received	 There were 11 deaths reported this month: - 3 due to heart attack - 2 due to pneumonia - 2 due to kidney failure - 1 due to natural causes - 1 due to cancer - 1 due to a terminal medical condition - 1 due to unknown causes

Attachment 2: Excerpt from the 2016/2017 DSS Quality Report

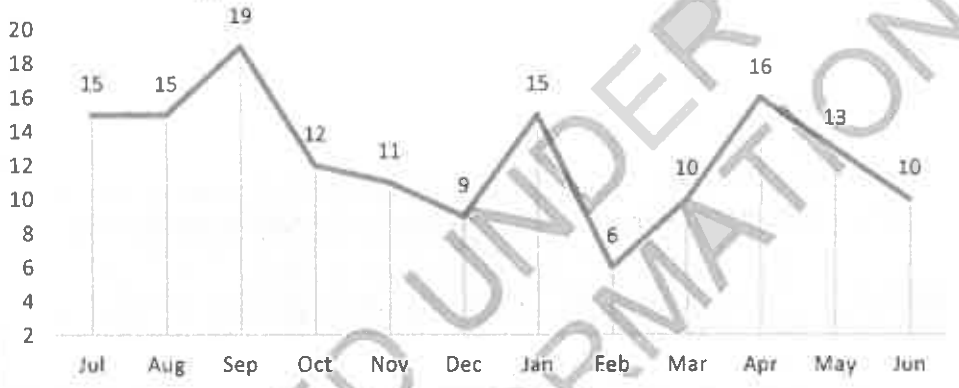
Section 5 Notification of Death (Community Residential only)

5.1. Number of Deaths

In 2016/17, a total of 151 deaths were reported to DSS, an increase of 8% in comparison to 2015/16. There is no identifiable trend based on this information[1].

Most death notifications were received in September/2016; the least number was received in February/2017, as figure 10 shows.

Figure 10. Number of death notifications received per month in 2016/17. Ministry of Health, New Zealand. 2017.



5.2. About the deceased

The majority of deceased people were male (54.3 percent).

The average age of people at death was 59 years (n=146, data missing for 5 users as no date of birth provided at time of death). This is lower than the life expectancy of the general New Zealand population which is 81.4 years.

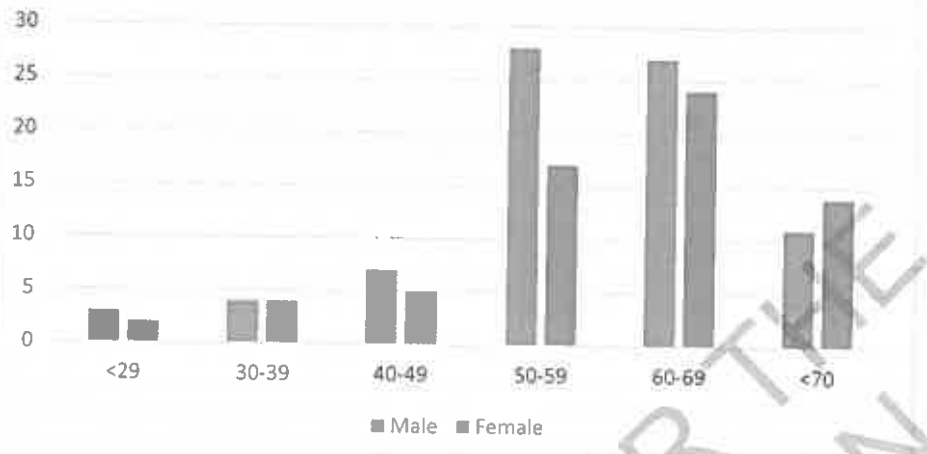
The average age at the time of death was higher amongst the female population (61 years), in comparison to the male population (58 years). The youngest female was 25 at time of death and the youngest male was 17 years old. The oldest female user was 89 at time of death and the oldest male user was 90 at time of death.

Figure 11 shows that the majority of women was between 60-69 years of age at time of death and the majority of men were 50-59 years of age at time of death.

[1] Note that the data presented in this section will have a variant total number, as there was missing information for a number of variables (i.e. data of birth not provided and age not being calculated). The missing information will be highlighted in each section below.

Attachment 2: Excerpt from the 2016/2017 DSS Quality Report

Figure 11. Number of deceased users by age and gender. Ministry of Health, New Zealand. 2017.



5.3. Cause of Death

The death notification form that is submitted by providers to DSS does not ask providers to specify the cause of death, but allows for providers to give details of events that led to death.

Overall findings:

- It is possible to note from the information submitted by providers that the main cause of death was related to respiratory issues (pneumonia and respiratory failure), that could be either related to the disability (like accidental aspiration pneumonia) or non-disability related chest infections.
- The second most emerging theme for cause of death was declining health related to the natural course of the person's disability and the deaths were expected, such as consequences of motor neurone disease, Huntington's disease or multiple sclerosis, among others.
- Unexpected deaths of unknown causes were also recorded by providers. In most cases, the coroner was involved in these deaths.
- Four deaths were recorded as accidents, with reasons given including drowning in the bath, choking and burns.
- No reported death was the result of suicide or self-harm.

5.4. Referral to Police and Coroner

Deaths that were referred to the Police and the Coroner increased in 2016/17 when compared to the previous year. In 2015/16, only nine percent of total deaths were referred to the Police or Coroner but in the in 2016/17, 24 percent of deaths were referred to the Police and/or Coroner.

The increase could reflect changes to reporting requirements in the Coroners Amendment Act 2016.

Attachment 3: Excerpt from the DSS Quality 6 Monthly Report Jul-Dec 2017

DEATHS IN RESIDENTIAL SERVICES

65 deaths reported

20% decrease in number of deaths

57.5 average age at time of death

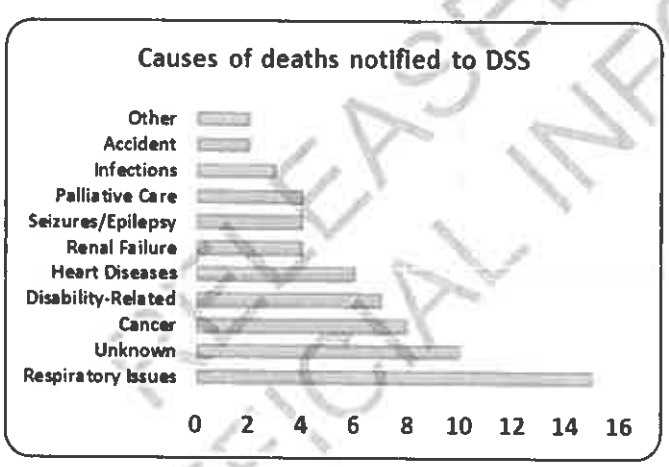
0 deaths reported as a suicide

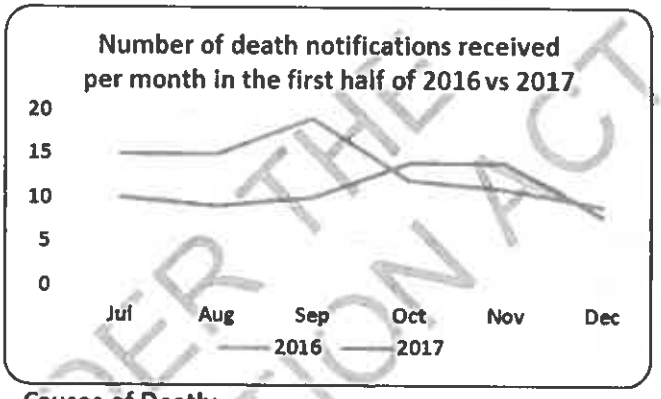
Number of Deaths:

- A total of 65 death notifications was received in community residential services (ID, PD and YPD).
- This represents a 20% decrease from the same period of the previous financial year.

About the Deceased:

- 54 percent of the deceased were male.
- The average age of people at the time of death was 57.5 years. This is lower than the life expectancy of the general NZ population, which is 81.5 years.
- The average age at time of death was slightly higher amongst the female population (58.1 years vs 57 years in male population).
- The youngest female was 31 at time of death and the youngest male was 25. The oldest woman was 89 at time of death and the oldest male was 81.
- The majority of women were aged between 60-69 years at death; men were between 50-59 years.





Causes of Death:

- The most common causes for reported deaths were respiratory issues, including pneumonia (by aspiration in some cases), followed by deaths which cause was unknown to the provider.
- Of the deaths of unknown cause (10): four were unexpected, as the person suddenly collapsed or was found deceased; two were a result of fragile health but the exact cause was unknown; and in four cases, the death occurred somewhere else (at home or respite) and no further information was available to the provider at the time the report was submitted to DSS, including one case where the person had died the previous year.
- The police was involved in half of deaths of unknown cause and in 21 percent of all other deaths. Coroner involved in 12 percent of deaths.
- Disability-related include expected deaths due to the natural course of a disease (i.e. motor neuron disease or Huntington's disease).
- Two deaths were a result of accidents, including an accidental medication overdose caused by staff.
- No death was reported as a suicide.